Who Should Be the Leaders of System Change? How Peers and Families Can Work Together

Presented for: Lived Experience 2.0
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“Every major innovation in mental health in the last 20 years has been led by peers, starting with recovery and peer support which have been fundamental.”

Ron Manderscheid
Executive Director
The National Association of County Behavioral Health and Developmental Disability Directors
Country in Crisis

EDUCATION
• For each year that children go to school, they report disliking it more and more. Level of enjoyment for reading also declines with each year of school (Gallup, 2013).
• Average student loan debt is $30,000 (WSJ, 2015)

EMPLOYMENT
• 70% of Americans hate what they do for a living (Gallup, 2013)

_Sadly, this is just the tip of the iceberg..._
U.S. Mental Health System in Crisis

- 40 fold increase in children diagnosed with “bipolar disorder” from the early 1990s to the early 2000s
- 7 fold increase in children under 13 on “antipsychotic medication” from 1993 to 2009
- Number of “mental disorders” listed in the DSM has increased from 106 in 1952 to 374 in 1994
- Surgeon General David Satcher reported in 1999 that half of Americans will have a diagnosable “mental disorder” at some point in their lives
- 80% Unemployment Rate for People in the Public MH System
- In 2015 we are averaged a school shooting every week
System Change: Open Dialogue

- Since the early 1980s, Open Dialogue has been the “mental health” system in Western Lapland, Finland.
- Views “psychosis” as happening in the space between relationships rather than residing in the individual.
- 80% success rate of avoiding hospital, medication, and achieving full recovery at 5 year follow up.
- Number of people diagnosed with “schizophrenia” has almost disappeared (by 2005, number of people diagnosed went from 33/100,000 to 2/100,000).
System Change: Open Dialogue

• Some providers are starting to offer Open Dialogue in the United States (Massachusetts, for example)
• Mary Olson founded an Open Dialogue training center in Massachusetts (see resources)
• Open Dialogue has been a provider led initiative, it has been a challenge to include peers in a meaningful way
• To be most effective Open Dialogue needs to be THE mental health system
System Change: Emotional CPR (eCPR)

What is eCPR?
A public health education program which prepares members of the public to assist a person who is experiencing an emotional crisis.

Why eCPR?
• There is a vast and compelling need for the general public to learn how to assist any person who is experiencing an emotional crisis.

• Just as CPR trains people to help someone in cardiac crisis, eCPR trains people to help others in emotional crisis.

  eCPR is a form of heart-to-heart connection for emotional resuscitation.
System Change: Emotional CPR (eCPR)

- e - Emotion
- C - Connect
- P - emPower
- R - Revitalize
System Change: Consumer Operated Service Programs

Consumer Operated Service Programs are Evidence-Based!

From the SAMHSA COSP Toolkit (see resources):

p. 9 “Are consumer-operated services effective? Many studies support the value and effectiveness of peer support services in helping individuals to address problems in their lives. Other studies give credence to specific elements of peer support such as positive relationships, meaningful activity, sense of community and belonging...”
Successfully transforming the mental health service delivery system rests on two principles:

First, services and treatments must be consumer and family centered, geared to give consumers real and meaningful choices about treatment options and providers - not oriented to the requirements of bureaucracies.

Second, care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience, not just on managing symptoms.

Resources

Families Healing Together (online classes): http://familieshealingtogether.com

Dignity and Advocacy Network: http://dignityandadvocacynetwork.org

Empatiko (will be offering connection courses soon): http://empatiko.org

The book *A Way Out of Madness: Dealing with Your Family After You’ve Been Diagnosed with a Psychiatric Disorder* by Daniel Mackler and Matthew Morrissey

Consumer Operated Services Evidence-Based Practices
https://store.samhsa.gov/product/Consumer-Operated-Services-Evidence-Based-Practices-EBP-KIT/SMA11-4633CD-DVD
Resources

The film HEALING VOICES: www.healingvoicesmovie.com

The training Emotional CPR: www.emotional-cpr.org

National Empowerment Center’s online store: http://www.power2u.org/mm5/merchant.mvc?

Consumer-Directed Transformation to a Recovery-Based Mental Health System: www.power2u.org/downloads/SAMHSA.pdf

President’s New Freedom Commission on Mental Health Final Report
https://store.samhsa.gov/shin/content/SMA03-3831/SMA03-3831.pdf
Resources

Open Dialogue
http://www.dialogicpractice.net

Emotional CPR
http://www.emotional-cpr.org

WMRLC Defining Principles
http://www.westernmassrlc.org/defining-principles

Intentional Peer Support
http://www.intentionalpeersupport.org

Hearing Voices USA
www.hearingvoicesusa.org
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