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

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VOCAL Conference . . . May 21, 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
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
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.
Successful civil disobedience outside Philadelphia Public Housing Authority to protest announcement of discriminatory policies (’85)

Organized self-help and advocacy groups
Group fears public will link mental illness, violence

By Mary Jane Fine

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 Springfielld Mall in which a woman with a psychiatric history had 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 social group for former 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 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 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 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 institutionalized," improperly, he said, "but you need only one person who does something violent like this, and everyone will get up in arms to change 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 Moon, "are putting their lives back together. They're not people to be feared."

Although they jokingly referred to jail-filled job resumes as "Swiss cheese resumes," group members said that explaining such lapses — marking hospitalizations — 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 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., 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 1 1/2 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)
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.
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, ok people," the 48-year-old Norristown, Montgomery County, resident and about 90 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."

Stacy 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, which was organized by people who have had psychiatric problems. About 1,000 people attended.

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 Messel, 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 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 shrink 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 Nation 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.
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

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
5 National TACs Help Movement Grow:

- www.mhselfhelp.org
- www.cafetacenter.net
- www.power2u.org
- www.consumerstar.org
- www.peerlink.us
Other National Groups Support C/S/X Movement

NARPA

BAZELON CENTER
for Mental Health Law

Mental Health America

NASMHPD

NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities
Paradigm shift: Establishment believes in recovery and accepts value of peer support


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.

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

- Who has authority to make needed changes?
- What laws, rules and policies are in place that affect the situation?
- What rights and complaint procedures exist?
- 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:

Effective Online Networking

- Gather e-mail addresses.
- Establish broadcast e-mail lists:
  - Send action alerts.
  - Inform your membership.
- Establish discussion lists.
- Create a website.
According to the Center for American Progress, a progressive think tank, Twitter can help you promote your cause.

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.

- Establish criteria to assess success.
- Establish a time frame for reviewing outcomes.
Do be:

* Brief
* Prepared
* Clear
* Honest
* Accurate

* 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)
Resources:

- Temple University Collaborative on Community Inclusion: [http://www.tucollaborative.org](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
“Tips for Legislative Advocacy,”
Justice for Immigrants:
“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
“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
"Ten Reasons to Lobby for Your Cause," Independent Sector: