



The Mental Health Association of New York City

THE FIRST ANNUAL MENTAL HEALTH POLICY ADDRESS

Delivered by

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- I am grateful to the Mental Health Association of NYC for the recognition I have received today. I am particularly grateful to Giselle Stolper, who has provided remarkable leadership of MHA of NYC for 20 years and was my co-conspirator in the creation of our Center for Policy, Advocacy, and Education nearly 8 years ago. I am also grateful to Carolyn Hedlund, the Executive Director of the Mental Health Association of Westchester, who joined us in creating the Center and supported its work with great commitment until she retired a several years ago. Remarkable women, remarkable people, remarkable leaders in the field of mental health.
- I am also grateful to the Mental Health Association movement for the opportunity it has given me over the past two decades to participate in a vast effort to make life better for people with mental illness, especially those who are disabled and rejected by society as a result.
- There are two tremendously important symbols of the Mental Health Association.
- One is a bell modeled on the Liberty Bell. Historically, it was used as the logo of Mental Health Associations everywhere. But it is more than a logo. Years ago the

national MHA forged a real bell from “shackles and chains” that had been used to restrain people with mental illnesses in institutions.

- This is what we have come from—a time when it was commonplace for people with serious mental illnesses to be housed in “asylums” and “hospitals” not worthy of their names, places where terrifying restraints, where harsh treatments that we now know to be little more than tortures, and where physical, verbal, and sexual abuse were day-to-day facts of life.
- The bell symbolizes the rights of people with psychiatric disabilities—their right to be recognized as human beings, their right to be treated with dignity and respect, and their right to liberty. It also symbolizes hope—hope for a decent quality of life, hope for satisfying and meaningful lives, and hope to overcome the horrors of acute madness, which have plagued the human species from its very beginnings.
- The second symbol of the Mental Health Association movement is its founder, Clifford Beers, a man who spent three terrible years in mental hospitals in the first decade of the 20th century, a man who suffered frequent abuse by the people who were supposed to care for him, a man who developed a grandiose dream while in the hospital to create a national and international movement to humanize the treatment of people with mental illness, and a man who realized his dream when he finally was able to leave the hospital and return to life in the community.
- Beers is the best possible symbol of the potential of people with mental illness and of the hope for recovery. He is a symbol as well of the power of advocacy and of the obligation we have as human beings to reject abuse and neglect of those who are mentally ill, to reject warehousing them in institutions and denying them a life in the

community, and to insist on their acceptance in the communities where they choose to live.

- Symbols, of course, are not actualities. High moral feelings are not achievements. And so we have to ask, what has become of the vision that Beers spun out in the first four decades of the 20th Century?
- The answer is that there has been remarkable achievement. Yes, there is much left to be done, but we can still take pride in what the field of mental health accomplished in the second half of the 20th century—after Beers had died.
- Sadly, he died in a psychiatric hospital (fortunately a good one) in the early 1940s during a period when people with mental illness in state hospitals suffered some of the worst abuses in the history of the United States because of the Depression and World War II.
- It brings to mind a poem by Robert Frost called “Death of The Hired Man” about a man who, having nowhere else to go at the end of his life, returns to a farm where he had once worked. He is described as a man who “has nothing to look backward to with pride and nothing to look forward to with hope.” And he was not welcomed.
- Beers returned at the end of his life to a hospital that took him in with great respect for his remarkable achievements. Unlike the hired hand, Beers had much to look backward to with pride and much to look forward to with hope, not for himself but for the field he had helped to shape.
- We too can look back with pride and forward with hope. Since the middle of the 20th century, the mental health system has been transformed, much in the image Beers envisioned, from an institution-based system to a community-based system. We

should be proud of that fundamental transformation, and we should be careful not to diminish the magnitude of this achievement even as we confront a myriad of major challenges to improve life for children whose growing up is interrupted and distorted by serious emotional disturbances, for adults trying to build lives for themselves despite psychiatric disabilities, and for older adults who frequently face emotional and cognitive barriers to aging well. We should not lose our sense of pride in what we have achieved even as we pursue major structural change so as to become what is strangely called "patient-centered" and "recovery oriented." (Imagine how mysterious those terms are to people outside our field.) We should not lose our pride even as we reshape our conception of what a mental HEALTH system should be, from a system that is just about mental illness to a system that also helps people to be mentally and physically healthy and to live well.

Think of what we have accomplished.

- We have made it possible for hundreds of thousands of people with mental illnesses who at one time would have been institutionalized to live where they prefer to live—in the community.
- But wait. The critics ask: how many are homeless, how many are in prison, how many are in nursing homes or adult homes?
- We need to answer. And you who will make the mental health policy of the future will have to transform policy again to end warehousing in shelters and the use of jails and prisons and nursing and adult homes as substitutes for asylums. You must make sure that more and more people are able to live decent lives in communities of their choice.

- But it is still true and important that many people with serious mental illnesses are living outside of institutions, have access to decent care, and are pursuing lives that they find satisfying and meaningful.
- That, as you know, did not happen at the beginning of the transformation from institution-based to community-based care. Deinstitutionalization—the first phase of communitizing mental health—was done poorly. Excessive optimism about the healing powers of medication and of simply being out of institutions led to a failure to put services in place that people with psychiatric disabilities need.
- During the most aggressive period of deinstitutionalization, from 1968 to 1973 when the population of New York’s state hospitals dropped from 80,000 to 40,000, people leaving did not become homeless. That happened later. But those who could not manage on their own and who did not return to their families lived in squalid and often dangerous single room occupancy hotels and in adult homes—many (but not all) as scandalous then as they were recurrently revealed to be over subsequent decades. Little treatment was available in the community for people discharged from state hospitals, and what was available was generally of very poor quality.
- In 1978 the concept of community support was introduced. It was a simple idea. People with serious and persistent mental illness need support to lead safe, tolerable lives in the community. They need housing, and they need rehabilitation and case management as well as good outpatient treatment and access to brief inpatient care in their local communities.
- This is still the fundamental vision of mental health policy in America, and it has driven tremendous positive changes over the past 32 years. In New York State

alone there are about 30,000 units of housing where none existed before. There are hundreds of rehabilitation programs. There has also been vast expansion of outpatient services, not only clinics but also day programs of various kinds.

Assertive community treatment and case management have become key elements of the system. Local inpatient capacity has also grown as the capacity of state hospitals has been reduced. The state hospitals that are left are far better places than they used to be because of major capital investments and a commitment to quality that began in the 1980s.

- And, very importantly, people who use mental health services and their families now play important roles in the planning, design, and delivery of services.
- During the early 1980s, children and adolescents with serious emotional disturbance began to get the attention they deserve. Child mental health leaders were appointed in governmental agencies. Plans were developed. A new vision emerged of comprehensive service networks providing access to needed clinical services, bringing together the diverse child-serving systems, and involving families as respected resources rather than as blamed causes of their children's disorders.
- Over the past 25 years there has been significant service expansion for kids, including not only outpatient clinics but also school-based services, home and community-based waivers, case management, therapeutic foster care, much improved residential treatment, and more.
- While the public mental health system was growing, so was the private sector. Thanks to ongoing advocacy as well as changes in professional standards and expectations, health insurance expanded to cover inpatient and then outpatient

mental health services. Employee assistance and similar programs also sprouted up in the workplace. The result was a vast increase in the number of people who get treatment.

- About 20 years ago advocacy for health insurance coverage of mental health moved from mere coverage to *equal* coverage of mental and physical health services—parity. This culminated in the last few years with the passage of Timothy's Law in NYS and federal parity legislation, which—to our great relief—was retained and improved in federal health care reform.
- Of course, growth of mental health coverage in the private sector also led to great concern among major employers and insurance companies that the benefit was being abused. Managed care emerged in response, and the success of managed care for cost containment in the private sector attracted the attention of state governments struggling to manage Medicaid costs and led to the introduction of managed care in Medicaid throughout the country. Whether this has improved care or impeded it is still a matter of debate as is the question of whether it should be extended to so-called "hard-to-serve" populations with co-occurring disorders.
- Over the past half-century, there has also been tremendous investment in mental health research. Even though it has not produced the breakthrough we keep seeming on the verge of, it has resulted in significant improvements in treatment and rehabilitation technology and determination to translate research into practice in both the private and the public sectors. As a result services are better and more effective than ever in history.

- So the system is unquestionably better, but as Richard Franks and Sherry Glied put it in the title of their very important book evaluating the first 50 years of community mental health, *Better But Not Well*.
- There is so much more to do. We have been pursuing an incremental mental health policy, chipping away at the need. But, to take housing as an example, in NYS we have averaged fewer than 1000 new beds a year. How many people have already died, and how many more people will die, waiting for decent housing if it takes another 35 years to develop the amount of **community-based** housing still needed?
- And treatment may be better, but is it good enough? We know it's not. We know it from personal experience if in no other way. There's not a person in this room, I would bet, who hasn't searched for a good mental health provider for themselves, a family member, or a close friend. If we have trouble finding the best care for ourselves, we'd better not kid ourselves that our system is good enough for all those strangers who turn to us for help. Better but not better enough!
- The mental health system is not yet extensive enough or good enough for adults with psychiatric disabilities, for kids with serious emotional disturbance, for older adults with serious mental illnesses who too often end up in nursing homes just because there is no alternative housing for people disabled by co-occurring physical and mental disorders.
- The system is not yet extensive enough or good enough either for the quarter of the American population that experience a less severe, but still painful and debilitating, diagnosable mental or substance use disorder every year. 60% of them do not get

treatment, and most that do do not get "minimally adequate treatment", as the National Co-morbidity Study Replication puts it.

- Will healthcare reform lead to great advances in access to good care? Maybe, but in complex ways that will depend on extensive integration of physical and mental health care that will be very hard to achieve.
- In addition, the concepts of prevention and mental health promotion have been rediscovered and expanded recently. New research apparently suggests that the hope of prevention of mental disorders may be in part achievable. I hope that the science is there to improve preventive interventions.
- And there are now voices for a major expansion of the realm of mental health from the treatment and prevention of mental illness, to the promotion of human well-being—not just the absence of mental illness but also the presence of what Aristotle referred to as *eudemonia*. Is there science behind this hope? I am skeptical about our ability to counter the tragic nature of the human condition. But maybe advances in psychological and sociological knowledge will make it possible for more and more young people to grow up with the kind of resiliency now so highly touted.
- So much work still to be done!
- I wish I had time to comment on all of it. Perhaps you'll take a look at a document we prepared last year with the ponderous title "A Mental Health Agenda for the 2nd Decade of the 21st Century", which contains a brief discussion of key mental health policy issues. You can find it on the MHA of NYC website or on my personal website, which has the remarkably narcissistic name, www.michaelfriedman.com.
- Just a few observations in the time I have left.

- First: for all the talk about “transformation” of the mental health system, there is remarkably little attention paid to the major demographic transformation underway in the United States—to the vast growth of minority populations and of older adults. MHA of NYC, as you know, has devoted considerable effort to geriatric mental health. I have been excessively honored for the work that Kim Williams and I—and many others—have done in this area. Yes, there have been some positive developments, but keep in mind that the elder boom begins in a few months. The first official baby boomers turn 65 in 2011, and over the next twenty years the population of adults 65 and older will become as large as the population of children and adolescents under the age of 18.
- WE ARE NOT READY. There are huge issues related to remaining in the community as one ages, huge issues of access, quality, cultural competence, integrated care, workforce shortages, ridiculously mis-designed funding systems, and more.
- There are other demographic matters besides ethnicity and age that we are not prepared for. I think particularly of veterans returning from Iraq and Afghanistan with high rates of post traumatic stress disorder, depression, substance abuse, and suicide. And I think of the recent rise in poverty, which hopefully is just the temporary outcome of a passing economic crisis and not a structural change in employment in the U.S.
- A second observation: the visions we have of a better mental health system and our hope of improved mental health status depend to a very large extent on the economy and on our ability as advocates to get increased funding for a population

and a system that have never been a high priority for our society. We have, I'm afraid, largely failed to gain recognition of the centrality of mental health to human well-being. *You cannot have a good life without mental health. It's perfectly obvious, but largely overlooked.*

- In addition, some mental health advocates argue vociferously that there is enough money for a very high quality mental health system if only it were re-arranged. Cut there, reinvest here, the argument goes. It is a bad argument that divides us against ourselves and is just not true. Yes, the system needs restructuring and yes, we can re-invest. But we also need more money. We should not agree year after year that the times are too tough to achieve more than holding down the cuts. For my entire career I have preached that there is no meaningful policy without money behind it. I strongly believe that the field of mental health has to continue to insist that money is the difference between rhetoric and reality.
- A third observation: because of increased reliance on Medicaid, the successful push for parity, and the growing interest in integrating physical and mental health services, the question has arisen of whether there should continue to be a separate mental health system or whether mental health should merge into the health system. Franks and Glied pose the issue as a choice between mental health “exceptionalism” and mental health in the mainstream.
- Without doubt the answer for people with serious and persistent mental illness is *mental health exceptionalism*. Why? Because mental health policy for this population is not, never has been, and never should be a subset of health policy. Mental health policy for this population is an amalgam of social welfare, criminal

justice, and health policy. It is as much about surviving and about getting support to live in the community as it is about medically oriented research, treatment, and rehabilitation.

- In addition, in the public mind, mental health policy is also about criminal justice. They worry about safety. We mental health advocates tend to worry more about people with mental illness who get swept unjustly into jails and prisons. When is it just for a person with mental illness to suffer the same punishment for a crime as a person without a mental illness? This is a key question of mental health policy; and it is not a subsidiary question of health policy.
- So, let me say it again, mental health policy is not just a subset of health policy.
- One final observation: I had a call the other day from a man I have been friendly with since I met him while he was a patient in New York hospital. He was upset about a friend in a psychiatric hospital. But, he told me, he himself is wonderful now that he is off medication and has realized that he is not now and never was mentally ill. Maybe he's right, maybe he's wrong. But why is this so important to him? It's because being mentally ill is still shameful in our society. We talk all the time about overcoming stigma, but I worry that we reinforce it in our practice. Goffman observed in the 1950s that one of the major characteristics of a total institution is that there are two classes of citizens--the inmates and the staff. Does our system still have two classes of citizens--the providers, policy makers, and advocates in one class and the recipients in another? Is it still us and them?
- I return now to where I began--to the critical importance of advocacy to win meaningful recognition of the rights of people with mental illness, to win their

acceptance in the community, and to expand a system of services and supports designed to help them to lead lives that they find meaningful and satisfying.

- For over a century the Mental Health Association movement has fought for these humanitarian goals and to put the mental health of the American people at the center of our nation's agenda for social progress.
- There have been many achievements, but we have--to paraphrase another poem by Robert Frost--miles to go before we sleep. I feel privileged to have been part of this vast effort and that I, along with our entire field, can look backward with pride. I am also convinced that we can look forward with hope, indeed with confidence, that much more will be accomplished in the next generation.
- One of the reasons that I am so confident is because of Kim Williams, who has become Director of The Center for Policy, Advocacy, and Education at MHA of NYC. Whatever I appear to have accomplished over the last 7 years, I have done with Kim, who started with me as a student at Columbia University School of Social Work. She has already made important contributions, and she is ready to make many, many more over the 35-40 years remaining in her career.
- Kim is a standout, but she is not alone. I am incredibly impressed by many remarkable young people I have met through my work and through my teaching. I have great hopes about what they will achieve.
- I thank you again for the recognition and honor I have received today.