

# 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**

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**[www.mhselfhelp.org](http://www.mhselfhelp.org) and [www.mhasp.org](http://www.mhasp.org)**

**Temple University, Sept. 10, 2013**

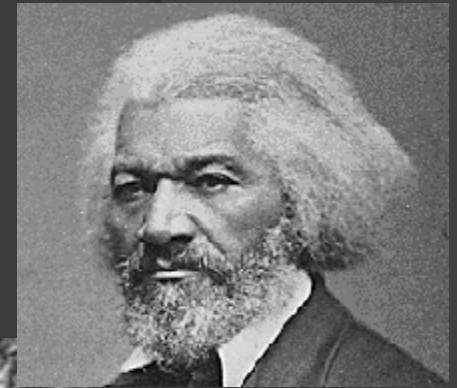
# Mid-20<sup>th</sup>-century organizing efforts include:



**Fountain House**  
**425 W. 47<sup>th</sup> Street, NYC**

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

# Civil Rights Movement Sparked C/S/X Movement



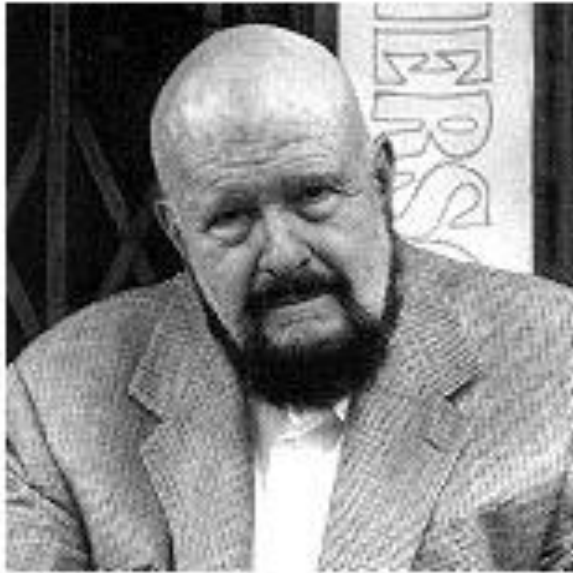
**“Those who profess to favor freedom, and yet deprecate agitation, are men who want crops without plowing the ground.”**

***--Frederick Douglass (1817-1895)***

A black and white photograph of a large crowd of people marching down a tree-lined street. Many people are holding signs with various slogans such as "WE MARCH FOR JOBS FOR ALL NOW!", "I.U.E. FOR FULL EMPLOYMENT", "END SEGREGATED RULES IN PUBLIC SCHOOLS", and "VOTING RIGHTS NOW!". Dr. Martin Luther King Jr. is visible in the center of the crowd, wearing a dark suit and a white shirt with a dark tie. He is surrounded by other men in suits, some of whom are shaking hands with him. The crowd is dense and extends far into the distance.

**Dr. Martin Luther King Jr. (center) at  
March on Washington, August 1963**

# Movement Roots Are in General Self-Help Movement (AA, etc.)



**Frank Riessman**

**1924-2004**

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

# 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**



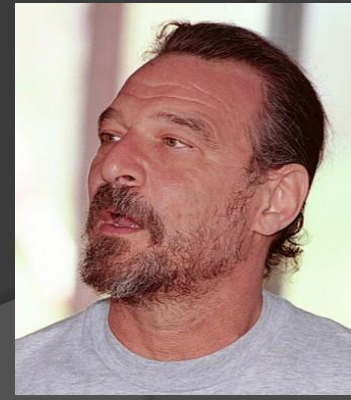
**Sally Clay**



**Dan Fisher**



**David Oaks**



**George Ebert**

# *Peer Advocacy Movement Grew out of Struggle for Rights & Empowerment*

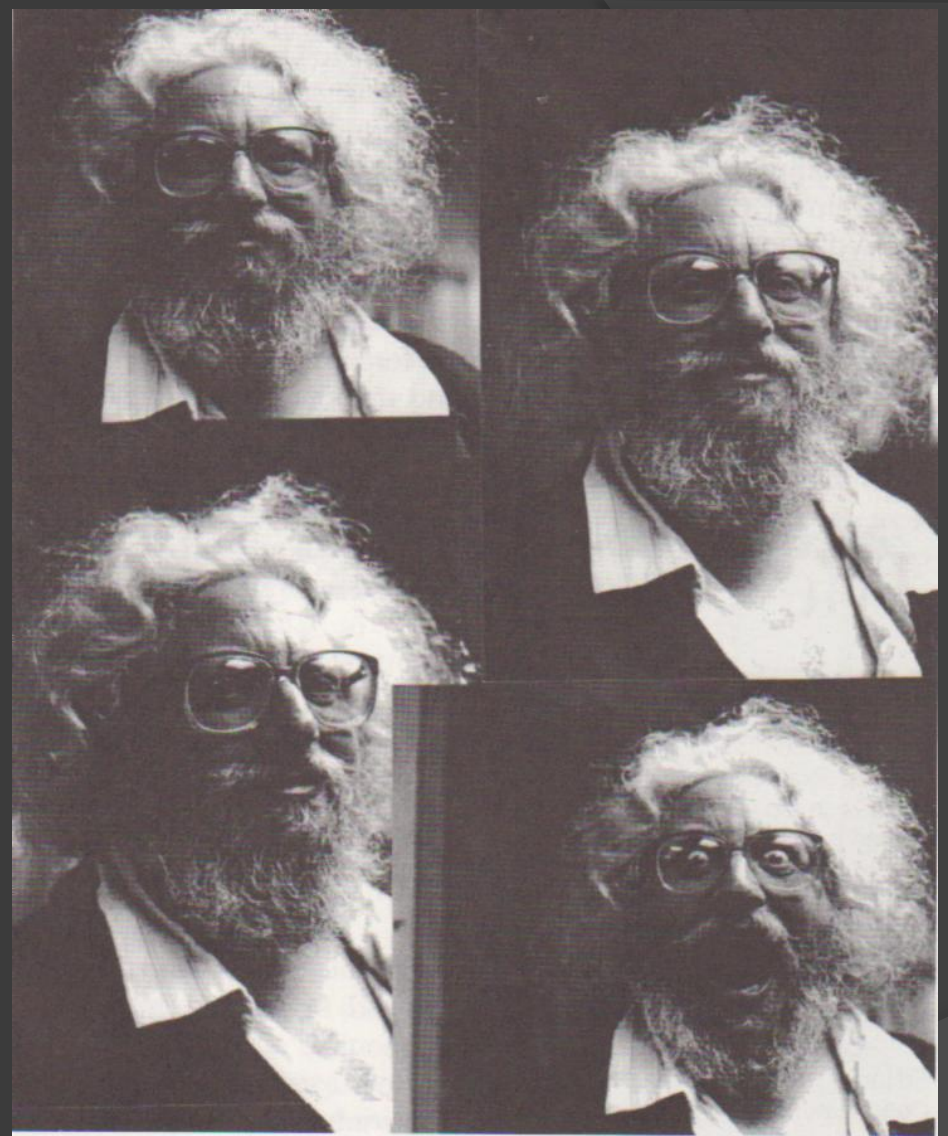
International Conference on Human Rights and Against Psychiatric Oppression, Vermont, 1985



# 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)***

<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.



**Joseph Rogers**

<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)



**Joseph Rogers**

# 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!



MHASP staffers protest PHA admissions policies. Depicted left to right are Susan Rogers, Alicia Christian, Glenda Fine, and Mark Davis.

photo by Michael Viola, Philadelphia Inquirer

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.

## Linked voices

PHILADELPHIA INQUIRER  
Saturday, May 11, 1985

### Group protests PHA proposal for mentally ill

By Janet McMillan  
*Inquirer Staff Writer*

Five advocates for the mentally ill chained themselves to the gates of the Philadelphia Housing Authority office yesterday, while others picketed the agency for an hour to protest proposed housing policies that they said were discriminatory.

About 25 people, led by staff members from the Mental Health Association of Southeastern Pennsylvania, marched in front of PHA's office at 2012 Chestnut St. in opposition to a proposed screening of tenants' mental health histories.

Wearing signs and chanting slogans, the group, which announced the demonstration earlier, arrived shortly after 10 a.m. and demanded that five of its representatives be allowed to meet with housing officials.

But the wrought-iron gates of the housing authority had been locked, and plainclothed and uniformed PHA security guards were stationed inside and outside the building.

The five representatives of the group then chained themselves to the gates. About 45 minutes later they were allowed inside the housing authority and met briefly with Garfield Harris, PHA's executive director. Afterward, they said that they had made little progress and that they would meet with their lawyers to discuss suing the authority.

"I demand that you listen to us. Listen to our demands," Joseph Rogers, an associate director of the mental health group, shouted through the gates at PHA officials who stood watching the demonstration. "We want equality!"

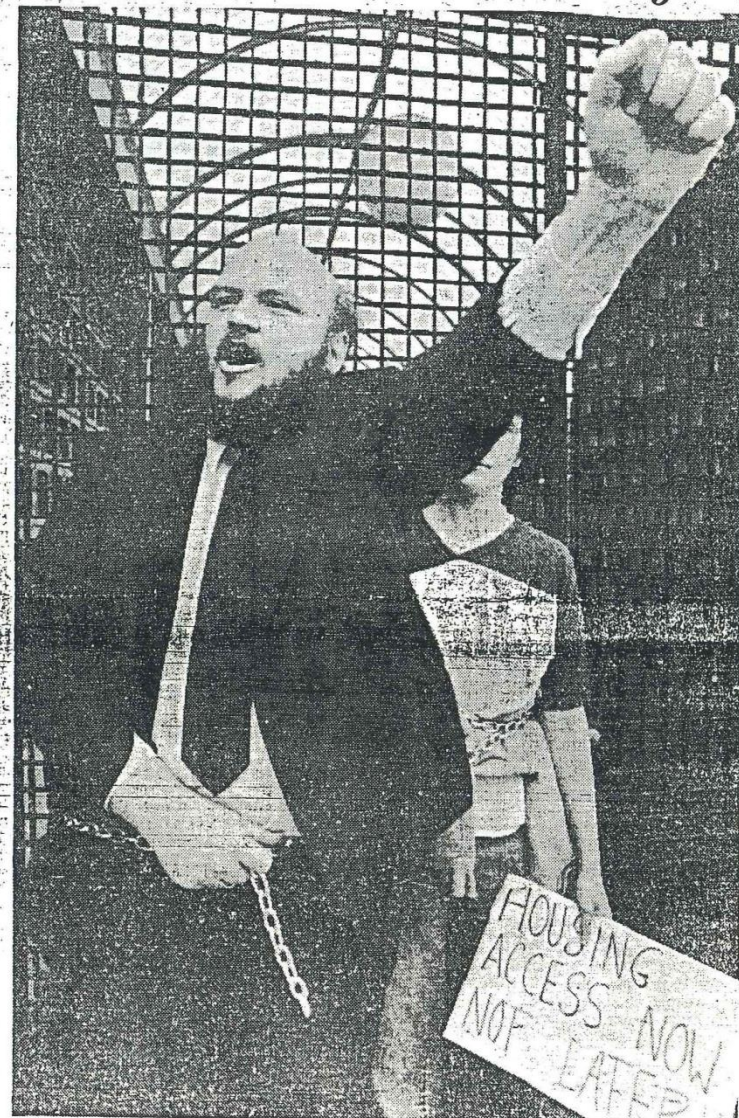
Alicia Christian, the mental health association's director of public information and education, held up a length of chain for protesters to see. "These are the chains of discrimination that are keeping the mentally ill from public housing," she said. "Those most in need of low-income housing are denied access. . . . We protest, and we protest grievously."

Officials of PHA said they were not discriminating against the mentally ill.

Association members said they were opposed to proposed housing regulations that would require a review of applicants' backgrounds for such things as mental instability, criminal records, drug abuse and poor credit ratings.

Rogers said the admissions policy would require that a person's ability

(See PROTEST on 2-B)



Rogers, chained to the gate; 'I demand that you listen to us. . . . We want equality!'

-turn over-

# Conferences Unite Movement



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



Dr. Bernard Arons

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

*Former SAMHSA administrator supported recovery movement, fought S&R*



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



[www.mhselfhelp.org](http://www.mhselfhelp.org)

**Grow:**

[www.power2u.org](http://www.power2u.org)



[www.cafetacenter.net](http://www.cafetacenter.net)



[www.consumerstar.org](http://www.consumerstar.org)



National Technical Assistance Center

[www.peerlink.us](http://www.peerlink.us)

# Other National Groups Support C/S/X Movement



Judge David L.

**BAZELON CENTER**

for Mental Health Law



**NASMHPD**

NATIONAL  
**DISABILITY RIGHTS**

NETWORK

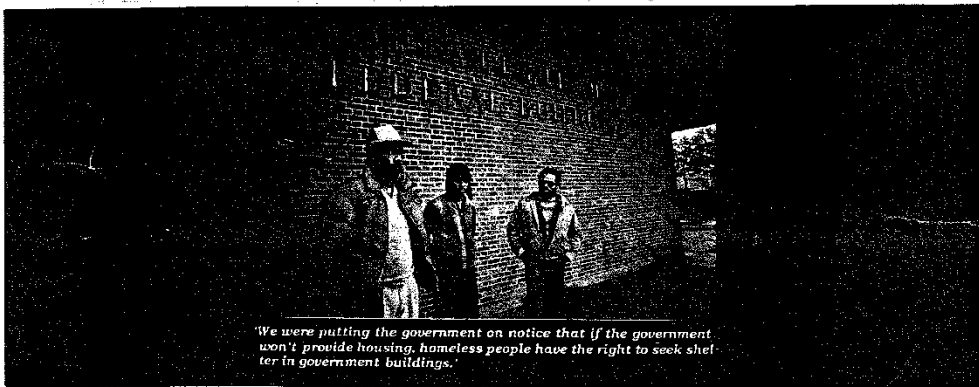
Protection & Advocacy for Individuals with Disabilities





**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.**

## ON THE STEPS OF THE COURTHOUSE



*'We were putting the government on notice that if the government won't provide housing, homeless people have the right to seek shelter in government buildings.'*

by Susan Rogers

On Monday, November 7th, at 2:45 p.m., I found myself locked up in an eight-by-ten-foot cell on the basement level of the Federal Courthouse at Sixth and Market Streets. The cell had white cinderblock walls with grey plastic benches running along two of them, and a very public toilet with a sink in the corner. The cell did not provide toilet paper or soap. Although spartan, the cell seemed remarkably clean. But I had nothing to compare it to, since this was my first arrest.

I, my five cellmates and 29 other people had been arrested at a protest against federal housing policies—a continuation of a similar demonstration held November 1st at the same Federal Building, in which I also participated. Both events were part of a coalition effort by groups of homeless people and their advocates around the country to gain more

***'My husband had the foresight to bring along his chains and padlocks, which he'd been using at demonstrations for years.'***

federal dollars for decent, affordable housing. On November 1st we in Philadelphia had issued a statement demanding that the U.S. government restore the \$25 billion cut from housing programs by the Reagan administration. We were putting the government on notice that until decent, affordable housing became available for every U.S. citizen, homeless people would seek shelter

in federal and state government buildings, since these buildings are the property of the American people. This statement was signed by residents of the Women of Hope shelter and the Mercy Hospice Shelter, and members of the Union of the Homeless, the Committee for Dignity and Fairness for the Homeless, the Philadelphia Catholic Worker, Philadelphia Jobs with Peace, Jeremiah House and Project SHARE.

I am a member of Project SHARE, a self-help organizing project of mental health consumers (a term we prefer to the more colloquial "mental patients," since it is less stigmatizing). Having been hospitalized a couple of times in a psychiatric ward, I was no stranger to the sound of the key turning in the lock. The main difference between jail and the hospital seemed to be that, in jail, everyone was in a

*(Continued on page 30)*

Sit-in at Federal Office Building (Phila. 1988) focused public attention on \$25 billion in cuts to low-income housing, which resulted in homelessness.



The Philadelphia Inquirer / RICK BOWMER

As other protesters listen, Laura Van Tosh, holding the City Paper, talks to associate publisher Philip R. Anderson.

## 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, picketed the offices of the City Paper in the rain yesterday, demanding an apology for the promotional ad for *Crazy People* which opens here next month.

Pennsylvania have asked Paramount Pictures to pull the advertising campaign.

In a 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 200 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."

"It doesn'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 126,250.

Yesterday, management took the unusual step of locking the front door; employees had

"Crazy People" poster.

"No, we have nothing else," said Schimmel, closing and locking the door.

Later, upstairs, 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 also met with Richard B. Colby Jr., public affairs director of the Philadelphia Mental Health Care Corp. When 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. We picked up the spirit of the campaign, and on reflection, that spirit was mean-spirited and wrong," Schimmel said.

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 positioned

**"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.**



Joseph Rogers  
Susan Rogers

Charlie King

Hikmah Gardiner

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



# 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, not 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.

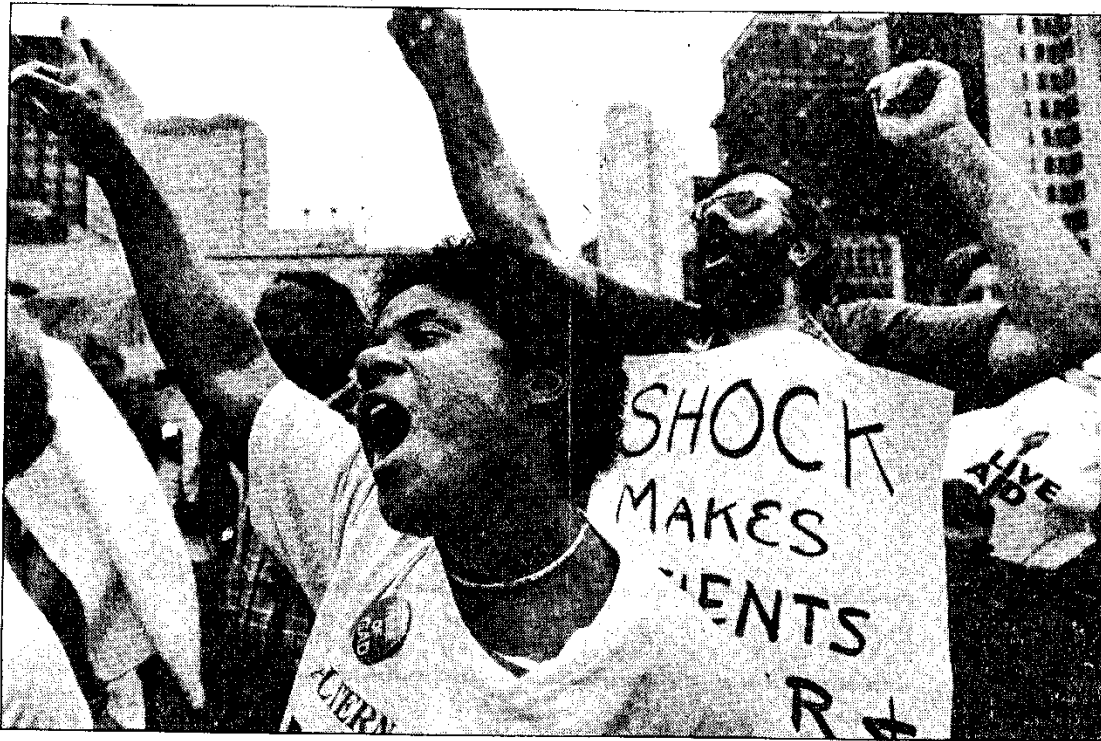
"The mental health system produces an artificial dependence and we're not allowed to be productive citizens," he said.

Hawthorne last held a 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 that was organized by people who have had psychiatric problems. About 1,000 people attended.



Robin Rombach/The Pittsburgh Press

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 to the mental health system.

Madeleine Maehl, 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 13 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 resort 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 and 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.

# Bastille Day Rally, 1990



**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**

- **“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**

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**



**SAMHSA Administrator  
Pam Hyde**

**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.**



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.*

# **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:



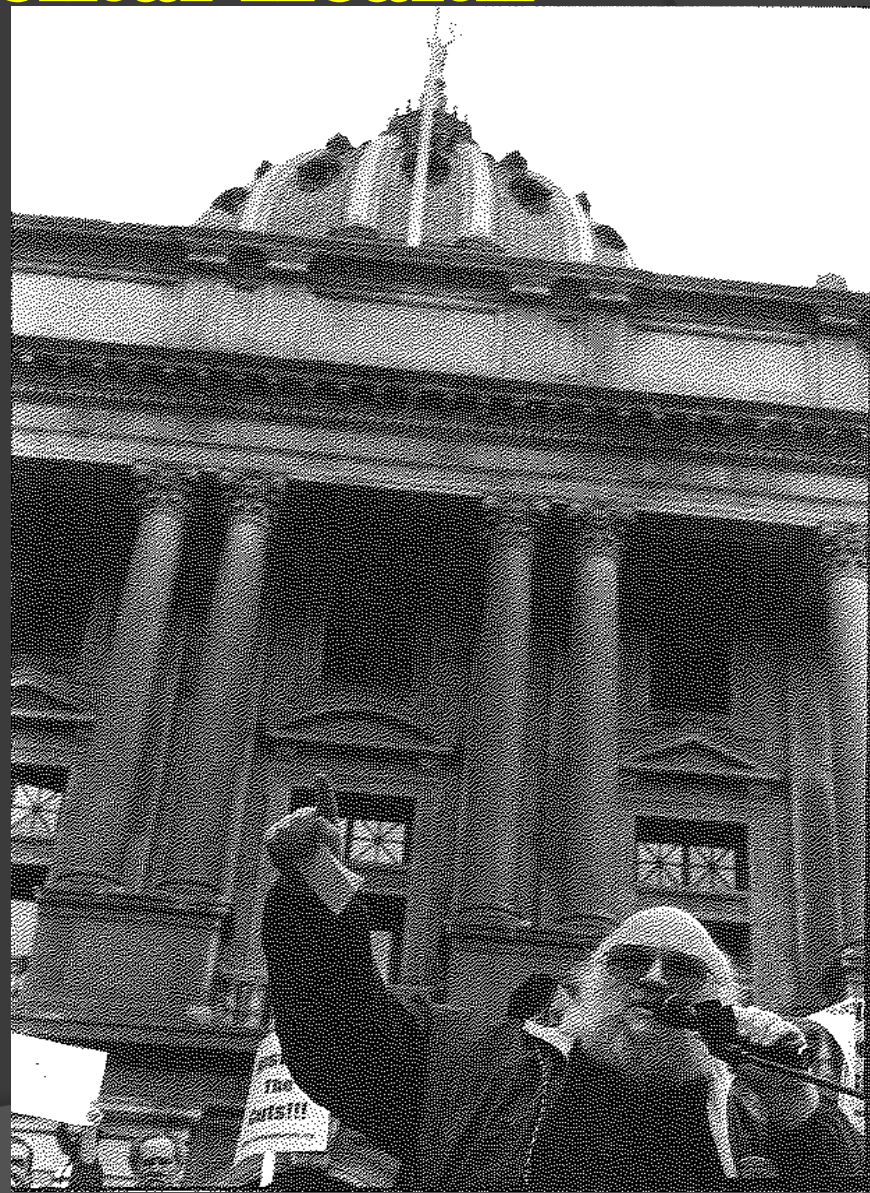
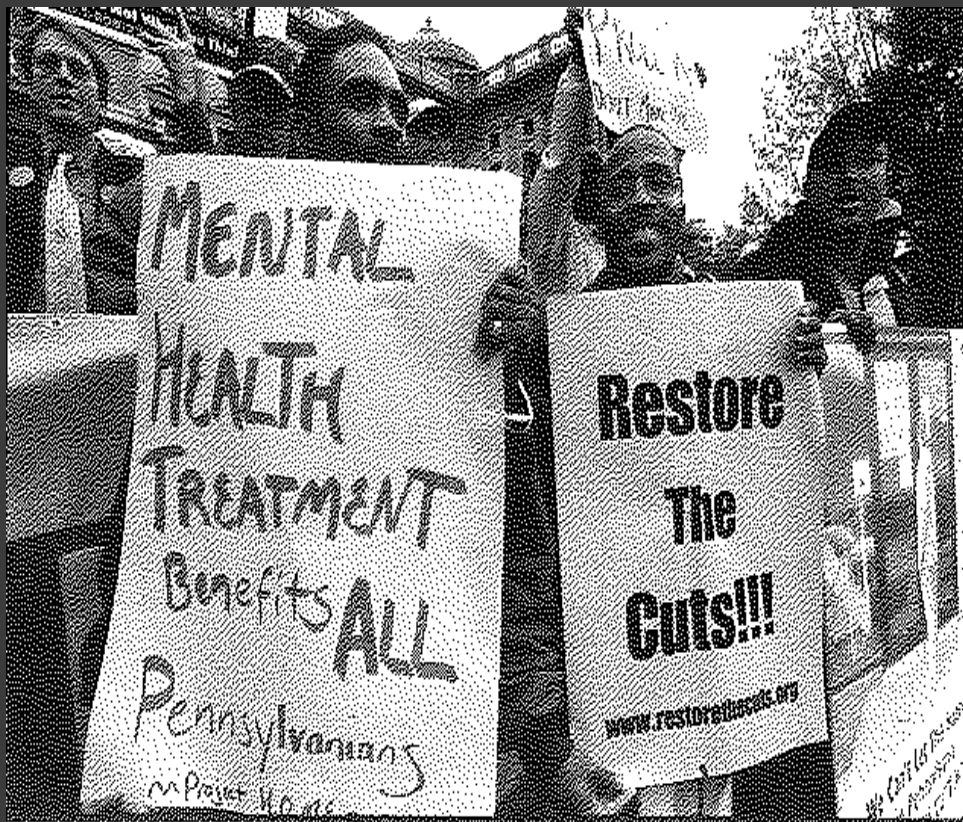
**MHASP's Johnathan Evans (right) – an award-winning outreach advocate who died on 7/19/13 – and an ACCESS-West Philly colleague talk to a homeless man (1992). Johnathan's obituary: <http://tinyurl.com/pyl738n>**

**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.



<http://gawker.com/5002297/pr-newswire-employee-slugs-release-loony+bin-rally-gets-fired>



## **MHASP Rally for Supported Housing, Philadelphia, 2008**

**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.**

# “Link Between Creativity and Mental Illness Confirmed in Large-Scale Swedish Study”

- **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

- MHASP spearheaded Occupy the APA, held May 5, 2012, in Philadelphia.  
<http://www.mhasp.org/events/2012/4/30/occupy-the-apa-may-5-2012.html>
- 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>
- The DSM-5 was published in 2013.  
<http://tinyurl.com/qhvs4xe>



Artist: Amy Smith <http://tinyurl.com/qdepdfe>



# Portland, OR, Gallery Features Artists in Recovery from Mental Health Conditions

“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

- Altered States of the Arts (founded in 1990)  
<http://www.alteredstatesofthearts.com/>
- 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/photovoic  
e-fight-stigma-mental-illness](http://cpr.bu.edu/resources/newsletter/photovoic<br/>e-fight-stigma-mental-illness)
- Meghan Caughey  
<http://www.meghancaughey.com/>
- Mike Skinner <http://www.mskinnermusic.com/>

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

*“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.mhasp.org>
- National Mental Health Consumers' Self-Help Clearinghouse:  
<http://www.mhselfhelp.org>
- Temple University Collaborative on Community Inclusion:  
<http://www.tucollaborative.org>