“We Do Research – What’s Your Story?”
A Participatory Action Research Study of Consumer Empowerment

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Participatory Action Research (PAR): PARadigm Shift
Participatory Action Research (PAR)

People in the organization or community under study participate actively with the professional researcher throughout the research process, from the initial design to the final presentation of results and discussion of their action implications.

W.F. Whyte
PAR: What is it?

The process by which oppressed people are actively involved in the study of [their own] social problems and the solutions to those problems.

S. Yeich & R. Levine

Those oppressed generate knowledge and disseminate findings through consciousness-raising, social critique and social change…with the explicit aim of transforming their oppression into empowerment.

Townsend et al
What is it?: An Emancipatory Project

- Research is a means, not an end
- Narrows the gap between trained researchers & members of disempowered groups
- Methods and power: Who benefits, who loses as a result of research/evaluation outcomes
- Knowledge is power
- Research is value-laden
  - Justice, equality, self-determination, empowerment
PAR: Roots and Antecedents

- Action Research – Kurt Lewin, 1946
- Adult Education – Friere
- Phenomenology
- Feminist and Antiracist Movements
- International Liberationist Movements
- Grassroots, Social Justice Movements
PAR Research Goals

- Liberatory
- Democratization of knowledge
- Transfer of Power to the Oppressed
- Emancipatory
Traditional Research and PAR Paradigms
(E. Rogers & V. Palmer-Erbs)

- Learning about research subjects
- Objectivity is valued
- Researcher as “Professional”
- Research conducted by “outsiders”

- Learning from and about subjects
- Subjective experiences also valued
- Researcher as “consultant,” “educator”
- Research must have input from “insiders”
Traditional Research and PAR Paradigms

- Subjects have one role – research subject
- Subjects are passive objects of study
- Controlled, experimental studies
- Subjects involvement ends when data collection complete
- Agenda: Professional and socio-political forces

- Subjects have dual roles – subject and researcher
- Subjects are actively involved in study
- Qualitative, ethnographic studies
- Subjects act as “change agents”
- Agenda: Concerns of constituents & end-users of services
Why do it: Two “I’s”

- **Involvement: Increase Participation**
  - Development of critical consciousness of participants and researcher (examine beliefs together)

- **Improvement: Promote Social Change**
  - Research for social change, not just knowledge
  - Research to promote improvement of lives
PAR: Why do it?

Better Research Outcomes

- Stronger consensus for change, and sounder models for change.
- Research results are client-centered: more relevant, credible, and meaningful to the lives of participants.
- Methodological strength: more valid and reliable data in regard to meanings.
- Increases effectiveness – mainstream research models maintain existing structures.
PAR: Why do it?

Benefits to Researcher Participants

- Increased sense of critical awareness
- Acquisition of new skills – “expert” knowledge
- Ownership and validation of legitimacy of their knowledge

Yeich & Levine
PAR: How to do it

- Research is collaborative:
- Research is strengths-based:
- Participants share in the research process – mutual influence
- Research allows for multiple methods
- Research is conducted in the context of the people concerned.
PAR: How to do it

Participant researchers are trained in scientific research methods.

Experience and worldview of participants is used to frame the research question.

Research designs are planned through participation of diverse (power, status, etc.) stakeholders.
WE DO RESEARCH,
WHAT'S YOUR STORY?

A PARTICIPATORY RESEARCH PROJECT
ABOUT EMPOWERMENT
Project to be Evaluated through PAR

NIMH DEMONSTRATION PROJECT

Mental health consumers
Families of consumers

Collaborate with

Regional assessment training center
Dept. of Mental Health

Consumer and Family Development Grant Goals

Increase participation of consumers and families
Promote networking and collaborative activities
Support development of consumer-run alternatives
Strengthen participation of local groups
V. RESEARCH DESIGN AND TRIANGULATION OF METHOD AND RESEARCHER PERSPECTIVES

- Qualitative and Quantitative
  - Focus Group Interviewing
  - Participant Observation
  - Survey Instrument
  - Immersion - General Cultural Participation and Understanding from Consumer Perspective
  - Family Researchers - General Cultural Participation and Understanding from Family Members Perspective
  - Academic Researchers - Research Methods, Skills and Experience

- Scales of Justice
  - Collaborative Team Approach
    - Systematic Data Collection
    - Data Analysis Sampling
    - Decisions Through Research Planning Meetings
Research Associates: Selection & Training

- Selection of Research Associates
  - Criteria, recruitment, interviewing, salary

- Training of Associates and Academic Researchers
  - Intensive 2-day Retreat
  - Training meetings prior to data collection
  - Research meetings throughout process
  - Collaborative data analysis
Statewide Sampling

- **Focus Groups: Consumer & Family Support Groups (15)**
  - Rural, Suburban, & Urban
  - Consumer Activist Org. & Project Steering Comm.

- **Individual Interviews (17)**
  - Key Informants from Consumer, Family, Consumer Training Ctr. & Div. Mental Health

- **Participant Observation (3 sites)**
  - Urban and Rural Consumer-run Drop-in Centers
Empowerment: Caterpillar to Butterfly
Empowerment: A Developmental Process

“Before I got involved with consumers, I spent 4 years hiding in a basement…it wasn’t until I got involved that I started getting better…to get me back to where I realized I had something to contribute…I can’t say enough about how important something like this can be to raising your self-esteem…If you think you’re worthless, there is not reason to do anything. It takes something like this, just to feel like you’re worth something.” (Consumer leader)

“It’s like using the beeper…every boy who grows up mentally ill wants to be a psychiatrist…After being a client for 20 years you learn something…this is a resource that should be used.”

(Consumer researcher)
## Factors of Empowerment

### Perspectives of Consumers

- Self-determination & Choice: Experience of Success & Failure
- Respect from Others
- Self-Respect
- Involvement & Belonging
- Contribution to Others
- “Coming Out”
- Information & Education
- Decision-making: Action & Responsibility
Consumer & Family Support Groups
Consumer and Family Support Groups

- Clusters and Spaces: Meetings according to unique needs of each group, sometimes stopping, but not forever.

  “Meaning? Having a friend makes all the difference in terms of feeling connected. These groups help you feel connected and that’s not something you get in a mental health center.” (Consumer)

  “The decision to go public with my daughter’s illness was a desire to share all the knowledge that I had acquired in trying to find help for our daughter. I didn’t want other people to struggle like I had looking for answers.” (Rural family member)
The Meteor Metaphor

Consumer and Family Leadership: Participation Effectiveness Training
Strengthen Participation & Effectiveness of Local Groups

Consumer & Family Leadership: The Meteor

“I haven’t seen a mental health client with that kind of talent in my life. It is something that was astounding.” (Consumer researcher)

“Moments of great glory, followed by a crash.” (Consumer researcher)

Training: not an inoculation, but a process of discovery

“I feel many people can be taught but [you] have to provide the right empowerment and support…needs to be repeated, not just one time. I’ve heard people say, ‘we did it and they didn’t learn nothing’…has to be done over time.” (Consumer)
The Garden of Mental Health: Networking & Collaboration

- Diversity
- Involvement
- Change of Perceptions
- Linkages
- Cooperation & Unity
- Information
- Conferences
- Education
The Garden of Mental Health: Networking and Collaboration

“In the garden of mental health a humongous vine has grown with thousands of blossoms all over its tentacles.” Consumer Researcher

“It helps our families to have consumers come to conferences because then they can hope for their own, who may not be functioning all that well…they learn what can happen…take very much to heart the talent they see.” Family Researcher
The Terrarium: An Artificial Environment that Promotes Growth
The Terrarium: Development of Consumer-Run Alternatives

“It has to be a broad inclusive thing that allows a softness…an environment where we can be allowed to discover. When you’ve lost your mind, it takes a long time to come back, past denial, illness management, then we can use our potential.” (Consumer)

“The drop-in center is about the art of self-determination. If the consumer don’t determine it, it won’t work…like raising kids, if you abuse children, don’t let them have their thoughts or become what they want, it becomes abuse. You can’t make people into what they are, you have to let them become…self-discovery, self-actualization rather than your [providers] idea.” (Consumer)
Experience of The Research Team

■ Power

“We gave the people that we interviewed a chance to have a voice.”

“I feel the ripples from the process flowing on and on, like a pebble in the ocean.”

■ Hope

“I learned that stigma is a barrier to hope; I know how it works now.”

“This is the research that reduces oppression.”
Experience of the Research Team

Growth

“The process gave me back my self-respect when I could tell you that I, too, am a consumer. It helped me grow and made me free.”

“Having a full voice is a big step in my own process.”

Trust

“I learned to trust myself and the process and the team.”

“Letting go of the control as a professional and a researcher meant facing buried stereotypes I didn’t know I had. Then I could trust the team and the process.”

(Academic researcher)