

History of the Consumer/Survivor Movement

by Gayle Bluebird

History connects us with our past, with those who have gone before us and those who have earned remembrance. Persons currently working as peer providers, including peer specialists, may not be aware of the rich history to which they now belong. The purpose of this account is to review the early history of the “Consumer/Survivor Movement” so that peers can learn about their roots, where they came from as it applies to their work today. It is time to pay tribute and to honor those early pioneers who created the path so that we could someday benefit and continue the journey.

The history of the consumer movement starts in the 70s, although there were many earlier pioneer advocates. Among these, probably best known is Clifford Beers who wrote “*A Mind that Found Itself*” (1908), a book which ultimately led to the establishment of the American Mental Health Association. But the history that most directly relates to the activities of consumers/survivors today began in the early 1970s at a time when the organized efforts of other civil rights groups such as the Black/African American Civil Rights Movement, the Women’s Movement for the right to vote, and less visible the Physical Disabilities Movement and the Gay Movement, were in full force.

De-institutionalization of large state mental hospitals had begun in the late 1960s consequent with laws established to limit involuntary commitment. It was at this time that ex-patients began to find each other, form in small groups and organize in different cities all over the country, though they would not initially know about each others activities. They met in living rooms, church basements or community centers, expressing outrage and anger at a system that had caused them harm. Many of them had been forcibly subjected to shock treatments or insulin therapy. Seclusion Rooms and use of restraints (spread eagled, tied down) were a common practice, as it still is in some hospitals today. People learned about or were witness to many who had died and were still dying in institutions. It was a time when mental patients were still being used as un-paid labor at state hospitals and in some hospitals sheeting in cold packs were used as methods for behavioral control.

Homosexuals or others with deviant anti-social behaviors were also being diagnosed and hospitalized as “mentally ill.” It was not until 1974 that the politically active gay community in the United States led the Board of Directors of the [American Psychiatric Association](#) to remove *homosexuality* from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). Our movement began to include persons who had been harmed by the system for being gay. Mark Davis, a leader of this sub-movement, later used humor with his “Drag with a Tag” act.

All of these ex-patients with whatever diagnosis given, felt de-humanized, indeed many of them had been told they had life-long mental illnesses and would never recover. Fully denying any belief in

“mental illness”, their initial goals were to create a Liberation Movement--**not to reform the mental health system**-- but to close it down. The term most used to define themselves, was “ex-inmate.”

The politics of these groups were considered radical and their protests were often militant, but while this stronger more vocal arm of the movement was being organized, there were equally strong voices among the protesters who focused on self-help (defined as both personal and interpersonal help), and people’s needs for supportive services. The concept of ex-patient- run alternatives was being conceived during this same period.

Among the first groups to form as an organization was the *Insane Liberation Front*, in Portland, OR (1970), followed by the *Mental Patients Liberation Project* in New York City and the *Mental Patients Liberation Front* in Boston (both in 1971), and in San Francisco, the *Network Against Psychiatric Assault* formed in 1972. (Chamberlin, 1990) The activities of these groups often included demonstrations at psychiatric hospitals and at conferences of the American Psychiatric Association; once forming a human chain that prevented conference attendees from entering. Another demonstration involved a month-long “sleep-in” at then Governor Jerry Brown’s office in California. Approximately 30 people occupied the office and remained there until their demands were heard; the primary issues were patients used as forced labor and un-investigated deaths of patients in institutions. Other protests were held at hospitals that used ECT; and there were marches in many cities hosting anti-psychiatry conferences; always featuring songs, chants and homemade signs with anti-psychiatry slogans.

The early protestors began to communicate with each other by means of a national newsletter and annual conference. *Madness Network News*, (which featured the byline “**all the fits that’s news to print**”), was published in San Francisco for over ten years, with subscribers both nationally and internationally. The newsletter provided an outlet for people to share their stories and political theories. Poetry and artwork was prominently included in every issue, much of it stark but poignant and directly relevant to the political issues presented.

An annual Conference called, *Human Rights against Psychiatric Oppression* was held in different parts of the country most often on campgrounds or college campuses. The first of these conferences was in Detroit in 1972. People came by bus, by hitchhiking, and in cars packed full. Although most people were surviving on social security disability, and had no other income, they found a way to get there as these conferences were among the few opportunities that people had to network and share political views and strategies. One early and significant product emerging from one of these conferences was the development of a Bill of Rights, not too dissimilar from Patients Rights today. Meetings often lasted into the wee hours while people debated issues and values. They tackled difficult subjects such as whether to take money from the government, whether to allow membership to persons who had not been hospitalized and whether to open their meetings to “sympathetic” professionals.

Judi Chamberlin, one of the early organizers, explains it this way, comparing our movement with other civil rights movements: “Among the major organizing principles of these movements were self-definition and self-determination. Black people felt that white people could not understand their experiences; women felt similarly about men; homosexuals similarly about heterosexuals. As these groups evolved,

they moved from defining themselves to setting their own priorities. To mental patients who began to organize, these principles seemed equally valid. Their own perceptions about “mental illness” were diametrically opposed to those of the general public, and even more so to those of mental health professionals. It seemed sensible, therefore, to not let non-patients into ex-patient organizations or to permit them to dictate an organization’s goals.” (Chamberlin, 1990).

Though the movement believed in egalitarianism leaders did emerge. Names still familiar, such as Judi Chamberlin, though deceased in 2010 will always be remembered as the Mother of our Movement. Sally Zinman is still active in the movement today in California today. To mention but a few others, Howie the Harp, (now deceased) started organizing in New York City but later moved to the West Coast; Su and Dennis Budd are still active in Kansas, George Ebert with Mental Patients Alliance in Syracuse, New York.

As the movement grew and changed many leaders would eventually decide to sit at the policy-making tables in order to have a voice and to get funding for drop-in centers and other types of alternative programs. Some of the activists would maintain their position of separatism never to participate in the evolving movement. Leonard Frank, one of the founders of the *Network Against Psychiatric Assault* in San Francisco, is an example. He chose instead to write a book, *The History of Shock Treatment* and has continued writing on different subjects, although always available for consultation.

In 1978 a landmark book was published; *On Our Own: Patient Controlled Alternatives to the Mental Health System*. This book, written by Judi Chamberlin, has been widely read, reprinted several times and is still considered an authority on the development of ex-patient controlled alternatives. One of the key principles she recommends is that alternatives be autonomous and in control of the hands of the users.

The 1980s was a transition time. The Federal Government began to take notice that ex-patients were organized and that they were operating successful programs independently without funds or outside support. The Community Support Program at the National Institute of Mental Health began to provide funding for these alternative programs.

In 1983 *On Our Own of Maryland* was the first to be funded with state funding: in 1985, the Berkeley Drop-In Center; the Ruby Rogers Drop-In Center, 1985, in Cambridge, MA; and in 1986, the Oakland Independence Support Center in Oakland California. The Berkeley Drop-in Center is still in operation and On Our Own of Maryland has transformed into a large statewide organization with many different programs.

IN 1986, Sally Zinman, Howie the Harp, and Su and Dennis Budd, wrote the first manual with funds from the Federal Government; SAMHSA (Substance Abuse Mental Health Services Administration). *Reaching Across* provided information about self-help and how to operate a self-help support group. In a chapter on Support Groups, Howie the Harp describes how peers and professionals provide support differently. “Support is not therapy”, he wrote. “In support, the goal is to comfort, to be available as a caring friend, to listen, and to share the knowledge of common experiences....[while] In a therapeutic relationship the client is requested to change the way he/she thinks or acts.”

The first Alternatives Conference was held in 1985, in Baltimore with funding from the Community Support Program at the National Institute of Mental Health, again, with funding from NIMH. By this time there were a variety of different voices with different perspectives on mental illness, some with more moderate views that, while opposed to forced treatment, were not entirely against the medical model.

The conference with over 300 persons attending was challenged by a need to come up with a name to call themselves. The term “consumer” was eventually selected and it was meant to signify “patient choice” of services and treatment. Many people still add the word “survivor” which usually means having survived the mental health system more than having survived an illness. Issues around self-referential terms continue to baffle; no one really likes “consumer”, but another commonly acceptable term has not yet been found to replace it.

1985 was also the year when the final edition of the *Madness Network News* was published and thus marked the decline of radical militant groups. The conference on Human Rights and Against Oppression was also discontinued that year, and a more moderate tone began to reflect the movement.

In 1986, following numerous reports and investigations of abuse and neglect in state psychiatric hospital and findings of inadequate safeguards of patient rights, Congress passed the Protection and Advocacy Act for individuals with Mental Illnesses (PAIMI) Act. This act provided funding to existing disability advocacy groups in each state to investigate complaints of abuse, neglect or the denial of legal rights to all people in mental health facilities and to some living in the community. Many of the activist consumers sat on advisory committees to the state PAIMI program and continue to do so.

In 1988 funds were provided by SAMHSA for 13 self-help demonstration programs. Though these may have been successful most of these programs did not survive when the federal funding ran out.

More clients or consumer began to sit on decision making bodies. Language had changed from negative to positive. The activities of the militant groups changed to activists voicing strong opinions for change rather than organizing demonstrations to protest.

By the 1990s many new consumer groups formed. Two national technical assistance centers were formed, The Self-Help Clearinghouse in Pa. under the direction of Joe Rogers, and the National Empowerment Center under the direction of Dr. Dan Fisher. Offices of Consumer Affairs were established at the state level in Departments of Mental Health and there was big growth in consumer-run alternative programs. Bill Anthony, Director of Psychiatric Rehabilitation, in Boston, in 1991, described it as the “decade of recovery.”

In 2000s we see an increase in gains for peer involvement in all areas of the mental health system. Peer Specialists are being trained in all parts of the country and are working in community as well as inpatient settings. Crisis alternatives are being established with one of the first ones, the “Living Room”, having been created in Phoenix, Arizona. Training is being provided by internet and in extensive hands-on training programs. The Alternatives Conference is in its 25th year and has changed from an advocacy/activist focus towards goals of skills building and promoting wellness and peer support.

Unmarked cemetery and gravesites are being restored in many states with Pat Degan and Larry Fricks coordinating the national initiative.

A national organization was formed, The National Mental Health Coalition that is bringing statewide organizations and individuals together for advocacy and federal policy development with Lauren Spiro serving as national director. The list of our successes is endless. What we can expect in the future is up to the visionaries of today; fulfilling and implementing new strategies for involving persons with psychiatric histories in every level of decision making and employment at all levels in mental health agencies and facilities. We envision a time when persons with psychiatric disabilities are welcomed into society, integrated into jobs and living on their own or in assisted housing in communities. With all of us working together institutions may yet become obsolete. There is still work to be done. As our movement continues to unfold our membership might well include all of us working together in partnership, persons receiving services, family members, providers, consumer/survivors and friends!

References:

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For other information on History of the Consumer Movement go to:

www.mindfreedom.org

<http://power2u.org/>