

Collaborations Between Researchers and Recovery Leaders: The UIC WRAP Research Study in Ohio

*Presented at Self-Determination: The Fierce Urgency of Now
A State of the Science Summit
Chicago IL, April 2009*

Funded by the U.S. Department of Education, National Institute on Disability & Rehabilitation Research, & the Substance Abuse & Mental Health Services Administration, Center for Mental Health Services, Cooperative Agreement #H133B050003B

Today's Presenters

❖ Judith Cook, Ph.D.*

❖ Carol Bailey Floyd **

*University of Illinois at Chicago, National Research & Training Center on Psychiatric Disability

**Mental Health Recovery and WRAP, Akron, Ohio

Wrap Research Challenges & Rewards

Carol Bailey Floyd
Mental Health Recovery and WRAP

The Research Study

Recovery through Wellness Recovery Action Planning in Ohio

Study Personnel

Judith A. Cook
Mary Ellen Copeland
Carol Bailey Floyd
Jessica Jonikas
Marie Hamilton
Lisa Razzano
Walter Hudson
Rachel McFarland

Participatory Action Research Involved
UIC Researchers Working with Mary Ellen
as Well as Ohio Consumers &
Organizations to Mount the Study



WRAP STUDY SITES



Toledo

Lorain

Cleveland

Canton

Dayton

Columbus

Why OHIO was chosen



- Availability of master trainers and WRAP facilitators state-wide
- Large population base to recruit study participants
- Areas of the state that are not already saturated with WRAP
- Cultural diversity in participants is possible
- State includes rural, urban and suburban areas
- Supportive state & local mental health officials and organizations

Requirements of WRAP Intervention Facilitators

- Individuals who've faced their own mental health problems
- Experienced in delivering the model
- Officially trained in the intervention version
- Willing to follow all study procedures



What Do WRAP Facilitators Get Out of This?

- Be part of introducing people to peer support/self help
- Make some money
- Chance to be part of the scientific process
- Opportunity to “grow” self help in your local area
- Involvement in an academic collaboration
- Chance to “make history”

What Do Research Participants Get Out of This?

- Receive support, increase their knowledge, take charge of their own recovery
- Chance to be part of the scientific process
- Exposure to the Peer facilitator role
- Chance to make some money



What Do “Communities” Get Out of This?

WRAP facilitators, the peer community, & community at large get...

- Services paid for by the project
- Exposure to the peer facilitator role
- Opportunities to legitimate peer models
- Chance to be part of the scientific process
- Dissemination of notion that recovery is possible

WRAP Study Intervention Challenges

- ✓ Finding qualified WRAP facilitators
- ✓ Identifying locations for intervention delivery
- ✓ Securing space on days and times that are convenient for participants
- ✓ Establishing a network of support for WRAP facilitators
- ✓ Including diverse regions of the state

WRAP Testimonials

- WRAP has helped me to be more motivated and hopeful. Now I have definite ways to help me avoid a major crisis. -- Sam

WRAP Testimonials

- WRAP has helped me be more relaxed. My speech is clearer. The day isn't long enough to use all the tools suggested to me. -- Cheryl

Importance of Maintaining Fidelity

- Establishing & maintaining fidelity assures you that the critical ingredients of the intervention are being delivered
- Fidelity prevents individual variations that lower the quality of the intervention
- Fidelity allows for protection of an intervention against negative influences such as personal biases or politics

Fidelity Training

- Occurs with teachers/providers BEFORE intervention implementation
- Co-led by researchers and key experts
- Discuss fidelity measure purpose and use
- Set up procedures for collecting weekly fidelity data

Going Into the Field



You Know You're Ready When...



- ✓ Peer facilitators have materials & are ready
- ✓ Participants know where to go & when
- ✓ Backups are in place (backup facilitators, intervention locations, someone on-call)
- ✓ Everyone is ready for anything
- ✓ Everyone knows who to contact with problems

Communication is Critical



- **Listservs**-study updates re: recruitment, intervention, early findings
- **Telephone calls**-check-ins, convey information, make requests
- **Teleconferences**-research team meetings, problem solving
- **Emails**-day to day management, problem solving, updates
- **Face to face meetings**-initial planning, training

Monitoring Fidelity

- Fidelity measures collected weekly and reviewed for trends and/or common problems
- On-site observations
- Weekly supervision calls between facilitators, project coordinator, and research staff

Unexpected Challenges: Recruitment

- Enrolling in a research study is NOT the same thing as deciding to participate in peer support/self help
- Recruitment gets harder & harder over time
- People get tired of hearing about the study & your requests for help getting the word out
- The potential for “inappropriate” recruits increases

Recruitment Strategies



- Think outside the box and the agency
- Know thy target audience and their schedules
- Network, network, network
- The power of the personal testimonial
- Who reads a flier?
- Mixed media for the computer age

Unexpected Challenges: Facilitator Retention

- Delivering self-help in a research study is NOT the same thing as providing “regular” peer support/self help
- Facilitators have lives
- People get bored
- People get new jobs
- Personality conflicts can develop
- People can experience relapses & other difficult times emotionally

Facilitator Retention Strategies

- Train back-up providers & keep them involved throughout the study
- Pay them well
- Show your gratitude – “Find One Hundred Ways” (Lionel Richie)
- Be prepared to offer in-kind payment if providers SSI/SSDI situations prevent them from receiving earned income



Update on WRAP Research Study

Judith Cook

UIC National Research & Training Center

WRAP Study Design

- The project is offering an 8-week WRAP group in cities across Ohio
- 400 individuals with mental health challenges participate in the study
- Participants are randomized to receive WRAP right away or 9 months later
- Participants are interviewed at baseline, 3 months post-baseline, and 8 months post-baseline & paid for their time

Study Progress and Accomplishments

Waves 1-5

- 852 individuals screened for Waves 1-5
 - 680 eligible and agreed to participate
 - 559 (82%) completed Time 1 interviews
- 279 individuals randomly assigned to the intervention group and 280 individuals randomly assigned to the control group
- Wave 1-5 WRAP classes completed for intervention group participants
 - On average, participants attended 5 of the 8 WRAP classes
 - 58% attended 6 or more classes

Wave 1-5 Study Participant Characteristics

- 67% female, 33% male
- Average age: 46 years, from 20-71 years old
- 65% Caucasian, 26% African American, 2.5% American Indian/Alaskan Native, <1% Asian/Pacific Islander, 7% other
- 4.5% Hispanic/Latino
- 83% High school graduate/GED or more
- 88% unmarried
- 68% living in their own home or apartment
- 75% had been hospitalized for psychiatric reasons
- Most common self-reported diagnosis:
 - 37% bipolar disorder; 24% depression; 22% schizophrenia spectrum
- Most (86%) were not working, but 50% foresaw themselves holding a job in the next year

Preliminary Outcomes

- WRAP participants* had significant improvement from Time 1 to Time 3 for the following outcomes:
 - Reduced psychiatric symptoms
 - Increased hopefulness
 - Reduced maladaptive coping
 - Decreased sense of public stigma re: mental illness
 - Increased quality of life
 - Increased ability to advocate for self
 - Increased recovery
 - Increased social support
 - Decreased need for services
 - Decreased empowerment

*Waves 1-3

First Journal Article Reporting Results Of an Independent Evaluation of WRAP Participant Outcomes!

Brief Reports

Initial Outcomes of a Mental Illness Self-Management Program Based on Wellness Recovery Action Planning

Judith A. Cook, Ph.D.
Mary Ellen Copeland, Ph.D.
Marie M. Hamilton, L.C.S.W., M.P.H.
Jessica A. Jonikas, M.A.
Lisa A. Razzano, Ph.D.

Carol B. Floyd
Walter B. Hudson, B.S.
Rachel T. Macfarlane, B.A.
Dennis D. Grey, B.A.

Objective: This study examined changes in psychosocial outcomes among participants in an eight-week, peer-led, mental illness self-management intervention called Wellness Recovery Action Planning (WRAP). **Methods:** Eighty individuals with serious mental illness at five Ohio sites completed telephone interviews at baseline and one month after the intervention. **Results:** Paired t tests of pre- and postintervention scores revealed significant improvement in self-reported symptoms, recovery, hopefulness, self-advocacy, and physical health; empowerment decreased significantly and no significant changes were observed in social support. Those attending six or more sessions showed greater improvement than those attending fewer sessions. **Conclusions:** These promising early results suggest that further research on this intervention is warranted. Confirmation of the efficacy and effectiveness of peer-led self-management has

the potential to enhance self-determination and promote recovery for people with psychiatric disabilities. (*Psychiatric Services* 60:246-249, 2009)

Although the concept of recovery from mental illness is relatively new, the fact that significant proportions of people with psychiatric disabilities can successfully self-manage their conditions has been documented for more than two decades (1). Some common self-management strategies for psychiatric disorders include writing down or talking about problems; speaking with or visiting friends; exercising; engaging in medication, artistic endeavors, or political activism; practicing good nutrition; and self-advocacy (2).

Although ample evidence supports the efficacy of structured self-management programs for chronic physical conditions such as diabetes and asthma (3), far less research has evaluated this approach for mental disorders. The study reported here examined changes in measures of recovery and other psychosocial outcomes among participants in a peer-led, self-management intervention called Wellness Recovery Action Planning (WRAP).

Unlike many traditional mental health interventions, WRAP is intended to help people manage a variety of long-term illnesses, whether or not they choose to receive formal services. In fact, WRAP educators are taught to avoid talking directly about

psychiatric diagnoses or using medical or illness-oriented language to frame people's needs (2). Instead, WRAP emphasizes holistic health, wellness, strengths, and social support. WRAP encourages people to move beyond simply managing symptoms to building a meaningful life in the community by using a highly individualized plan for recovery. Instructional techniques promote peer modeling by using personal examples from facilitators' and participants' own lives to illustrate key concepts of self-management, allowing participants to witness the lived benefits of WRAP.

Methods

The sample consisted of the first 109 individuals who enrolled in an ongoing study of WRAP at one of five sites in Ohio. Between October and December 2006, individuals were recruited from service delivery sites, including traditional treatment settings (such as community mental health centers, outpatient clinics, and residential programs) and self-help and peer support settings (such as consumer-run drop-in centers and mental health support groups). One-hour telephone interviews were conducted by personnel at the Survey Research Laboratory at the University of Illinois at Chicago. The first interview occurred immediately before the intervention, and the second was conducted in the month after the intervention.

Respondents received research honoraria of \$50 and \$25, respective-

Dr. Cook, Ms. Hamilton, Ms. Jonikas, Dr. Razzano, Ms. MacFarlane, and Mr. Grey are affiliated with the Department of Psychiatry, University of Illinois at Chicago, 1601 W Taylor St., 4th Floor MC 912, Chicago, IL 60612 (e-mail: cook@tripcc.com). Dr. Copeland and Ms. Floyd are with Mental Health Recovery and WRAP, Inc., West Dummerston, Vermont. Mr. Hudson is with the Copeland Center for Wellness and Recovery, Chandler, Arizona.

More Unexpected Challenges: New Political & Administrative Environments

- Mental health systems change (commissioners leave, new governors elected) & can become less enthusiastic collaborators
- Local areas have shifting priorities
- States and counties encounter fiscal crises
- Peer organizations/networks are often vulnerable

Strategies for Shifting Environments



- Make no enemies – don't ally your project with any one administration, political party, or advocacy group
- Look for ways to do favors & be supportive of one another
- Make each other "look good"
- Be generous with the credit
- Keep in mind your shared fate

Thank you!

Questions?
Comments?