TRANSITIONS:  
... from an illness/maintenance model to a wellness/recovery model

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Peer Advocacy Movement Grew out of Struggle for Rights & Empowerment

International Conference on Human Rights and Against Psychiatric Oppression, Vermont, 1985
Ex-patients’ Rights Groups Form in 1970s and Early 1980s

...in Mass., Calif., N.Y., Penn., Fla., Ore.

Top (l-r): Judi Chamberlin, Sally Zinman, Jay Mahler, Ed Knight, Leonard Roy Frank
Bottom (l-r): Joseph Rogers, Sally Clay, Dan Fisher, David Oaks, George Ebert
On Our Own: Patient Controlled Alternatives to the Mental Health System

An early leader of the c/s/x movement

Judi Chamberlin (1944-2010)
An early leader of the c/s/x movement

“Our problems are due to real causes.”

“We are people, not diagnoses.”

“Our needs are basically the same as those of everyone else.” . . .

Howie the Harp (1953-1995)

http://tinyurl.com/o8kfe8v
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
Right to Refuse

1975: *O’Connor v. Donaldson*: U.S. Supreme Court rules that people cannot be institutionalized against their will unless they are a danger to themselves or others.

1982: Ruling in *Rogers v. Okin* established a limited right to refuse treatment (psychiatric drugs) in Massachusetts.
Civil Rights of Institutionalized Persons Act (1980)

... gives the Department of Justice the power to sue state or local institutions that violate the rights of people held against their will, including those in psychiatric institutions.
PAIMI Was Established in 1986

• Protection and Advocacy for Individuals with Mental Illness (PAIMI) programs:
  – protect and advocate for the rights of people with mental health conditions and
  – investigate reports of abuse and neglect in facilities that serve such individuals.

• PAIMI Act was subsequently amended to allow P&As also to serve individuals with mental health conditions in the community. [http://www.ndrn.org/](http://www.ndrn.org/)
President George H.W. Bush signs ADA (1990), with Justin Dart at right.
“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

Peer supporter and peer involved in The Friends Connection (MHASP)
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
“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:

• Self-Direction
• Individualized and Person-Centered
• Empowerment
• Holistic
• Non-Linear

• Strengths-Based
• Peer Support
• Respect
• Responsibility
• Hope
Peer Support Works

“Between the ages of 19 and 36, I experienced 48 psychiatric hospitalizations and an increasing number of DSM-IV diagnoses. During these 17 years, I was unable to stay out of a hospital for more than two months before being re-hospitalized.” – Gina Calhoun (quoted in People First, Spring 2009, published by MHASP)

Gina Calhoun, CPS, has received several awards, including ACMHA’s 2012 Timothy J. Coakley Behavioral Health Leadership Award.

She is Nat’l Director for Wellness and Recovery Education of the Copeland Center for Wellness and Recovery.
Peer-run Services Help People with Even the Most Severe Mental Health Conditions

MHASP’s Homeward Bound, a residence for individuals with long-term homelessness and serious mental health conditions, has successfully helped people for a quarter-century.
Peer-to-peer services treat recipients as equals:

Johnathan Evans *right* (an award-winning outreach advocate who died on 7/19/13), with an ACCESS-West Philly colleague *center*, talk to a homeless man (1992). Johnathan was homeless when he was brought in from the cold by another MHASP outreach advocate in 1987. Johnathan’s obituary: [http://tinyurl.com/lh75fxr](http://tinyurl.com/lh75fxr)
Choice and Self-Determination Are Key

• “[B]uilding a responsive mental health system with services like mobile crisis teams, assertive community treatment teams (ACT), and supported housing, is the best strategy for ensuring that people receive needed treatment.

• “When people are dangerous due to mental illnesses, they should be hospitalized.

• “When safety is not an issue, treatment should be voluntary, because this approach holds the best promise for long-term engagement in treatment.

• “Outpatient commitment is not a quick-fix that can overcome the inadequacies of under-resourced and under-performing mental health systems.

• “Coercion, even with judicial sanction, is not a substitute for quality services.”

– Bazelon Center for Mental Health Law

http://tinyurl.com/p6q9dva
Force and coercion . . .

- are traumatizing – and the majority of individuals with mental health conditions are already trauma survivors. [http://www.samhsa.gov/nctic/](http://www.samhsa.gov/nctic/)
- drive people away from treatment.
- are expensive.
  - Cost of enforcing Assisted Outpatient Treatment (AOT) diverts resources away from people already receiving care.
  - With AOT, there would need to be a huge increase in funding of mental health services.

*continued . . .*
Studies of Outpatient Commitment Are Misused
http://tinyurl.com/qf3mex8

“The literature provides clear evidence that alternative community-based health treatment programs can produce good outcomes for people with severe mental illness.”

http://tinyurl.com/qgks9e7

“Opening Pandora’s Box: The Practical and Legal Dangers of Involuntary Outpatient Commitment”

http://tinyurl.com/pvycp5l

continued . . .
Psychiatric Advance Directives Are a Great Alternative to Force!

• 61% of participants in a facilitated advance directive session completed such a document or authorized a proxy decision maker, compared with 3% of control group, who only received written information about advance directives.  
  [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3747558/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3747558/)

• National Resource Center on Psychiatric Advance Directives is a good resource:  
Study Finds Psychiatric Factors Are Not Linked To Multiple Homicide Victims

- Study published in *Amer. J. of Psychiatry* (Sept. 2013) found “no relationship between the presence of psychiatric disorders and the use of firearms.”

- “[T]he presence of a psychiatric disorder was not related to offenses involving multiple victims.”

- These findings seem to “counter the popular notion . . . that perpetrators of mass gun violence are invariably mentally ill.”

- Study looked at defendants charged with homicide in a U.S. urban county 2001-2005 who got a psychiatric evaluation after arrest. “The study identified only 15 individuals – just 5 percent of the sample – who had a mental disorder and no co-occurring substance use disorder.” [http://tinyurl.com/pgvg4m6](http://tinyurl.com/pgvg4m6)
We helped close Byberry (PSH) and helped ensure that the dollars followed the patients into the community (1990).
“It was really a risk for her, but she cared about the other patients there, and she was outraged . . . She never, ever stopped fighting.” – Anne Jennings, Anna’s mother, about Anna’s involvement in the closing of Philadelphia State Hospital

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