

President Carter's Commission on Mental Health (1978)

President Carter commissioned a comprehensive review of mental health services that generated a series of recommendations. The report identified the key role of community based supports and recommended that:

"A major effort be developed in the area of personal and community support which will recognize and strengthen the natural networks to which people belong and depend. These largely untapped community resources contain a great potential for innovation and creative commitment in maintaining health and providing needed human services."

(The President's Commission on Mental Health, 1978 p.15)."

Peer Support Services – State Medicaid Director Letter (8/15/07)

...Now, more than ever, there is great emphasis on recovery from even the most serious mental illnesses when persons have access in their communities to treatment and supports that are tailored to their needs. Recovery refers to the process in which people are able to live, work, learn and participate fully in their communities.

...CMS recognizes that the experiences of peer support providers, as consumers of mental health and substance use services, can be an important component in a State's delivery of effective treatment. CMS is reaffirming its commitment to State flexibility, increased innovation, consumer choice, self-direction, recovery, and consumer protection through approval of these services.

...Peer support providers should be self-identified consumers who are in recovery from mental illness and/or substance use disorders. **Supervision and care coordination** are core components of peer support services. Additionally, peer support providers must be **sufficiently trained** to deliver services.

http://www.cms.hhs.gov/SMDL/downloads/SMD081507A.pdf

The Peer Support Research Paradigm Conundrum

Peer Support Services – Does it Work?

It Depends on it

Is it as good as...

Is it better than...

Can it help...

A key question in all models of comparative research is - what is <u>IT</u>

The Comparative Outcomes Challenge



In head-to-head taste tests, 7 out of 10 coffee lovers preferred Costa cappuccino to Starbucks.



WE MAKE IT BETTER

"Source independent curvey by Tangdate Dranding Limited, December 2000. In bland head faste bette between Control copposition and a copposition from the Control Contr





The Best Ones Are Rich, Warm, and Can Keep You Up All Night Long



Peer Support Research

- Peer-based interventions, which are based on the idea that those who have experienced mental illness can offer help and **support** to others, have become increasingly popular over the past decades. A recent estimate suggests that groups, programs, and organizations run by and for people with serious mental illness and their families outnumber professionally run mental health organizations by a ratio of almost 2 to 1 (Lucksted et al. Psychiatr Serv 60:250-253, February 2009
- •The evidence base for peer provided services is small (Woodhouse and Vincent 2006)
- •Users and "carers" have been involved in delivering and evaluating mental health services, but the effects of this involvement have not been rigorously assessed. We found "randomised" controlled trials and other comparative studies containing evidence about positive or negative effects of involving users in the delivery or evaluation of mental health services. (Simpson, House: *BMJ* 2002;325;1265)
- •Although ample evidence supports the efficacy of structured self-management programs for chronic physical conditions such as diabetes and asthma, far less research has evaluated this approach for mental disorders. (Cook et al. Psych Services 60:246-249, February 2009

What are Peer Support Services, Who Performs Them, and What do they Do?

Certified Peer Specialist Roles and Activities:

Location

At an Agency or on the Phone In a Client's Residence or in Transit

Modality

Supporting People in Groups
Supporting People Individually

Natural Supports

Working with Families
Working with Community Members or Employers

Salzer, et al. Psychiatric Services 61:520–523, (2010)

The Peer Support Research Paradigm Conundrum – What Peer Specialists Do

How consumer provider services address patient and treatment system factors.

Factors that contribute to poor outcomes for those with SMI

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Patient Factors			Treatment System Factors		
Social isolation	Disconnection with ongoing outpatient treatment	Powerlessness & demoralization regarding illness	Overburdened providers	Fragmented services	Lack emphasis on recovery, rehabilitation, empowerment
T	Consun	ner provider services	s address each of th	e factors:	J.
Enhance social networks by •role modeling •facilitating peer support activities	Engages patients; makes treatment more relevant through collaboration	Activates patients; teach coping & street smarts; provide hope through role modeling	Supplement existing treatment; increase access	Provide case management/ system navigation to increase access	Emphasize recovery: • liaison between consumer and system • advocate for community integration over symptom stabilization

[&]quot;Toward the Implementation of Mental Health Consumer Provider Services" Chinman, Young, Hassell, Davidson: The Journal of Behavioral Health Services & Research 33:2 April 2006

Certified Peer Specialist Roles and Activities: Results from a National Survey

(Salzer, et al. Psychiatric Services 61:520–523, 2010)

Survey Results

- •Included CPS from 28 states
- •Male = 33%, Female = 66%, Other = 1%
- •Average Length of Employment = 23.8
- Months
- •Average Hours Worked/ Week = 29.6

Certified Peer Specialist Roles and Activities: Results from a National Survey

(Salzer, et al. Psychiatric Services 61:520–523, 2010)

Ethnic-Racial	N =
Identification	251
White/Caucasian	79%
Black/African American	12%
Hispanic/Latino	3%
Asian Pacific Islander –	1%
Hawaiian Native	
Native American	1%
Multiracial	4%

Gender	N = 260
Male	33%
Female	66%
Other	1%

Certified Peer Specialist Roles and Activities: Results from a National Survey

(Salzer, et al. Psychiatric Services 61:520-523, 2010)

Respondents $= 257$
62
50
28
21
20
7
10
15
44

Peer Support Activities 5 = Always		
-Higher Level	1 = Never	
Peer Support	4.48	
Encouragement of Self-Determination and	4.26	
Personal Responsibility	400	
Support Health and Wellness	3.87	
Addressing Hopelessness	3.84	
Communication with Providers	3.6	
Illness Management	3.62	
Addressing Stigma in the Community	3.56	
Developing Friendships	3.51	
Leisure and Recreation	3.25	
Education	3.16	
Transportation	3.06	
Developing WRAP Plans	3.04	

(Salzer, et al. Psychiatric Services 61:520-523, 2010)

Peer Support Activities	5 = Always
- Lower Level	1 = Never
Family Relationships	2.95
Employment	2.94
Citizenship	2.83
Spirituality and Religion	2.74
Developing Psychiatric Advance Directives	2.27
Parenting	2.14
Dating	1.74

(Salzer, et al. Psychiatric Services 61:520-523, 2010)

Research Questions Based on Peer Support Specialists (PSS) Roles:

- •If the roles, settings and functions of Peer Support Specialists differs widely, what are the research implications for outcomes research for Peer Support Services?
- •Are there unique features of the Peer Support Specialists work that confound the research process?

An Challenge for studying Peers Support Specialists in the Workplace

"Many questions and concerns arise about the hiring of peers and embedding them within the mental health system.

For example, lower wages for CPSs have been reported along with limited career paths; lack of supervision, support, desk space, and computers; and exclusion from team meetings and access to medical records."

Chinman, Lucksted, Gresen R, et al: Early experiences of employing consumer providers in the VA. Psychiatric Services 59:1315–1321, 2008

Three Primary Forms of Peer Support

- 1. Naturally occurring mutual support groups
- 2. Consumer-run services
- 3. The employment of consumers as providers within clinical and rehabilitative settings.

Four Broad Models of Peer Support

- 1. User run drop-in
- 2. Formalized peer specialists
- 3. Training programs for peer specialists
- 4. Peer education
 - a. Davidson, Chinman, et.al.: Clinical Psychology: Science And Practice V6 N2, SUMMER 1999
 - b. Woodhouse, Vincent: Scottish Recovery Network, August 2006

How to Evaluate Outcomes of Peer Support Services



Challenges -

- •Many studies have low numbers of participants
- •Randomization is difficult and sometime unethical
- •Outcomes require long term longitudinal follow up
- •Outcomes are often difficult to define and unclear targets for measurement
- •Measurement requires both quantitative and qualitative methods
- •Financial supports have been scarce

An Overview of The Research Base for Peer Support

Study Domains

- 1.Outcomes of Consumer as Provider (CP) Services
- 2.Peer Led Recovery Model Interventions
- 3. Consumer Run Organizations
- 4.Peers as Mutual Support
- **5.Peer Support in Medical Care**

Outcomes of Consumer as Provider (CP) Services

Study Design	Outcome	Reference
Randomly assigned patients with SMI to a case management team either made of all CPs or all non-consumers	Found CP's as effective on a variety of standardized measures of functioning and symptoms over a 2-year period	Solomon P, Draine J. 1995
Randomly assigned patients to one of three types of case management teams: traditional, client-focused (e.g., consistent with recovery), and client focused with a CP	Found no differences after 12 months between any of the groups on functioning, disability, quality of life, and family burden	O'Donnell M, Parker G, Oct 1999
Randomly assigned patients to one of two types of assertive community treatment (ACT) teams: all CP or all non-CP case managers	Although both groups spent a similar amount of time on case management activities, patients of CPs did have fewer hospitalizations and longer community tenure between them. However, there were no differences on arrests, ER use, or homelessness	Clarke GN, Herinckx HA, Kinney RF, et al Sep 2000
Assessed patient outcomes of three teams: (1) intensive case management with CPs as an adjunct; (2) intensive case management plus a non-consumer assistant; or (3) intensive case management without any assistants	Individuals of the CP team had greater gains in quality of life, self-image, outlook, and social support and fewer major life problems than those on the other two teams.	Felton CJ, Stastny P, Shern DL, et al Oct 1995
Compared patient outcomes of two teams: standard case management and a similar team with a CP.	Patients in the CP group had fewer inpatient days, improved social functioning, and some improvements in quality of life.	Klein AR, Cnaan RA, Whitecraft J. 1998

Source: CHINMAN et al. The Journal of Behavioral Health Services & Research 33:2 April 2006

Peer Led Recovery Model Interventions

Study Design	Outcome	Reference
Study team developed and pilot-tested the Health and Recovery Program (HARP), an adaptation of the Chronic Disease Self-Management Program (CDSMP) for mental health consumers. A manualized, six-session intervention, delivered by mental health peer leaders, helps participants become more effective managers of their chronic illnesses. A pilot trial randomized 80 consumers with one or more chronic medical illness to either the HARP program or usual care.	At six month follow-up, participants in the HARP program had significantly greater improvement in patient activation than those in usual care and in rates of having one or more primary care visit (68.4% vs. 51.9% with one or more visit. Intervention advantages were observed for physical health related quality of life, physical activity, medication adherence.	Druss, B. et al: Schizophrenia Research, Vol 118, Issue 1 Pages 264-270 (May 2010)
Study examined changes in psychosocial outcomes among participants in an eightweek, peer-led, mental illness self-management intervention called Wellness Recovery Action Planning (WRAP)	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.	Cook, J., et al: Psychiatr Serv 60:246-249, February 2009
Approximately 550 participants who were enrolled in (NAMI) Peer -to- Peer during the data collection period (2005–2006) were invited to complete a brief, anonymous survey before participating in the program and immediately after.	Analyses from 138 participants indicated that they gained significant benefits, especially in areas central to the Peer -to- Peer curriculum—specifically, knowledge and management of their illness, feelings of being less powerless and more confident, connection with others, and completion of an advance directive	Lucksted, A., McNulty, K., Brayboy, L., and Forbes, C., Psychiatr Serv 60:250-253, February 2009

Consumer Run Organizations

Study Design

Study evaluated the impacts of participation in mental health Consumer/Survivor Initiatives (CSIs), organizations run by and for people with mental illness. A nonequivalent comparison group design was used to compare three groups of participants: (a) those who were continually active in CSIs over a 36-month period (n = 25); (b) those who had been active in CSIs at 9- and 18-month follow-up periods, but who were no longer active at 36 months (n = 35); and (c) a comparison group of participants who were never active in CSIs (n = 42). Data were gathered at baseline, 9-, 18-, and 36-month follow-ups.

Outcome

The three groups were comparable at baseline on a wide range of demographic variables, self-reported psychiatric diagnosis, service use, and outcome measures. At 36 months, the continually active participants scored significantly higher than the other two groups of participants on community integration, quality of life (daily living activities), and instrumental role involvement, and significantly lower on symptom distress.

Reference

Philip T. Yanos, Ph.D., Louis H. Primavera, Ph.D. and Edward L. Knight, Ph.D. Consumer-Run Service Participation, Recovery of Social Functioning, and the Mediating Role of Psychological Factors Psychiatr Serv 52:493-500, April 2001

New clients seeking community mental health agency (CMHA) services was randomly assigned to regular CMHA services or to combined Self-help agencies (SHA-CMHA) services at five proximally located pairs of SHA drop-in centers and county CMHAs. Clients (N=505) were assessed at baseline and at one, three, and eight months on five recovery-focused outcome measures: personal empowerment, self-efficacy, social integration, hope, and psychological functioning.

Overall results indicated that combined SHA-CMHA services were significantly better able to promote recovery of client-members than CMHA services alone. Segal SP, Silverman CJ, Temkin TL. Self-help and community mental health agency outcomes: a recovery-focused randomized controlled trial. Psychiatr Serv. 2010 Sep;61(9):905-10.

Peers as Mutual Support

Study Design Outcome Reference Travis J, Roeder K, Walters H Participants were depressed patients with 32 participants (59.3%) completed the Piette J, Heisler M, Ganoczy continued symptoms or functional intervention. Participants completing the study D. Valenstein M. Pfeiffer P. Telephone-based mutual peer impairment treated at one of the three averaged 10.3 calls, with a mean call length of support for depression: a pilot outpatient mental health clinics. 26.8 min. The mean change in BDI-II score study. Chronic Illn. 2010 Sep;6(3):183-91 Participants were partnered with another from baseline to study completion was -4.2 (p<0.02). Measures of disability, quality of life patient, provided with basic communication skills training, and asked and psychological health also improved. to call their partner at least once a week Qualitative assessments indicated that using a telephone platform that recorded participants found meaning and support call initiation, frequency and duration. through interactions with their partners. **DISCUSSION:** Telephone-based mutual peer Depression symptoms, quality of life, disability, self-efficacy, overall mental and support is a feasible and acceptable adjunct to physical health and qualitative feedback specialty depression care. were collected at enrolment, 6 weeks and 12 weeks. Randomized controlled trial evaluated the Chien WT. Thompson DR. One-week and 12-month post-intervention Norman I. Evaluation of a effectiveness of a bi-weekly, 12-session, were compared between groups. Results peer-led mutual support family-led mutual support group for indicated that the mutual support group group for Chinese families of people with Chinese caregivers of schizophrenia experienced significantly greater schizophrenia. Am J sufferers over 6 months compared with improvements in families' burden, functioning Community Psychol. 2008 standard psychiatric care. Conducted with and number of support persons and length of Sep;42(1-2):122-34. 76 families of outpatients with patients' re-hospitalizations post-tests. The schizophrenia in Hong Kong and were findings provide evidence that mutual support assigned randomly to either a mutual groups can be an effective family-initiated, support group or standard care. community-based intervention for Chinese schizophrenia sufferers.

Peer Support in Medical Care

Study Design	Outcome	Reference
A total of 345 adults with type 2 diabetes but no criteria for high A1C were randomized to a usual-care control group or 6-week community-based, peer-led diabetes self-management program (DSMP). Randomized participants were compared at 6 months.	RESULTS: At 6 months, DSMP participants did not demonstrate improvements in A1C as compared with controls but baseline A1C was much lower than in similar trials. Participants had significant improvements in depression, symptoms of hypoglycemia, communication with physicians, healthy eating, and reading food labels. They also had significant improvements in patient activation and self-efficacy. At 12 months, DSMP intervention participants continued to demonstrate improvements in depression, communication with physicians, healthy eating, patient activation, and self-efficacy. There were no significant changes in utilization measures.	Lorig K, Ritter PL, Villa FJ, Armas J. 2009
Study conducted a pre- and post-program evaluation of a 7-week facilitated breast cancer peer support program in a cancer support house.	The key themes emerging from the pre and post programe focus groups included: The need for mutual identification; Post-treatment isolation; Help with moving on; The impact of hair loss; Consolidation of information; Enablement/empowerment; The importance of the cancer survivor; Mutual sharing.	Power S, Hegarty J. 2010
Study examined enablers and barriers to peer support participation and model preferences among people with colorectal cancer.	Participants demonstrated enthusiasm for peer support. Feeling unwell and worry about accessing toilet facilities were main barriers, while accessing information about treatment side effects and making treatment decisions were main positive features. Both models (telephone and inperson) were acceptable to participants with high satisfaction rates reported and findings suggested that the two models catered to different peer support needs.	Ieropoli SC, White VM, Jefford M, Akkerman D. 2010

What does the Research Reveal about Peer Support Services?

Study Domains

1.Outcomes of Consumer as Provider (CP) Services

 When Peer Support Services are a part of ongoing treatment services and teams – favorable outcomes are noted. Needs further exploration about the evidence base for what is best practice

2.Peer Led Recovery Model Interventions

• There are effective models/tools that support recovery. There has not been much comparative effectiveness research across models.

3. Consumer Run Organizations

• Evidence suggest successful outcomes. A future challenge is to demonstrate the role of consumer run organizations in the full continuum of clinical services

4.Peers as Mutual Support

• Mutual support is a successful in promoting recovery. A question remains for how to best deploy this approach in standard care

5.Peer Support in Medical Care

 Peer Support is effective and well deployed in other medical conditions. Further research is needed to build evidence base

Pillars of Peer Support: Transforming Mental Health Systems of Care

Through Peer Support Services

www.pillarsofpeersupport.org
January, 2010.

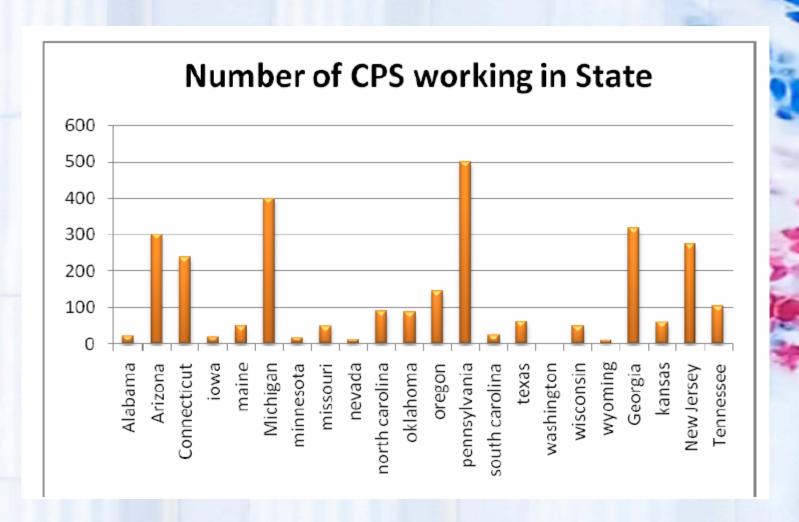
The Pillars of Peer Support Services Summit

The Carter Center

Atlanta, GA

November 17-18, 2009

Approximately how many consumers are employed as peer specialists in your state? N = 21 Range = 9 to 500



Source: www.pillarsofpeersupport.org (2010)

What is your state's Medicaid reimbursement rate for peer support? N = 13



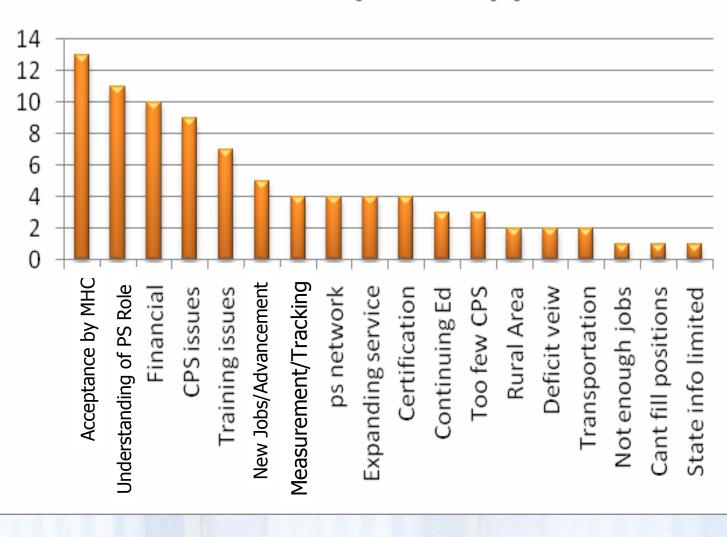
Source: www.pillarsofpeersupport.org (2010)

Required Hours of Training N = 17



Source: www.pillarsofpeersupport.org (2009)

Barriers with peer support services





Is This a Valid Statement About How Consumers Learn Recovery?

Learning Recovery "The most common way across the ages in which consumers have learned about recovery is through peer support services. Peer Support has consumers learn recovery through active participation in the tasks. A Consumer's participation may be very limited at first while the consumer gains an understanding of the process through observation and making small contributions but the involvement develops into full participation and eventually task ownership."

Actual Quote

Apprenticeship Learning "The most common way across the ages in which students have learned process on the way to becoming skilled practitioners is through apprenticeship (Collins, Brown, & Newman, 1989; Rogoff, 1990).

Apprenticeship has students learn process through active participation in the task. Student participation may be very limited at first while students gain an understanding of the process through observation and making small contributions but the involvement develops into full participation and eventually task ownership".

Guzdial, and Kehoe (1998) Apprenticeship-based learning environments: *Journal of Educational Multimedia and Hypermedia*. http://guzdial.cc.gatech.edu/papers/ABLE/

We know that peer support works from other fields of research

There is an established research base for the role of Apprenticeship Learning, Mentorship, and Coaching. These are all common elements of learning to live with and recover from chronic illnesses. This research base is directly applicable to peer support and chronic disease management.

A Final Thought About the Future of Peer Support - and Your Role

8 laws of social change (Attributed to Henry Cadbury)

Individuals and small groups can change history by practicing the eight laws of social change.

- 1) Individuals and groups must share a common purpose or intent consensus
- 2) Individuals and groups may have goals, but must not be attached to "cherished" outcomes.
- 3) The goal may not be reached in the lifetime of the participants.
- 4) Accept and be OK with the idea that you might not get credit for the success of a goal.
- 5) Each person in the group must have equal status in spite of any hierarchies.
- 6) Members must forswear violence by word, thought and act.
- 7) Our private selves must be consistent with our public postures.
- 8) People are not exploitable resources. People are what make change happen and the most important element

