History of the C/S/X (Consumer/Survivor/Ex-Patient) Movement, and Creativity and Recovery

Susan Rogers, Director
National Mental Health Consumers’ Self-Help Clearinghouse
and Director of Special Projects, MHA of Southeastern PA
1211 Chestnut St., 11th Floor, Philadelphia, PA 19107
267-507-3812, srogers@mhasp.org
www.mhselfhelp.org and www.mhasp.org
Temple University, Sept. 10, 2013
Mid-20th-century organizing efforts include:

- **WANA (We Are Not Alone) (1940s):**
  - People released from psychiatric hospitals
  - Came together for mutual support
  - Founded Fountain House in NYC
    - Created clubhouse model

Fountain House
425 W. 47th Street, NYC
Civil Rights Movement
Sparked C/S/X Movement

“Those who profess to favor freedom, and yet deprecate agitation, are men who want crops without plowing the ground.”

--Frederick Douglass (1817-1895)

Dr. Martin Luther King Jr. (center) at March on Washington, August 1963
Movement Roots Are in General Self-Help Movement (AA, etc.)

“It is important to go beyond self-help and mutual support to systems advocacy.”

Frank Riessman
1924-2004
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

Sally Clay
Dan Fisher
David Oaks
George Ebert

Joseph Rogers
Peer Advocacy Movement Grew out of Struggle for Rights & Empowerment

International Conference on Human Rights and Against Psychiatric Oppression, Vermont, 1985
“We want as full as possible control over our own lives. Is that too much to ask?”

Movement Values

• Control
• Choice
• Self-determination
• Empowerment
• Recovery

Howie the Harp (1953-1995)

http://www.youtube.com/watch?v=dm5Uo6czoAw
“Peer support is ...”

... a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another’s situation empathically through the shared experience of emotional and psychological pain.”

– Shery Mead
Since 1984, MHASP has helped create a revolution

As a result of the vision and leadership of Joseph Rogers, now MHASP’s chief advocacy officer, MHASP has developed and implemented innovative peer-to-peer services that have revolutionized the mental health care field while continuing to advocate effectively for systems transformation.

http://www.youtube.com/watch?v=7W-EDyejo54
MHASP has often taken it to the streets:

• “Chain-in” at Philadelphia Housing Authority (1985)
• Sleep-out at State Office Building (1987) led to $4.5 million in funding for homeless housing programs!
• Arrests at Federal Office Building (1988)
• Sit-in by MHASP and other groups in CMHS director’s office led to more funding for consumer-run programs (1993)
1984: Joseph Rogers Founded Project SHARE
Organized self-help/advocacy groups, and more

Early demonstrations include civil disobedience outside Philadelphia Public Housing Authority to protest announcement of proposed discriminatory policies (1985). The demonstration was successful; the policies were not issued!
A press release attracted all three TV network affiliates and the two major Philadelphia daily newspapers.

The c/s/x movement has used street theater effectively to communicate with the press and public.
The Alternatives conferences are organized by and for people with psychiatric histories. (Above: closing ceremony of Alternatives ’85, the first Alternatives conference, which 450 attended.) The conferences include a talent show.
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.
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 recovery movement, fought S&R

Dr. Bernard Arons

Charles G. Curie
MHASP’s National Mental Health Consumers’ Self-Help Clearinghouse

- In 1986, Joseph Rogers saw the need for a national technical assistance center to support the growing peer recovery movement, and founded the Clearinghouse.
- The Clearinghouse provides technical assistance to the peer recovery movement and to others nationally and internationally.
- As a result of the Clearinghouse’s success, now there are five such federally funded centers.
5 National TACs Help Movement Grow:

www.mhselfhelp.org
www.power2u.org

www.cafetacenter.net
www.consumerstar.org

www.peerlink.us
Other National Groups Support C/S/X Movement

NARPA

Judge David L.
BAZELON CENTER
for Mental Health Law

Mental Health America

NASMHPD

NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities
Sleep-out in front of PA State Office Building (1987) led to $4.5 million from the state for housing programs for homeless people with psychiatric disabilities.
Sit-in at Federal Office Building (Phila. 1988) focused public attention on $25 billion in cuts to low-income housing, which resulted in homelessness.
“Crazy People” (1990): Project SHARE’s protest against a local ad campaign – WARNING: Crazy People Are Coming – led to stories of recovery in the local media.

Promotion for movie protested

Ad for ‘Crazy People’ is called offensive

By Carolyn Acker
Inquirer Staff Writer

The ads for the movie are bad enough, they said. Big yellow signs on billboards and bus shelters that read, Warning: Crazy People Are Coming. Then, the weekly City Paper ran a promotion in Thursday’s edition, offering free tickets to a screening of the movie. In order to win, readers were asked to come to the newspaper office yesterday and ‘prove to us you’re crazy.’

“I brought my medication and said, ‘I’m crazy,’” recounted Laura Van Tosh, angrily shaking a bottle of pills drawn from her purse. “I got the last ticket, and I tore it up in his face. ‘I said, ‘I think what you’ve done is disgusting.’”

And she said associate publisher Philip R. Anderson told her, “Thank you for sharing that with me.”

Van Tosh and eight other employees of Project SHARE—a self-help organization for the mentally ill—picked the offices of the City Paper in the rain yesterday, demanding an apology for the promotional ad for Crazy People, which appears here next month.

Pennsylvania have asked Paramount Pictures to pull the advertising campaign.

In the letter mailed yesterday, Robert J. Lerner, executive director of the Mental Health Association, called the campaign “terribly offensive” and hinted broadly at a boycott. Outside the City Paper’s office, in the 236 block of South 13th Street, protesters marched in the rain, carrying placards that read: “It could happen to you.” “The mentally ill should not be laughed at” and “End stigma.”

“I don’t mean anything,” said Anderson, who wrote the ad and addressed the group. “Yes, it does” countered Van Tosh.

“Anyone who asked for tickets, we gave them,” said Anderson. “We didn’t say, ‘Dance around’ . . . We did not ask anyone to act crazy.”

Although Anderson told the group he sympathized and agreed with their cause, he appeared to be talking about the movie—not his ad. He told them to put their complaints about the promotion in a letter to the paper.

The City Paper is an alternative-style newspaper, distributed free of charge. It claims a readership of 25,250.

Yesterday, management took the unusual step of locking the front door—emotions had “Crazy People” poster. “Now we have nothing else,” said Schimmel, closing and locking the door.

Later, Spilman, Schimmel asked Anderson whether the protesters wanted an apology. “Maybe we ought to consider that,” Schimmel said. “Sometimes you do stupid things . . . without knowing.”

Then, the publisher went downstairs and brought Van Tosh back to his office, where he met with Richard B. Colby Jr., public affairs director of the Philadelphia Mental Health Care Corp. When he the three emerged about a half-hour later, Van Tosh flashed a thumbs-up sign.

Schimmel announced the newspaper would print an apology for the ad. “This was part of a promotional campaign,” said Schimmel. “We picked up the spirit of the campaign, and, on reflection, that spirit was mean spirited and wrong.”

He said the paper would not run an ad when the movie opens, which would mean about $250 in lost revenues. And, he said, the paper would learn more about Project SHARE and run stories that present “alternative views” of mental illness.

As he spoke, Schimmel carefully monitored...
Bastille Day rally at Alternatives ‘90 to combat discrimination and prejudice, organized by the National Mental Health Consumers’ Self-Help Clearinghouse.

Charlie King

Hikmah Gardiner

Joseph Rogers
Susan Rogers
Mental patients rally in search of a fair chance and fewer labels

By Steve Twedt
The Pittsburgh Press

Twenty-five years after being diagnosed as having paranoid schizophrenia, Nelson Hawthorne believes his biggest roadblock to a normal life is society, not sickness.

Carrying a sign that read "Label jars, ok people," the 48-year-old Norristown, Montgomery County, resident and about 60 other current or former mental patients and friends rallied at Market Square yesterday to protest discrimination against people who have undergone psychiatric treatment.

"The mental health system produces an artificial dependence and we're not allowed to be productive citizens," he said.

Hawthorne lost his job five years ago and, while he still applies for work occasionally, "one of the questions on the application is always: 'Have you been hospitalized for psychiatric treatment?' They don't say anything. They can't really say anything. You just never get an interview."

Stacey Pope, 31, of Jacksonville, Fla., said she lost her retail sales job when she was hospitalized for five days. She was diagnosed as severely depressed three years ago, but doctors now think she is schizophrenic.

"When you're going through it, you just feel hopeless," she said.

The rally was part of Alternatives '90, a five-day national conference concluding today at Duquesne University. The conference was organized by people who have had psychiatric problems. About 1,000 people attended.

Erin Newland, front, of Connecticut, and John Fijalek of Maine took part in mental health rally.

The group hopes to fight the stigma of mental illness, to improve the quality of life for the mentally ill and to develop alternatives in the mental health system.

Madeleine Nash, 39, a rape counselor from Big Spring, Texas, who has been both a patient and a staff development coordinator at a state hospital, said, "Society needs to see the mentally ill not as weirdos, not as freaks, but as people with needs, like someone who has heart problems or kidney problems. It's just affecting us in a different area."

During the past 10 years, she has witnessed hospital aides who "have no perception of what a schizophrenic is, or what a psychotic is, or how to communicate with that person. So they have to react to the physical."

At the same time, she added, mental patients have their own responsibility for removing the stigma they face by not using their illness to manipulate others or to shirk difficult tasks.

Mental health professionals, mental health patients, or consumers, have to meet halfway," she said.

"The professionals want complete control and the consumers want complete control. There's got to be some compromise."

Yesterday was designated National Mental Patients Rights Day and the conference theme, "Together Tearing Down the Walls," was designed with yesterday's celebration of Bastille Day in mind. Bastille Day is the French holiday marking the anniversary of the 1789 freeing of prisoners — some of whom were mentally ill — from the Bastille prison.
We helped close Byberry (PSH) and ensure that the dollars followed the patients into the community (1990).
President George H.W. Bush signs ADA (1990), with Justin Dart at right.
Paradigm shift:
Establishment believes in recovery and accepts value of peer support

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

SAMHSA 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
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.
MHASP operates approximately 40 services, many of which are peer-to-peer:

- Advocacy
- Peer resource centers
- Peer specialist training/certification
- Targeted and forensic case management
- Supported housing
- "Parenting Plus" classes for parents with mental health conditions, and other family services
- Peer-run national technical assistance center funded by SAMHSA
- Community wellness center in N. Philadelphia
- Others
Peer-to-peer services treat recipients as equals:

MHASP’s Johnathan Evans (right) – an award-winning outreach advocate who died on 7/19/13 – and an ACCESS-West Philly colleague talk to a homeless man (1992). Johnathan’s obituary: [http://tinyurl.com/pyl738n](http://tinyurl.com/pyl738n)
MHASP helped design HealthChoices and helped preserve CBH as a city-run non-profit.

MHASP management and staff are among the advocates, City officials and concerned citizens attending the 12/11/96 Philadelphia City Council hearing on Community Behavioral Health.
MHASP Organizes Successful Rally to Restore Funds for Mental Health Programs (Nov. ’03)
MHASP Provides Technical Assistance Internationally

One example: Jeanie Whitecraft of MHASP’s Institute for Recovery and Community Integration traveled to Japan to teach an introduction to the Wellness Recovery Action Plan (WRAP).
MHASP Helped Bring the Crisis Intervention Team Model to Philadelphia

First Phila. CIT graduating class, February 1, 2007
“Loony Bin Rally”

- Lemonade from lemons: MHASP Rally for supported housing (2008) – Wire service called it “loony bin rally,” which resulted in an apology and lots of publicity.

See article in Behavioral Healthcare about the rally at link below.

http://www.behavioral.net/article/rallying-better-housing
Chester County Certified Peer Specialists on graduation day, Nov. 14, 2008, with MHASP facilitators Crystal Edwards (front left) and Christopher Mooney (rear, second from right)

MHASP’s Institute for Recovery and Community Integration trains and certifies CPS.
Bipolar disorder is more prevalent in individuals with artistic or scientific professions, such as dancers, researchers, photographers and authors.

Authors also were more common among individuals with most of the other psychiatric diagnoses (including schizophrenia, depression, anxiety syndrome and substance abuse).

Authors were almost 50 per cent more likely to die by suicide than the general population.

Creative professions were more common in the relatives of individuals diagnosed with schizophrenia, bipolar disorder, anorexia nervosa and, to some extent, autism.

The results give cause to reconsider approaches to treating mental health conditions.

http://www.sciencedaily.com/releases/2012/10/121016084934.htm
Occupy the APA

- The goal was to call attention to the fact that the DSM-5, which was to be rolled out to the APA membership at its annual meeting at the Philadelphia Convention Center, medicalized natural human emotions. [http://tinyurl.com/pcyl2p2](http://tinyurl.com/pcyl2p2)
- The DSM-5 was published in 2013. [http://tinyurl.com/qhvvs4xe](http://tinyurl.com/qhvvs4xe)
Artist: Amy Smith  http://tinyurl.com/qdepdf
“J. Pepin Art Gallery features contemporary artists who are reframing the perception of mental illness. Along with their works, each artist shares their creative journey and how having a mental illness plays a role.”

http://www.jpepinartgallery.com/
Creative Explorations comprises ...

• . . . artists, writers, musicians, photographers and professionals who meet to share creative work and engage in discussion.
• “Gatherings are in an open forum for people to connect through sharing the inner expressions that derive from the universal human experience.
• “Some share their creative work, while others choose to simply listen.”

http://www.creativeexplore.org
Virginia Tech Art Exhibit Explores Creativity and Mental Health

- The Virginia Tech Carilion School of Medicine’s sixth art exhibition explores the therapeutic value of art, especially as it pertains to mental health.
- The exhibition, called “Creativity and Mental Health,” features the works of more than 70 people, many of whom have received care at Roanoke Valley mental health agencies and clinics.
- The exhibit will run through October 2013.

http://www.vtnews.vt.edu/articles/2013/07/071513-vtc-artandmentalhealth.html
Stand Up for Mental Health

In David Granirer’s Stand Up For Mental Health course, individuals with mental health conditions turn their problems into stand up comedy, then perform their acts at:

- conferences;
- treatment centers;
- psych wards;
- for various mental health organizations, corporations, government agencies;
- on college and university campuses; and
- for the general public.

http://standupformentalhealth.com/
Creativity Can Be Central to Recovery

- Magnificent Minds Project http://www.magnificentmindsproject.com/
- Faces of Mental Health Recovery Public Art Project http://www.mhapa.org/faces-of-mental-health-recovery-public-art-project/
- PhotoVoice http://cpr.bu.edu/resources/newsletter/photovoicefight-stigma-mental-illness
- Meghan Caughey http://www.meghancaughey.com/
- Mike Skinner http://www.mskinnermusic.com/
“The Anna Institute celebrates and honors the life of Anna Caroline Jennings, by using her artwork and life experience to educate others on the hidden epidemic of childhood, trauma and their horrific lifelong impacts on society, and paths to prevention and healing.”

http://www.theannainstitute.org/a-bio.html
Resources:

- Mental Health Association of Southeastern Pennsylvania
  http://www.mhhasp.org

- National Mental Health Consumers’ Self-Help Clearinghouse:
  http://www.mhsselfhelp.org

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