
A Handbook for
**PARTICIPATORY
ACTION RESEARCHERS**

Karen Danley, PhD
Marsha Langer Ellison, PhD



Center for Psychiatric Rehabilitation
Sargent College of Health and Rehabilitation Sciences
Boston University

Copyright © 1999 Center for Psychiatric Rehabilitation, Trustees of Boston University.

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or any information storage or retrieval system without permission in writing from the publisher.

This work was developed by the Center for Psychiatric Rehabilitation, Sargent College of Health and Rehabilitation Sciences, Boston University, with funds provided by the National Institute on Disability and Rehabilitation Research. The Center is supported in part by the Center for Mental Health Services and the National Institute on Disability and Rehabilitation Research.

Center for Psychiatric Rehabilitation
Sargent College of Health and Rehabilitation Sciences
Boston University
940 Commonwealth Avenue West
Boston, MA 02215

CONTENTS

Acknowledgementsiv

CHAPTER ONE:	AN INTRODUCTION TO PARTICIPATORY ACTION RESEARCH	1
	In the Beginning	1
	Purpose of This Handbook	1
	What Is Participatory Action Research?	1
	What Are the Types and Purposes of PAR?	2
	PAR Values	2
	Organizational Commitment to PAR	4
	Problems Associated with PAR and Some Solutions	4
CHAPTER TWO:	OPERATIONAL PRINCIPLES AND STRATEGIES	7
	An Introduction	7
	A Brief History	7
	Operations and Recommended Activities	10
	Recruiting and Selecting Research Team Members	10
	Role/Relationship Clarification	15
	Training and Supervision	17
	Team Management and Support	18
CHAPTER THREE:	SOME FINAL THOUGHTS	21
	Observations of Team Members with Psychiatric Disabilities	21
	Observations of Professional Team Members	21
	In Conclusion	22
	<i>References</i>	23
	<i>Appendix</i>	25

ACKNOWLEDGMENTS

The authors wish to acknowledge the efforts of the members of our Participatory Action Research Team, whose labor was the source of our learning and this handbook. They are:

Gloria Fay Dickerson
Thomas A. Emmet
Victoria Palmer-Erbs
Cheryl Gagne
Allison Kehne
Martin Koehler
Pamela J. Kramer
Mark M. Miller
Sharon Morgan
Jacqueline Ramseur
Anne Sullivan
Harvey Towers
Robert Walker, Jr.

Many thanks are also due to Dr. William A. Anthony, Executive Director of the Center. It is Dr. Anthony's leadership that has established a core set of Center values which reflect those intrinsic to PAR and which served as fertile ground for our PAR project. We are grateful to Dr. E. Sally Rogers, Director of Research at the Center, who provided expertise and guidance that helped maintain project integrity. Additionally, Jessica Jonikas of the National Research and Training Center on Psychiatric Disability provided numerous and very helpful suggestions.

The authors also gratefully acknowledge the National Institute on Disability and Rehabilitation Research (NIDRR), the source of funding for this project (Grant # 133G20070). NIDRR has pioneered the use of PAR in federal research projects, thus enhancing the probability that potential beneficiaries of funded research have access to the creation and implementation of relevant research initiatives.

CHAPTER 1 *An Introduction to Participatory Action Research*

IN THE BEGINNING

Our Participatory Action Research (PAR) project originated as a field initiated research grant funded by the National Institute on Disability and Rehabilitation Research (Grant # H133G20070). A primary goal was to investigate the feasibility, methodology, and success of implementing Participatory Action Research (PAR) with people who have psychiatric disabilities. PAR was the research method used to investigate the career paths of people with psychiatric disabilities. The subjects of the investigation were 50 people who had received career development services from the Center for Psychiatric Rehabilitation 5 to 8 years earlier. At the start of the project the authors envisioned culling a team of people from the pool of 50 participants to collaborate in a qualitative exploration of their vocational development since receiving services. While conducting this exploration the authors also intended to explore and evaluate the functioning of the PAR methodology.

PURPOSE OF THIS HANDBOOK

This handbook provides some guidelines for conducting one model of PAR with people who have psychiatric disabilities. It evolves from our investigation into and experience of PAR that is extrapolated into generic principles and strategies. Many of the examples and learnings offered are drawn from this particular experience of PAR in a singular environment and context. Therefore, it must be emphasized that while we have used this experience to suggest procedures for how to do PAR, this is not a “cookbook” for how PAR can be done. PAR will vary according to context, the research undertaken, and of course the predilection and composition of the PAR research team itself. Whenever possible, the handbook offers suggestions on how the principles and strategies that are outlined might be modified to respond to different operating conditions.

We also wish to emphasize that this PAR experience pertains directly to working with people who have psychiatric disabilities. A number of points made are partic-

ularly important in light of the nature and lived experience of psychiatric disability, e.g., the frequent consequences of distrust, disenfranchisement, and powerlessness. Nonetheless, we believe that the strategies described are generic enough that the handbook can be applied to virtually any PAR endeavor both with people who have other disabilities or those with no disabilities.

WHAT IS PARTICIPATORY ACTION RESEARCH?

Participatory Action Research (PAR) refers to a research method, typically concerned with organizational self-assessment, in which the subjects of the study “participate with the professional researcher throughout the research process, from the initial design to the final presentation of the results and discussion of their action implications” (Whyte, 1989).

There are several roots to contemporary applications of PAR and each shed light on its unique features. First is the term “action research.” This refers to investigations of strategies or principles that can explain or improve a situation. It is linked with evaluation research in its aim to uncover problems or strengths that can be used to better develop an organization or service. It will typically result in “action steps” that are context bound rather than in developing or testing theory that can be generalized.

Another root, “participatory research,” emphasizes that stakeholders in the research outcome must participate in the research process. Stakeholders are needed to ensure that the “outside” research professionals do not misconstrue or render meaningless information sought or collected due to their lack of first hand knowledge of the situation (or due to not being “members” of the socio-cultural group). Stakeholder presence in the research process also ensures that the resulting actions steps are “owned” by the stakeholders, that there is “greater consensus for change” (Walton & Gaffney, 1991). Found frequently in third world development efforts, participatory research is seen as a liberating process for stakeholders (Rosenwald, 1988). The professional researcher is construed as a consultant or educa-

tor to the research effort rather than as the expert or professional.

PAR has also developed out of the challenges made by qualitative research to the traditional scientific paradigm; however, it can also be used with quantitative research. The scientific paradigm holds that objectivity in the research endeavor must be held as purely as possible. Subjects therefore cannot also be researchers, as they will necessarily “bias” the investigations. Qualitative research holds that on the contrary, “objective” researchers are also biased by the paradigm of investigation that they utilize, by the socio-political context of the investigation, and by the very language and concepts used. In fact, the only way to understand the meaning of any event is by understanding it according to the concepts, language, and objectives of the people who are the actors in the event itself. Therefore, the subjects of the research can and should be participants in the defining and interpretation of the research. Subject participation challenges traditional research philosophy but does not make PAR incompatible with traditional research. In the concluding chapter of this handbook, some strategies for using PAR successfully without compromising quantitative rigor are presented.

More recently, PAR has been touted as a model by which constituents of services can be more involved in the research process. It serves to involve people more fully in the services that are offered them as well as to ensure the appropriateness of the methodology and the relevance of the outcomes. In this framework, PAR is essentially a political process and it has been embraced by national funding bodies in disability research (Rogers & Palmer-Erbs, 1994). Together these influences have led to the formation of a research strategy that is quite unique from traditional research strategies. A summary of the differences between PAR and more traditional research methods, developed by Rogers & Palmer-Erbs (1994), is presented in Table 1.

WHAT ARE THE TYPES AND PURPOSES OF PAR?

PAR has emerged in different forms and models that vary according to context and purpose. It is probably easiest to conceptualize the varying forms of PAR as points along a continuum of power held by the constituents of the study. On one end are advisory committees which, while a conceptual stretch, are sometimes called PAR because constituents have some participation but ultimately very little power or authority over the project. On the high end, the constituents (as is often the case in business settings) have full control

over the research process including hiring and firing authority over the professional researchers (who are typically under contract to the business). Mid-points on the continuum may be expressed by hybrid projects such as the one described here in which constituents have high degrees of control but professionals are beholden to outside funding bodies and thus the professionals retain decision-making authority in some areas. Another mid-point may be expressed when the PAR participants are related to the stakeholders but are not the actual subjects of study; as for example, when the PAR team is made up of people with psychiatric disabilities but they are not the service recipients of the organization being studied.

PAR also varies by its purpose. Typically, PAR is concerned with an evaluation for the purposes of developing “actions steps” to improve the efficiency and/or effectiveness of a specific operation. PAR can also be used for more abstract research and theory development. PAR is also compatible with instrument development and quality assurance efforts. Although it is linked with qualitative methodologies, it can be used in quantitative and experimental studies.

What remains the same in all models is that “all relevant stakeholders do what only researchers usually do...(It) is a way of learning how to explain a particular social world by working with the people who live in it to construct, test, and improve theories about it so they can better control it (and) better control the circumstances of their lives” (Elden & Levin, 1991).

PAR VALUES

There are several implicit values that permeate the PAR process (McTaggart, 1991). In the project described here, the following emerged as operating values.

Power Sharing

The premise of PAR is equal participation by the research constituents with the professional researchers. PAR means that the course of the project from conception to implementation of action steps involves collaboration of both the professionals and the constituents. To do this properly, professionals must relinquish traditional prerogatives and authorities. There must be a professional acquiescence to the research group as a whole at critical decision points such as when defining project goals and determining how information will be collected and interpreted. How to do this without compromising research quality is explored later. Moreover,

Table 1— Differences in Emphasis Between Traditional Research and Research Using a Participatory Action Research Paradigm

TRADITIONAL RESEARCH PARADIGM	PARTICIPATORY ACTION RESEARCH PARADIGM
Emphasis is on “learning about” research subjects	Emphasis is on “learning from and learning about” research subjects
Objectivity vis-à-vis research and subjects is valued	Subjective experiences of subjects are also valued
Researcher acts as “professional”	Researcher acts as “consultant,” “educator”
Research is best conducted by “outsiders”	Research must have input from “insiders,” i.e., those being studied
Subjects have one role; that of research subject	Subjects have dual roles both as subjects and as researchers
Subjects are passive objects of study and do not contribute to the research process	Subjects are actively involved in the conceptualization, design, implementation, and interpretation of research studies
Traditional paradigm lends itself to controlled, experimental research studies	Participatory Action Research paradigm also lends itself to qualitative, ethnographic studies and to studies of the disability experience
Subjects’ involvement in research ends when data collection is complete	Subjects act as “change agents” converting results of research into new policy, programmatic or research initiatives
Research agenda shaped by professional and socio-political forces	Research agenda influenced directly by the concerns of many constituents, including the end-users of services

Excerpted from Rogers, E. & Palmer-Erbs, V. (1994). Participatory Action Research: Implications for research and evaluation in psychiatric rehabilitation. *Psychosocial Rehabilitation Journal*, 18(2), 3-12.

research decisions and administrative decisions are often linked; so in PAR, the whole team should make decisions about who will collect the information, how and how often members will be paid, and under what circumstances the team should meet. Another area crucial to team decision making is how the team should conduct itself. How will discussions be led, how will decisions be made, how will conflict be handled, how will meeting agenda be determined? In all of these ways PAR is to be understood as an explicitly empowering process. PAR implies a steady group of representatives who execute the project from start to finish and not an ad hoc group called in at various points of the project.

For example, implementing a survey designed by professional researchers may be participation but it is not PAR.

Mutual Respect for Experience/Expertise

Another premise of PAR is that the two main actors of the research process, the stakeholders or constituents and the professionals, each have a unique and equally important contribution. Professionals bring to bear their knowledge of the project and research process. The constituents bring their unique understanding of the experience of having a psychiatric disability. One is no less important than the other is, and one cannot

replace the other. Instead the two groups each bring their unique perspectives and together create a situation of co-learning. It should hardly be said that an atmosphere of respect that emphasizes the dignity and importance of each team member should prevail. For professionals this may mean a concerted and conscious attempt to guard against paternalism and exclusionary or distancing behaviors, such as use of professional jargon and acronyms.

Informed Decision Making

The key to successful PAR is an informed group of stakeholders. It is foolhardy to expect collaboration in conducting research tasks when the decision makers have little knowledge on which to base their decisions; and yet this is often the case in advisory councils with constituent attendance. This need for knowledge implies the necessity for incorporating training as an on-going function within the research project. Our efforts at teaching and training PAR team members in research tasks is described more fully in Chapter 2.

Maximum Involvement

A close corollary to shared decision making is maximum involvement. Professionals should be cautious about carving out areas that remain exclusively in their province. As much as possible, the research team should be brought into all areas of research planning, administration, implementation, and completion. Maximum involvement necessarily implies shared responsibility. However, professionals in PAR may be beholden to many other parties than are the consumer members, e.g., funding bodies, the employing organization, and their profession. This may mean that typical sanctions must be utilized to ensure the unfolding of the research process (e.g., standard accounting procedures are used to keep track of research funds, or, a PAR team member may be asked to leave if they do not properly fulfill their duties). Unless these responsibilities are somehow also shared with the consumer PAR members, these respective responsibilities are unbalanced, forcing a skewed relationship to the PAR process and an unnecessary difference in perceptions.

ORGANIZATIONAL COMMITMENT TO PAR

Before undertaking PAR it is important to consider the organizational climate, which can supply either tremendous support or tremendous difficulties to the process. In this PAR project the authors were fortunate

to be operating within an organization that has long supported client self-determination, and that perceives people with psychiatric disabilities as those who can best understand their own situation. All interactions with consumers are marked by respect and dignity. Without such organizational support, the values and practices of PAR may well be viewed with suspicion or derision and may be actively blocked. Issues around payment or hiring of PAR members with psychiatric disabilities may be especially difficult. If this is the case, testing the organizational waters and re-education of organizational personnel may be in order prior to initiating PAR.

Special difficulties may also arise with a review board of procedures for assuring human rights. Such boards typically require spelling out all instruments and data collection strategies. However, with PAR this is undetermined until the team is convened. A frank discussion about PAR may help the board to understand and approve procedures. In addition, construing PAR team membership as a consultative role rather than as subjects under research conditions may help sort out review board concerns.

PROBLEMS ASSOCIATED WITH PAR AND SOME SOLUTIONS

A variety of difficulties in implementing PAR can be anticipated. This section reviews potential problems and offers suggestions for addressing them. PAR data set has potential for being biased. PAR can present thorny problems, especially for researchers who are adhering to traditional principles. Foremost among these is the use of subjects to develop research about themselves. For some PAR projects, the team members are also the subjects of the research. This may be the case particularly when the overall number of subjects is low, and there is an inclination to include data on the PAR team members in the larger pool of data collected. In qualitative research this is less of an issue; however, in traditional research the PAR data set has potential for being biased by virtue of the team members' association with the project's goals, instrument development, and so forth. Some ways to handle this are:

- Use the PAR team members as a pilot or test group for data collection (such data are typically not included in the overall analysis);
- Use the team members as a unique sub-sample of information; and,

- Test whether there are significant differences between the data of the team and that of the remaining subjects, if there are none, then combine the two sets of data.

In our study, quantitative instruments were administered prior to the commencement of the team, thereby circumventing this problem. Qualitative interviews of team members were combined with those of the additional subjects.

Issues of Confidentiality

Confidentiality concerns may arise if team members have access to data on people they know. This may pose a problem for both the subject who may not realize that an acquaintance has access to confidential information, and to the team member who may not wish to know intimate information about peers or colleagues. Up-front discussion with the team about this problem can yield solutions such as:

- Use traditional methods such as numeric identifiers for protecting confidentiality;
- Ask PAR team members to excuse themselves from reviewing data of people they know;
- Make deliberate efforts to separate people who know each other (e.g., a team member does not interview someone they know); and
- Strongly emphasize and stress the importance of confidentiality with team members.

PAR May Be Time Consuming

Like anything “done by committee” and done democratically rather than autocratically, PAR has been cited for lengthening the research process. In this project we did not find this to be the case. External funding restraints and team members’ desire to see concrete progress prodded the research agenda forward. The work was completed in time frames consistent with other Center research projects. However, as discussed in the next chapter, we were aided by the fact that many team members had trusting relationships already established with many staff team members. When this is not the case, the time needed to build a trusting relationship between parties may have to be planned.

Fluctuating Participation

A steady group of representatives is advocated here. Such continuity should promote cohesion, the building of trust, sharing of power, and research outcomes. However, this is not always possible. Some projects call in

different groups of constituents at different or selected points of the project. Most likely these groups are better conceived as advisory panels than as PAR participants. Some groups may be steady but widely disparate, as in national projects. Clearly the objective here is to utilize all communication avenues to the fullest so a sense of group purpose can be established. Teleconferencing, video-conferencing, live television broadcast, and electronic communication can be helpful in this, as will occasional convening of the group at key points of the project.

Even when a steady and local group of constituents are convened, some attrition in the group must be expected. People will drop out or leave due to changing circumstances, changing interests, and changing health status. Further, PAR participation is likely to be an infrequent and unreliable source of income for some members and it may be abandoned when something better comes along. This may happen even after considerable investment has been made in the individual’s participation. Moreover, attendance is likely to fluctuate over meetings. Periods of absence due to hospitalization must be anticipated. Changes in team membership can affect group morale.

The best approach to these problems is to provide for them up front. Convening a team that at first has more members than is desired will solve inevitable attrition. Critical tasks such as leading a group is best planned by having several members trained for the same function so that anyone can step in for another in the event of an absence. Being prepared for recruiting new members over the life of the project is also necessary. Finally, a multi-step recruitment process that permits dropping out at several points may lead to a more committed team, and the provision of supports and accommodations over the life of the team may help team attendance. These last two points are explored in greater detail in Chapter 2.

Unmanageable Meetings

Professional researchers may imagine that PAR team meetings will be racked with conflict, brought off course with irrelevant discussion, or entangled by symptomatic or inappropriate behavior. As detailed in the next chapter, we found it necessary for the team as a whole to decide how team meetings would proceed, how decisions would be made, and how discussions would be handled. A more critical component for meeting success, however, was the presence on the team of people (either professional or non-professional) with strong clinical and group dynamic skills who could respond to and channel emerging problems. Group pressure to behave appropriately also helps. Accommo-

dations can be used such as individuals taking a break from the meeting and/or discussing problems on a one-to-one basis. Certainly, frequent scheduled breaks, refreshments, and a pleasant environment contribute to functional meetings.

PAR Erodes Research Rigor

Many researchers embarking on PAR fear that once power is shared, decisions will be made that compromise the quality of the research program. In NIDRR's policy statement on Constituency Oriented Research and Dissemination (Fenton, 1993) this problem is addressed by leaving final research decisions with the researchers and final interpretation of data and action steps with the constituents. Such an approach, although convenient, is actually not in keeping with original PAR implementation. The co-creation of theory and process by both sets of actors seems integral to PAR (Elden & Levin, 1991). Based on our experience with this PAR project, we found that in the end, it was never necessary for one party to wrest power from another to ensure good research decisions. What was necessary however, was a very careful elucidation of all the premises of research, how and why research preferences came to be, along with an honest appraisal of the "latent" goals of the individual researchers and of the sponsoring agency, such as publication in professional journals or sustaining organizational reputation in order to secure more funding. Equally necessary was an up front and totally honest demarcation of what was, and what was not, negotiable in the deliberations of team. For example, certain project goals, instruments or procedures used, or the roles of the professionals on the team may not be negotiable. With all of these cards "laid out on the table" we found the constituent team members to be eminently reasonable and that the research was only enhanced by their participation.

CHAPTER 2 *Operational Principles and Strategies*

AN INTRODUCTION

This might be called the “how to” chapter. From our own personal PAR experience, four interrelated operations emerged as crucial to effective project implementation. In some cases, we actually had the foresight to plan the activities related to these operations in advance; in other instances, the need to do them emerged from our mistakes and ongoing interactions as team members. In all cases, the activities we chose were those that we identified as necessary to achieve project goals while adhering to the values intrinsic to PAR. To reiterate, those values are: mutual respect, maximum involvement, informed decision making, and power sharing.

A BRIEF HISTORY

As background, we will first provide the reader with a brief summary of our actual project experiences with each of the four operations we found to be essential to productive PAR team functioning. They are:

1. Recruitment and Selection
2. Role/Relationship Clarification
3. Management and Supervision
4. Training and Support

Recruitment and Selection

A recruitment/selection strategy was devised to elicit interest from the highest possible number of potential members, while maximizing the possibility for long term commitment of team members. Former project participants were invited to participate in project orientation sessions in which the project was explained in more detail and explicit benefits and requirements of becoming team members were discussed so that attendees could decide if they felt willing and able to participate at the level the project required (see Figure 1). Of the 30 who attended these sessions, 12 elected to partic-

ipate in the research project. These individuals then participated in an individual interview during which further questions were clarified and individual concerns and needs were addressed. All individuals who still stated their intention to become team members were included on the research team. Of the 12 who elected to become team members, 2 chose to disengage during the course of the project and 10 remained as contributing team members throughout the project.

Clarifying Roles and Relationships

The various roles and responsibilities of team members were clarified initially and on an ongoing basis (see Figure 2).

Emphasis was placed on valuing all roles equally, based on the differential contributions of team members. All team members were considered to be offering expertise. Professional team members contributed their knowledge and skill concerning research methodologies while constituent team members contributed their expertise and perspective derived from having lived the experience of psychiatric disability. Team members with disabilities also brought a variety of technical knowledge and skill to the team, including data collection, process recording, data analysis, and data synthesis. Individuals had previous helping relationships with many project staff. Therefore, it was necessary to explain and differentiate the new relationships inherent in team functioning such as colleague and employer/employee.

Training and Supervision

Professional team members began by training themselves in the fundamentals of PAR, so that the project could be structured to adhere as nearly as possible to PAR principles. The research director on the project provided ongoing training for all team members in the fundamentals of research implementation, so that all members could make informed decisions that impacted the quality of research outcome. Team members with disabilities collaborated with professional team members on the feasibility and utility of various research methods when working with subjects who have psychiatric disabilities. Individuals with special talents and interest in actual implementation of research tasks were

FIGURE 1— Sample: PAR Fact Sheet for Career Education Program (CEP) II Research Project**What is the CEP II research project?**

CEP II is a research project designed to determine the long term effect of the original CEP program on the career paths of the participants.

What are the goals of the CEP II research project?

One goal is to identify the key factors that helped individuals who were in the original CEP project to identify and achieve their career goals. Another goal is to determine if Participatory Action Research (PAR) methods are useful tools for conducting this type of research project.

What is the PAR process?

Participatory Action Research (PAR) is a type of research in which the individuals who are the focus of the study participate as research team members with professional researchers in all research activities

Why is PAR being used for this project?

At the Center, we have always believed that the best rehabilitation outcomes are achieved through teamwork between our staff and our participants. The PAR method provides us with the opportunity to extend this belief into our research activities.

What does it mean to be a research team member?

As a team member, you will be paid to meet with the project staff on a regular basis to share your ideas and to help make decisions concerning all major aspects of the research project. You may also offer suggestions for what you think would work better. As you learn more about being a researcher, you may assume additional levels of responsibility for other aspects of the project.

What special competencies will I need?

For the most part, you will need to be knowledgeable about your own experiences in trying to reach your career goals. These experiences may be both good and bad, happy and unhappy, successful and unsuccessful. You will also need to be willing and able to describe your experiences and to participate cooperatively as a team member.

How will I benefit from this experience?

Some potential benefits include:

- Financial compensation of \$10/hour.
- A chance to gain research experience, knowledge, and skills.
- An opportunity to use your personal experiences, both good and bad, as a source of help for others.

How will others benefit from my participation?

Some potential benefits to other include:

- The development of a “user friendly” research method.
- The Center will have the opportunity to be a pioneer in a new type of research.
- Other people in the field of psychiatric rehabilitation will be able to learn how to improve services and research activities.

How much time will my participation as a research team member require?

It is likely that the PAR team will meet monthly for three hours for each of the next 12 months. It is possible that we will find it necessary to form smaller subcommittees of the team that will meet more often. It is also possible that we will find that there is a need to schedule more frequent meetings.

Is it possible to work in other aspects of the research project?

It is likely that the need for other job roles and functions will emerge. If your interest, experience, and abilities match those needed for these functions, you will be considered for the positions.

Will I be reimbursed for travel expenses?

Yes. You will be reimbursed for all expenses you incur that are directly related to the responsibilities of the research team.

What do I do if I want to be a research team member?

Let us know today or call one of us after this meeting. We will call you to set up an individual interview to confirm your interest. If, after the interview, it is a “Go” decision, we will complete the necessary paper work so you can be hired.

FIGURE 2— “WHO’S WHO” on the Current PAR Team**Principal Investigator**

The principal investigator is responsible for supervising all project activities and for making decisions about how project resources are used. Initially, (s)he will run the project management team. Later on, another team member may take over this task.

Research Director

The research director oversees all research activities and will act as a consultant to the team on research issues and methods.

Project Director

The project director is responsible for the day-to-day operations of the project. (S)he will be a resource to the research team in research design and methods as we make decisions about what we think will work best. (S)he will develop all of the instruments and procedures we use to gather, track, and analyze the information we collect. (S)he will also make sure that we are using the PAR method correctly.

Research Team Coordinator

The research team coordinator will organize team meetings and will be responsible for providing instruction and support to research team members. (S)he will be available to help team members who need assistance by acting as a “coach” for those who might need some help to fully participate.

Research Team Member

Research team members participate in all project activities. They will provide a personal perspective to guide the design, development, and implementation of all aspects of the research. They will participate equally in all decision-making. Those with special expertise may, if so desired, perform specific research tasks under the direction of the research director.

Research Assistant

The research assistant provides technical support to the project director and research team coordinator. On the team, she will supervise the PAR organizer who will handle all logistics for the team meetings. (S)he will also assist the project director and data manager with collecting and analyzing the data.

Evaluation Specialist

The evaluation specialist assists the project director and the research director with design and development of the project. Also, the evaluation specialist uses the instruments and procedures developed for the project to actually gather research information. (S)he will observe the procedures we are developing and will keep accurate notes that describe the procedures we use. This will help us to describe our activities in the project final report.

Research Associate/Data Manager

The data manager makes sure that all information gathered during the project is recorded and entered into the computer so that no data is lost. (S)he will make sure that we do not lose any information. (S)he will also be taking notes and recording the proceedings as we conduct our meetings.

PAR Organizer

The PAR organizer provides administrative support for the PAR team members. (S)he will handle all logistics for the monthly meetings. (S)he will make phone calls to PAR team members to confirm monthly meetings, record and distribute copies of the monthly meeting minutes, arrange for refreshments, and process travel reimbursements.

trained to perform these tasks and supervised by the research director. When expertise needed was not present in the team, outside experts were invited in to provide additional guidance and training.

Management and Support

The research director provided a schedule of tasks over time that required completion so the project could be finalized within the funding time frame. The team

selected a method for formative evaluation of the PAR experience. Within given agency and funding source parameters and constraints, all operational procedures were designed by the team. Team operations began with a discussion concerning the frequency and duration of team meetings as well as the choice of the type of decision making process that the team would use.

The project director and the research director assumed overall responsibility for all team activities. We found it helpful to fully differentiate management and

support roles for staff. This differentiation greatly reduced the possibility of role conflict when the demands of these two roles were mutually exclusive. For example, while management roles demanded a focus in group productivity, the support role focused on the needs of individual members (see Figure 3). A crucial management tool was the capacity of the project director to create and maintain an interpersonal climate, through skillful facilitation of group process, supportive of inclusion and involvement for all individual and collective efforts of the team. Another critical management tool was the capacity and willingness of the research director to simplify, translate, and manage research procedures in a style that operationalized this inclusion and involvement. Due to the nature of the severe disabilities present among the members, one professional staff member was assigned the sole responsibility of resource coordinator who was responsible for responding to individual requests for assistance/or accommodation. Any member who felt the need for a particular type of assistance or accommodation was referred to this staff person. The major accommodations requested and provided were reimbursement for extraordinary transportation expenses (one member traveled by train for an hour to attend meetings) and flexibility in time commitments. Logistical support for team operations was provided by a person with a psychiatric disability who was not from the subject pool. This person also provided reminders for upcoming meetings and follow-up calls to track the progress of between meeting assignments or sub-group meetings. During the meetings, she recorded the minutes and assumed responsibility for preparing and serving refreshments.

Finally, numerous other tasks required specialized roles, including interviewers (data collectors), transcribers, data analysts, instrument developers, and data entry personnel. After discussion, some of these roles were kept outside of the PAR team itself, although PAR team members could apply to participate in them. Other roles were kept within team functions, but individuals received compensation for additional time spent performing these tasks.

OPERATIONS AND RECOMMENDED ACTIVITIES

In the next section of this chapter, each operation is described briefly in terms of purpose and rationale. Then, the activities recommended for implementing each operation are described in some detail. While each of these operations is presented discretely, the imple-

mentation was not and cannot be linear (see Figure 4). Figure 4 illustrates how operational tasks may be distributed over the life of a project. In fact they occur contiguously and simultaneously. Obviously, the beginning point is selection and recruitment, but it is possible that it might be necessary to add new team members at any point in the team's "life span". The clarification of roles and relationships is an important part of recruitment and selection, but it is also necessary to perform this operation continuously. Training and supervision begins with the first informative project announcement, continues during recruitment and selection, and permeates team functioning. Management and support activities are the glue that cements all operations.

The activities within each operation, while conceptually discrete, are also highly interrelated. They are described here separately to give the reader a clear picture of the tasks required to conduct operations successfully. These activity descriptions can also be helpful as indicators of current capacity to conduct PAR in a particular setting. A group or individual contemplating a PAR project might "measure" the current level of resources, particularly the human resources, available in relation to the demands of performing the PAR activities described here. This diagnosis of capacity can also help identify gaps in knowledge and skill in of the professional PAR team members. Perhaps even more important, those contemplating a PAR project need to compare their agency's value system with the values found to be essential to promoting a productive and positive PAR experience. If agency values are antithetical to PAR, that is, if the agency that controls resources does not demonstrate through its existing policies and procedures *mutual respect, maximum involvement, informed decision making, and power sharing* with its' constituents, the probability of smooth and constructive implementation of PAR is dubious at best.

RECRUITING AND SELECTING RESEARCH TEAM MEMBERS

The goal for recruiting and selecting constituent team members with disabilities is to engage representative research subjects who are willing to contribute their knowledge and expertise to the research effort for the duration of the project. A strong commitment is required so that a fully functioning team will sustain productive activity through project completion. PAR is a new endeavor in the attempt to include and to partner with people who have psychiatric disabilities in

FIGURE 3— Functional Sketch of Key Management and Support Roles

	KEY STAFF FUNCTION	MAJOR DUTIES	PREFERRED COMPETENCIES
MANAGEMENT	Project Management	Oversee project implementation Conduct team meeting Recruit, hire, and supervise team members Manage resource allocation Assure project completion	Previous experience with project management Skills and experience in facilitating group process Excellent interviewer skills Experience working with people who have psychiatric disabilities
	Research Management	Schedule research tasks Facilitate research decisions Teach research skills Maintain research integrity	Broad knowledge of methodology Experience with shared decision making Teaching skills and experience Commitment to PAR philosophy
SUPPORT	Research Team Coordination	Define consumer team member needs Develop and manage special accommodations and individual resources Provide direct support to team members	Ability to “connect” individually Ability to define individual needs Skills/experience with individual resource management Knowledge of psychiatric disabilities Skills in developing accommodations
	Logistics Coordination	Maintain contact with team members between meetings Document team-meeting proceedings Purchase and prepare refreshments	Good organizational skills Good telephone skills Personal experience of psychiatric disability Good listening skills Good writing skills Good conversational skills

serious research and evaluation efforts. Therefore, there are no studies to guide the development of recruitment procedures and selection criteria. Past experience, and some research data from vocational and employment projects, does suggest that one of the single best predictors of program completion is personal investment and motivation. That is, people who choose to be involved freely and in relation to their own personal goals, are

more likely to “stick with it” than those who are chosen by professionals according to professionally derived criteria.

The recruitment and selection process suggested here reflects both state-of-the-art knowledge and the values inherent in PAR. Recruitment is a professional staff activity designed to cast a wide net for potential members. However, team members elect to participate by

FIGURE 4—Examples Of Operational Tasks By Research Project Phase

PHASES OF RESEARCH PROJECT ACTIVITY ^D		
PAR OPERATIONS ^F	Project Start-up	Research Design and Instrumentation
Recruitment and Selection	Identify potential team members Develop the process to promote effective self-selection	Bring on new team members if needed over the course of the project
Clarifying Roles and Relationships	Developing role function descriptions of all team members Differentiate relationships from previous personal experiences	Review competencies brought to the team by the research director and those brought by consumer members
Management and Support	Assure availability of financial resources to pay consumer team members Hire resource coordinator and logistics manager Select, with all team members, procedures for meeting management, decision making, and conflict resolution Arrange times for orientation meetings to assure access for the majority of interested applicants	Manage team and meeting discussions to ensure timely decision-making and inclusive, respectful process Manage team process to assure timely and appropriate creation of instruments Identify any individual accommodation/support needs of consumer team members
Training and Supervision	Training for professional staff on PAR values and philosophy Basic project awareness training for all interested members of the subject pool Train or orient organizational supervisors to PAR approach	Train team on research design alternatives, their ramifications and purposes Train team on alternatives for instrumentation and requirements for designing new instruments

FIGURE 4— (continued)

Data Collection	Data Analysis	Interpretation and Dissemination
<p>Develop job descriptions for data collectors</p> <p>Design hiring process with team</p> <p>Hire data collectors</p>	<p>Recruit team members or outside research assistants for data analysis</p>	<p>Hire outside assistance for product production as needed</p>
<p>Define nature of Interviewer role</p> <p>Address potential role conflict between being a data collector, a research subject, and a research team member</p> <p>Delineate relative responsibilities of consumer and professional members in hiring data collectors</p>	<p>Clarify difference in relationship with research director performing specific research tasks (employee/employer) versus performing general team member functions (collegial)</p>	<p>Provide opportunity for co-learning and co-location of theory between consumer and professional team members</p>
<p>Address specific accommodation/support needs of data collectors</p> <p>Manage team decision making on data collection procedures</p>	<p>Address specific accommodation/support needs of preliminary data analyzers</p> <p>Manage team decision-making on data analysis approach and implementation</p>	<p>Manage team decision-making on data interpretation and on dissemination activities</p>
<p>Train data collectors on basic data collection requirements, i.e., procedures used, demeanor, responses to anticipated problems in data collection</p> <p>Orient team to data collection issues and strategies</p> <p>Supervise work performance of data collectors for quality and timeliness</p>	<p>Train all team members on nature of data analyses</p> <p>Train specific team members to complete preliminary data analyses</p> <p>Supervise work performance of data analyzers for quality and timeliness</p>	<p>Review dissemination alternatives and their purposes</p>

well constructed, sequenced exploratory tasks that maximize the amount and quality of information they receive. A multi-stage recruitment process allows people to “opt out” at varying points, thereby facilitating selection of a group of people more likely to sustain involvement for the project’s duration. In all recruitment activities, professionals provide assistance with processing new information that will facilitate a thoughtful decision. Recruiting and selecting research team members involves:

- Advertising the PAR opportunity,
- Orienting potential team members, and
- Obtaining team member commitment.

Advertising the PAR Opportunity

Advertising the PAR opportunity is announcing the possibility for team membership to the entire research subject pool. Informing the entire subject pool assures the broadest possible representation for team membership. The announcement may take the form of a brochure or a personal letter. The letter approach is particularly effective if it is sent from an individual with whom potential members have a past or present positive relationship.

Within the announcement, it is important to include a brief description of the project, the reason for inviting participation, the general requirements for team membership, the potential benefits to both the individual and to the larger group, and a scheduled time and place (more than one if possible) for attending a project orientation session. A tear-off form that indicates the potential member’s intentions concerning further involvement as well as the preferred orientation session and personal contact information such as phone number and preferred times for phone contact will help project staff to make arrangements for the orientation sessions and provide means for more direct communication. A stamped self-addressed envelope will enhance the probability of a better return rate. It is also helpful to identify a project contact person and a phone number that the potential team member can use to obtain more information before deciding to attend the orientation session.

Orienting Potential Team Members

Orienting potential team members is informing potential members about the details of the project and the role and responsibilities of a research team member. A concrete image of the expectations and benefits associated with joining the team is presented so that each individual can make an informed decision about mak-

ing a commitment to the project. One of these benefits is financial. The spirit of PAR suggests that constituent team members must be paid for their time and effort and reimbursed for travel expenses, as are professional members. Payment for services also helps to define the nature of expectations. This must be made explicit, as it presents a potential risk as well as a benefit, since most team members receive SSI benefits that might be affected. Face-to-face meetings are the preferred mechanism for project orientation. A small group format can be useful because the small numbers provide the opportunity for dialogue but also maximize the efficiency of project staff time. The structure and process of a small group also simulates the interpersonal and cognitive nature of research team activities. A project fact sheet is a useful tool for providing information in simple terms, free of (see Figure 1).

A job description for a research team member position presents the range of knowledge and skills that will be helpful in performing research team functions. This description should be general at this point, since specific skills will be acquired by participation in research team activities. A thorough discussion of potential demands and benefits of team membership helps individuals to consider the physical, intellectual, and emotional implications of becoming a team member. The staff member who conducts the orientation session should be a skilled facilitator, one who can help individuals to examine the information presented from their personal frames of reference. Structuring the length of the orientation session to correspond to the possible length of time for a research team meeting provides an immediate and concrete experience that individuals can use to judge their ability and desire to engage in group activity for such a time period. Providing an exercise that represents a simple research task such as reviewing research instruments or tabulating frequencies offers an opportunity for individuals to gauge their interest in research activity.

Obtaining Team Member Commitment

Obtaining team member commitment is confirming the individual’s desire and willingness to fulfill the role and responsibilities of becoming a research team member. Obtaining commitment verifies the person’s intention to be a full participant in research team activities. Individual conferences with a project staff member offer the best venue for obtaining commitment because the person can freely discuss questions and concerns that are unique to his/her situation. As was true with the orientation conductor, the staff person who conducts the conferences must be a skilled facilitator, one who can help the potential member to

examine both the emotional and intellectual content of his/her decision.

Summary

Team member recruitment and selection is a process of providing maximum access and thoughtful consideration for members of the subject pool so that they can make informed decisions about accepting and fulfilling the role and responsibility of becoming research team members. This multi-step process is time consuming and labor intensive. However, judicious and effective investment of staff effort during recruitment and selection will minimize attrition during project implementation and lay an important foundation of trust between professional and constituent team members. The length of time allotted to this form of recruitment and selection process will also vary widely depending upon the nature and strength of a pre-existing relationship between the researchers and potential constituent team members. Researchers who have no previous personal history with the members being recruited should anticipate a lengthier recruitment effort and the potential need for more orientation time. Additional incentives, such as paid attendance at pre-selection activities, may increase the numbers of applicants willing to consider team membership.

ROLE/RELATIONSHIP CLARIFICATION

Participatory Action Research may be a new experience for both professionals and for people with disabilities. In some instances, it may be a first encounter between team members in any context. In other instances, previous relationships between team members may have been in another context. In any instance, new roles and relationships will require members to interact in prescribed ways that are likely to be very different from previous experiences or expectations. Members must develop trust in one another to perform necessary functions competently and respectfully. This trust will develop only if individual members understand and accept the requirements of the various personal and professional interactions inherent in research team activities.

Developing this trust is not an easy task. In most instances, previous interactions between mental health service recipients and professionals have been encumbered by a serious imbalance of power, with professionals being the most likely to control the terms of the interaction. People with disabilities and professionals with no previous experience with one another may

bring stereotypes and assumptions derived from former bad experiences or from no experience. People with disabilities may view professionals with apprehension and doubt that they can truly be open to the experience of disability, or that they can be allowed access to that experience without passing judgement. Mental health professionals may harbor doubts that untrained individuals, particularly those with psychiatric disabilities, can fully contribute to a research effort. They may, in fact, be concerned that such serious activity as research may have a detrimental effect on the consumers' mental health. When team members do have previous experience with working together, but in a context other than research (such as client/staff), there may be a tendency to revert to interactions inherent in these old relationships rather than those required by the new roles.

The goal of Role/Relationship Clarification is to explain differential responsibilities of team members so that historical preconceptions are eliminated and confusion concerning performance expectations is minimized. This clarification is equally necessary for both professionals and constituent team members. It is also essential that this be both an initial and an ongoing activity. Clarifying roles and relationships involves:

- Identifying essential member functions,
- Defining performance requirements, and
- Communicating expectations.

Identifying Essential Member Functions

Identifying essential member functions is distinguishing the unique roles that individual team members must fulfill for the entire team to work efficiently and effectively. Identifying essential member functions specifies the range of roles necessary for productive teamwork. Clarity in these roles facilitates all research team operations and helps to structure team makeup and interactions.

The range of roles in any PAR team will be dictated by the goals for the research. However, it is likely that the types of roles that will be needed for PAR teams that include members who have psychiatric disabilities will include, at a minimum, a research director, a project director, research assistants, a member support coordinator, a logistical support specialist, and, of course, team members with disabilities who can offer their experience and expertise as the contextual basis for the research effort. One person may play several roles; conversely, roles may be shared by two or more people. It is also likely that new roles will emerge and role demands will change during the course of the research. As constituent team members become more skillful and

knowledgeable, they may, in fact, assume many of the roles initially played by professionals. If PAR activities are implemented in the true spirit of PAR principles, mutuality will grow, and power will be redistributed so that, over time, professional members may find themselves acting much as consultants to a newly emerging group of competent researchers.

Defining Performance Requirements

Defining performance requirements is specifying the demands of each role played by team members. In essence, it is a job description that describes the range and variety of activities inherent in role performance. These role definitions are equally important to professional and constituent team members as they serve as guidelines for behavior that contributes to team performance. Clarity concerning these requirements helps team members to modify behaviors that might interfere with the goals of the research team. For example, a project manager might also be a program manager in a program where a consumer team member is a client. These pre-existing and sometimes concurrent roles dictate that they behave and relate as staff and client, while their current roles require that they behave and relate as colleagues. As another example, two constituent members may be friends, but in the context of PAR, one may be in charge of a research team activity that requires giving direction and feedback to the other. Clarity concerning the requirements of role performance helps members to identify their learning, accommodation, and support needs. For example, a professional team member who is a program manager may need to learn how to design a research survey. Or, a constituent team member may need to have additional coaching so that (s)he feels confident in presenting personal ideas in a group. Or, a researcher may need to learn how to teach, so that (s)he can share the information needed for all team members to make good research decisions.

Communicating Expectations

Communicating expectations is informing team members about the role demands of all team members and the nature of the relationships between the roles. Communicating expectations makes requirements for productive team operations explicit. Expectations will vary according to team roles. For example, if a constituent team member functions contemporarily as research assistant, (s)he may find that operating under the direct supervision of a professional team member involves meeting stiffer expectations than does the role of generic team member. Dual roles are always confusing for anyone; for someone who is assuming new roles and

responsibilities that are unfamiliar as well as complex, the experience can be overwhelming, particularly if pre-existing relationships cloud the picture. Professional staff must assume responsibility for explicitly defining roles and for making role requirements, and their potential sources for conflicting messages, clear to constituent team members. To the degree possible, these expectations should be communicated initially during the recruitment and selection process. However, since PAR is an organic and dynamic methodology, new roles and relationships will emerge throughout project duration. As this happens, new role definitions and performance expectations must be developed and disclosed so that necessary shifts in relationships can occur. Ideally, such disclosure will occur before the fact. However, in reality the first indicator that this has happened may be a role conflict within the group. When this occurs, the project manager, or another observant team member, will need to help the team to “call the question” and to redefine team member functions so that expectations for role performance are clear and the source of the role conflict is removed.

Since members will differ in their capacity to receive information, it is important to communicate expectations in as many media as are necessary given the PAR team membership. Preparing and sharing information in written form is extremely useful since it provides a reference point for other forms of communication. Explaining, and in some cases demonstrating the behaviors involved in role performance may be necessary to achieve maximum communication. For example, the research director may want to show how data is entered into a computer, or the project manager may demonstrate how (s)he will manage a team member disagreement. Also, while much of the communication will occur within the context of a PAR team meeting, there will be instances when some members may want and need individual conferences and discussions to fully understand the information presented.

It is also crucial to create mechanisms and a forum through which the consumer team members can feel safe in communicating their expectations of professional team members, particularly in expressing what adjustments or accommodations would be most likely to help them be full participants in the team member role. For example, one participant may need frequent calls between meetings to remain engaged; another may need a wake-up call; yet another may require an opportunity to meet with a staff person after a meeting to clarify information and to discharge anxiety. In our project we found that inviting and assisting team members to identify and communicate their needs, either within the group or with the resource coordinator removed many barriers to participation.

Summary

Participatory Action Research frequently requires team members to perform in unfamiliar roles and relationships. Therefore, it is useful to describe these fully so that team members share a common image of their own roles, the roles of others, and the nature of the relationships between the roles. The dynamic quality of PAR necessitates that this be both an initial activity and an ongoing strategy for promoting productive team functioning.

TRAINING AND SUPERVISION

The many roles required for effective PAR team operation require a wide range of knowledge and skills. Some will be more skilled and knowledgeable than others will, and there will be some roles that require knowledge and skill that few if any team members possess. The diverse knowledge and skills brought to the team by all members strengthen its potential potency. However, unless attended to fully, discrepancies in experience can divide rather than unite team activities. To overcome possible team fractures, learning is essential for all members. Shared knowledge increases the possibility for all members to contribute equally to research decisions; shared skills improve overall team competency. The vehicle for sharing knowledge and skill among team members is training and supervision. Training is the formal provision of instruction to equalize team member knowledge and skills. Supervision is the surveillance and guidance of a less knowledgeable or skilled individual by one who is more skilled or knowledgeable. The goal of training and supervision is to maximize the knowledge and skills of all team members, so that group and individual performance is enhanced. In this context, both training and supervision are identified as sources of learning for PAR team members. Training and supervision involves:

- Determining learning needs, and
- Structuring learning opportunities.

Determining Learning Needs

Determining learning needs is defining gaps in team members' knowledge and skills that are necessary for the team to complete research goals. Determining learning needs identifies the focus for learning activities. Professionals are selected to be team members because they have expertise and experience with selecting, applying, and implementing research methodology; constituents

are recruited for the team because of their personal knowledge of the context of living with the experience of psychiatric disability. In general, then, if the "playing field" is to be equalized, and the research is truly to be a team effort, expertise and experience must be shared among all members. It is also likely that all team members may share some common knowledge or skill deficits that only an external "expert" can remediate. The most important step in determining learning needs is to acknowledge their common existence. Setting a tone that establishes the reality and assumption of ignorance as inherent in all team members helps to diminish the presumption of a higher order of value being placed on any member's knowledge or skill. Some learning needs of team members will be clear initially, as the goals of the research project are explored. Others will emerge only as the project progresses. The key is to establish a climate of openness and honesty among team members so that any member feels safe in expressing a lack of knowledge or skills and confident that, if need be, the resources of the project will be targeted on developing what is essential for full team participation.

Structuring Learning Opportunities

Structuring learning opportunities is arranging chances for all team members to acquire new knowledge and skills. Structuring learning opportunities creates the possibility for addressing and overcoming gaps in needed knowledge and skills. Opportunities for acquiring research knowledge and skill are best created as an inherent part of PAR team meetings. It is clear that, if all team members are to make informed decisions on all aspects of project implementation, they must have, at least, an understanding of the research process and the varying methodologies that promote it. They must also know the potential consequences of the choices they make. One way to assure this shared knowledge base is to incorporate formal processes for instruction and information sharing into team meetings.

At every new phase of project implementation—overall design, instrument development, data collection, data analysis, and data interpretation—the researcher on the project takes responsibility for instructing the team in the nature of the activities involved; the possible alternatives for implementing the activities; and the research implications, positive and negative, for selecting each of these possibilities. Handouts, comparative charts of typical research tasks, reprints from elementary research textbooks or like materials, will promote understanding. Didactic presentations that de-mystify research and present it simply and elementally without compromising research princi-

ples or integrity help to remove informational and emotional barriers for participants.

Using our project as an example, under the topic of research design, the project director presented a summary of different types of research (e.g., experimental, quasi experimental, survey, and qualitative exploration) their methods, and implications of their use. A survey design was selected using a semi-structured interview format. When the instrument development phase was initiated, the director distributed materials on proper question development. Survey questions were generated through a prompted brainstorming session, and several team meetings and committee meetings were used to further reduce and refine the questions. With the instrument finalized, the team met on data collection procedures. The team decided on face-to-face Center located interviews, using consumer interviewers. The professionals delineated the administrative and supervisory mechanisms necessary for developing a cadre of interviewers. Team members revised interviewer job descriptions, hiring procedures, and participated in hiring selections. Potential interviewers were drawn from the PAR team and from clubhouses and drop-in centers. Supervision and training of interviewers and general management of data collection occurred outside team auspices. In pairs, team members conducted data reduction activities. After reviewing several ways in which interview data can be analyzed, the team chose "concept mapping" (Trochim & Cook, 1994). This proved to be a highly successful method for providing equal representation among team members for categorizing, labeling, and interpreting data.

When presenting research "how to's" and what for's" the presenter must convey respect for those who are hearing these principles for the first time. The presenter must also communicate faith in the capacity of the learners that they can truly understand and come to be able to use these principles. Once it is clear that all team members have a functional understanding of the research perspective, the team process can then be structured to allow consumer team members to teach professional staff about the feasibility and impact of implementing possible research strategies within the frame of reference of someone who has a psychiatric disability. For example, while an open-ended questionnaire has the benefit of eliciting the most information from a research subject, the lack of structure in such an instrument may be experienced by someone with a thought disorder as disorienting and anxiety provoking. As another example, while a standard instrument for evaluating "quality of life" may promote comparisons with other normed samples, the content may have no relevance to a particular constituent group who has quite a different definition of quality of life. Structuring

learning opportunities within team operations ensures that selected research activities reflect the informed perspectives of all team members.

Team members who not only select to participate in, but also to conduct research activities, may require skill training and supervision. For example, team members may assist with data collection or data analysis. If not previously skilled in these techniques, they will need some explicit instruction and supervised practice to assure their competence, before actually implementing these tasks. It is probable that not all team members will want to be involved in all tasks, nor does supervision necessarily occur within the PAR team meetings. Therefore, opportunities for acquiring and perfecting these skills will necessarily occur at additional and/or adjunct sessions. These fledgling researchers will also need individual or group supervision throughout the duration of the activity, just as any junior researcher would require. In addition, the professional members of the team may wish to conduct ongoing peer supervision for themselves to monitor and correct impulses to assert control inappropriately.

As a framework for assuring adherence to PAR principles, the entire team may want to conduct peer supervision. One strategy for building this framework is a periodic process review of past meetings and personal team member experiences. An overall project evaluation, designed and conducted by the team (guided by standard evaluation standards), is also warranted.

Summary

If knowledge is power, then sharing knowledge is sharing power. For PAR to achieve its aims, sharing power among team members is essential. Training and supervision are an efficient and effective means of power sharing. When opportunities for learning become an essential operation within the team process, fear of losing power or having it supplanted is diminished, team productivity is promoted, and the rigor and meaning of research is enhanced.

TEAM MANAGEMENT AND SUPPORT

In the final analysis, the goal of the PAR team is to complete all research tasks efficiently and effectively so that project goals and objectives are achieved. Accomplishing this outcome requires both management of, and support for, team and individual member functioning. It is crucial that while the values of the PAR process are honored, the intention of the research project

remains primary. The integrity of the project requires organizing team activities that balance the honoring of a PAR philosophy with facilitating the achievement of intended research outcomes, according to accepted research standards and within established time and operational commitments. This is best achieved by full disclosure by professional staff of information concerning both the PAR process and the research goals and objectives with all team members so that time lines, outcomes, operational parameters and restrictions, and external expectations imposed by such sources as governing and/or funding bodies are clear to all. Where true limits to power sharing exist, they must be honestly acknowledged. For example, if the funding sources expectations or organizational policies will supersede team decisions, this must be known by all members. It is essential that actual degrees of freedom for team decisions be clear at the outset so that trust in the process is not violated. Given this common information base and understanding of operational limitations, the team can establish both management and support structures that will facilitate project implementation. Managing and supporting the PAR team involves:

- Determining management and support needs,
- Formulating operational strategies, and
- Assigning responsibilities and resources.

Determining Management and Support Needs

Determining management and support needs is defining the activities required to help team members, both as a group and as individuals, to work at maximum capacity to accomplish project goals and objectives. Identifying these activities clarifies operational procedures for the team. It also helps to differentiate management activities from support activities, that is, those procedures that provide control and direction to project efforts versus those that strengthen and sustain team member participation. It is important to differentiate these activities since their implementation sometimes involves conflicting role expectations. For example, while management activities require someone to keep the group on task, support activities may require diverting attention from the group to focus on individual needs. Examples of management activities include the establishment of meeting times and places; creating resources and payment mechanisms for compensating and reimbursing consumer team members; selecting a structure for the agenda; creating, organizing, preparing for, and implementing group activities; and selecting a group decision model and decision-making method (e.g., majority rule versus consensus building). Examples of support activities range from providing basic

logistical and clerical assistance, such as typing and copying materials, recording minutes, and obtaining and preparing refreshments, to accommodating individual disability needs, such as providing individual assistance with reading the materials, providing tapes of sessions to members who are absent due to illness, and arranging for “coaching sessions” for people who experience emotional barriers related to group participation.

To some degree, determination of management and support needs can begin in advance of the actual establishment of the team. In the best of circumstances, people with disabilities would be involved in early phases of project design and relevant discussions of needs could be included as part of the project planning process. However, in many instances, actual constituent involvement does not occur until a research project has been funded. In this case, project professional staff can use previous experiences to hypothesize what some of these needs might be. However, final conclusions can not be made without team member input.

Formulating Operational Strategies

Formulating operational strategies is creating procedures that address defined management and support needs. These procedures clarify what, when, and how management and support needs will be met. Clarifying these procedures makes operations explicit and minimizes the possibility for confusion. In so far as possible, all members of the team should be involved in the discussion, creation, and approval of these procedures. When procedures have been developed in advance of the creation of the team, they should be examined and modified to include team member perspectives. When modifications are not possible due to external organizational requirements, limitations on these possibilities should be presented as one of the parameters of the discussion. As mentioned previously, a formative evaluation process can also provide a useful methodology for monitoring the effectiveness of project management.

Assigning Responsibilities and Resources

Assigning responsibilities and resources is specifying accountability and allocating project assets and supplies to ensure that selected procedures will be implemented as designed. Specifying accountability diminishes the possibility of confusion and role conflict. Allocating project assets defines the portion of the project’s budget that will be needed to make effective management and support a reality. Examples of helpful supports are personal accompaniment while traveling to team meetings, scheduled phone contacts between team meetings, reimbursement for extraordinary transportation

costs, child care, meeting refreshments, and telephone time with professional staff to review personal concerns and fears regarding performance as a team member. When implementing PAR with people who have severe psychiatric disabilities, it is advisable to set aside a sizeable portion of the budget for the support function. In fact, since support needs will vary widely and sometimes may require intensive staff involvement, it is recommended that responsibility for the support function be assigned to a professional member of the staff who can devote full attention to this function when needed. For example, a team member who experiences an exacerbation of symptoms that requires hospitalization, may want and be able to continue team participation while hospitalized if kept informed and assisted to make contributions to the team activities. This additional effort may require a professional team member to visit the hospitalized member so that (s)he can continue to engage in some team activities although (s)he is unable to be present physically. Segregating this function also helps to reduce the potential for staff to experience conflicting role expectations that are inherent in the performance of management versus support activities. In addition to professional staff, there may also be constituent members who want to and can assume a level of responsibility for support activities. However, it is important that this activity not be left to constituent members by default.

Summary

Successful attainment of research project goals requires well developed management and support strategies specifically designed to address individual and group needs. Considerations regarding responsibility and resource assignment are best made as the project is being designed and proposed. However, changes recommended by team members with disabilities during project implementation may require a reconsideration of original budget allocations. Since management and support activities are often inherently adversarial, it is important to differentiate them in terms of procedures and staff responsibilities. In a PAR project, it is also essential that the strategies selected for management and support be based on operational principles that reflect the values of mutual respect, maximum involvement, informed decision making, and power sharing. Adherence to these principles may require redistribution of project assets to assure the availability of appropriate resources and support for individual team members who experience barriers to participation which are associated with their psychiatric disabilities. Mechanisms, such as some type of formative process evalua-

tion, are useful for improving faithful replication of the PAR paradigm.

CHAPTER **3** *Some Final Thoughts*

A few final thoughts are shared below regarding the implementation of PAR with people who have psychiatric disabilities. These reflect constituent observations from both the formative evaluation of the PAR project and from the musings and resulting surprises of the professionals engaged in the PAR project. While originating from this unique experience with PAR, we believe they can be generalizable enough to the PAR process as a whole to be useful to readers of this handbook.

**OBSERVATIONS OF TEAM MEMBERS
WITH PSYCHIATRIC DISABILITIES**

As noted in the “how to” section of this handbook, a formative evaluation of a PAR project is essential to good project management, as well as being academically interesting. Doing so reflects not only a sound research principle, but when done as a process evaluation over the course of the project, it can serve as a self-correcting mechanism for potential problems such as: professional dominance in decision-making or discussion, insufficient information or support for team members, poor communication, or absence of trust. For this project, the team selected a reflection and review process, scheduled quarterly during which members shared their experiences, verbally or in writing, of being on the team. The discussion was tape recorded, transcribed, analyzed for content themes by one of the constituent team members, and then reviewed and revised in a team discussion. The content analysis showed that the discussion themes could be grouped under three rubrics of: reflections (made on the PAR process), values (that permeated the PAR experience), and PAR methods (as assessed by the members).

Overall, constituent team members consistently reflected on their enjoyment of actually being able to participate in (and not just hear or learn about) a research project. This fostered a sense of accomplishment, a sense of competence, an appreciation for the experiences and learnings they brought to the PAR team, along with the development and utilization of skills. Among the PAR values identified by members were authenticity, equality, worthiness (both of them-

selves and of the project), trust, co-learning or mutuality, and camaraderie. As for beneficial methods, members noted: the helpful provision of boundaries and structure, knowing what is “not negotiable,” having sufficient information, the de-mystification of research, and the empowerment of participants. Such evaluations gave the professionals confidence that the process (as well as the product) was developing appropriately.

OBSERVATIONS OF PROFESSIONAL TEAM MEMBERS

The reflections of the professional team members are categorized and described below.

PAR Works

Embarking on PAR with people who have psychiatric disabilities can be daunting. With no previous experience or models in the literature, we had no way to forecast the problems we might encounter nor our ultimate success. However, we found that each meeting of the PAR team increased our enthusiasm and confidence in PAR and in our decision to apply this methodology to this project. Research material and information presented was readily and correctly absorbed by members. Intelligent and lively discussion ensued. Decisions were made. The research program moved forward and was completed. Moreover, the decisions reached by the team were all sound, they resulted in successful and quality research, and they were often different from, and better than, the decisions that might have been made had the professionals acted alone.

PAR Is Manageable

There were no occasions when members’ psychiatric disabilities or limited research experience posed uncontrollable interactions or obstacles to project goals. As psychiatric rehabilitation service providers, our knowledge of and familiarity with the probable needs of constituent members led to the inclusion of specific support roles and functions by designated professional team members. These support functions built into the team and the clinical capacities of some of the profes-

sional members contributed to our ability to anticipate potential sources of difficulty and to create and manage conditions that facilitated constructive engagement and problem solving. Researchers who lack direct service experience with this population may want to include some team members who have direct service experience to design and implement strategies that promote maximum collaboration among all team members.

PAR Energizes

Professionals were also surprised to find that having succeeded in convening a committed, well-informed, and trusting team, an *esprit de corps* or camaraderie emerged. Meetings were marked by humor, open and genuine communication, and by respect and mutual learning. While attendance did vary for each meeting, and all members needed several prompts around meeting times and commitment, on the whole, most meetings were stimulating and enjoyable.

PAR Illuminates

An assumption of PAR is that professionals cannot fully know the experience of the subjects of their research, in this case, people with psychiatric disability, and that subject input is essential for appropriate construction and implementation of theoretically sound research. This assumption bore true. Repeatedly, constituent input overturned the expectations of the professional researchers. Their participation widened research aims, narrowed methodological dilemmas, illuminated areas not seen by researchers, made instruments or processes more sensitive, and brought forward the needs of consumers—including needs for greater involvement and responsibility. This is not to say that team members must be highly educated. Educational status among team members varied from virtual illiteracy to master's degrees. What was essential was the professionals' willingness and ability to show respect, appreciation, acceptance, and inclusion of the viewpoints of all members irrespective of how articulately or eloquently expressed. Basically, to be true to PAR values and principles, professional team members had to "walk the walk" instead of just "talk the talk."

IN CONCLUSION

Professional researchers in the fields of mental health and psychiatric rehabilitation are increasingly called upon to abandon their academic ivory towers and to conduct research in the "real world" that reflects the reality of the people it is supposedly designed to help. To do so with integrity, researchers must find methodologies that can integrate rigorous designs with meaningful questions. Ultimately, the meaning must come from the lived experiences of people who have psychiatric disabilities. The rigor must be derived from the pooled experience of skilled researchers. We believe that the paradigm that offers an opportunity for this unique blend of meaning and rigor is Participatory Action Research (PAR). We hope that this handbook can provide a foundation and framework for professional psychiatric rehabilitation research professionals and people who have psychiatric disabilities to launch new and exciting joint research efforts that honor the experience and expertise of all who would choose to be PAR team members. We believe that all constituents of mental health and psychiatric rehabilitation will gain much from both the process and outcome of such endeavors.

REFERENCES

- Elden, M. & Levin, M. (1991). *Cogenerative learning*. In: *Participatory Action Research*, Whyte, W.F. (Ed.). Newbury Park, CA: Sage Publications.
- Fenton, J., Batavia, A., and Roody, D. (1993). Proposed Policy Statement on Constituency-Oriented Research and Dissemination. Washington, DC, DOE/NIDRR.
- McTaggart, R. (1991). Principles for participatory action research. *Adult Education Quarterly*, 41(3), 168-187.
- Rogers, E.S. & Palmer-Erbs, V. (1994). Participatory Action Research: Implications for research and evaluation in psychiatric rehabilitation. *Psychosocial Rehabilitation Journal*, 18(2), 3-12.
- Rosenwald, G.C. (1988). Toward a formative psychology. *Journal for the Theory of Social Behavior*, 18(1), 1-32.
- Trochim, W., Cook, J.A., & Setze, R. J. (1994). Using concept mapping to develop a conceptual framework of staff's views of a supported employment program for individuals with severe mental illness. *Journal of Consulting and Clinical Psychology*, 62(4), 766-775.
- Walton, R. and Gaffney, M.E. (1991). Participatory action and participation. The merchant shipping case. In: *Participatory Action Research*, Whyte, W.F. (Ed.). Newbury Park, CA: Sage Publications.
- Whyte, W.F. (1989). *Participatory Action Research*. Newbury Park, CA: Sage Publications

**LONG-TERM OUTCOMES OF PARTICIPANTS IN A
CAREER EDUCATION PROGRAM FOR YOUNG ADULTS
WHO HAVE PSYCHIATRIC DISABILITIES**

Briefing Paper No. 1 of 3

Between 1985 to 1989, 50 young adults with psychiatric disabilities participated in a study investigating the effects of a career education program, based on the choose-get-keep approach to psychiatric vocational rehabilitation. This program, held on the Boston University campus consisted of both classroom instruction and intensive professional and peer support). In the original study, participants showed significant gains in self-esteem and in educational/vocational status, as well as a significant reduction in hospitalization rates, when comparing measures taken prior to and post participation (Unger, Anthony, Sciarappa, & Rogers, 1991). In 1995, a follow-up study, funded by the National Institute on Disability and Rehabilitation Research (NIDRR Grant #H133G20070), determined the long term outcomes (5–8 years) of participants in this study. Measures used during the first study were re-administered to ascertain stability of gains. In addition, a quality of life measure was also administered.

Summary of Major Findings

- The significant gains initially found for current employment were maintained.
- The significant gains initially found for current educational enrollment were not maintained.
- Significant gains in being currently involved in either work, education or training were maintained.
- Significant gains in self-esteem scores were maintained.
- Significant reduction in hospitalization rates were maintained.
- Quality of life scores tended toward the middle range of a seven-point scale of “terrible” to “delighted.” Lower self ratings were noted for satisfaction with the amount of pay, overall income, and hours worked. Higher rates of satisfaction were found for living arrangements, and availability of medical care.

Conclusions and Recommendations

This study suggests that most of the positive effects of the university-based career education program were maintained following a minimum of a 5 year hiatus from the program. Future research using a randomized control group design is necessary to rule out whether these gains would have been achieved and maintained without the intervention. The lack of significance of educational gain as measured in the current study is interpreted as the natural trend not to remain in an educational setting beyond the time needed to complete the requirements of the program. The continued significant reduction in hospitalization suggests that individuals who are pursuing career development goals are not using high cost medical services. A new measure of quality of life suggests that subjects were at least moderately satisfied with their overall circumstances.

Programs which serve young adults with psychiatric disabilities should consider providing a career education intervention to improve the long term possibility for vocational achievement and personal success and satisfaction.

Systems that fund programs that serve young adults with psychiatric disabilities should invest in career education program interventions such as the one provided by Boston University as a mechanism for potentially reducing future medical costs.

References

- Unger, K., Anthony, W.A., Sciarappa, K., & Rogers, E.S. (1991). A supported education program for young adults with long-term mental illness. *Hospital and Community Psychiatry, 42*(8), 838-842.

For further information please contact:

Marsha Langer Ellison, Ph.D.
ellison2@bu.edu

Home page: <http://www.bu.edu/sarpsych>

LONG-TERM OUTCOMES OF PARTICIPANTS IN A CAREER EDUCATION PROGRAM FOR YOUNG ADULTS WHO HAVE PSYCHIATRIC DISABILITIES

Briefing Paper No. 2 of 3

Between 1985 to 1989, 50 young adults with psychiatric disabilities participated in a career education program based on the choose-get-keep approach to psychiatric vocational rehabilitation developed by the Boston University Center for Psychiatric Rehabilitation. This program, held on the Boston University campus consisted of both classroom instruction and intensive professional and peer support. In 1995, a follow-up study, funded by the National Institute on Disability and Rehabilitation Research (NIDRR Grant #H133G20070) was funded to investigate the long term outcomes (5–8 years) of participants in this program. This paper reports the findings of the qualitative measures of that study. The study utilized a Participatory Action Research (PAR) model in which subjects and researchers collaborated to collect, analyze, and interpret data regarding the career related experiences of these individuals following termination of program participation. A semi-structured interview process was designed and implemented. Consumer interviewers conducted the interviews. Concept mapping was chosen by the PAR team as the preferred method for analysis. Interviews of 18 former participants and 6 persons from a wait-listed control group were analyzed. While the original intent of the project was to focus exclusively on vocational outcomes (e.g., education and employment), the consumer members of the PAR team strongly recommended a broader interpretation of “career” as the focus for the interview. Two basic questions were the focus of the study: “what major life changes occurred for participants post program participation?” and, “what did participants believe to be the causes of these changes?”

Major Findings

What major life changes occurred for participants post program participation?

The concept mapping process revealed three major categories of life change as expressed subjectively by participants: 1) Losses, 2) Increased Resources and Opportunities, and 3) Personal Growth and Development. Subcategories of Losses included relationship losses, leaving people and places, negative health effects of medications, unwelcome changes, and social isolation. Subcategories of Increased Resources and Opportunities included fiscal autonomy and independence,

education, personal and professional support, personal commitment to new directions, relationships supporting spiritual and psychological well being, and social activities. Subcategories of Personal Growth and Development included spiritual growth and development, personal mastery, and positive life changes associated with new skills and supports.

What did participants believe to be the causes of these changes?

As sources of change, participants reported three major categories of events: 1) Loss, 2) Relationship, and 3) External and Instrumental Influences. Subcategories of Loss included family separations and disconnections, and negative side effects of medication. Subcategories of Relationship included family and friends, “healing” relationships, traditional and alternative supports and participation in the Career Education Program. External and Instrumental Influences included increased financial resources, independent housing, and spiritual and community involvement.

Conclusions

Individuals with psychiatric disabilities who had previously participated in a university-based career education Program describe both positive and negative changes during the 5–8 years following program involvement. The major negative experience was categorized as loss, much of which was closely associated with having a psychiatric illness. However, former participants also identified two major categories of positive change: those associated with increased resources and opportunities, and those associated with personal growth and development.

Individuals with psychiatric disabilities who had previously participated in a university-based career education program specified former program participation as a cause of major life change, primarily in terms of the relationships they made with staff and with co-participants. They identified primary categories of sources for major life change as loss, relationship and community and instrumental influences beyond their immediate families and circle of professional resources.

Implications and Recommendations

While vocational rehabilitation professionals define school and work placement as measures of positive outcome, school and work were identified as means to ends rather than as ends in and of themselves. In fact, “work,” as an outcome, was mentioned only in the context of promoting fiscal autonomy, independence, and personal mastery. Also, while professionals sometimes see personal growth and development as a prerequisite

to obtaining increased resources and opportunities, respondents in this study gave them equal weight as areas of change within their lives. The distribution of these items within the concept map also suggests that respondents viewed them as closely interrelated but not linear. In addition, while professionals tend to attribute life changes to professional intervention, people with psychiatric disabilities identify this as an important but not singular cause of change. Rather, family, friends, spiritual leaders, and a range of personal contacts and experiences are specified as important sources of change.

The findings of this study underscore the importance for rehabilitation professionals to develop and maintain a comprehensive ecological understanding of their clients' personal perspectives, networks, and goals. These findings also suggest the importance of viewing a range and variety of people and experiences in the clients' world as potential resources that can greatly influence the probability of positive rehabilitation outcome. Helping professionals might also do well to develop and maintain a more measured perspective concerning the degree to which professional interventions are perceived by service recipients as a primary source of life change.

For further information please contact

Marsha Langer Ellison, Ph.D.
ellison2@bu.edu

Home page: <http://www.bu.edu/cpr/>