

MENTAL ILLNESS, ADVOCACY & RECOVERY: READY OR NOT?

Jeffrey Geller, MD, MPH

A national mental health program should recognize that major mental illness is the core problem and unfinished business of the mental health movement.

Action for Mental Health, 1961

Mental health advocates in America have been in existence since the opening of the first public asylum – Eastern State Hospital in Williamsburg, Virginia – in 1772. Advocacy and the role of advocates still continues today, 240 years later, as the mental health community lobbies for the rights and concerns of individuals living with mental illness. Advocacy efforts focus on various issues such as comprehensive health insurance coverage (e.g., the federal Patient Protection and Affordable Care Act), the implementation of advance directives, and the need for specialized services for children with mental health conditions and their families. This Psychiatry Issue Brief explores the history of recovery and advocacy, barriers and strategies to the advocacy movement, and potential pitfalls of advocates not working together toward shared goals.

Recovery as Central to Advocacy

Recovery, probably the fundamental focal point in contemporary advocacy, is a concept that has waxed and waned in its centrality to American psychiatry since the golden age of the “lunatic asylums,” which were founded on the principle of recovery. Psychiatrists in asylums were focused on removing suffering individuals from the sources of stress (families, work) to a healing environment (asylum) where the superintendent, assisted by small number of staff, could pursue the cure of each individual patient and return the patient to the community. By viewing insanity as an acute disease that could be cured at each episode, and



by only looking at discharges, superintendents reported cure rates as high as 90+ percent. By the 1880s, Pliny Earle, Superintendent of the asylum in Northampton, Massachusetts, had documented the fallacies in the superintendents' statistics (Earle, 1887).

From the late 1880s to the end of World War II American psychiatry lost its focus on recovery being a central advocacy goal. The size of state hospital populations – made up of people with mental illnesses, with neurosyphilis, who were elderly, or who simply had nowhere else to go – grew beyond anyone's expectation – to single state hospitals with 16,000 to 18,000 patients. The focus on recovery reappeared in the 1950s with an emphasis in state hospitals on social skills, work, and returning patients to the community and the workforce (Geller, 2000). Before recovery could gain a foothold, hospital-based recovery was lost to the new focus of just getting patients out of the hospital, retrospectively labeled, “deinstitutionalization.”

In more recent years the concept of recovery has again been highlighted within professional and grassroots psychiatric and mental health communities. The American Association of Community Psychiatrists was the first

professional group to focus on the modern version of recovery, as evidenced by the guidelines the organization established on Recovery in 2003 (AACP 2003). Recovery became an American Psychiatric Association focus with the adoption of a position statement on recovery in July 2005 (APA 2005). The Substance Abuse and Mental Health Services Administration has, of late, pushed the recovery agenda with all the tools within its portfolio.

As in any movement, there are some who are out front. Some leaders of the rebirth of the focus of recovery include Judy Chamberlin (deceased) and Dan Fisher, MD, PhD, of the National Empowerment Center; Pat Deegan, of the Institute for the Study of Human Resilience; Fred Frese, PhD, of the Northeast Ohio Medical University; and William Anthony, PhD, of the Boston University Center for Psychiatric Rehabilitation. Anthony was the first person not self-identified as being or having been a person with serious mental illness to call for a fundamental shifting of psychiatric treatment to a recovery model (Anthony, 2000).

Barriers to Advocacy

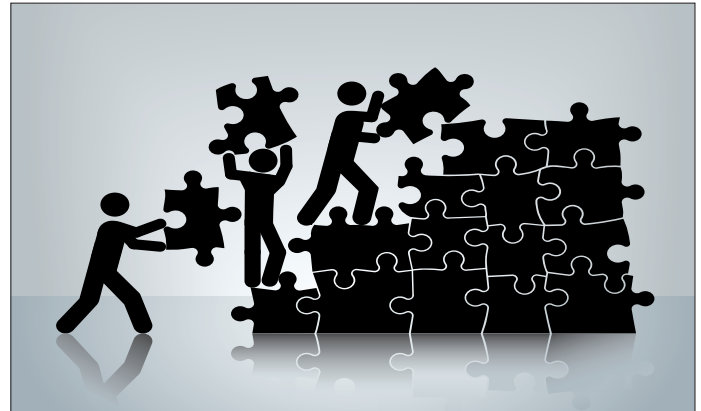
Impediments to effective advocacy for improved treatment and community-based services have remained largely unchanged for 50 years. One barrier to successful advocacy has been the lack of cooperation, which can deteriorate to strident antagonism and open hostility, between the three major cohorts of mental health advocates: professionals, persons with mental illnesses/consumer groups, and families and other supporters of persons with mental illnesses. The other barrier to advocacy is the infighting within the cohorts, e.g., between psychiatrist and psychologist, patients for and against psychotropic medication, and family members for and against involuntary medications for outpatients.

Only when these different cohorts can consistently advocate together for improvements in the system of care for persons with mental illness will advocacy for this population emerge from its marginalized state, and movement toward government reform be achieved.

Advocacy Strategies

The three cohorts of advocates emphasize different methods of advocacy. Professionals focus on lobbying through organizations that often have a paid lobbyist to inform legislators, consumer groups utilize rallies and protests, and families organize to educate and lobby policymakers. The emphasis on multiple methods of advocacy has tended to mask the common agendas of

these separate cohorts. For example, consumer groups protest against the use of restraint, while professionals work to reduce restraint to an absolute minimum. Given that these groups have fairly comparable objectives it could be assumed that these two groups could sit down to address the reduction of restraint with a shared goal - but this rarely happens.



Advocate Together

Each of these advocacy groups have a legitimate point of view, but only when people who populate the world of psychiatry – patients, doctors, consumers, nurses, victims and beneficiaries –advocate together, can the resources for recovery be fully mobilized to achieve positive outcomes. As recommended in the World Health Organization's 2003 publication, *Advocacy for Mental Health*, these advocacy groups “should establish a dialogue with representatives of all groups involved in mental health advocacy in the countries or regions concerned. It is important to understand their needs, motivations and diverse methods of advocacy. Helping them to find common issues and goals can contribute to the formation of alliances and coalitions. Helping them to identify their similarities can give them more strength and power to advocate both with the general population and with policy-makers, without the loss of their identities.” (p. 61) Advocates need to come together to develop consensus positions on:

- a non-discriminatory, inclusive health insurance schema,
- a campaign to end stigma,
- a plan for prevention of comorbidities,
- places for rehabilitation/recovery and
- a system of workforce development geared toward both treatment providers and employment specialists who assist persons with psychiatric disabilities to enter or return to competitive employment.

The choice is ours. Are we ready or not?

We appreciate your feedback: Please click here to answer our brief survey

References

American Association of Community Psychiatrists (2003). AACP Guidelines for Recovery Oriented Services. http://www.communitypsychiatry.org/publications/clinical_and_administrative_tools_guidelines/ROSGuidelines.aspx

American Psychiatric Association. (2005). Use of the concept of recovery: A position statement.

Anthony WA (2000). A recovery-oriented service system: Setting some system level standards. *Psychiatric Rehabilitation Journal* 24:159-168.

Earle P (1887). *The curability of insanity: a series of studies*. Philadelphia, J.B. Lippincott.

Geller JL (2000). The last half-century of psychiatric services as reflected in *Psychiatric Services*. *Psychiatric Services* 51:41-67.

Joint Commission on Mental Illness and Health (1961). *Action for Mental Health*, Basic Books, New York.

World Health Organization (2003). *Advocacy for mental health. Mental Health Policy and Service Guidance*. Geneva.

Mental Illness, Advocacy & Recovery: Ready or Not? - J. Geller