

Milestones of the Consumer/Survivor/Ex-patient (C/S/X) Movement for Social Justice

The consumer/survivor/ex-patient movement has a rich and complex history, and it is impossible to tell the story using only 10 milestones. These milestones are intended only as an introduction and it is hoped that the reader will delve further into the history of the c/s/x movement. (In the milestones below, c/s/x movement activists will be referred to by various names, such as peers.)

1969: The Insane Liberation Front (ILF) is organized by Howie the Harp, Dorothy Weiner and Tom Wittick in Portland, Oregon. It is the first-known modern self-help/advocacy group organized by ex-patients and dedicated to liberation from psychiatry. Subsequently, similar groups were founded around the country, including Mental Health Consumer Concerns, founded in 1977 by Jay Mahler in Contra Costa County, California, which is the oldest c/s/x-run organization in continuous operation in the U.S. Today, there are numerous such organizations in nearly every state and territory, including varied and sophisticated models, such as peer-run crisis respites – some of which are modeled after Soteria House, created in 1971. Many of these organizations publish newsletters and other materials. The first-known national publication of the c/s/x movement is Madness Network News, which published its first edition in 1972.

1973: The first of 13 annual International Conferences on Human Rights and Against Psychiatric Oppression is held at the University of Detroit. The last one was held in Vermont in 1985. These conferences led to the creation of the Alternatives conferences.

1975: The U.S. Supreme Court, in *O'Connor v. Donaldson*, rules that people cannot be institutionalized against their will in a psychiatric hospital unless they are determined to be a threat to themselves or to others. Also, *Rogers v. Macht* (*Rogers v. Okin* or *Rogers v. Commissioner of Mental Health*) is filed and was finally adjudicated in 1982; this ruling established a limited right to refuse treatment (psychiatric drugs) in Massachusetts. In addition, in 1975, the book *One Flew Over the Cuckoo's Nest*, by Ken Kesey, was made into an award-winning movie starring Jack Nicholson. The movie drew attention to the horrors of mental illness treatment.

1978: *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, by Judi Chamberlin, is published by McGraw-Hill. It becomes a standard text of the c/s/x movement.

1979: Loren Mosher, chief of schizophrenia studies at the National Institute of Mental Health (NIMH), reports superior one-year and two-year outcomes for Soteria House patients treated without neuroleptics.

1980: The Civil Rights of Institutionalized Persons Act (CRIPA) 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 residing in institutions for the treatment of mental illnesses.

1984: The Committee for Truth in Psychiatry, an organization of survivors of electroconvulsive therapy, is organized by shock survivors Marilyn Rice and Linda Andre. Subsequently, “[f]or the first time, a product liability suit against a shock machine manufacturer . . . resulted in a successful settlement for the plaintiffs. The suit was brought by Imogene Rohovit of Iowa City, Iowa, and her daughters, alleging that Mrs. Rohovit, a single mother and former nurse, has been brain damaged and rendered unable to work by shocks inflicted by the MECTA Model D machine in 1989.” <http://www.ect.org/news/suit.html> In 2009, Rutgers University Press published *Doctors of Deception: What They Don't Want You to Know About Shock Treatment*, by Linda Andre. The c/s/x movement has also organized to end the practice of

seclusion and restraint, and there has been progress in this regard. For example, former SAMHSA administrator Charles G. Curie, when he served as Pennsylvania's top mental health official, instituted a policy of moving toward the complete elimination of seclusion and restraint in state hospitals.

1985: The first annual Alternatives conference, in Baltimore, Maryland, is organized by On Our Own of Baltimore and funded by the National Institute of Mental Health-Community Support Programs. These conferences have been held nearly annually ever since; Alternatives 2012 is the 26th Alternatives conference.

1985: At Alternatives '85, the National Mental Health Consumers' Association – the first national c/s/x organization – is founded under the leadership of Joseph Rogers. At a meeting of the organization in Pottstown, Pennsylvania, in 1986, five steering committee members left to form the National Alliance of Mental Patients (later the National Association of Psychiatric Survivors). The schism proved fatal to both organizations, and both are now defunct. A people-of-color caucus first met at Alternatives '92, in Philadelphia; at Alternatives '94, the caucus organized more formally as a national organization of people of color in the c/s/x movement. Altered States of the Arts – founded through the leadership of Gayle Bluebird, Howie the Harp, Dianne Cote and Sally Clay – was founded at Alternatives '90. Support Coalition International (now MindFreedom International) was also founded in 1990.

1986: The first c/s/x-run national technical assistance center – the National Mental Health Consumers' Self-Help Clearinghouse – is founded by Joseph Rogers in Philadelphia to serve the c/s/x movement. Today, the Substance Abuse and Mental Health Services Administration provides funding through a competitive grant process for three c/s/x-run national technical assistance centers and two c/s/x-supporter national technical assistance centers.

1986: The passage of the State Comprehensive Mental Health Plan Act (P.L. 99-660) mandates “the provision of case management services to each chronically mentally ill individual in the states who receives substantial amounts of public funds or services.” This established case management as a distinct benefit under Medicaid. Medicaid amendments improved mental health coverage of community mental health services, added rehabilitative services, and expanded clinical services to individuals who were homeless. P.L. 99-660 also requires stakeholder involvement in the State Block Grant program, thus acknowledging the importance of the voice of the users of services. Also, Congress passed the Protection and Advocacy for Mentally Ill Individuals (now called the Protection and Advocacy for Individuals with Mental Illness) Act of 1986 (P.L. 99-319; 42 U.S.C. 10801 et seq.), designed to extend to individuals with mental illnesses in institutions the services of the protection and advocacy agencies that had previously been established to safeguard the rights of individuals with developmental disabilities.

1986: The first peers (including award-winning movement activist Pat Risser) are trained to work for the mental health system as professionals – Consumer Case Manager Aides – in Denver, Colorado, through the leadership of Paul Sherman, Ph.D. The services of these peer providers were billable to Medicaid under the Medicaid Rehabilitation Option Waiver in effect for Colorado. This was the precursor to the successful effort in 2001 by the Georgia Mental Health Consumer Network, under the leadership of Larry Fricks, to obtain approval from the Centers for Medicare & Medicaid Services (CMS) to bill Medicaid for peer support services. Many states have followed suit, and the profession of peer specialist has burgeoned. This includes the creation, in 2004, of the National Association of Peer Specialists, through the leadership of Steve Harrington.

1990: The Americans with Disabilities Act, a landmark civil rights law that prevents discrimination based on disability, is passed. Joseph Rogers, a leader of the c/s/x movement, served on the Congressionally appointed Task Force on the Rights and Empowerment of Americans with Disabilities, which – under the leadership of Justin Dart,* known as the father of the ADA – helped pass the bill. In 1999, the U.S. Supreme Court, in *Olmstead v. L.C.*, 527 U.S. 581, upheld the community integration mandate of the ADA by ruling that it is a violation of the law to keep individuals in restrictive inpatient settings when more appropriate community services are available.

1998-2004: The Consumer-Operated Services Program Multi-Site Research Initiative studied – and proved – the effectiveness of peer-run programs. Jean Campbell, Ph.D., a c/s/x movement activist and researcher, is the organizer of this initiative, and her pioneer efforts have led to other research studies of c/s/x-run programs. As a result, peer support is an evidence-based practice.

2003: The report of the President’s New Freedom Commission on Mental Health declares “that America's mental health service delivery system is in shambles,” leading to unnecessary and costly disability, homelessness, school failure and incarceration. The Commission recommended fundamentally transforming how mental health care is delivered in the United States with a primary goal of recovery for everyone. The Commission further stated that the transformed system must be consumer- and family-driven. Dan Fisher, M.D., Ph.D., a leader of the c/s/x movement, served on the Commission, ensured that a variety of peer voices were heard, and was influential in the report.

2006: The National Coalition of Mental Health Consumer/Survivor Organizations (now the National Coalition for Mental Health Recovery) was founded through the leadership of Dan Fisher, M.D., Ph.D. This organization, comprising statewide c/s/x networks as well as associate and individual members, is a national voice of the c/s/x movement.

2012: The Substance Abuse and Mental Health Services Administration (SAMHSA) appoints Paolo del Vecchio, an individual with a mental health condition who began working at SAMHSA in 1995, as director of the Center for Mental Health Services, the federal mental health authority.

*At the Second National Summit of Mental Health Consumers and Survivors, **Justin Dart**, one of the heroes of the disability rights movement who is known as the father of the ADA, said, “One of the first priorities of the empowerment society will be real rights for all – including people with psychiatric disabilities and psychiatric survivors. We must create and enforce laws that abolish the persecution which we suffer every day in every aspect of life. We must abolish involuntary confinement, physical and psychological abuse, coercion, outpatient commitment, and forced treatment of any kind.

“But rights are only the beginning. We must guarantee to each person – with and without a psychiatric disability – the tools to create the good life. I speak of the obvious: quality food, shelter, education, technology, and comprehensive health care, INCLUDING FULL, CONSUMER-CONTROLLED SERVICES FOR PSYCHIATRIC DISABILITIES. And much more: we must guarantee a society of choice and of reinforcement for positive contributions. WE MUST CREATE A SOCIETY OF PROFOUND LOVE FOR EACH HUMAN LIFE. LOVE, EMPOWERS A THOUSAND TIMES MORE THAN ANY DRUG EVER MADE.

“Colleagues, this is a powerful agenda. But can we win against the forces of ancient stigma and billion-dollar politics? Not quickly, not easily, and not simply by appealing to government. We must BECOME GOVERNMENT through elective and appointed office and voluntary action. We must create a politics in which government will be forced to empower. WE must carry the fight to the media and to the people in

every community. We must reframe the public dialogue. We must make the empowerment of all the first issue of American politics. The time has come to shout, "NO MORE SECOND-CLASS CITIZENS!" "AMERICA FOR ALL!"

"Colleagues, I know that YOU are already good soldiers. But we must increase our tiny army ten thousand percent. And we can do it. A relatively small constituency of people with HIV-AIDS overcame massive stigma to become a real force. If they can do it, we can do it.

"The community of people with psychiatric disabilities and of psychiatric survivors is by far the largest constituency among people with disabilities. There are tens of millions of us. We have members who are geniuses, who are millionaires, who are stars of sports and entertainment, who are leaders of government, business, science, academia and religion. We have the potential to be one of the most powerful forces in the culture. But it's not going to happen until WE unite and until WE organize.

"Colleagues, this is very personal to me. I have suffered depression, still do. My beautiful mother, my only brother and two other members of my family with psychiatric disabilities have taken their own lives rather than face the daily persecution.

"Each one of you has experienced atrocity – many far worse than I have. We experience physical and psychological holocaust.

"Let us rise above our differences. Let us lift our eyes to the dream. Let us embrace each other in that most profound love for the sacred value of each human life. Let us unite in passionate action. No soldier ever died in a better cause."