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

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

Judi Chamberlin (1944-2010)

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
“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)

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](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.
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


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

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

Former SAMHSA administrator supported peer movement, fought seclusion & restraint.
Paradigm shift:
The establishment believes in recovery and accepts the value of peer support.

“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](https://tinyurl.com/2p885y23)
We helped close Byberry (PSH) and helped ensure that the dollars followed the patients into the community (1990).
“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
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.”


National and International Peer-Run Organizations Are Founded.
5 National TACs Serve the Movement

The National Mental’ Self-Help Clearinghouse (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)
- 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.

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.

www.ncmhr.org
Other National Groups Support C/S/X Movement

NARPA

Judge David L.
BAZELON CENTER
for Mental Health Law

Mental Health America

NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities
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/ktrqsugx](http://tinyurl.com/ktrqsugx)