



National Mental Health Consumers' Self-Help Clearinghouse



Knowledge is the key to open new doors

Technical Assistance Guide

History of the Mental Health Self-Help and Advocacy Movement

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The modern self-help and advocacy movement of people diagnosed with mental illness began about 30 years ago. But as early as the mid-nineteenth century, there are records of former psychiatric patients working to change laws and public policies concerning the “insane.”

For example, beginning in 1868, Elizabeth Packard, founder of the Anti-Insane Asylum Society, published a series of books and pamphlets describing her experiences in the Illinois insane asylum to which her husband had had her committed. But in the nineteenth century, individuals fighting for patients’ rights, such as Mrs. Packard, met great opposition. Due to ignorance and fear—many still believed that mental illness was the result of demonic possession—such early attempts at activism were largely ignored.

A few decades later, another former psychiatric patient, Clifford W. Beers, founded the National Committee on Mental Hygiene, which eventually became the National Mental Health Association. Beers sought to improve the plight of individuals receiving public psychiatric care, particularly those committed to state institutions. His book, *A Mind that Found Itself* (1908), described his experience with mental illness and the treatment he encountered in mental hospitals.

Beers’ work was significant because he stimulated public interest in the care and treatment of people with mental illness. However, he did not try to organize people who, like himself, had psychiatric histories; Beers knew that the public was not ready to listen to him or to others with similar experiences. Instead, he used his connections to involve concerned citizens who had standing in the community. However, there was still enormous opposition to the idea of patients’ rights.

In the 1940s, a group of former psychiatric patients founded WANA (We Are Not Alone). Their goal was to help others make the difficult transition from hospital to community. Their efforts led to the establishment of Fountain House, a psychosocial rehabilitation service for people leaving state mental institutions. Members of Fountain House supported one another by creating a community among people struggling with serious mental illness. This initiative laid the groundwork for the “clubhouse” model, which promotes the importance of meaningful work in people’s lives, and which would serve as a model for psychiatric rehabilitation programs developed in the 1960s and 1970s.

The 1950s saw the advent and widespread use of psychotropic (mind-altering) medications. These drugs allowed many individuals—people who would once have been committed to asylums for life—to be released to live in the community. The goal of this “deinstitutionalization” movement was to allow people with mental illness to escape being warehoused in what were often terrible conditions, so that they could enjoy increased independence and opportunities. While the idea of releasing people from institutions was a worthy one, many people fell through the cracks because of the lack of community-based mental health services. In addition, many of the psychotropic drugs

had terrible side effects, such as tardive dyskinesia (irreversible, involuntary, and disfiguring movements of the face and extremities.) In the 1950s, there was also a great deal of experimentation in the treatment of mental illness. Such now-discredited “treatments” as insulin shock therapy and lobotomies were administered, often against the will of the patient.

With the rise of the civil rights movement in the late 1950s and early 1960s, people began to organize to fight against inequality and social injustice. The civil rights movement inspired other groups to take on these same issues. By 1970, the women’s movement, gay rights movement, and disabilities right movement had emerged.

It was in this context that former mental patients in several cities across the country began to organize groups with the common goals of fighting for patients' rights and against forced treatment, eradicating stigma, ending economic and social discrimination, and creating peer-run services as an alternative to the traditional mental health system.

Unlike professional mental health services, which were based on the medical model, peer-run services were based on the principle that individuals who have shared similar experiences can help themselves and each other through self-help and mutual support. These groups provided peer support, education, and advocacy.

Many of the individuals who organized these early groups identified themselves as psychiatric survivors. Their groups had names such as Insane Liberation Front and the Network Against Psychiatric Assault. They saw the mental health system as destructive and disempowering.

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By 1980, individuals who considered themselves consumers of mental health services had begun to organize self-help/advocacy groups and peer-run services. While sharing some of the goals of the earlier movement groups, consumer groups did not seek to abolish the traditional mental health system, which they believed was necessary. Instead, they wanted to reform it. Consumer groups encouraged their members to learn as much as possible about the mental health system so that they could gain access to the best services and treatments available.

Recipients of mental health services demanded control over their own treatment and began to have an influence on the public mental health system. Whether they considered themselves consumers or survivors, movement activists demanded a voice in mental health policy-making: a “seat at the table.” Increasingly, they gained access to mental health policy-making and advisory committees. In addition, the number of peer-run services—drop-in centers, employment services, residences, and others—increased. Many of these services incorporated and received 501(c)3 (tax-exempt) status. Many received funding from federal, state, and local agencies. Studies found that peer-run services were effective, and cost-effective.

The latest challenge to the self-help/advocacy movement is the advent of managed care. Peer-run services must now decide whether to adapt—and become more like traditional service providers—in order to qualify for funding under new credentialing and reporting requirements, or to adhere strictly to their original policies, which were much more relaxed.

The past 100 years have seen a great deal of improvement in the treatment and perception of individuals with mental illness. People diagnosed with mental illness have brought about many of these changes within the mental health system and in society. Through self-help and advocacy, consumers/survivors/ex-patients have improved conditions in their own lives as well as the lives of others.

The movement still has a long way to go, but there is strength in numbers. As self-help/mutual aid/advocacy groups continue to form, they join the community of individuals working to improve the quality of life of everyone diagnosed with a mental illness.