



A History of the Consumer/Survivor/Ex-Patient Movement

Presented for: TheMHS Carer Forum

Presented by: Oryx Cohen,
Chief Operating Officer

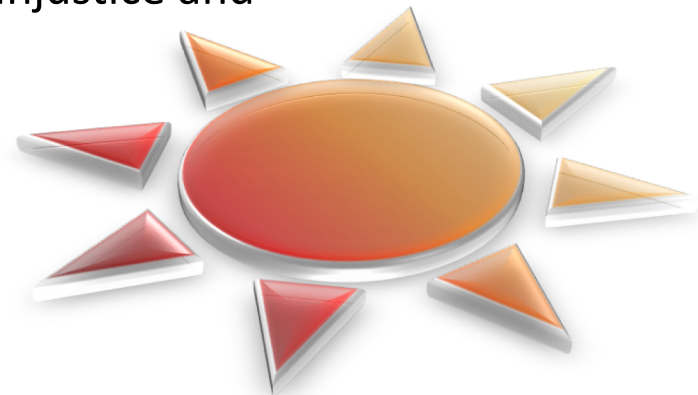
8 February, 2021

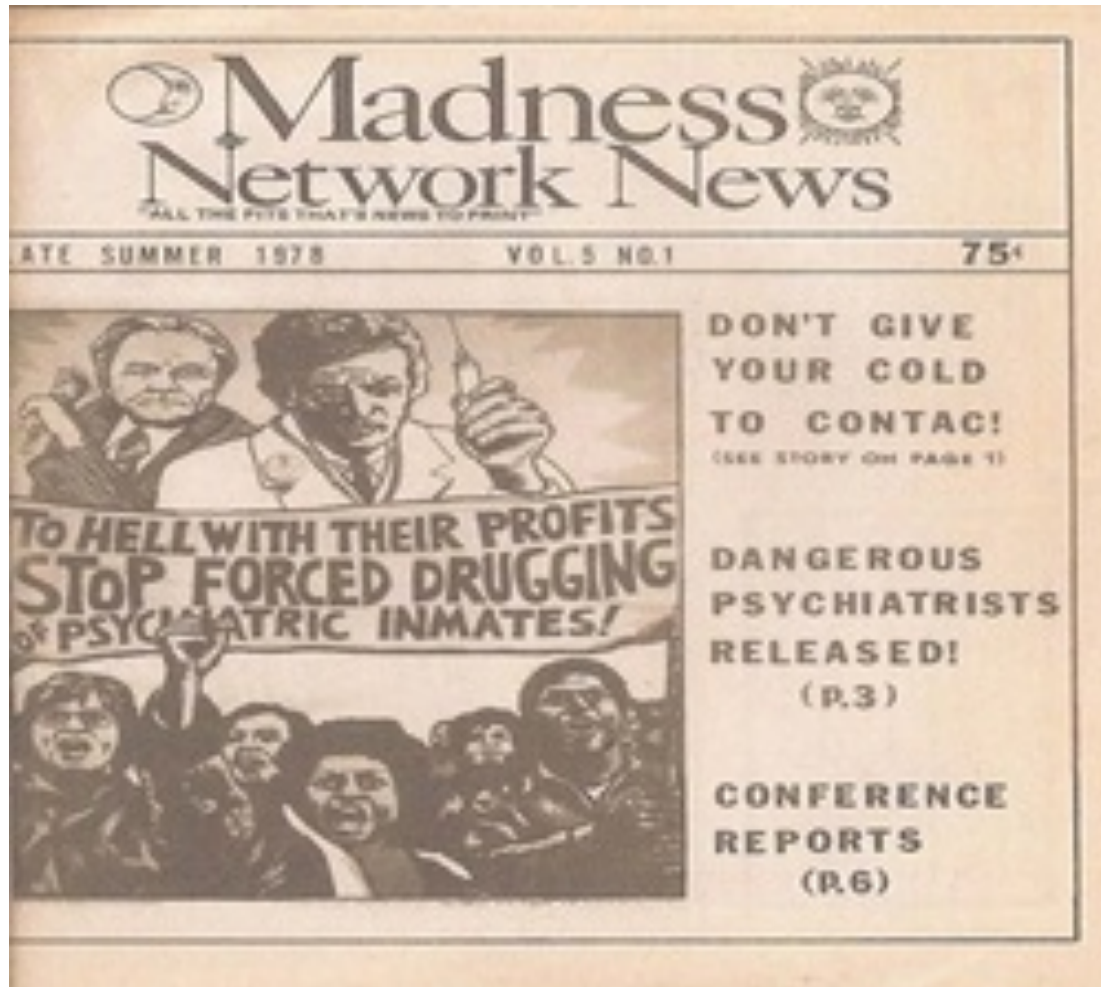




The Modern Movement Part I: The Independent Movement

- Early 1970s – Pockets of Independent Radical Activism
- Insane Liberation Front – Portland, OR, '70
- Mental Patients Liberation Project – NYC, '71
- Mental Patients Liberation Front – Boston, '71
- Network Against Psychiatric Assault – San Francisco, '72
- Australia: Campaign Against Psychiatric Injustice and Coercion (CAPIC) '75 (estimate)
- *Madness Network News*
“All the fits that’s news to print”







National Organizing Begins

- Human Rights Against Psychiatric Oppression Conference – Detroit, 1972
- MindFreedom International forms in 1990*
- Lack of national organizing in Australia

*What is now MindFreedom International (which publishes the *MindFreedom Journal*) used to be called Support Coalition International (the journal was called *Dendron* at that time)



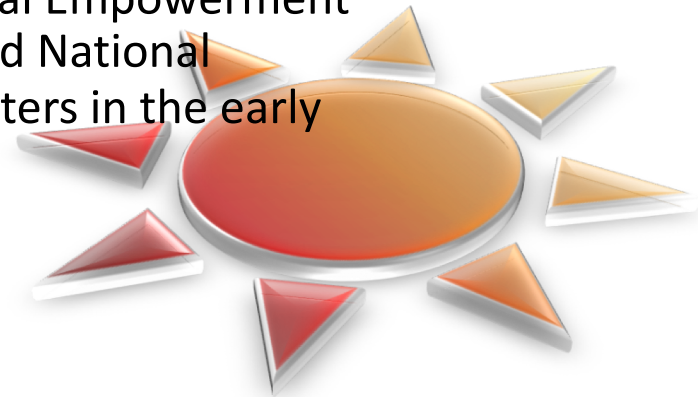


Judi Chamberlin (1944 -2010)



The Modern Movement Part II: The Movement Gets Funded

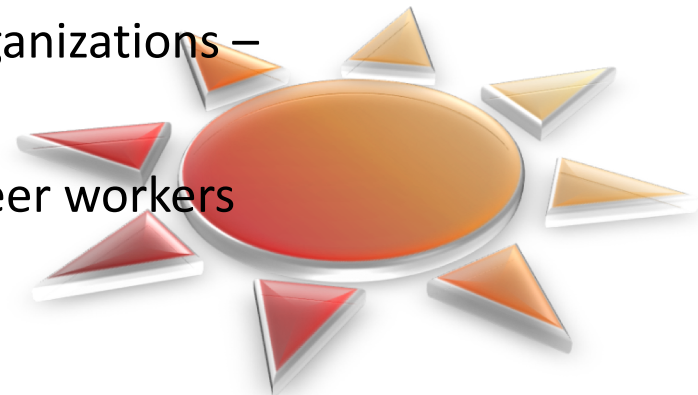
- Government funding begins in the 1980s
- On Our Own of Maryland is first to receive State funding in 1983
- Alternatives Conference begins in 1985 with Federal funding with Baltimore hosting
- The Self-Help Clearinghouse and National Empowerment Center become first two federally funded National Consumer-Run Technical Assistance Centers in the early 1990s
- Similar things happen in Australia





Certified Peer Specialists

- In 2001, Georgia and Arizona became the first two states to have Certified Peer Specialists (CPSs) funded by Medicaid
- Since that time thousands of people from several states across the country have become CPSs
- Most work for traditional provider organizations –
Thus co-optation is a huge problem
- Australia now provides training for peer workers





Where We Are Now

- Now there are 5 federally-funded National Consumer-Run and Consumer Supporter TA centers
- National Coalition for Mental Health Recovery formed in 2006 and now has representation from 32 states
- VMIAC and Our Consumer Place have emerged as strong consumer-run organizations with national influence in Australia
- Systems change is slowly happening





Resources

Presenting the Consumer/Survivor/Ex-Patient Movement

<https://www.youtube.com/watch?v=9uTbEBPkAAk>

Madness Network News

<http://www.madnessnetworknews.com>

The Ex-Patients' Movement: Where We've Been and Where We are Going by Judi Chamberlin

<http://www.power2u.org/articles/history-project/ex-patients.html>

History of the Consumer/Survivor Movement by Gayle Bluebird

<http://www.power2u.org/downloads/HistoryOfTheConsumerMovement.pdf>

The History of the Consumer Movement in Australia by Merinda Epstein

<https://www.vmiac.org.au/info/movement>





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

Presented for: Lived Experience 2.0

Presented by: Oryx Cohen,
Chief Operating Officer

October 26, 2017





"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

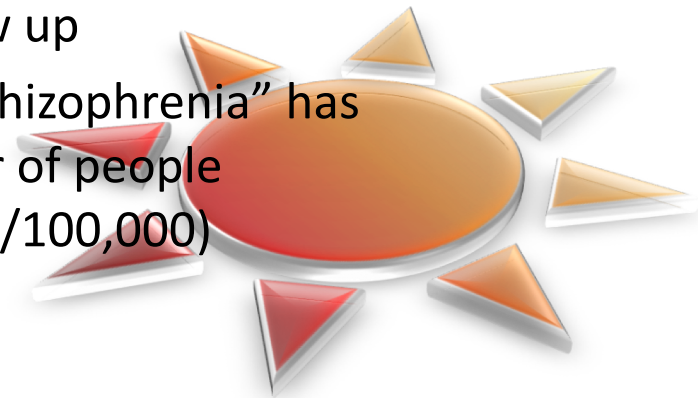
Executive Director

The National Association of County Behavioral
Health and Developmental Disability Directors



Working Together: 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)

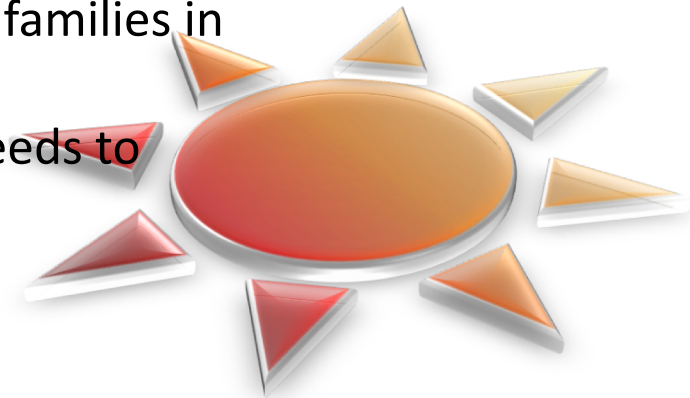






Working Together: Open Dialogue

- 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 and families in meaningful ways
- To be most effective Open Dialogue needs to be THE mental health system





Working Together: 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 trauma-informed

**eCPR is a form of *heart-to-heart connection* for
emotional resuscitation.**



Working Together: Emotional CPR (eCPR)

- e - Emotion
- C - Connect
- P - emPower
- R - Revitalize





Working Together: ReAwaken

- First ever ReAwaken conference was ReAwaken Australia in 2019 in Adelaide, SA!
- Over 100 consumer/survivors, family members, and professionals gathered from all across Australia
- The website speaks for itself:
<https://www.reawakenaustralia.com.au>





Working Together: Summary

- Consumer/survivors speak for consumer/survivors; family members (carers) speak for family members; partnerships are led by consumer/survivors
- Crisis occurs in the spaces between people. When a family member is in crisis, the entire family is in crisis.
- Parents and families are neither totally responsible or totally without responsibility – the dangers of extremism
- Deep listening and respect is critical





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