# IL-NET

CIL-NET · SILC-NET

Empowering Persons with Psychiatric Disabilities: The Role of the Peer Model in CILs

The Recovery Movement and its Relationship to Independent Living

Presenter:

Daniel Fisher, MD, PhD
Executive Director
National Empowerment Center

History of the Consumer/Survivor Movement
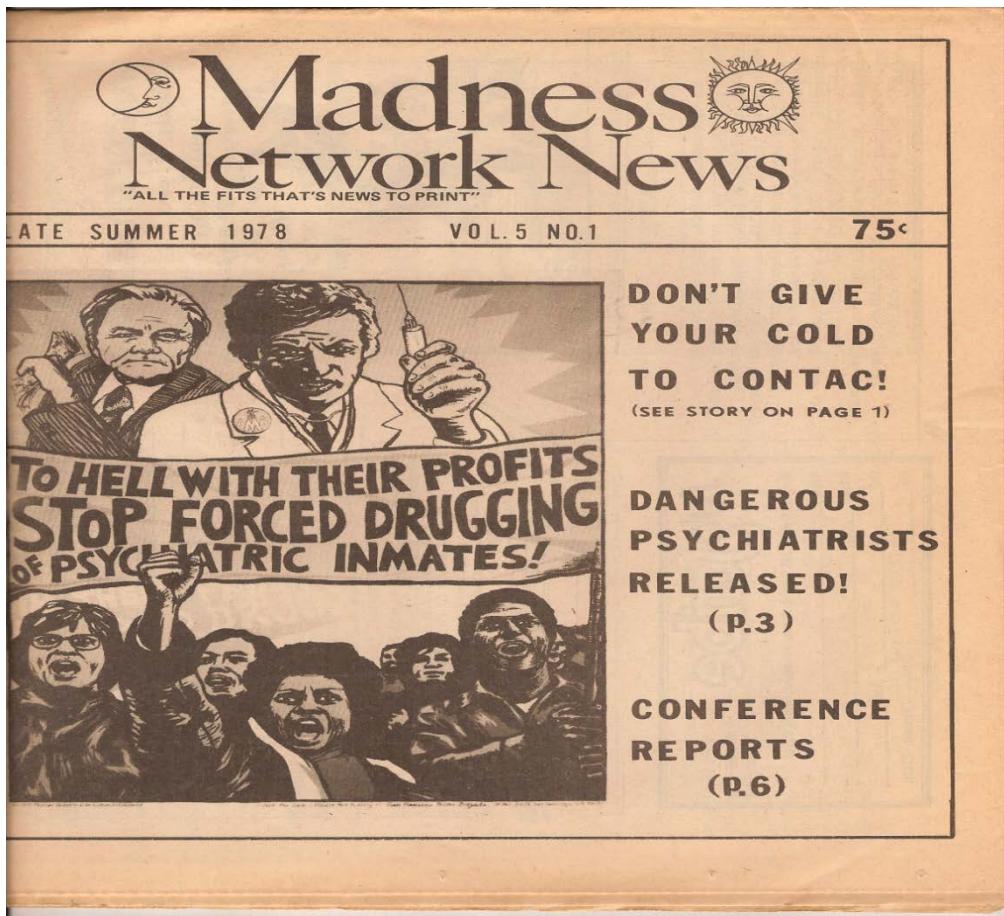
Adapted from Sally Zinman and Gayle Bluebird

Introduction

- In the 1960s and 1970s, social change movements and civil rights were part of our culture.

- State hospitals across the country were being shut down, laws limiting involuntary commitment

- Anecdotally, once released from these mental hospitals, people began meeting together in groups outside the hospital with shared feelings of anger about their abusive treatment and the need for independent living in the community.

Howie the Harp

"**Crazy folk (as he called us) are the most talented people in the galaxy. Instead of diagnosing, locking up, and treating us, the world should recognize our true worth and support our talents, creativity, and sensitivity,**" **said Howie the Harp, who carried a harmonica with him everywhere, to make music, mediate conflict, and create peace.**

Activities in 1970s

- Political, militant activism—demonstrations, values

- Annual Conference on Human Rights and Against Psychiatric Oppression held at campgrounds and college campuses

- *Madness Network News*, vehicle for communication

- Landmark book published in 1978: *On Our Own: Patient Controlled Alternatives to the Mental Health System* by Judi Chamberlin

Madness Network News—1976 Cover

Photograph of a 30-day "sleep-in" protest in then-Governor Jerry Brown's office to protest deaths and abuses in State hospitals in CA

Cover of Madness Network News, "ALL THE FITS THAT'S NEWS TO PRINT", OCTOBER 1976, VOLUME 4: NUMBER 1, 50 CENTS. Photo with sign reading "SLEEP-IN AT GOV. BROWN'S OFFICE"

Leonard Roy Frank
Editor Madness Network News
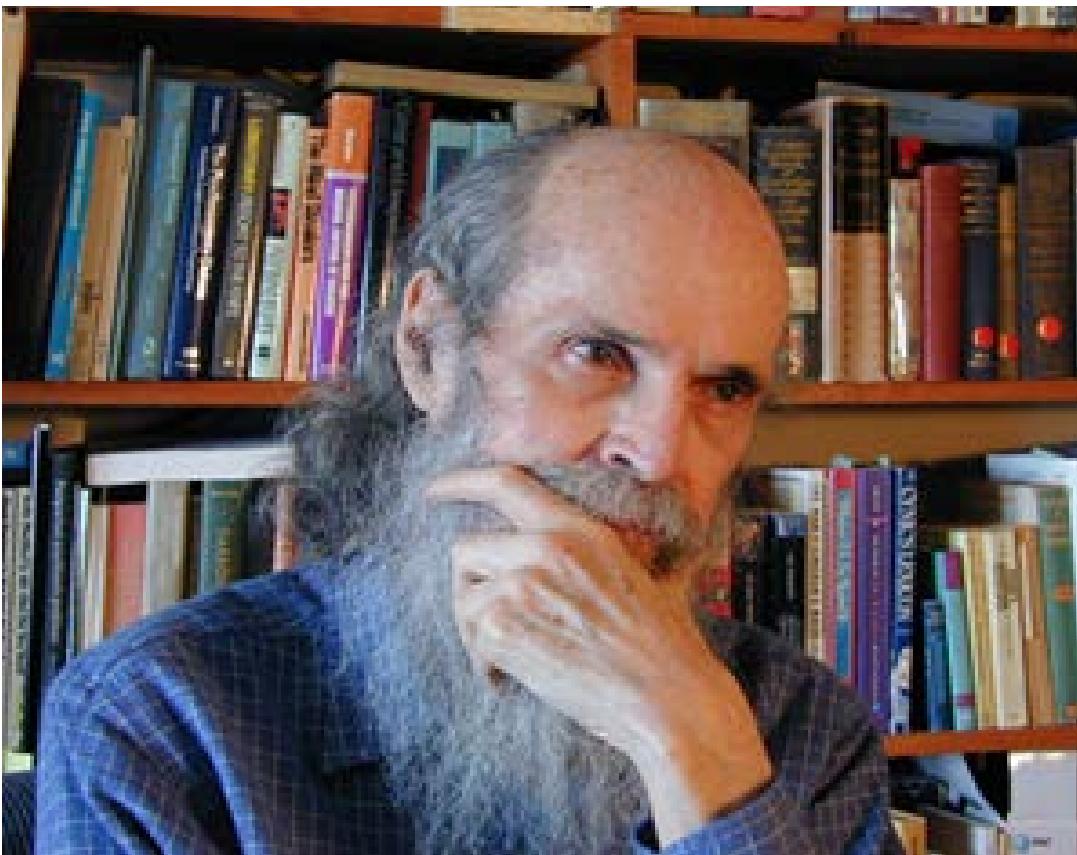
Cookie Gant

1949–2003

"Artiste Extraordinaire"

Early activist, outspoken poet, and performer, she spoke as a person with a disability, shock survivor, lesbian, and seller of buttons and other wares.
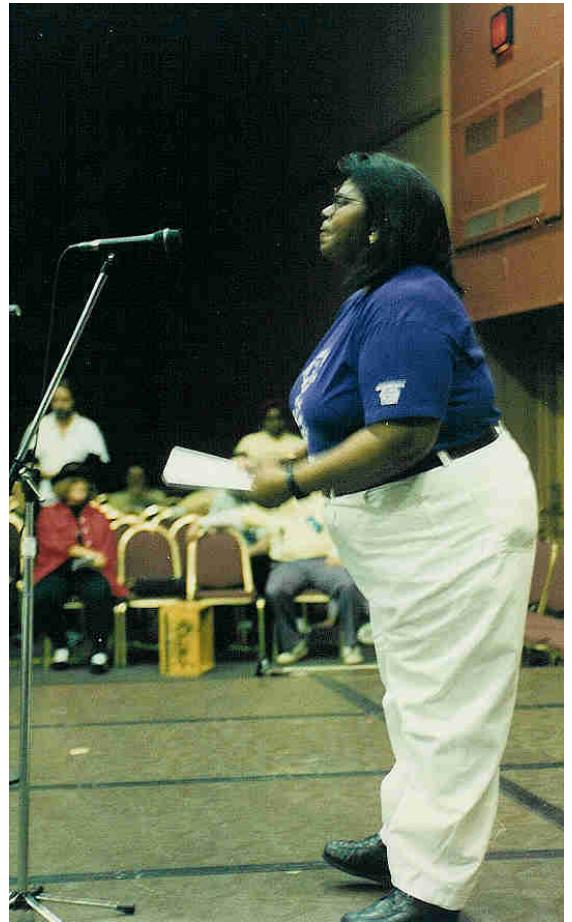
Principles

A Liberation Movement

- Against forced treatment
- Against inhumane treatment—medications, lobotomy, seclusion and restraints, and ECT
- Against Sanism
- Anti-medical model
- For consumer/survivor-run alternatives
- Nothing about us without us

Transitions—1980s

The 1980s formed a transitional time:

- We began the process of reentering the world that had so hurt us.

- A transitioning from words to deeds, conceptualizing to implementing.

Sally Zinman, Director CA Network MH Clients

Principles of 1980s

Expressed in positive rather than negative ways:

- Self determination and choice

- Rights protections

- Stigma and discrimination reduction

- Holistic services

- Self-help/peer-support programs

- Finding our Voice in system

- Facilitation of recovery

Activities of 1980s

- Growth of mental health system funded first self-help/peer-support programs, early drop-in centers.

- Beginning of statewide consumer-run organizations

- First National Alternatives Conference in 1985

- Growth of rights protection organizations—Protection and Advocacy, Inc.

- More consumers/survivors sitting on decision-making bodies

Well-Being Project
- Research by and for mental health clients
- 500 persons interviewed
- 61% of clients stated creativity was essential to their well-being
- 24% stated they lacked creativity in their lives
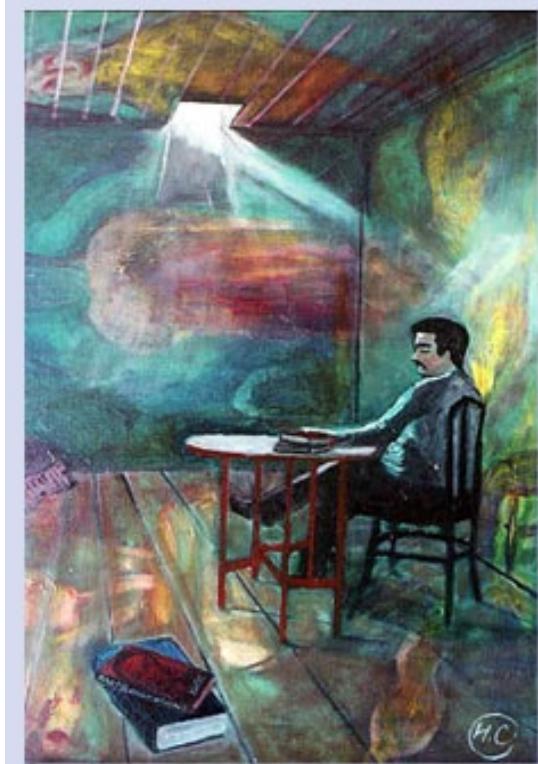
Alone and Waiting
1984 oil on canvas
24" x 18"

art by Jean Campbell

Parallels

Parallels between Recovery for People with Mental Illness and Independent Living for People with other Disabilities

	Recovery	Independent Living
Goal	Full Participant in community	Living Independently in the Community
Identity	Person first not your Diagnosis	Person first not your Impairment
Principles	Self-determination & Choice	Consumer-control & And Choice
Supports	Move from clinical to Life Coaches & peer support	From Clinical, Institutional to PCA's & Peer Support
Self-help Centers	Consumer-run Recovery Centers	Independent Living Centers

Declaration of Equality and Independence for Persons with Disabilities

- Over 200 years ago our not yet disabled forefathers declared that we the people are all created equal and have equal rights. However, that dream only applied to certain privileged groups. We now want to include people with disabilities, in that ideal of liberty, justice, and equality, just as people of color, GLBTIQ, and women have more recently been included.

Emotional CPR®

Goal: to train people to assist others through an emotional distress and to make this practice accessible to people around the world

National Empowerment Center

Email: info@emotional-cpr.org

Tel: 877-246-9058

Web: www.emotional-cpr.org

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 a person's physical heart needs attention in a cardiac crisis, a person's **emotional heart** needs attention in an emotional crisis.

  - **eCPR is a form of *heart-to-heart connection* for**

    - **emotional resuscitation.**

(page 3 in the workbook)

Three Elements of eCPR

- **C** = **Connect** with Compassion and Concern to open up Communication

- **P** = **emPower** to experience Passion, Purpose, and Participation in Planning

- **R** = **Revitalize** one's sense of belonging in community through Reestablishing equilibrium and balance and Reconnecting to Relationships, Routines, and Roles

Ways Emotional CPR Heals Trauma

| Dimensions	Impact of Trauma	Outcomes of Emotional CPR
Relatedness	Alienated	Emotionally **C**onnected
Power	Voiceless	Emotionally **P**owerful
Emotional State	Numb and disassociated	Emotionally **R**evitalized

Monologue vs. Dialogue

Trapped in Monologue

Heart to Heart Dialogue
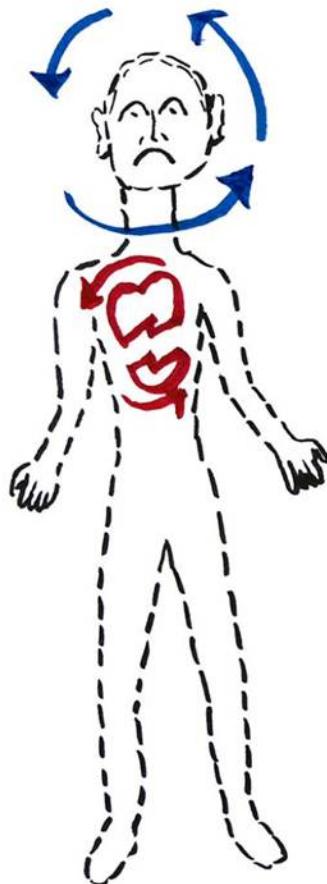
Trauma / Loss

Connection
emPowerment
Revitalization
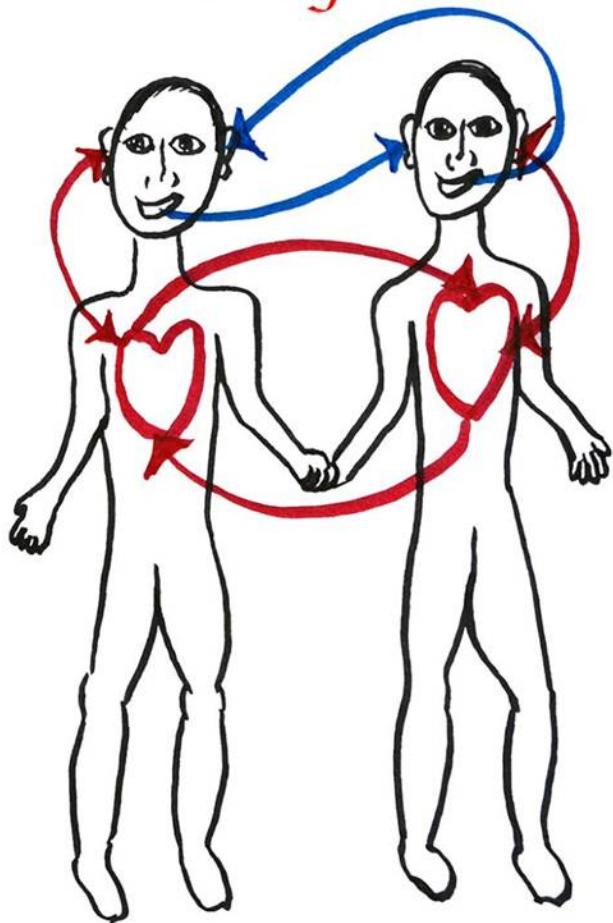
Two Persons in Dialogue
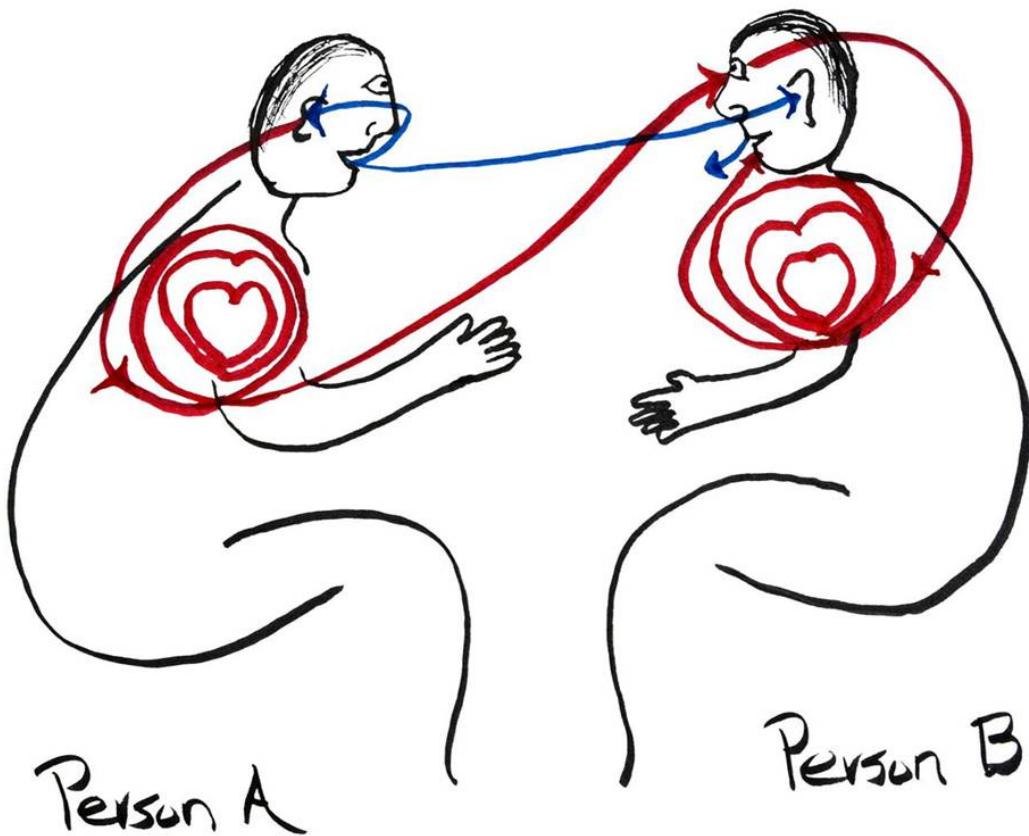
Anderson, T. 2006

Emotional CPR (INTENTIONS)

1. I will use my eyes, my ears and my heart to feel your presence in my being (Connecting)

2. I will share my emotional response in being with you, and I will stay with you (Connecting)

3. I will not fix you or judge you but be with you (emPowering)

4. I am not sure what is best for you but together we will uncover your power (emPowering)

5. We are creating life together in the present moment (Revitalizing)

Empowering Persons with Psychiatric Disabilities: The Role of the Peer Model of CILs

Mental Health and Centers for Independent Living

June 2 - 4, 2015
Baltimore, MD

Mike Bachhuber, Executive Director
Independent Living Council of Wisconsin, Inc.

History – CIL Perspective

- Paralyzed Veterans of America founded 1947
- 1962 Ed Roberts sued for admission to Univ. of Calif.
- 1960s – People with disabilities saw progress from social movements such as—
  - Civil rights for African Americans and others
  - Consumerism
  - Self-help
  - Demedicalization/self care
  - Deinstitutionalization/normalization/mainstreaming
- People with disabilities and allies successfully advocate for laws such Architectural Barriers Act of 1968.

History – CIL Perspective, cont'd.

- The Urban Mass Transit Act of 1970 requires all new American mass transit vehicles be equipped with wheelchair lifts.

- Judith Heumann founds Disabled in Action in 1970

- Ed Roberts founds Rolling Quads in 1970

- In 1971, Congress amends Fair Labor Standards Act to allow sheltered workshops for people with disabilities other than blindness

- Ed Roberts founds (Berkeley) Center for Independent Living in 1972

- Activists demonstrate in Washington, New York and elsewhere to oppose veto of Rehabilitation Act in 1972

- PVA and others sue for accessible transportation in 1972

- Rehabilitation Act of 1973 enacted, provides rights for people with disabilities in federally-funded programs

- Atlantis Community (Denver) and Boston Center for Independent Living founded in 1974

- Education for All Handicapped Children Act enacted in 1975 (now known as IDEA)

- Protests against lack of Rehabilitation Act regulations start in 1977 and continue, in some places, until after Sec. of Health Education and Welfare Califano signs regulations April 28

History – CIL Perspective, cont'd. 3

- People with Disabilities organized at Atlantis Community block intersections in Denver on July 5-6, 1978 to protest lack of accessible transportation

- Rehabilitation Act Amendments of 1978 create funding for Independent Living and create National Council on Disability

- First federal CILs funded in 1979 (10 states, 11 CILs)

- Supreme Court upholds reasonable accommodation requirement in *Southeastern Community College v. Davis* (1979)

History – CIL Perspective, cont'd. 4

- Americans Disabled for Accessible Public Transit (ADAPT) founded in 1983

- National Council on Independent Living founded in 1983

- National Council on Disability calls for civil rights law in 1983, follows with *Toward Independence* in 1986

- Association of Programs in Rural Independent Living founded in 1986

- In 1988, Congress passes Air Carrier Access Act and Fair Housing Amendments Act, protecting rights of people with disabilities in air travel and housing

- Congress also passes "Tech Act" providing funding for Assistive Technology services in 1988

- Congress overrides veto of Civil Rights Restoration Act correcting bad Sec. 504 case law in 1988

- Original version of ADA introduced in 1988

- Congress passes ADA in 1990, signed into law July 26 by President George H.W. Bush

- Department of Transportation promulgates regulations requiring bus lifts in 1990

History – CIL Perspective, cont'd. 6

- *Helen L.* case establishes right to most integrated setting in 1995

- U.S. Supreme Court upholds ADA in 1998 *Bragdon* case

- Supreme Court upholds ADA integration requirement in *Olmstead v. L.C. (Lois Curtis) and E.W. (Elaine Wilson)* in 1999

- Congress passes Ticket to Work Act in 1999

- Congress passes Help America Vote Act in 2002

- Congress passes ADA Amendments Act in 2008

- New ADA regulations issued in 2011 spur fight over accessibility of swimming pools

- NCIL members approve resolution at 2006 Conference calling for mental health civil rights subcommittee
- NCIL President creates Mental Health Civil Rights Task Force chaired by Carol Jean Reynolds
- Julie Alexander and Mike Bachhuber co-chair in 2009
- Subcommittee focuses on education in IL Community and advocacy, preparing resolutions on involuntary electroshock approved by membership in 2011
- Krista Erickson joins committee in 2010 succeeding to co-chair. Shoshanna Fawley joins her as co-chair in 2013 as Mike Bachhuber resigns to co-chair ADA/Civil Rights Subcommittee

CIL Perspective

- CILs must provide services on a cross-disability basis "to individuals with a range of significant disabilities...."

- 51.4 M adults with disabilities in US in 2010 (Census)

- People with mental/emotional disabilities
  - 8.9 M report disability due to anxiety, depression or other mental or emotional conditions
  - 4.7 M "other mental or emotional condition"

- Other sources show that approximately 50% of people with other disabilities have ongoing symptoms of "mental illness"

- By 2013, 21% of all SSI disability recipients come from 2 diagnostic groups: mood disorders & schizophrenia

CIL Perspective, cont'd.

- Safe to assume that CILs serve people with psychiatric disabilities
    - Do consumers identify mental/emotional disability?
    - If not, why not?

Empowering Persons with Psychiatric Disabilities: The Role of the Peer Model of CILs

Prejudice, Fears, and Discrimination: "Stigma"

June 2 - 4, 2015

Baltimore, MD

Mike Bachhuber

Language and Cultural Competence

- People with lived experience in mental health systems often have strong feelings about their relationship to those systems.
  - Some are fine being called patient, consumer, or client
  - Others consider themselves survivors or ex-patients
- Because treatment has been associated with coercion and trauma for many, terms become very important.