Since the 1970s, people with psychiatric labels in the United States have organized to protest the inhumane treatment we have experienced from psychiatry; to critique the biomedical model of “mental illness”; to protect and expand our human and civil rights; to end forced treatment and other harmful practices; and to demand broadly available alternatives to psychiatric treatment for people experiencing emotional distress or extreme states.

Judi Chamberlin, a movement pioneer in the U.S., described the movement’s rise in the early 1970s, with grassroots groups in different cities, each not knowing that other groups existed. She said it was:

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\text{[l]ike a mushroom […] there was this big thing underground and then it popped up in a whole bunch of different places “[…] a lot of groups got started, not only in different parts of the United States, but different parts of the world.}
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\text{(Chamberlin and Penney, 2002: 20)}

These groups initially focused on consciousness-raising, helping participants recognize that they were not broken or deficient, but that they and their peers had been harmed by the coercive psychiatric system.

These groups quickly moved from consciousness-raising to organizing. Judi Chamberlin recalled the early days in New York City:

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\text{Oh, it was really exciting […] We were challenging this thing that was this horrible force in our lives and we’re going to bring out the truth. We’re going to expose it. We wrote up these flyers, and we used to distribute flyers in front of Bellevue Hospital so that people could take them into the people they were visiting, to let people know they’re not alone. And we organized. We got invited to talk at college classes. And we got invited to talk on the radio. And “One Flew Over the Cuckoo’s Nest” was playing Off Broadway, and we leafleted the audience to say it’s not just the things on the stage, this is real.}
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\text{(Chamberlin and Penney, 2002: 18)}
As the movement grew and spread across the country, local groups learned about each other’s existence through word of mouth. Beginning in 1973, they organized an annual low-budget national Conference on Human Rights and Psychiatric Oppression, and developed a common agenda focused on opposition to involuntary commitment and all kinds of forced treatment. *Madness Network News* started as a San Francisco-area newsletter in 1972 and gradually evolved into a newspaper format covering the ex-patient movement in North America and worldwide. Movement groups worked to get a seat at policy-making tables at the local, state, and national levels, and made some headway in the 1980s.

By the mid-1980s, the movement had made inroads with the National Institute of Mental Health and survivor activists started to get invited to policy meetings. But in 1986, that agency began funding an annual “consumer” conference called Alternatives, which allowed them to censor and control the agenda. This was the start of the co-optation of some parts of the movement, as the government-funded conference soon supplanted the survivor organized Conference on Human Rights and Psychiatric Oppression. The more moderate “consumer” wing of the movement, which was not overtly anti-psychiatry, gained a foothold as they competed for limited government funding. The introduction of government funding began to highlight rifts between groups that opposed the medical model and forced treatment, and the more moderate groups who were generally in agreement with the philosophy of mainstream psychiatry and wanted to act in partnership with the system, rather than in opposition (Chamberlin, 1990; Chabasinski, 2012).

My own introduction to the movement came in 1989, when, as a staff member at the New York State Office of Mental Health, I worked on a planning project that required the agency to seek input, not just from mental health professionals, but from people who had used mental health services. Until then, I had not realized that my own negative experiences with the psychiatric system as a teenager and young adult had relevance to my work. On this project, I met activists in the consumer/survivor/ex-patient movement, and immediately recognized that I was one of them. Perhaps naively, I came out as a psychiatric survivor in a large meeting that included professionals. The ex-patients in the group seemed excited to learn that I was one of them; many of my colleagues seemed shocked, although my supervisor was supportive.

The consumer/survivor/ex-patient activists took me under their wing, gave me materials laying out the movement’s critique of biological psychiatry, talked with me about movement history, and introduced me to activists around the country. Two years later, I was appointed special assistant to the state Office of Mental Health commissioner, charged with bringing the perspectives of current and former service users into policy-making. This was initially empowering: I hired several other psychiatric survivors as staff, we met regularly with movement activists to strategize on policy matters, and we ensured that service users were included in important policy discussions.

But official enthusiasm for our participation dimmed as the leadership slowly came to the realization that we were not interested in “reforming” the system or making it more “consumer-friendly,” but that we took issue with the underlying premises of the psychiatric system and considered its coercive power a threat to human rights. This fundamental disagreement came to a head when the governor proposed, and OMH leadership supported, legislation to create what they called Assisted Outpatient Treatment and we called Involuntary Outpatient Commitment. This law allows forced treatment in the community, including forced drugging, of people who do not meet the criteria for inpatient commitment. The consumer/survivor/ex-patient movement rightly saw this as a serious deprivation of liberty. My staff and I helped the movement organize to oppose the legislation, while our employer worked to get it passed.
The law passed, I ultimately lost my job, and the agency leadership made sure my former position was filled by a “consumer” who shared the values and beliefs of the psychiatric establishment. At the same time, I watched as “peer specialists”, a job title I helped create to bring genuine peer support to people within the mental health system, became increasingly co-opted, as the role became focused on supporting the treatment system. Peer specialists’ roles changed; they now are required to do things like pressure people for medication “compliance” and report their behavior to clinicians. The use of “peer specialists”, particularly in coercive settings, has exploded in recent years. Many mad movement activists are alarmed by this rampant co-option and call for a moratorium on these roles, with a renewed focus on funding independent peer advocacy (Penney and Stastny, 2019).

In 2020, the situation of the psychiatric survivor movement in the U.S. feels somewhat discouraging. While the independent psychiatric survivor movement grew in the 1970s and 1980s, several factors, including the co-opting effects of government funding, resulted in the contraction of the independent movement in recent decades. There has been a corresponding rise of the so-called “peer movement” and “recovery movement”, which have philosophies more in line with the beliefs of the mainstream mental health industry. As discussed earlier, in the 1970s and 1980s, organized survivors worked hard to get a seat at federal and state policy-making tables, demanding to present alternative views to the patriarchal medical model of psychiatry (Chamberlin, 1990). Currently, many ex-patients who work inside the system are not even aware of the history of the psychiatric survivor movement, which was rooted in opposition to the oppressive policies of the system. In the U.S, it feels as though survivor knowledge currently has no more influence on mental health public policy now than it did 40 years ago – and perhaps even less, as the pharmaceutical industry now has more power and the state has more authority to coerce people with psychiatric labels into “treatment”.

I see the emergence and growth of Mad Studies in Canada and the U.K. as a very promising development that gives me hope. A field of academic study that focuses resources and attention on survivor’s experiential knowledge and that supports research conceived of and led by survivors will hopefully provide increased opportunities to have our views taken seriously by policy-makers and practitioners. I would love to see this development take root in the U.S. While I’m aware of a handful of psychiatric survivors who are researchers or hold academic appointments, the term Mad Studies does not appear to be used in the U.S. In the 1990s, I was part of a national group called the Consumer/Survivor/Ex-Patient Research and Policy Workgroup; it would be wonderful to revive that group.

References