Living Our Best Life: A Life in the Community

Susan Rogers, Director
National Mental Health Consumers'
Self-Help Clearinghouse
www.mhselfhelp.org
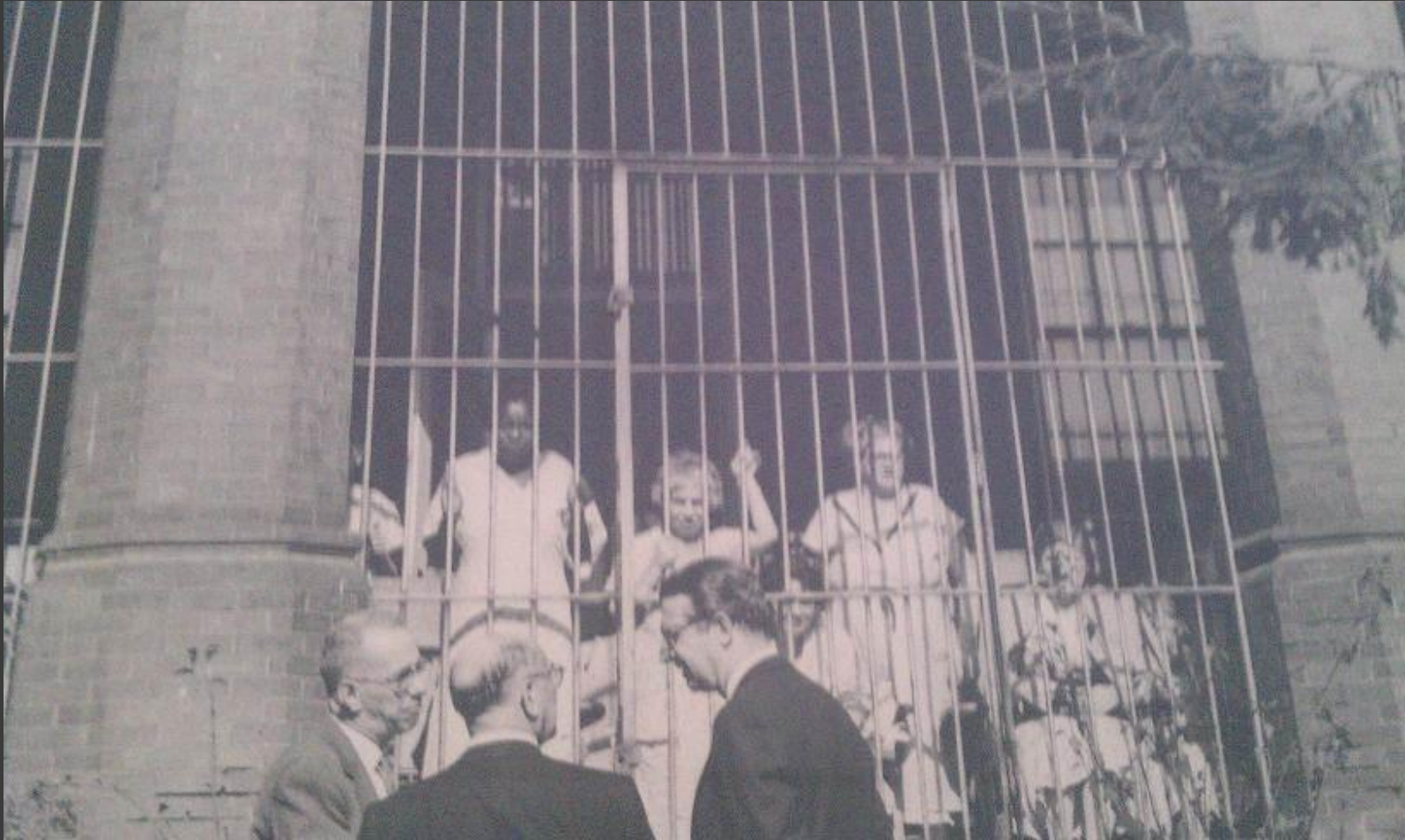selfhelpclearinghouse@gmail.com
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NDRN Conference, 6/21/18

the *Clearinghouse*

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Bring Back Asylums? Let's Not!

Outside Philadelphia State Hospital in the mid-20th century, with the "inmates" behind bars

Quotes from "Trump Wants More Asylums…" NY Times, March 5, 2018

- **"Locking people up long-term is no treatment at all. The idea that we could be going back to those days—we did this before, and it failed and failed badly—it's crazy and discriminating."—*Jennifer Mathis, Dir. Of Policy & Legal Advocacy, Bazelon Center***

- **"You're told when to go to bed, where to go, what to eat and when. They take all your freedom away, and in my eyes [you're] not placed where you get any help."—*Joseph Rogers, Exec. Dir., National Mental Health Consumers' Self-Help Clearinghouse***

Philadelphia State Hospital (Byberry)

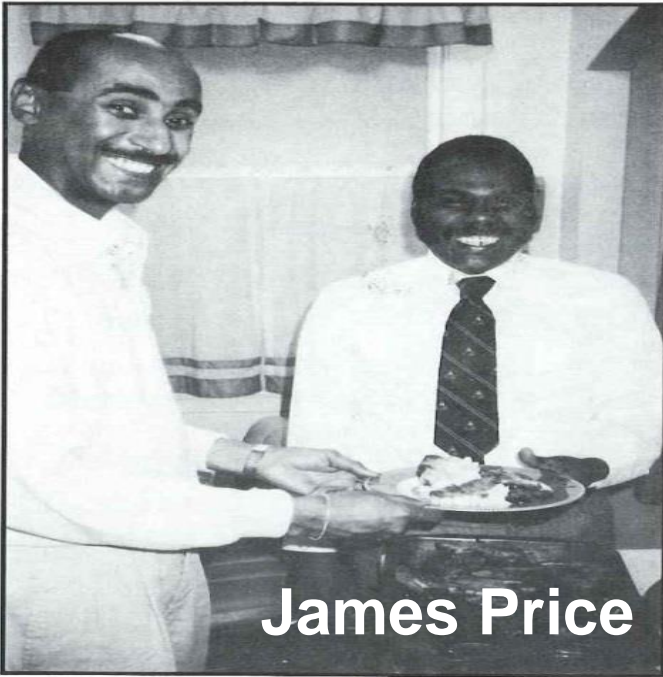We helped close Byberry (PSH) and ensure that the dollars followed the patients into the community (1990).

Philadelphia State Hospital (Byberry)

Byberry Miracle: The Inside Story

The Closing of Philadelphia State Hospital and the Development of a Community System of Care

James Price

- **"It was hard living there. They would put me in seclusion and restraints and give me needles."**

- **After release, his life included living in his own apartment, seeing friends and family, holding a job, and volunteering at his church.**
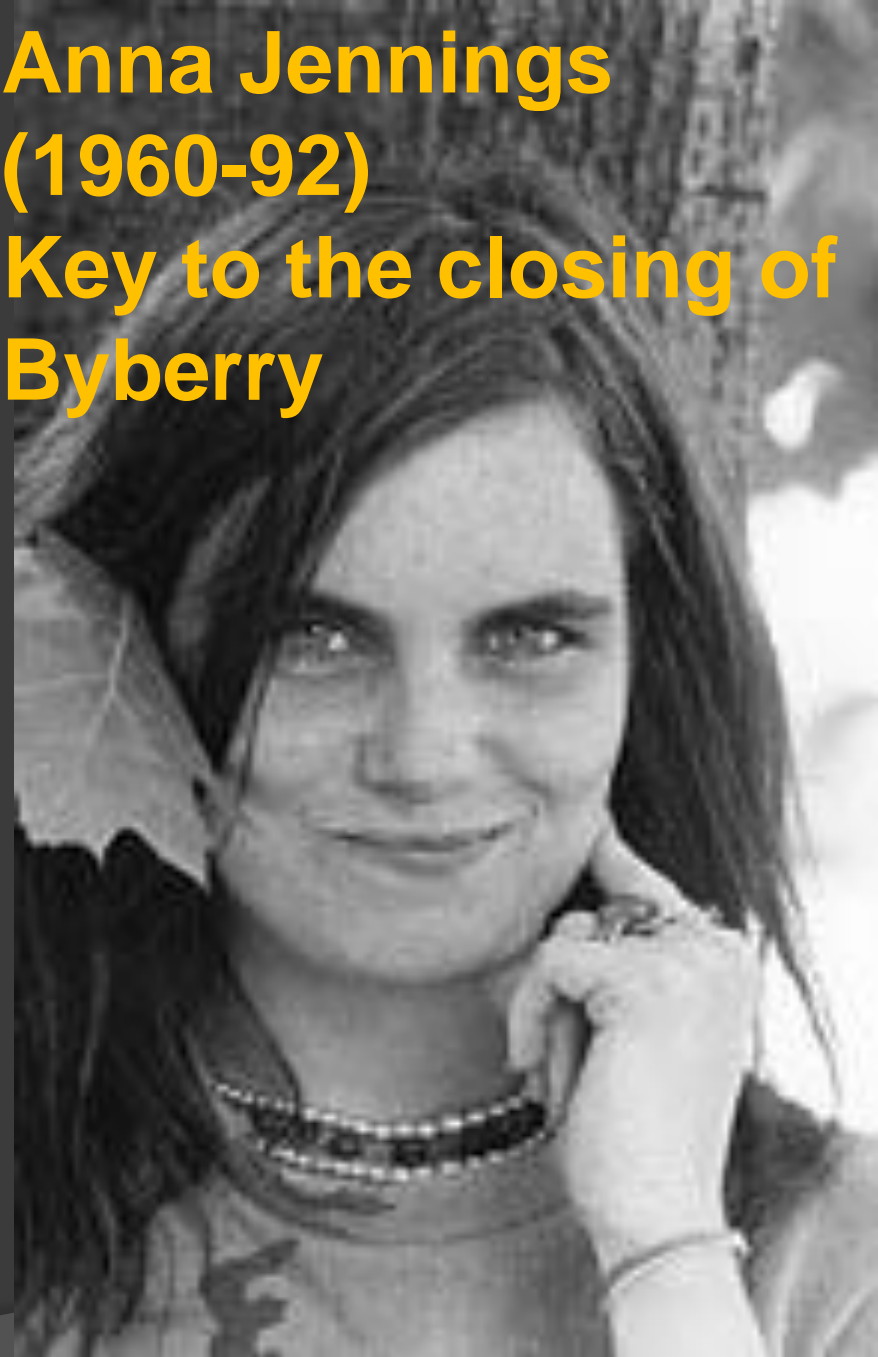
"I am only one. But still I am one. I can-not do everything. But still I can do something. And because I cannot do everything, I will not refuse to do the something that I can do."

-Edward Everett Hale, author and clergyman (1822-1909)

Anna Jennings (1960-92)
Key to the closing of Byberry

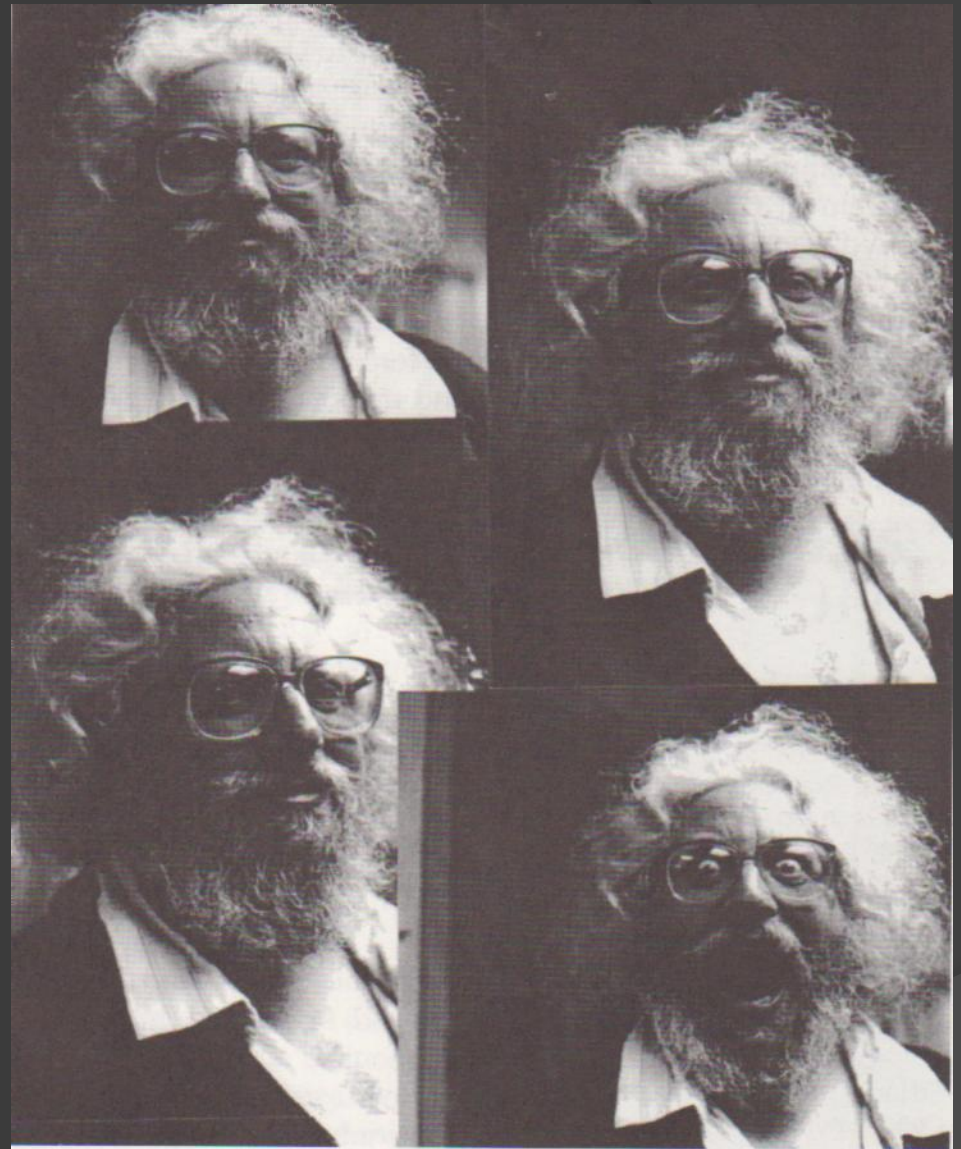# C/S/X Advocacy Movement Grew out of Struggle for Rights and Empowerment

International Conference on Human Rights and Against Psychiatric Oppression, Vermont, 1985

Movement Values

- **Control**
- **Choice**
- **Self-determination**
- **Empowerment**
- **Recovery**

"**We want as full as possible control over our own lives. Is that too much to ask?**"

Howie the Harp (1953-1995)

Recovery Is Real!

- **Recovery from mental disorders and/or substance abuse disorders is a process of change through which individuals:**
  - **Improve their health and wellness**
  - **Live a self-directed life**
  - **Strive to achieve their full potential**

Four Dimensions of Recovery*

- **Health:** Make informed, healthy choices that support physical and emotional well-being.

- **Home:** Have a stable and safe place to live.

- **Purpose:** Engage in meaningful daily activities, such as a job or school, volunteering, caring for your family, or being creative. Work for independence, income, and resources to participate in society.

- **Community:** Build relationships and social networks that provide support.*

* **www.MentalHealth.gov**

"What does recovery mean to me?...

"…To have **hope**. To feel like a useful, needed person. . . . It's giving back . . . helping other people. Believing in yourself. Overcoming obstacles in achieving my goals." – *Sheilah Hill, Shining River Press*

Many Success Stories

Gina Calhoun spent 17 years in psychiatric institutions. During this period, the longest she was able to stay out of the hospital was two months. Now…

Gina Calhoun, a CPS, is in great demand as a public speaker, and has served as the National Director for Wellness & Recovery Education at the Copeland Center

Promoting Biological Nature of Mental Health Conditions Inflames Prejudice, Some Experts Say

- **"'These approaches are not evidence-based. They are ideologically based. It's not an accident that a lot of them are funded by drug companies.'"—*Prof. John Read, quoted in "Hyping Biological Nature of Mental Illness Worsens Stigma, Baltimore Sun, 6/2/18***

A recovery-oriented system assumes that recovery:

- …can occur without professional intervention.

- …can occur even though symptoms recur.

- …does not feel linear.

- **Recovery** from the consequences of a mental health condition is sometimes more difficult than **recovery** from the condition itself.

Recovery from a mental health condition does not mean that one was "not really mentally ill."

Peer Support Is Vital for Recovery

John Minson Galt, Superintendent of Eastern State Hospital in Williamsburg, VA (1841-1862), hired former patients as aides.

And there were even earlier examples – probably dating back to the dawn of human history, but documented "in the moral treatment era inaugurated by Pussin and Pinel in France at the end of the 18th century, and [peer support] has re-emerged at different times throughout the history of psychiatry."–*Larry Davidson, Ph.D., Yale*

PEOPLE FIRST

Thomas J. Ridge, *Governor*
Feather O. Houstoun, *Secretary of Public Welfare*

Volume 8, Number 1   Spring 1998

News About Pennsylvania's Mental Health System

Non-traditional services are gaining acceptance as helpful in recovery

Debbie (right) is a volunteer with Compeer, Inc., in Rochester, N.Y. She spends time with Falon (left), helping her reintegrate into the community. (Photo courtesy Compeer International, Inc.)

Traditional view is challenged on several fronts

By Peggy Salvatore

Non-traditional and consumer-provided mental health services have typically been considered "alternative." But that view is being challenged with increasing vigor both by consumer groups and by professionals who have had experience either studying the field or working in it. The challenge is significant, as the state gears up for statewide implementation of HealthChoices — its mandatory managed care plan for Medical Assistance recipients.

"I believe the services we are talking about are core services," said Carol Ward-Colasante, chief of the Division of Planning and Policy for Pennsylvania's Office of Mental Health and Substance Abuse Services (OMHSAS) of the Department of Public Welfare.

"Serious mental illness is a biopsychosocial disease," she said. "Experience shows that a combination of life supports and clinical treatment works better than either alone.

Volunteer companions provide support in Compeer

Compeer has been providing volunteer friends for people with serious and persistent mental illness since its beginnings in Rochester, N.Y., in 1973. During the past 25 years, the organization has grown nationally and internationally. This is largely due to the soundness of its founding principle: mitigate the loneliness and isolation that accompany mental illness and the effects and frequency of symptoms will decrease.

"People with a support system do better," said Mimi Brulia, associate director of Compeer of the Lehigh Valley, a program of Family and Counseling Services

Peer support is increasingly accepted as a key component in recovery. **One such program is Compeer, which matches individuals in supportive relationships.** *Many Compeer friendships are between two individuals with psychiatric histories.*

Peer-to-peer services treat recipients as equals:

(R to L) The late Johnathan Evans (an award-winning outreach advocate) and an MHASP ACCESS-West Philly colleague talk to a homeless man (1992)

IOC (a/k/a AOT)

- **Involuntary Outpatient Commitment (IOC) has been renamed Assisted Outpatient Treatment (AOT), in an Orwellian attempt to make it more palatable.**

- **"…outpatient commitment statutes are not widely viewed as helpful in the public mental health system.**

  - **"Although many states have such a statute, most states use it only rarely, according to a survey of state mental health commissioners by NASMHPD.**

  - **"Many states, in fact, choose not to implement their outpatient commitment statutes because they possess a woefully inadequate system of community-based services."—Joseph Rogers' testimony on SB 226, 10/2/07**

Better services, *not court mandates,* work best.

- **There's no evidence that using court orders to mandate outpatient treatment is effective.**
- **IOC (AOT) is costly. It would take:**
  - **27 IOC orders to prevent one instance of homelessness**
  - **85 to prevent one hospital readmission, and**
  - **238 to prevent one arrest.**

Other mental health interventions ARE effective:

- **Peer-run crisis respites**

- **Supportive housing**

- **Mobile crisis services**

- **"An alternative to involuntary outpatient commitment [is] giving psychiatric advance directives the weight of law."— Joseph Rogers' testimony on SB 226, 10/2/07**

Alternatives 2018 Policy Priorities

- **Ensure significant peer participation in the development of national and state mental health policies.**

- **Strengthen respect for the values of peer support and recovery as we integrate peer support into community mental health, medical health, and social services.**

- **Develop and sustain alternatives to involuntary treatment by increasing the availability of peer-run crisis respites and other peer-run crisis supports. (continued)**

Alternatives 2018 Policy Priorities
(continued from previous slide)

- Fund basic human needs for individuals with mental health conditions.

- Educate the general public and legislators as to the true meaning of recovery, of a life in the community and its connection to healing from trauma.

- Protect the human rights of persons labeled with mental health conditions.

- Increase self-determination through self-directed care.

- Create a consumer-driven evaluation of the behavioral health system's progress towards a recovery-based system.

Resources

- **"Federal Multi-site Study Finds Consumer-Operated Service Programs Are Evidence-Based Practices"** **https://tinyurl.com/yabd8unk**

- **"Peer-run Crisis Alternatives"** **https://power2u.org/crisis-alternatives/**

Resources

- "Recovery Is Possible" https://www.mentalhealth.gov/basics/recovery-possible

- "Return to Asylums? Let's Not!" https://www.madinamerica.com/2015/02/return-asylums-lets-not/

- "Trump Wants More Asylums—And Some Psychiatrists Agree," *NY Times*, 3/5/18 https://www.nytimes.com/2018/03/05/health/mental-illness-asylums.html

Resources

- "Stigma Is Social Death:…" http://www.freedom-center.org/pdf/debreidystigma.pdf

- "Prejudice and Schizophrenia: A Review of the 'Mental Illness Is an Illness Like Any Other' Approach," by J. Read, et al. http://www.freedom-center.org/pdf/read_prejudice_schizophrenia_biol_stigma.pdf

- "Hyping Biological Nature of Mental Illness Worsens Stigma, *Baltimore Sun*, 6/2/18 http://www.baltimoresun.com/news/opinion/oped/bs-ed-op-0603-health-stigma-20180531-story.html

Resources

- **"Amici Curiae Brief of National Mental Health Consumers' Self-Help Clearinghouse, et al." in *Olmstead v. L.C.* https://tinyurl.com/y7fxprct**

- **"Let's Call Mental Health Stigma What It Really Is—Discrimination" https://tinyurl.com/ycxfq8mk**

- **World Health Organization: Social Determinants of Mental Health https://tinyurl.com/jutm3we**

Resources Re: IOC/AOT

- **National Coalition for Mental Health Recovery: "Involuntary Outpatient Commitment Myths and Facts" https://tinyurl.com/yakjxlg9**

- **Allen, M., Smith, V.F. "Opening Pandora's Box: The Practical and Legal Dangers of Involuntary Outpatient Commitment." *Psychiatric Services*, Vol. 52, No. 3 https://tinyurl.com/yasoe6w5**

- **Bazelon Center for Mental Health Law, "Position Statement on Involuntary Commitment" https://tinyurl.com/y9lkqgyq**

- **Testimony by Joseph Rogers on SB 226, Oct. 2, 2007 https://www.mhselfhelp.org/clearinghouse-resources/**

Peer Support Evidence Base

Humphreys, K. Individual and Social Benefits of Mutual Aid Self-Help Groups. Social Policy. March 22, 1997.
http://www.highbeam.com/doc/1G1-20220441.html

**Davidson, et al. (2012) Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry*
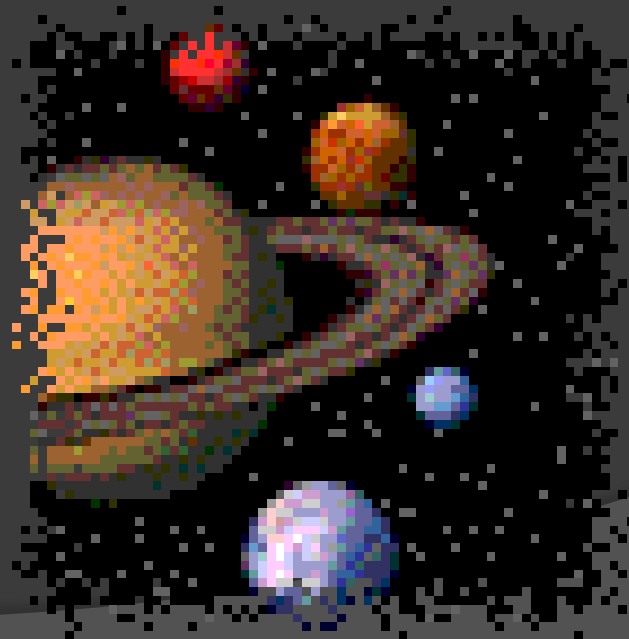http://tinyurl.com/qcfqnwo**

Peer Support Evidence Base

Consumer/Survivor-Operated Self-Help Programs: A Technical Report **https://ce-credit.com/articles/100157/ConsumerOperatedSelfHelp100157.pdf**

Bergeson, S. Cost-effectiveness of Using Peers as Providers **https://tinyurl.com/yckxhgjv**

Resources

- **National Mental Health Consumers' Self-Help Clearinghouse: http://www.mhselfhelp.org**

- **Consumer-driven Services Directory: http://www.cdsdirectory.org/**

- **Temple University Collaborative on Community Inclusion: http://www.tucollaborative.org**