

Carrying the Torch: **Past, Present and Future of the C/S/X Movement**

**Joseph Rogers, Executive Director
National Mental Health Consumers' Self-Help
Clearinghouse**

**1211 Chestnut St., 11th Floor, Phila., PA 19107
800-553-4539, ext. 3844, jrogers@mhasp.org
VOCAL Conference . . . May 21, 2013**



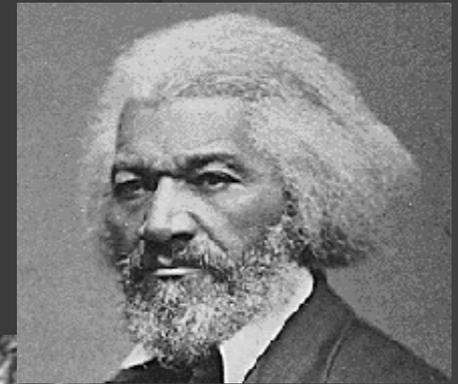
Mid-20th-century organizing efforts include:



Fountain House
425 W. 47th 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 on 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', 'VOTING RIGHTS NOW!', 'END SEGREGATED RULES IN PUBLIC SCHOOLS', and 'NO MORE SEPARATE BUT EQUAL'. In the center of the crowd, Dr. Martin Luther King Jr. is visible, 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 background.

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**



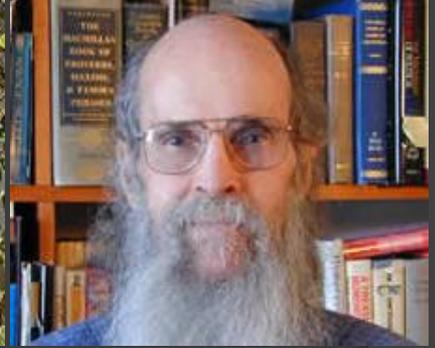
Sally Zinman



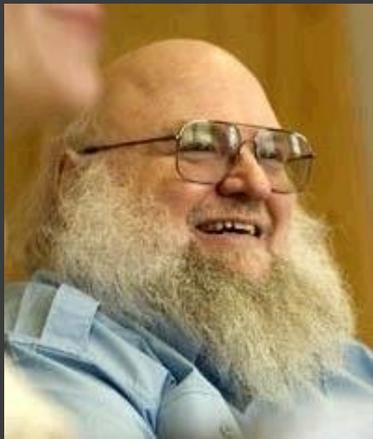
Jay Mahler



Ed Knight



**Leonard
Roy Frank**



Joseph Rogers



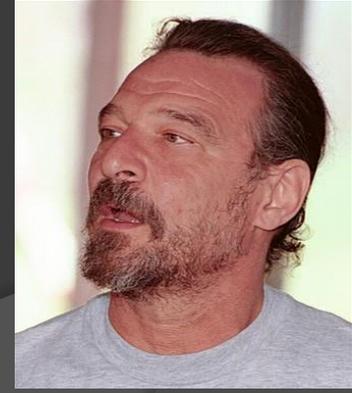
Sally Clay



Dan Fisher



David Oaks

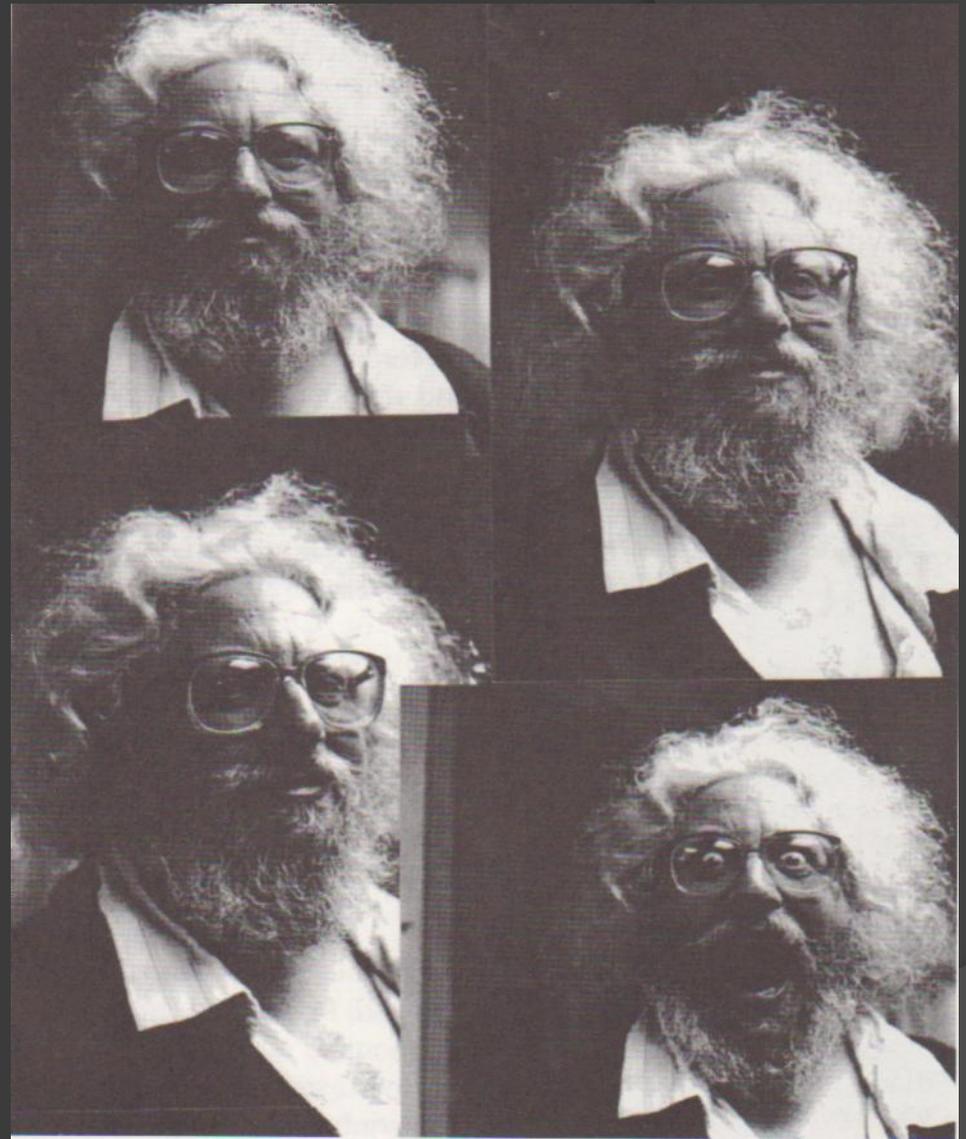


George Ebert

Movement Values

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

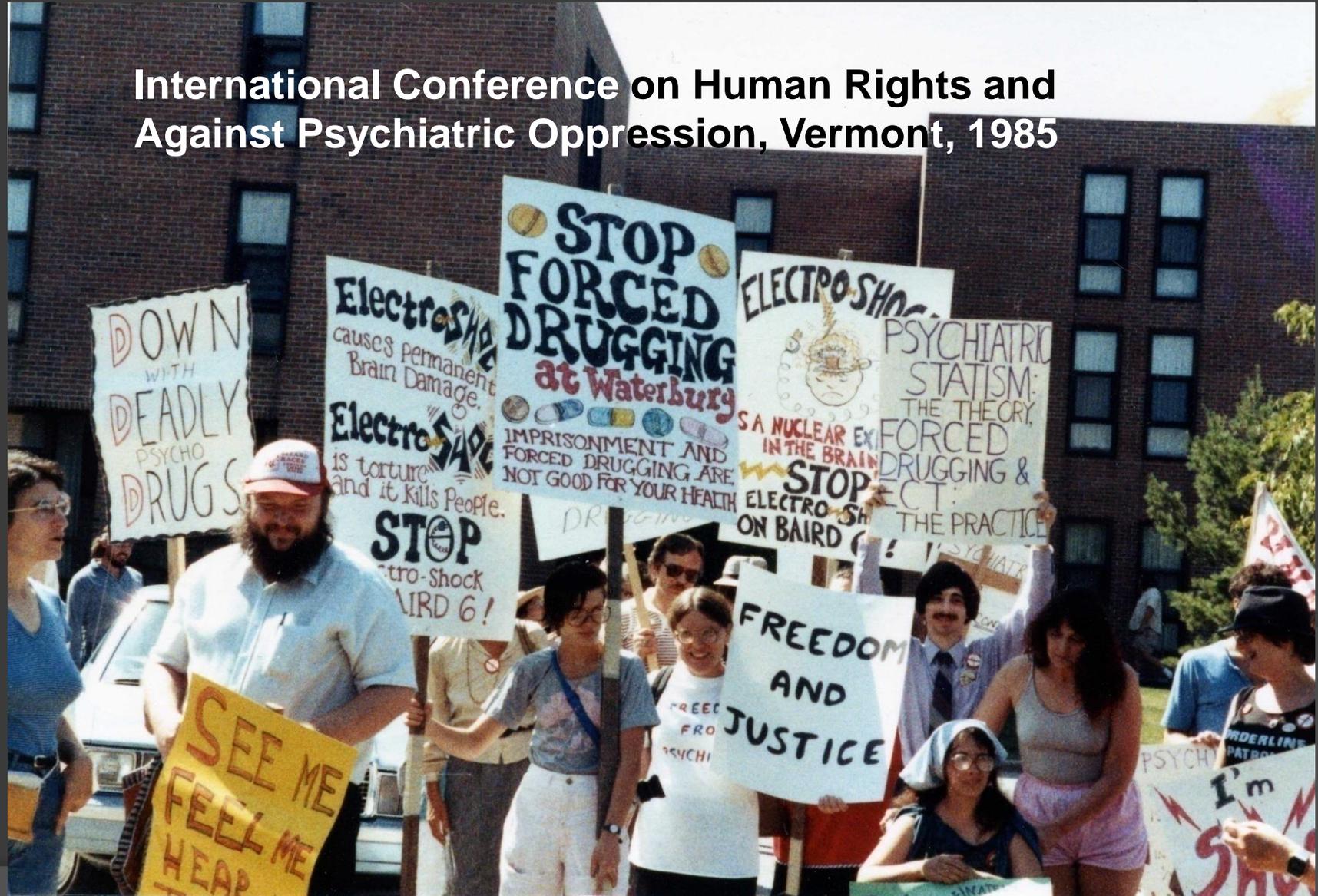
“We want as full as possible control over our own lives. Is that too much to ask?”



*Howie the Harp
(1953-1995)*

Taking it to the streets

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



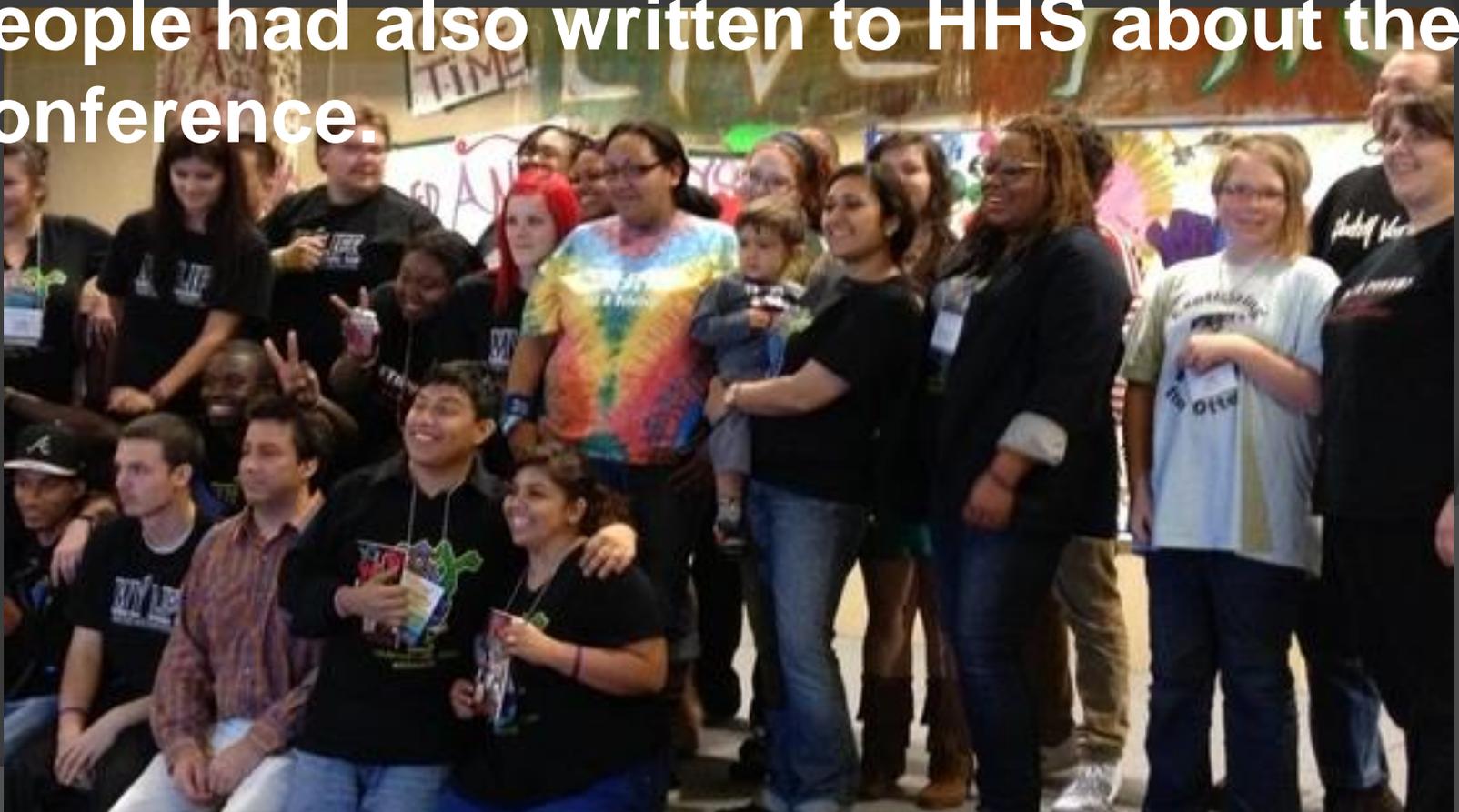
Conferences Unite Movement



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.)

Alternatives 2013 Approved!

When SAMHSA red tape delayed funding, a petition initiative garnered 500 signatures and was sent to HHS. Many people had also written to HHS about the conference.



Project SHARE founded 1984

Organized self-help and advocacy groups

Successful
civil
disobedience
outside
Philadelphia
Public
Housing
Authority to
protest
announcement
of
discriminatory
policies ('85)



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

Philadelphia Inquirer
PHILADELPHIA, PA
AM-454,471 S-819,304

Group fears public will link mental illness, violence

By Mary Jane Fine
and Donald C. Drake
Inquirer Staff Writers

Joseph Rogers was 19 then, a patient in a psychiatric ward and scared.

"There was real despair — the fear that I was going to be there forever," he recalled. "You're being 'put away.' You really feel that."

Rogers is 33 now, associate director of the Mental Health Association of Southeastern Pennsylvania — and he's scared once again.

His concern this time centers on Wednesday's violence at the Springfield Mall, in which a woman with a psychiatric history has been charged with shooting nine people, killing two of them. His fear is that such incidents will lead the public to associate mental illness with violence and to be more reluctant to accept former mental patients into the community.

The founder of Project SHARE, a self-help group for current and former mental patients, Rogers was sufficiently concerned that he issued a news release urging a "reasoned response" to the incident.

"There are millions of former mental patients who work at their jobs, love their families, and are your neighbors," it read in part. "They are productive members of society. If the tragic actions of a very few individuals mean that people like these millions will lose their freedom, this kind of tragedy will claim millions of victims, not just a few."

Ever since a 1975 U.S. Supreme Court decision, state and federal mental health laws have been designed to prevent unjust confinement of mental patients, by prohibiting involuntary commitment to a



John Hood (left) and Joseph Rogers, members of a group for current and former mental patients

mental hospital unless the person exhibits "a clear and present danger" to himself or others.

Rogers and other members of Project SHARE — which stands for Self-Help and Advocacy Research Exchange — say they fear that a "lock 'em all up" attitude will result in the

tightening of commitment laws.

Amiram Elwork, a psychologist and director of the graduate program in law and psychology at Hahnemann University, said that until psychiatrists and psychologists know enough about mental illness to predict and treat violent behavior, the

pendulum of societal response to the mentally ill will swing wildly from the extreme of being excessively liberal to the extreme of being excessively restrictive with mental patients.

"Current laws may be protecting 100,000 people from being institu-

tionalized" improperly, he said, "but you need only one person who does something violent like this, and everyone will get up in arms to charge the laws again."

Violence among the mentally ill is uncommon, Elwork said, occurring in perhaps 1 or 2 percent of patients. Rogers pointed to several studies showing that former mental patients are no more prone to violence than any other members of society.

"What happened in this situation, I don't know, and it needs to be investigated," Rogers said of the mall shootings, but he added that existing laws should have prevented the tragedy.

Beyond the fear of more restrictive laws, Project SHARE members say they worry that finding housing and employment will become even more difficult for them than it already is. Several of them said they had recently decided to "go public" about their illnesses in the hope of educating the public.

The vast majority of people with mental illnesses, said Carmen Meek, 31, are "putting their lives back together. They're not people to be feared."

Although they jokingly referred to gap-filled job resumes as "Swiss cheese resumes," group members said that explaining such lapses — marking hospitalizations — to prospective employers can be a serious problem. Perhaps the most basic problem the group faces is simply the stigma they and their families face from the label of "mental illness."

Mark Davis, 29, said he covered up his own illness — which eventually resulted in a suicide attempt after

completion of graduate school — because he feared both the stigma and being "put away" in a mental hospital. Finally diagnosed as manic-depressive after his sixth hospitalization, Davis has been living independently for the last year.

Davis and John Hood, Jr., 27, recently spoke to a neighborhood group in North Philadelphia hoping to counter resistance to the establishment of a group home in the area. Before the meeting, the group adamantly opposed the home, Davis said, but afterward, half said they would not object.

Rogers — whose wife of nine years, Susan, is also a group member — was a student at Valencia Community College near Orlando, Fla., when he first entered a hospital for depression.

"In the classroom, I might find myself feeling alienated, upset," he said. "It manifested itself in withdrawal. I'd end up staying at home, sleeping late."

He remembers the period as one of "quiet despair" during which he threatened suicide. Rogers was hospitalized several times before a lawyer was able to have him released into a community-based halfway house, where he spent 1½ years. Several years ago, he again was hospitalized briefly, he said, but now considers himself "a survivor" — of both his illness and the system that treated him.

Now, Rogers worries that any progress made by Project SHARE, organized 15 months ago, will be overshadowed by tragedy.

"We've been working for 15 months," he said, "and then there's one incident. And that's what people remember."

Demonstrations May Be Successful:

•“Chain-in” at Philadelphia Housing Authority (1985)

•Sleepout at State Office Building (1987)

Demonstrations sometimes only raise consciousness, create solidarity:

•Arrests at Federal Office Building (1988)

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



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

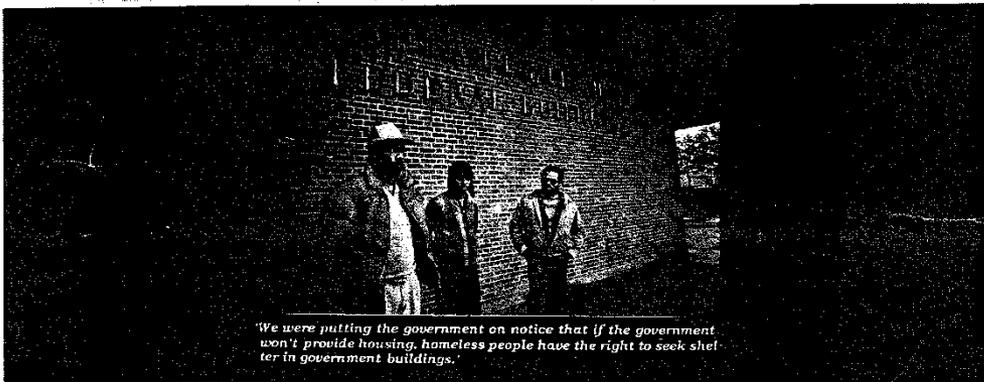
The Philadelphia Inquirer / MICHAEL VIOLA

—turn over—



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.



Joseph Rogers
Susan Rogers

Charlie King

Hikmah Gardiner

Bastille Day rally at Alternatives '90 to combat discrimination and prejudice, organized by 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.

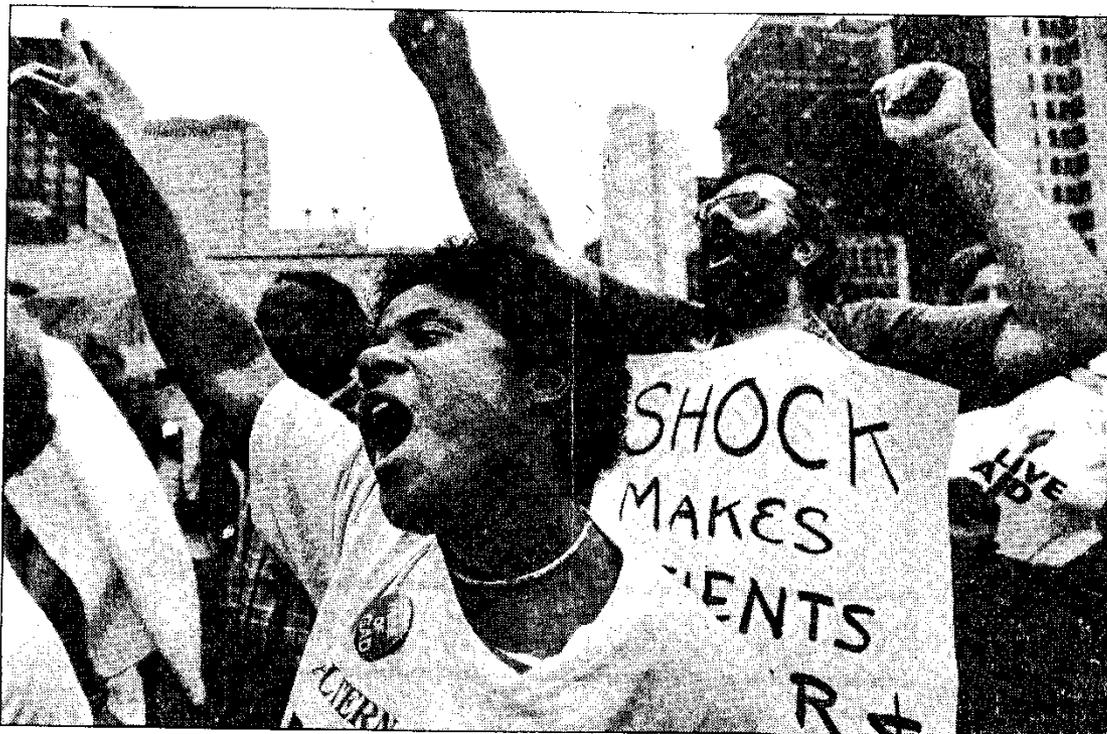
"The mental health system produces an artificial dependence and we're not allowed to be productive citizens," he said.

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

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.





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

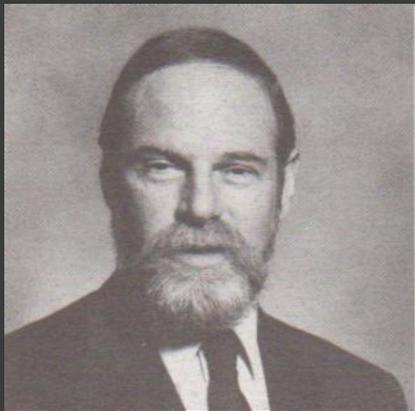




**President George H.W. Bush signs ADA (1990),
with Justin Dart at right.**

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



5 National TACs Help Movement



www.mhselfhelp.org

Grow:

www.power2u.org



www.cafetacenter.net



www.consumerstar.org



National Technical Assistance Center

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



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 (top); CMHS Director Paolo del Vecchio (bottom)

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.

How Are Changes Made?



- ⦿ Who has power?
- ⦿ How would those in power benefit by the change?
 - Create positive incentives that make the change attractive to those in power.

To Motivate Activists:

- ◎ **Make it easy for people to get involved.**
- ◎ **Create a sense of purpose.**
- ◎ **Define clear and specific goals:**
 - . . . that are achievable in a reasonable time period.
 - . . . whose achievement will improve people's lives.
- ◎ **Give people responsibility.**

Create an Advocacy Plan



- Determine your goal(s).
- Frame your goal(s) in positive terms.
- Research what it will take to achieve your goal(s).

Prioritize Goals

- ◎ Start with the goal that has the greatest potential for achievement:
 - Success will bind the group.
 - Success will create motivation for continued efforts.
 - Stick with it.

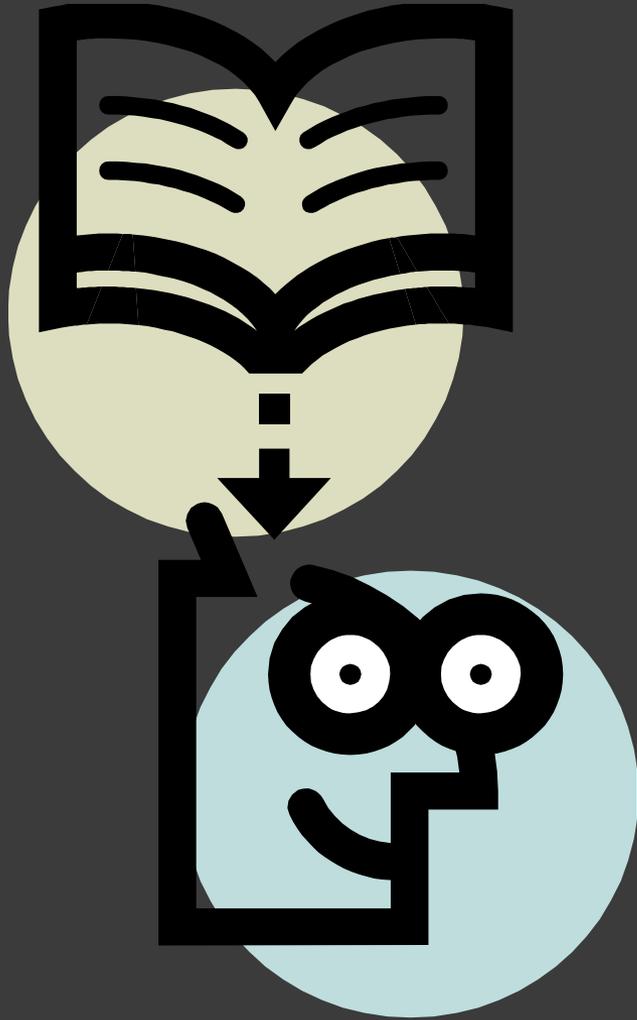


Gather Information

- ① Who has authority to make needed changes?
- ② What laws, rules and policies are in place that affect the situation?
- ③ What rights and complaint procedures exist?
- ④ What facts support the need for change?



Knowledge Is Power



- Learn as much as you can about the government/ non-government organization or agency you're trying to change.
- Attend meetings, public hearings and conferences.
- Acquaint yourself with staff.

Strategy Development

- ◉ What do the powers-that-be need to hear?
 - **Tailor message to audience.**



Two components:

- * Appeal to what is right.
- * Appeal to audience's self-interest.

Whom do they need to hear it from?

- Experts
- Authentic voices



Debbie Plotnick at PA House hearing, October 2007



Legislative visit with PA State Senator Bob Mensch, August 2010

How can we get them to hear it?

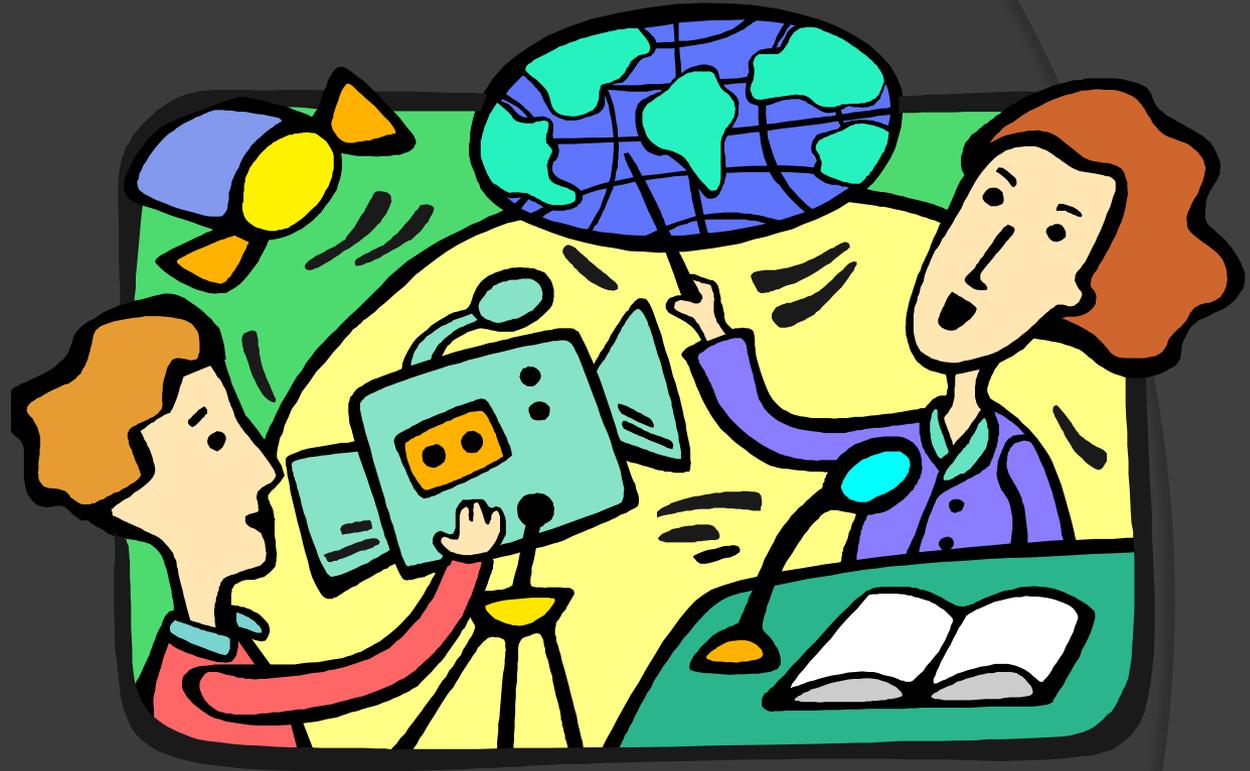
- Phone calls
- Letters
- Meetings
- Direct action



Regional Rally for Recovery Rights, organized by MHASP at Philadelphia's City Hall, May 11, 2006. Funding for peer support was one of many issues on the agenda.

Facebook and Other Social Media

70 percent
of
journalists
use social
networks
to assist in
reporting:



<http://blog.journalistics.com/2009/70-percent-of-journalists-use-social-networks-to-assist-in-reporting/>

Effective Online Networking

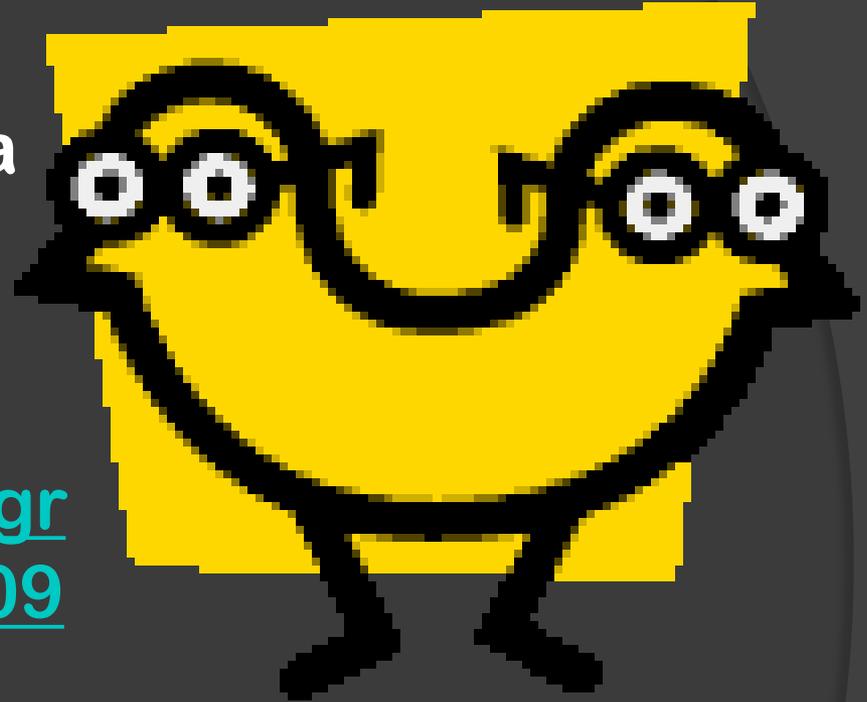
- ⦿ Gather e-mail addresses.
- ⦿ Establish broadcast e-mail lists:
 - Send action alerts.
 - Inform your membership.
- ⦿ Establish discussion lists.
- ⦿ Create a website.



Twitter

According to the Center for American Progress, a progressive think tank, Twitter can help you promote your cause.

http://www.americanprogressaction.org/issues/2009/07/twitter_tips.html



How do we begin?

- Achievable goals to build constituency
- Lay groundwork



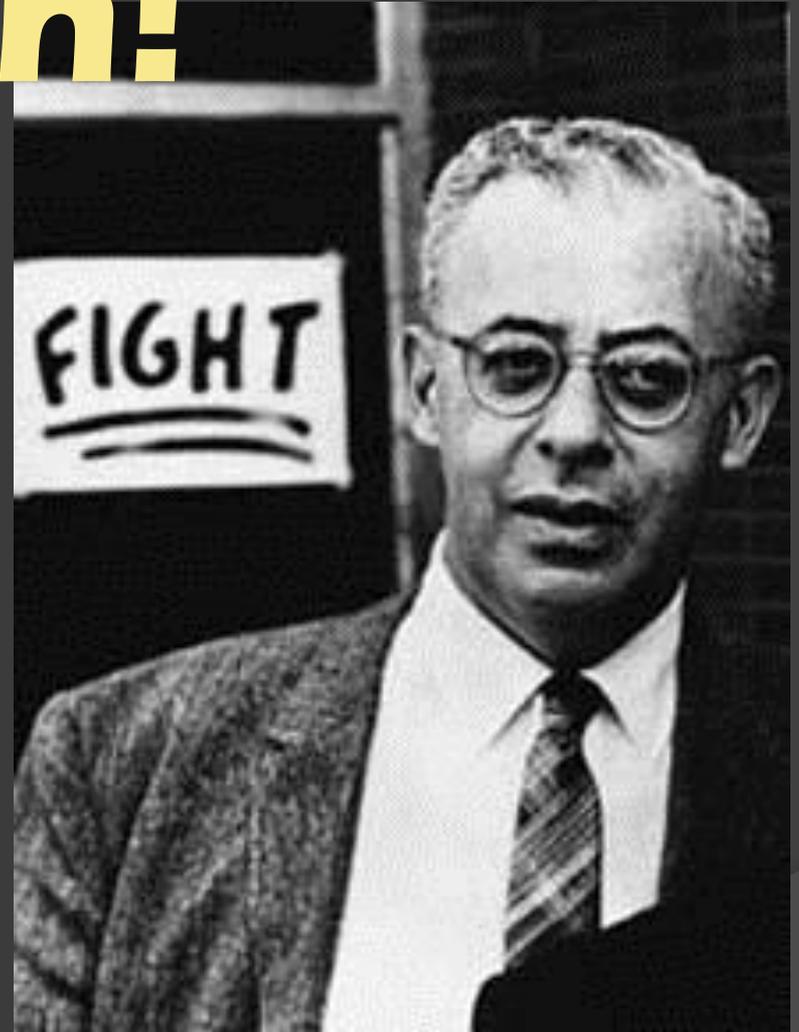
How can we tell if it's working?

- Evaluate what we've done.
- Make mid-course strategy corrections.



Make it fun!

*"A good tactic
is one that
your
people enjoy."*



**Saul Alinsky
(1909-1972)**

Be Ready to Negotiate

- ◎ Study the offer.
- ◎ Don't accept an initially offered solution too quickly.
 - It may be designed to appease rather than create real change.
- ◎ Be ready to suggest an alternative.

“You cannot risk being trapped by the enemy in his sudden agreement with your demand and saying, “You’re right—we don’t know what to do about this issue. Now you tell us.”

–Saul Alinsky

Consider accepting the offer on a trial basis.

- ① Establish criteria to assess success.
- ① Establish a time frame for reviewing outcomes.



Do be:

- ★ **Brief**
- ★ **Prepared**
- ★ **Clear**
- ★ **Honest**
- ★ **Accurate**

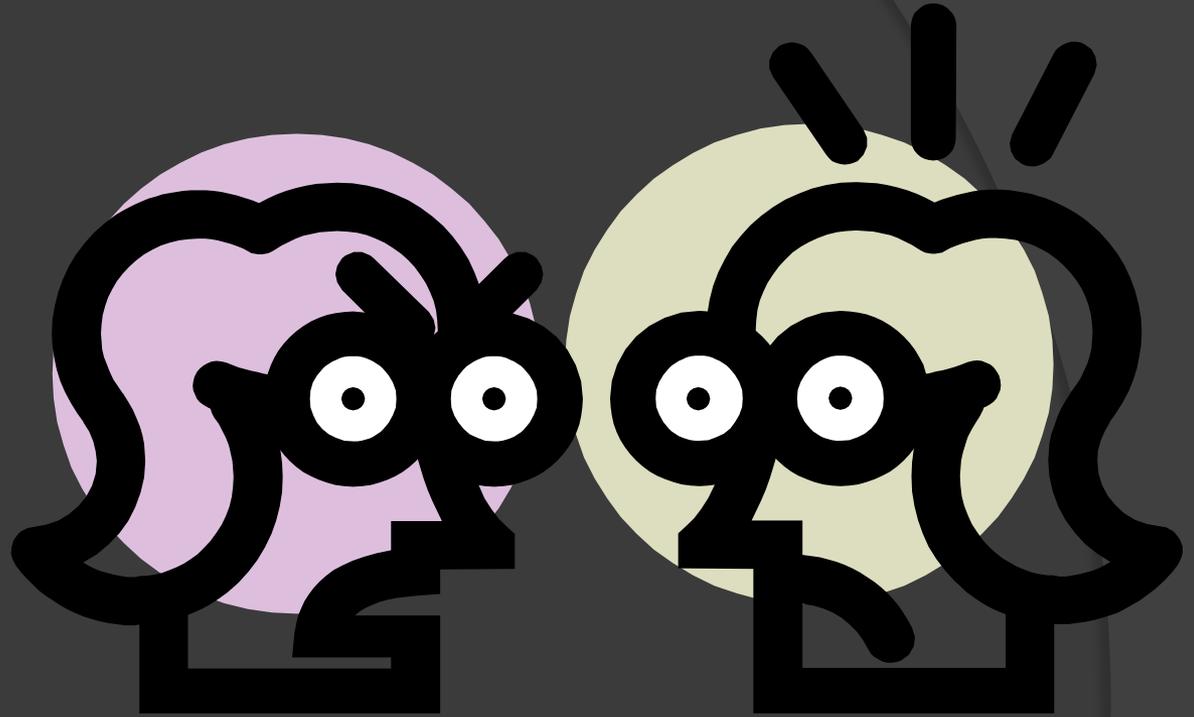
HELLO!

The word 'HELLO!' is written in a bold, 3D-style font with a yellow-to-purple gradient. The letter 'O' is replaced by a yellow smiley face emoji with a simple black outline for a face. The exclamation point is also in the same gradient and 3D style.

- ★ **Persuasive**
- ★ **Timely**
- ★ **Persistent**
- ★ **Grateful**

DON'T:

- Be argumentative
- Be demanding
- Bluff
- Promise rewards
- Knock the opposition



“I am only one. But still I am one. I cannot 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.”

-Helen Keller (1880-1968)

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



Resources:

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

Resources:

- ◎ Google:
 - 48,300 websites for “advocacy tips” in a quarter of a second
 - Not all of the sites will be useful, but many will. (See slides at the end of this presentation for some useful sites.)
- ◎ Public library

Resources:

- “Tips for Legislative Advocacy,”
Justice for Immigrants:
<http://www.justiceforimmigrants.org/documents/advocacy-tips.pdf>

Resources:

- ◎ “An Activists’ (sic) Strategy for Effective Online Networking,” One Northwest:
http://www.geocities.ws/s7ss/Effective_Online_Networking.html
- ◎ “Systems Advocacy,” Brain Injury Resource Center:
<http://www.headinjury.com/advosystem.html>

Resources:

- “Advocacy Tools and Guidelines,” CARE:
- <http://www.care.org/getinvolved/advocacy/tools.asp>
- “A Guide to Disability Rights Laws,” U.S. Department of Justice:
<http://www.usdoj.gov/crt/ada/cguide.htm>

Resources:

- ◎ “Ten Reasons to Lobby for Your Cause,” Independent Sector:

<http://www.gcn.org/files/10reasonstolobby.pdf>