Mental Health Consumer Movement 101:
The story of a social change movement

Definitions in the context of this Issue Brief:

"Consumers are people presently receiving services.

Psychiatric survivors are those who are out of the system and feel they survived the system.

Ex patient was an early term to designate that we were no longer patients.

Some of us now refer to ourselves as persons with lived experience of recovery.

Overall, though, we prefer to be called people, just like everyone else." [i]

Introduction

The Consumer/Survivor/Ex-patient (C/S/X) Movement began approximately in 1970. However, there were former mental patients who had recorded their abusive treatment in hospitals and attempted to change mental health laws and policies prior to this time. Among these was Clifford Beers, a person with lived experience, who wrote *A Mind that Found Itself*, 1953, an autobiography of his experience in mental hospitals. This book led to the formation of what is now known as Mental Health America, with its multitude of state and local Chapters. However, Clifford Beers did not organize C/S/X s; he turned to professionals to spearhead mental health reform.   It is well documented that only the empowered advocacy of those who are most impacted by services and policies can ultimately drive systems transformation. [ii]

Perfect Storm

In the 1960s and 1970s, social change movements were part of our culture, inspired by the African-American civil rights movement and civil unrest and resistance. Women, LGBT, and people with physical disabilities organized for social change.

At this time, the big State hospitals across the country were being shut down, and new laws limiting involuntary commitment and its duration were being instituted. For decades, mental patients had been denied basic civil liberties, suffered systemic inhumane treatment, and spent lifetimes locked up in State hospitals.

Anecdotally, once released from these mental hospitals, people began meeting together in groups outside the hospital. These former "patients" shared feelings of anger about their abusive treatment and the need for independent living in the community. Their peers validated their feelings. From these isolated groups across the country, a new civil rights movement was born. It was predicated on the desire for personal freedom and radical systemic change; it was a liberation movement.

Early C/S/X Movement

In the early 1970s, not only were people diagnosed with mental illness not at the table, they were not in the room. Everything was "about us without us." Once you were diagnosed with a mental illness, you were considered mentally ill for life with a downward trajectory. There was widespread denial of patient rights and patient abuse was common. The early C/S/X movement confronted this environment with militarism and separatism. The 1970's was a time of C/S/X finding each other, realizing that they were not alone, of militant groups and actions, of self and group education, of defining core values, and of finding and growing a voice out of the anger and hurt bred by what was experienced as the oppression of the mental health system.

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The early C/S/X groups were autonomous, believing strongly in local control. Given the members' experience of being controlled in hospitals, they were adamant about having control over their own lives and groups. The groups were separatist, meaning that they met only with others who shared the same history. There was minimal outreach to the thousands of ex-mental patients who would eventually make up the C/S/X movement. Most importantly, the early C/S/X groups would not accept support from the mental health system, which was considered the enemy.

Meeting in campgrounds, or piggy backing on professional conferences, these early pioneers brainstormed basic principles, all within a civil rights movement for people diagnosed with mental illness. These basic principles were:

- Against forced treatment and for self-determination and choice
- Against Inhumane treatment – excessive medications, Electric Convulsive Treatment (ECT), seclusion and restraints
- Fighting against stigma and discrimination
- Anti-medical model - verging on anti-psychiatry - and for holistic services that respond to the multiple life needs of a person
- Emergence of the concept of "mental patient" run alternatives to the mental health system and peer support
- Involvement in every aspect of the mental health system

The activities of this time were those of a group of people who were not invited to the table or even in the room; they were militant as a way to being heard.

- Political activism – demonstrations
- Unfunded Annual Conference on Human Rights and Against Psychiatric Oppression held at campgrounds and college campuses
- A news vehicle for communication called Madness Network News, "all the fits that's news to print"
- Small autonomous groups, mostly on two coasts with militant names, e.g., Network Against Psychiatric Assault, Insane Liberation Front, Mental Patient Liberation Front

- Most common self-description is as "psychiatric inmate."
- Self and group created information and education
- Support (consciousness raising) groups

A landmark book published in 1978, *On Our Own: Patient Controlled Alternatives to the Mental Health System* by Judi Chamberlin opened up the eyes of the mental health system to this burgeoning mental patients' rights movement.
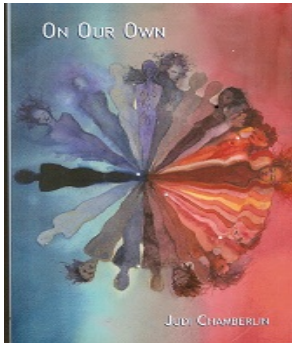
On Our Own: Patient Controlled Alternatives to the Mental Health System (1978), by Judi Chamberlin

Moving Forward - Beginning to Achieve Goals

The 1980s was a transitional time- from conceptualization to implementation. It was a time that many of the C/S/X goals were beginning to be realized. However, not coincidentally, it was also a time when significant founding endeavors ended. There were many decisions made that left the more purist among the early pioneers behind.

The small band of C/S/X activists began to mainstream, to outreach to the thousands of consumers that never heard of the mental patient liberation movement. In addition to local autonomous groups, state networks of consumers began to form. The C/S/X movement began to collaborate with non- consumer groups. The biggest shift in thinking and most controversial was the decision to take money from the mental health system. The C/S/X movement needed funds to move from words to deeds, from conceptualization to implementation. It takes funding to open up a drop-in center or to serve your peers in a consistent way. This was the most hotly contested issue among the growing C/S/X movement. Many of the more purist in this movement left because of the decision that was ultimately made.

The activities of this period of time included:
- Growth of mental health system funded consumer run and staffed programs called drop-in centers
    - 1983   On Our Own in Baltimore, Maryland
    - 1985   Berkeley Drop-In Center, Berkeley CA
    - 1985   Ruby Rogers Drop In Center Cambridge Mass.
    - 1986   Oakland Independence Support Center, Oakland CA
- The Community Support Program (CSP) National Institute of Mental Health, begins to fund consumer/survivor-run programs
    - 1988   Thirteen consumer run demonstration projects funded
- The beginning of statewide consumer run organizations
    - 1983   California Network of Mental Health Clients was the first funded statewide organization
- Many mental health system funded consumer trainings and conferences
    - 1985   The first national CSP funded Conference for consumers called "Alternatives".
- Rights Protection gains in legislatures and court cases
- "Consumers" begin to participate on decision-making bodies

However, with the rise of realizing goals, came the end of the more militant forms of organizing. Madness Network News stopped publishing in 1986. The last Conference on Human Rights and Against Psychiatric Oppression was in 1985. There was a significant decline in the more radical groups.

Getting What C/S/X Wanted

Since the 1990s, C/S/X have seen the fruition of changes they had sought. Consumer run programs, educational and employment opportunities have grown substantially. Attitudes about recovery have changed. Instead of the expectancy of chronicity for people labeled with mental illness, the concept of recovery has emerged.

Examples of C/S/X achievements:

- Employment of consumers in the mental health system, as peer support specialists and within management positions
- System funding and growth of consumer run/peer support programs
- Incorporation of consumer-run/peer support into the mental health system, such as Recovery Wellness Centers, peer support specialists, peer certification, and MediCal funded peer support
- Research on consumer-run programs/peer support, and the emergence of self-identified consumer researchers
- Multiple training opportunities, including consumer developed trainings
- Consumer involvement in most levels of the mental health system. In fact, consumer involvement is mandated in California's behavioral health system
- Consumer partnerships with other behavioral health and related groups
- Working with policy makers to legislate and otherwise change policy
- Effective advocacy from the inside as well as the outside, walking the hallways of power as well as demonstrating outside
- National organizations formed: National Coalition for Mental Health Recovery and International Association of Peer Supporters

Evidence of System Change because of the C/S/X movement

There is evidence of system change as a result of the C/S/X movement and its advocacy at all levels of the mental health system.

C/S/X values are embedded within California's Mental Health Services Act:
- Services are designed to be voluntary
- Promotion of self-help/peer support programs
- Involvement of consumers at all levels of mental health system; in fact, mandated involvement of consumers at planning processes of the mental health system
- Involvement of consumers as part of and in the training of the mental health workforce
- Promotion of recovery as a goal

Consumers have initiated new genres of services:
Consumer run programs and peer support are essential components of most mental health systems and designated as best practices by the federal government.

Recovery has replaced maintenance as the goal for people diagnosed with mental illness.

> ## *"We envision a future when everyone with a mental illness will recover."*
> *Achieving the Promise: Transforming Mental Health Care in America,*
> *The President's New Freedom Commission on Mental Health*, 2003.

"Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it's the only thing that ever has." Margaret Mead

A small group of thoughtful committed citizens can (and have) changed their world. [iii]

[ii] Fisher, Daniel, MD, PhD, (2016). Heartbeats of Hope: The Empowerment Way to Recover Your Life, p.1X. Daniel B. Fisher

[ii] Kendrick, M. *et. al. (*2006). Key Components of System Change. ILRU Community Living Partnership National State-to-State Technical Assistance Center.

[iii] This Issue Brief is taken from Zinman, Sally. **History of the Consumer Movement**, first presented as part of Zinman, Sally, Budd, Su, Bluebird, Gayle. (December 17, 2009). **History of the Mental Health Consumer Movement**. Resource Center to Promote Acceptance, Dignity and Social Inclusion Associated with Mental Illness, Substance Abuse and Mental Health Services Administration, US Department of Health and Human Services, Webinar.

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Resource Guide

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