

# History of the Consumer/Survivor/ Ex-Patient (c/s/x) Movement

**Joseph Rogers, Executive Director  
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Clearinghouse**

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<https://www.mhselfhelp.org>**

***Alternatives 2022  
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# Roots of Peer Advocacy Movement Are in Civil Rights Movement and Self- Help Movement (AA, etc.).

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



# Ex-patients' Rights Groups Form in 1970s and Early 1980s

...in Massachusetts, California, New York, Pennsylvania, Florida, Oregon



**Judi Chamberlin**



**Sally Zinman**



**Jay Mahler**



**Ed Knight**



**Leonard Roy Frank**



**Joseph Rogers**



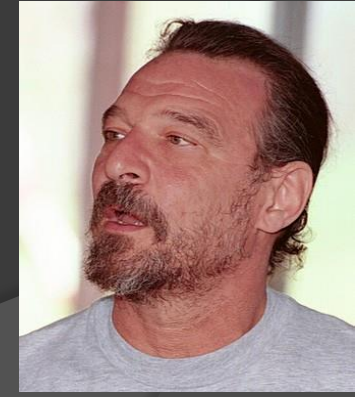
**Bluebird**



**Dan Fisher**

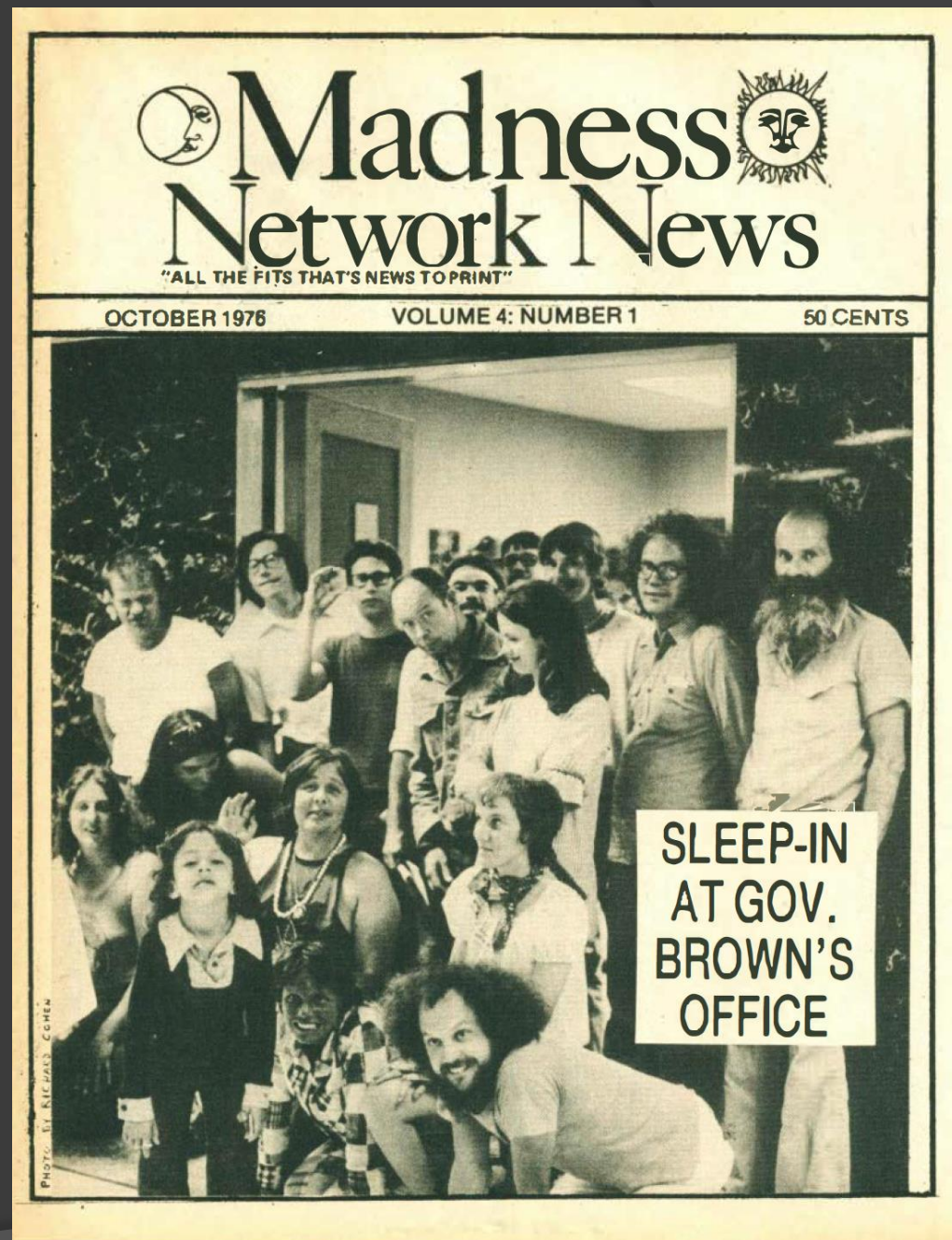


**David Oaks**



**George Ebert**

**“*Madness Network News*, founded in 1972 by two women inmates of Agnews State Hospital [in California], was an anti-psychiatry journal that served as the focal point for organizing throughout North America, and even overseas.”-*Mad in America***



***On Our Own: Patient Controlled Alternatives to the Mental Health System (1978)*** “makes a compelling case for patient-controlled services—a real alternative to the institutions that destroy the confident independence of so many.”-*NEC*

**An early leader  
of the c/s/x  
movement**



**Judi Chamberlin (1944-2010)**

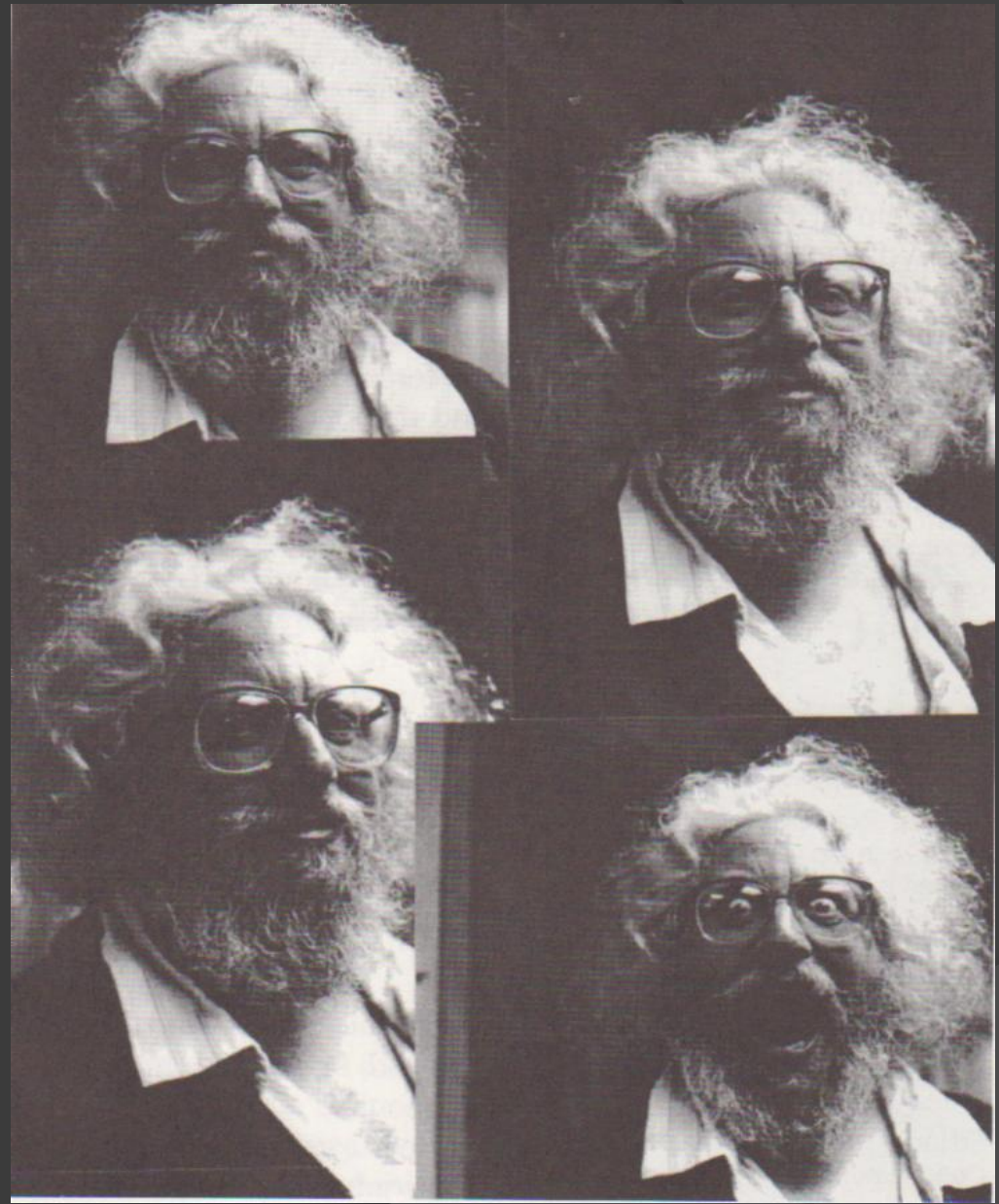


# Movement Values

- 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**



**Howie the Harp (1953-1995)**

# Right to Refuse

1975: *O'Connor v. Donaldson*: U.S. Supreme Court rules that people cannot be institutionalized against their will unless they are a danger to themselves or others.

1982: Ruling in *Rogers v. Okin* established a limited right to refuse treatment (psychiatric drugs) in Massachusetts.



# Civil Rights of Institutionalized Persons Act (1980)



Philadelphia State Hospital

The Act gives the Department of Justice the power to sue state or local institutions that violate the rights of people held against their will, including those in psychiatric institutions.



# PAIMI Was Established in 1986

- ◎ **Protection and Advocacy for Individuals with Mental Illness (PAIMI) programs:**
  - **Protect and advocate for the rights of people with mental health conditions, and**
  - **Investigate reports of abuse and neglect in facilities that serve such individuals.**
- ◎ **The c/s/x movement played a role in the PAIMI Act's 2000 amendment to allow P&As also to serve individuals with mental health conditions in the community. <https://tinyurl.com/23sdv9ub>**



# Movement Evolves, Gains Power

- “A seat at the table”
- Serving on boards and committees
- Closing state hospitals
- Legislative advocacy
- Support on federal level

*Neal Brown (right) and Jackie Parrish of the federal Community Support Programs Branch, now part of SAMHSA, helped the movement gain financial support.*

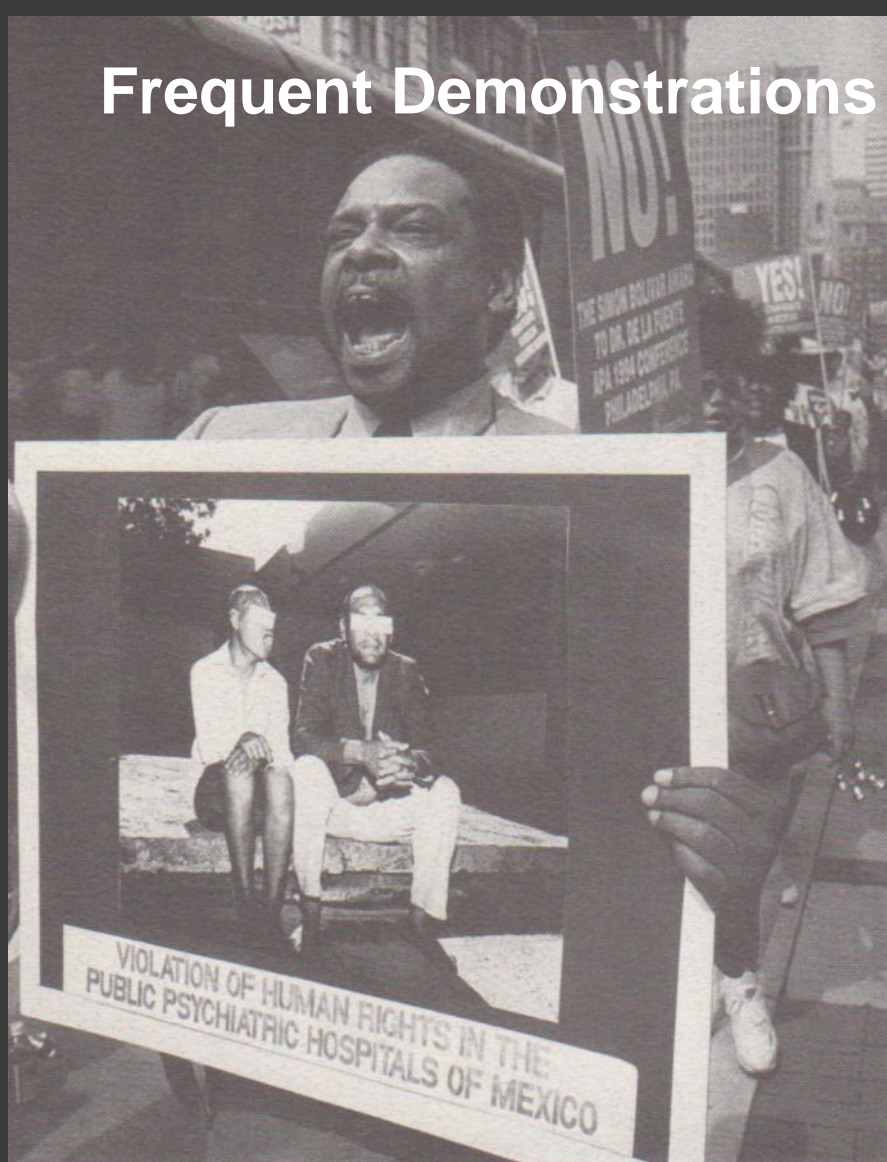


# Alternatives '85 Closing Ceremony



The first Alternatives conference—Alternatives '85, in Baltimore—was organized by On Our Own of Baltimore; 450 attended. The Alternatives conferences were held on college campuses until 1992. The Alternatives conferences are organized by and for peers.

# Frequent Demonstrations for Rights & Justice



**Project SHARE demonstrates outside APA annual meeting in Philadelphia, May 25, 1994.**

*Above, Johnathan Evans.*



**Demonstration at Alternatives '89, organized by South Carolina SHARE**



**Bastille Day march and rally at Alternatives '90 in Pittsburgh to combat discrimination and prejudice, organized by National Mental Health Consumers' Self-Help Clearinghouse**

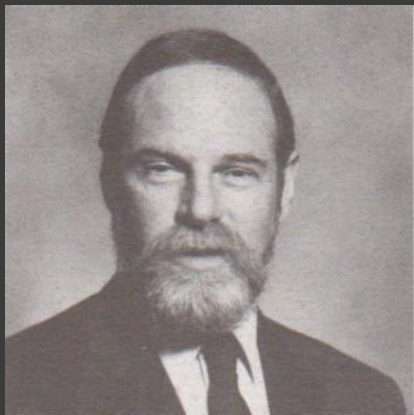




**President George H.W. Bush signs the ADA (1990), with Justin Dart at right. (The 1999 *Olmstead* decision upheld the ADA's community integration mandate.)**

# DECADES SPENT CONVINCING THE ESTABLISHMENT OF PEER SUPPORT'S VALUE

- Presenting at conferences
- Attending meetings of professionals and administrators
- Serving on boards and committees
- Writing and publishing articles



Dr. Bernard Arons,  
then-Director, CMHS

***1993 sit-in led to more funding for peer-run programs.***

***Former SAMHSA administrator supported peer movement, fought seclusion & restraint***



Charles G. Curie

## ***Paradigm shift:***

**The establishment believes in recovery and accepts the value of peer support.**

- **“Mental Health: A Report of the Surgeon General” (1999)**
- **Report of the President’s New Freedom Commission on Mental Health (2003)**



**Michael F.  
Hogan,  
Chair,  
President’s  
New  
Freedom  
Commission**



**Then-U.S.  
Surgeon  
General David  
Satcher**



# **“Powers-that-be” realize that recovery-oriented, peer-run services are key to recovery**

In 2004, SAMHSA officially recognizes **Peer Support** as one of the *10 fundamental components of recovery*.

The 10 are:

- **Self-Direction**
- **Individualized and Person-Centered**
- **Empowerment**
- **Holistic**
- **Non-Linear**
- **Strengths-Based**
- **Peer Support**
- **Respect**
- **Responsibility**
- **Hope**



Then-SAMHSA  
Administrator Pam Hyde



Then-CMHS Director,  
now Office of  
Recovery Director,  
Paolo del Vecchio

# Peer-to-peer services treat recipients as equals:



Johnathan Evans (*right*) (an award-winning outreach advocate who died on 7/19/13), with an ACCESS-West Philly colleague (*center*), talk to a homeless man (1992).

**Johnathan was homeless when he was brought in from the cold by another MHASP outreach advocate in 1987.**

Johnathan's obituary: <https://tinyurl.com/2p885y23>



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

**Anna Jennings (1960-92)**  
**Key to closing of PSH**

***“It was really a risk for her, but she cared about the other patients there, and she was outraged . . . She never, ever stopped fighting.” – Anne Jennings, Anna’s mother, about Anna’s involvement in the closing of Philadelphia State Hospital***

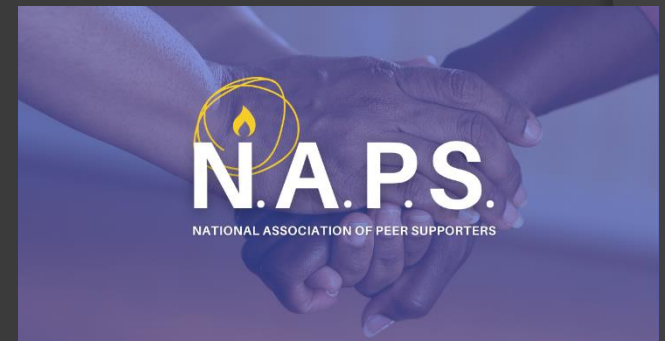
**<http://www.theannainstitute.org/a-bio.html>**



# National and International Peer-Run Organizations Are Founded.



MindFreedom International, founded as Support Coalition International in 1990, took on its current name in 2005. It fights to win human rights and alternatives for people labeled with psychiatric disabilities.



The National Association of Peer Supporters, founded in 2004 as the National Association of Peer Specialists, is dedicated to promoting peer support in mental health systems. Its mission is “to grow the peer support profession by promoting the inclusion of peer specialists throughout healthcare and other community systems in the United States.”

# 5 National TACs Serve the Movement

The National Mental' Self-Help Clearinghouse ([www.mhselfhelp.org](http://www.mhselfhelp.org)), founded in 1986, was the first national peer-run technical assistance center to be funded by SAMHSA. It is still in operation, although now without federal funding.

**The current SAMHSA-funded national peer-run technical assistance centers are:**

- ➔ **National Empowerment Center (the second SAMHSA-funded national peer-run TA Center ([www.power2u.org](http://www.power2u.org)))**
- ➔ **Doors to Wellbeing (<https://www.doorstowellbeing.org/>)**
- ➔ **Café TA Center (<https://cafetacenter.net/>)**
- ➔ **Peer Experience National TA Center (<https://www.peersupportfl.org/pentac/>)**
- ➔ **Youth MOVE National Peer Center (<https://youthmovepeercenter.org/>).**

**A national coalition of statewide consumer/survivor organizations, founded in 2006 to ensure that consumers/survivors have a major voice in the development and implementation of health care, mental health, and social policies at the state and national levels, empowering people to recover and lead a full life in the community.**

**[www.ncmhr.org](http://www.ncmhr.org)**



**National Coalition for  
Mental Health Recovery**



***Senator Tom Harkin, of Iowa, shares a special time with Dan Fisher, Rachel Freund, and Lauren Spiro at the Presidential Forum in Columbus Ohio, July 26, 2008.***

# Other National Groups Support C/S/X Movement



Judge David L.

**BAZELON CENTER**  
for Mental Health Law



**NASMHPD**

NATIONAL  
**DISABILITY RIGHTS**

NETWORK

Protection & Advocacy for Individuals with Disabilities





# Youth Are the Future & It Starts Now



Youth leader Letty Elenes:

**“I’ve been let down by the system.”**

“I’ve been asked to let go of my culture and my beliefs.”

**“I will continue to fight for social justice change.”**

“Youth are the future and the future starts now.” <http://tinyurl.com/ktrsugx>