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MENTAL HEALTH IN AMERICA: LOOKING BACK WITH PRIDE AND AHEAD WITH HOPE

By

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In the early 1970s at the height of deinstitutionalization in New York, I worked at a psychiatric rehabilitation program on the West Side of Manhattan that primarily served people who had been in state psychiatric hospitals for 5, 10, 20, even 40 years. Each week I went to Manhattan State Hospital to meet patients who might be willing to visit our program. The hospital was isolated on an island in the East River and was composed of three tall, foreboding cement structures that looked very much like buildings in Stalin's Soviet Union. Ironically, they had been built in 1955 at about the same time that New York State passed the first community mental health act in the United States.

Patients who were brought to the hospital first went to an admissions area where they were stripped, searched, deloused, showered, given a cursory physical examination that included rectal and vaginal exams, handed shabby hospital clothing—rudimentary dresses or pants and shirts—and then taken to a locked ward. The doors were opened using skeleton keys of the kind frequently featured in horror movies to create a sense of the ominous. Inside the ward, they found a barracks style dormitory with fifty cots, placed fairly close together. There were some small private rooms, but they were reserved for patients being rewarded or for those too disturbing or dangerous to be close to other patients for an entire night. There was a nurses' station that overlooked the sleeping area on one side and the so-called "day room" on the other. That was the room where patients ate their meals and spent their days dozing off in chairs or pacing the floor, unless they were lucky enough to go to the modern rehabilitation facility across the campus, which was very much underused because people eligible for it were also eligible for discharge—the priority in that period of history. The wards were generally understaffed and the personnel under-educated and underpaid. Physical, sexual, and verbal abuse of patients both by other patients and by staff was, if not common, not nearly as rare as it should have been.

The patients who were discharged either went home to live with their parents or siblings or to adult homes or to live in squalid often dangerous rooms in the slum areas of the city. Adult homes were the subject of repeated scandals in the years after deinstitutionalization, as were the single-room occupancy apartments where many lived among very poor people, people addicted to drugs, sex workers, pimps, and petty criminals. People with serious mental illness were easy prey and too frequently were victims of assault, sometimes murder. These people relied on meagre, monthly public assistance benefits which didn't go very far. They could frequently be found begging for cash, food, and cigarettes, which they also retrieved from the sidewalks for a few drags or to collect tobacco to roll their own.

There were some treatment facilities in the community in the early 1970s. There were two state clinics for the West Side, for example, one on 110th Street at the top of the district, the other on East 17th Street, another part of the city. For the most part these clinics prescribed and/or distributed medications after brief monthly, medication management visits with people who had credentials or were training to be psychiatrists, but mostly were not very good at what they did. Many of them did not speak English. The medications were mostly first generation phenothiazines or Haldol. Their side effects of obesity, apathy, sexual dysfunction, and tics and tremors (tardive dyskinesia) were common. The Parkinsonian side effects were treated with drugs that controlled shaking but also probably had countertherapeutic side effects.

Have I painted too bleak a picture? Perhaps a bit. Many of the people who were discharged blended into the general population and managed on their own or with the help from family and friends. And many of those who were in chronic states of severe, long-term mental illness were helped to avert acute psychotic episodes, which often included angry, screaming unforgiving voices and unrelenting delusions. Despite their chronic psychoses and very limited social skills, many had friends and found some pleasure in life. Some of them became active members of rehabilitation communities such as Fountain House or The Bridge, where I worked. Almost all of them were happy not to be in the hospital, a fate that they feared because of terrible experiences many of them had had there. So, most of them were better off in the community than in the hospital. But overall, their lives were challenging, to put it mildly.

This is the past that we can proudly say we have put behind us.

The transformation began in the mid-to-late 1970s as journalistic exposés revealed the very poor quality of life and treatment of people who had been discharged from, or were no longer admitted to, state hospitals.

Legislators were alarmed. For example, Senator Frank Padavan, who chaired the NYS Senate's mental hygiene committee, held hair-raising

hearings on the West Side and elsewhere and pushed through legislation to support the development of community residences for people with serious mental illness or developmental disabilities.

At the same time the National Institute of Mental Health developed a model for community support programs (CSP) that was adopted in NYS in 1978. This model was built on recognition that state hospitals—however poorly they did it—did provide a place for people with serious, disabling mental illness to live; provided food, clothing, and other essentials; provided physical health care; provided social contacts; and even—until it was outlawed as exploitation in the early 1960s, provided work. The CSP model wrapped these supports together in the community by calling for supportive housing; adequate public assistance, rehabilitation; crisis, outpatient, and inpatient treatment in local facilities; and case management to coordinate care. (The model also noted the need for better physical health care, but due to the fragmentation of funding for physical and behavioral health services, that did not happen for the most part, which is one reason for the low life expectancy of people with serious mental illness.)

The past 45 years have been largely devoted to incremental implementation of the concept of community support with modifications and improvements that have resulted in 100's of thousands of supportive housing units, great expansion of rehabilitation, significant expansion of outpatient services largely funded by Medicaid, and what I called in a recent article in *Behavioral Health News* "the triumph of recovery". Some state hospitals have survived the process of deinstitutionalization, but they are smaller, better, and offer a more diversified range of services than in the days when they were huge, overcrowded, and understaffed facilities isolated out in the country largely cut off from the rest of the mental health system.

In addition, families of people with serious mental illness, who at one time were disparaged as the cause of their progenies' mental illness, have become a powerful voice in the world of mental health advocacy.

People with mental illness have also risen from being disdainfully regarded as people who cannot speak for themselves to advocates who speak strongly, loudly, and intelligently for themselves. And they are becoming valued members of the mental health workforce as peer advocates, providers, administrators, and public officials.

Over the past four+ decades, the public mental health system has also changed in several additional, important ways. It is now more responsive to the needs of people with mental and/or substance use disorders who are not disabled but who need treatment to salvage their lives. It has placed a significant priority on the mental health needs of children and adolescents, whose needs went largely unrecognized in public policy until the early 1980s. And, at the same time, there was some recognition of the special needs of people of color (then called "minorities"), who were then and still

are underserved in comparison to Whites. Efforts to reduce these disparities via affirmative action and building cultural competence have not been as successful as we hoped for, but treatment of people of color has become far better than the segregation of the races that dominated the system until the passage of the Civil Rights Act in 1964.

Since the advent of CSP, the realization also has grown that substantial numbers of people with serious mental illness cannot or will not come for service to settings labeled as mental health programs. It is critical to go to them in the community rather than sitting in offices waiting for them to arrive and angrily throwing them off the rolls when they do not. Assertive community treatment is growing as a way to reach out to and engage people who may benefit from behavioral health services if they are provided in home and community settings.

In addition, crisis services are now being remodeled with the development of a national 988 crisis intervention number, the shift away from reliance only on police to respond to severe psychiatric crises, and the development of crisis centers as alternatives to emergency rooms. And there have been some changes to the criminal justice system—such as mental health courts—to divert people with mental illness who commit minor crimes away from jails and prisons.

All of this and more has taken place through persistent advocacy for incremental improvements. We can take pride in this.

But it needs to be said, over and over again, that there is much more that needs to be done to improve our nation's behavioral health systems.

Obviously, I left out of my historical account of improvements the growth of homelessness and of the numbers of people with serious mental and/or substance use disorders in jails and prisons. Some, of course, argue that these shameful facts reveal that the move from an institution-based to a community-based mental health system was a dreadful historical mistake. I do not agree. I believe that homelessness was more the result of gentrification and the consequent loss of housing for poor people and the result of cuts to eligibility for disability benefits than the result of reducing the size of the state hospitals. And I believe that the increase in the numbers of people with serious mental illness in jails and prisons reflects criminal justice policies designed to put minor offenders—particularly drug users—behind bars for excessively long times.

But the debate about whether the system needs to move in the direction of more, longer-term, and more mandated inpatient service or to more rapid expansion of community services is critical to resolve in the coming years.

And there's much more that needs doing. More housing is needed. Public assistance needs to be secured for the future. Criminal justice reform needs

to go further. The capacity of the service system needs to be increased, especially with the development of a larger and more competent workforce. Access to services needs to improve. The quality of services also needs to improve, including better translation of research findings into practice. Fragmentation within the mental health system, between the mental and substance use service systems, and between physical and behavioral health needs to be reduced. We've talked about that, since the 1960s. Time to get it done. In addition, stigma needs to be reduced. And, at the heart of all possibility for change, is funding. Without money policy talk is empty rhetoric. There's too much of that.

The details of all this would take volumes. I just want to mention three areas that I think are particularly important—(1) reducing disparities, (2) addressing social drivers of mental illness and health, and (3) changing systems of response to problems of the human mind from blind silos of mental illness, substance use, and dementia to integrated systems rooted in understanding the unity of the mind.

- (1) The rise of "anti-racism" and its criticism of the mental health system for its past abuses of people of color is offering important insights into race and mental health. Hopefully, these insights will lead to greater success in reducing disparities than previous efforts of affirmative action and cultural competence.
- (2) The psychological fallout of the pandemic highlighted the power of the so-called "social determinants of mental health". Treatment alone and biomedical research alone, will not reduce the prevalence of mental disorders or adequately improve the quality of life for people with cognitive and/or behavioral health disorders. The role of the mental health system in addressing societal conditions that breed mental illness or support mental health needs to be resolved sooner rather than later.
- (3) Finally, I think we need to get serious about addressing the co-occurrence of mental disorders, of mental and substance use disorders, and of behavioral and cognitive disorders. We will need to shake up the established order to do that. But if we don't do it, we will remain trapped in organizational structures that may be better than they once were but still are not good enough.

I often quote Robert Frost when I talk about America's mental health system because we have much to "look backward to with pride" and much to "look forward to with hope". But we have "many miles to go before we sleep".

(Michael B. Friedman is a retired social worker who has worked in the field of mental health for over 50 years. He teaches mental health policy at Columbia University School of Social Work and serves as a volunteer social advocate as Chair of the Cognitive and Behavioral Health Advocacy Team of AARP Maryland. His writings can be found at www.michaelbfriedman.com. He can be reached at mf395@columbiauniversity.edu.)