MEETING THE NEEDS OF OLDER PEOPLE WITH PSYCHIATRIC DISABILITIES

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By
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Professor Rebok has asked me to talk with you today about policy issues related to older adults with schizophrenia or other psychotic conditions.[*]

A few notes first.

(1)   In this presentation I will refer to this population as "older adults with psychiatric disabilities" or with "serious and persistent mental illness" (SPMI) so as to be clear that I am talking about the portion of the population with serious mental illness who continue to need significant help as they age. An arguable number of people who experience serious mental illness over the course of their lives substantially recover; they are not who I will talk about today.

(2)   Also, I will not be talking about the fate of older adults with serious and persistent mental illness during the pandemic even though they are at very high risk of illness and death due to COVID. I am optimistic that the pandemic will come to an end. But there were vast unmet needs before it began and will be again after it ends. That is what I will focus on today.

(3)   A word about the approach to policy that I have taken today. Policy discussions sometimes deal with the big picture and do not explore specific policies—laws, regulations, budget items and the like—in detail. Other policy discussions dig into the very important weeds of governmental and organizational policy. In this presentation, I will say virtually nothing about specific laws, regulations, and the like. I will instead identify the problems that older adults with psychiatric disabilities confront and make broad policy suggestions to address these problems.

(4)   And lastly, I hope you will notice that the fundamental question I will ask is not about the treatment needs of people with serious and persistent mental illness, but about issues that need to be addressed to **help them lead satisfying lives**. Good treatment is part, but only

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[*] In this presentation I will not refer to the research literature on which my claims are based. You can find citations in a chapter I and others wrote for an anthology compiled by Carl Cohen, et al a couple of years ago.
http://michaelbfriedman.com/mbf/images/Schizophrenia_in_Later_Life_PF.pdf

part, of that. As public health students, I hope that is already obvious to you.

(5)   I also hope that you know something about the symptoms and life course of people with schizophrenia and other psychotic conditions such as psychotic depression and bi-polar disorder. But just in case you don't: Schizophrenia usually begins in the late teens or early 20s, often disrupting lives of great promise. There is some later onset. It and other psychoses are characterized by inability to grasp reality. This includes distortions of perception, such as hallucinations, and cognitive distortions such as delusions. They frequently involve emotional lability (extreme ups and downs) and behavioral problems including poor social skills and inability to concentrate on tasks. For people with serious and **persistent** mental disorders, low functioning generally persists over time with intermittent acute psychotic episodes. This description does not do justice to differences among people with schizophrenia, psychotic depression, bipolar disorder, etc. But it will have to do for this presentation.

Now to policy matters.

The American mental health system does not adequately address the needs of older adults with long-term serious mental illness.

Too many people with SPMI lose their lives prematurely. They die 10-20 years younger than the general population. In essence, they are victims of health disparities including poor access to health care and high suicide rates as well as low life expectancy.

Too many are homeless or imprisoned. Half of the homeless population in Baltimore, for example, is 50+. Estimates for jails and prisons range from 10-20%.

Too many do not get enough from governmental income supports to maintain housing in the open market and have enough left for food and other necessities.

Too many lose supportive housing as they age due to the development of chronic physical conditions, including dementia, which mental health housing programs are not equipped to deal with.

Too many go to nursing homes because appropriate alternative residential services are not available.

Too many get inadequate mental health treatment or no treatment at all.

- There are **too few clinically, culturally, and geriatrically competent practitioners**.
- There are frequent **misdiagnoses**, including overdiagnosis of schizophrenia in people of color that results in treatment plans of questionable value including overuse of anti-psychotic medications
- **Crisis services** are often not available at the time that crises occur and often rely too much on the police.
- **Clinics are not necessarily the appropriate clinical service provider** for older adults.
- **Fully integrated treatment** for physical, mental, and substance use disorders is rare.
- **In-home services** (now more available due to telehealth) still are not adequately available, and making telehealth permanent is a critical advocacy challenge at this very moment.
- **Psychiatric day treatment** programs are generally designed for younger adults and rarely can address either chronic health conditions that are increasingly common in old age or dementia.
- **Medical day treatment** often becomes an alternative source of day care for placid older people with SPMI and perhaps co-occurring dementia, but these programs usually are not designed to address psychiatric disorders.
- In the **transition from mental health-oriented programs to LTC**, people with SPMI often **lose the most important relationships** in their lives.
- **Inpatient treatment** may be in short supply. (There is a debate about this, which I will discuss later.)

In addition to shortfalls in treatment, too many older people with psychiatric disabilities are unable to benefit from **psychiatric rehabilitation** because it is generally designed for young adults and focuses on vocational rehabilitation not relevant to adults of retirement age.

A key element of psychiatric rehabilitation is a **recovery orientation**. Too few mental health service programs have a recovery orientation, i.e., understand that people with SPMI can have lives they find satisfying and meaningful despite the persistence of a serious mental disorder.

In addition, the sit and wait for people in need to come in for service that is common in the mental health system simply doesn't work for many people with SPMI. And there are too few **outreach and engagement** efforts to find and connect with older people who are unable or unwilling to go to a place where mental health services are provided. For example, there are very few Assertive Community Treatment Programs for older adults.

As a consequence of widespread **stigma and discrimination**, many older adults with SPMI are cut off from mainstream society. This includes:

- Discrimination in housing
- Being effectively excluded from houses of worship, which are extremely important to people with mental illness who find a sense of meaning in spiritual experience.
- Being unwelcome in senior centers and other places where older adults congregate.

Exacerbating **exclusion from mainstream society** is the **lack of collaboration between the mental health and aging services systems**.

Sadly, **research regarding the barriers to satisfaction in older people with SPMI is exceedingly limited**, with gaps in epidemiological, clinical, services, and translational research.

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All of these problems, and more, are taking place during an historical period of huge demographic and social changes in the United States particularly:

- The rapid growth of the population of older adults
- The rapid growth of the population of people of color
- The rediscovery of racial/ethnic health disparities
- The growth of economic disparity.

I don't know about you, but I'm exhausted just reviewing this list of issues.

What can be done to address them?

Obviously, part of what is needed is better practice. But there are also needs for governmental and private sector initiatives and policies to make better practice a realistic possibility.

The policy change at the top of my list (and not everyone would make it their number 1 priority) is a major effort to **increase life expectancy** of people with SPMI.   This would include:

- Requiring physical health care providers to make care accessible to people with SPMI or to participate in fully integrated care
- Providing resources for the development of more wellness programs
- Enhanced suicide prevention
- Redoubling efforts to reduce homelessness, which brings with it the high health risks of hard lives on the streets
- Increasing the effort to address the co-occurrence of substance use disorders.

Also high on my list are **public income supports**—SSDI, SSI, general welfare, and SNAP (food stamps)—which vary up and down with the political winds and for which eligibility is often a political football. Recently a so-called Trusts Act has been introduced to stabilize the Security Trust Fund—presumably with cost controls that I have not yet researched.

Also, in my view, far more attention is needed to the **housing needs** of older adults with SPMI especially the development of residential programs that are:

- Accessible to those with physical disabilities and
- Equipped to manage chronic physical conditions.

Because such housing programs are not widely available, many older adults with psychiatric disabilities and co-occurring dementia or chronic physical disabilities are **inappropriately placed in nursing homes**. This can be reduced by:

- Creating appropriate residential alternatives
- Providing supports to enable people with SPMI to live in the community, and
- Enhancing family support.

Because many older adults with SPMI end up being served in long-term care programs and facilities, it is important for these to have the capacity to provide care for mental health conditions as well as for dementia and physical disabilities. Establishing regulatory and accrediting requirements regarding the core skills of long-term providers and regarding training will be key to achieving this.

All of this is part of **long-term care reform**, which has inched ahead in fits and starts since the mid-1970s. It's time to get serious about this.

Of course, **treatment for older adults with SPMI also needs to improve**. This includes:

- Restructuring crisis services to provide 24/7 availability and training for, and reduced use of, the police
- Modernizing or replacing the clinic model
- Increasing access to in-home services especially with expanded use of tele-health services
- Developing psychiatric day treatment programs that can serve older adults with chronic health conditions and/or dementia
- Perhaps increasing inpatient resources. (More later.)

Fundamental to improving treatment is **full integration of treatment for physical, mental, and substance use disorders**. Very complex systems of care, such as medical homes and accountable care organizations have been put in place to achieve this. How successful they are is open to question.

For people with SPMI, **psychiatric rehabilitation**, of which there are several forms, is a core service. These programs are generally structured with the goals of younger adults in mind, especially the goal of work. Accreditation, licensing, and funding regulations need to be modified to respond to the life circumstances of older people for whom work is no longer a primary life goal.

Because many older adults with psychiatric disabilities cannot or will not go to places that provide mental health services, **increased outreach and engagement efforts are essential**. Especially important is the development of assertive community treatment programs specifically for older adults.

Ageism in the American society leads to the perception that old age is essentially a time of hopelessness, of sad deterioration leading to increased disability and death. This runs counter to the belief in "recovery" that is at the core of psychiatric rehabilitation. Building a **recovery orientation** into services for older adults with psychiatric disabilities is critical, and this needs to be reflected in accrediting, regulatory, and funding requirements.

Central to all efforts to improve mental health services for older adults with psychiatric disabilities is **building a clinically, culturally, and geriatrically competent workforce**. This cannot be accomplished without very substantial investment in recruitment, scholarships and fellowships, loan forgiveness, etc. This needs to include expanded use of peers in various, innovative paraprofessional roles. And, very importantly, more people of color are needed as part of the direct service, management, and leadership workforce.

Greater effort to **overcome stigma and discrimination** is also needed. This includes:

- Overcoming de facto discrimination in housing, which continues despite the Fair Housing Act and the Americans with Disabilities Act
- Working with houses of worship to welcome people with serious mental illness, who often find their sense of meaning in spiritual experience. (There's a very interesting Constitutional issue here regarding separation of church and state. Years ago I proposed the development of a chaplains without walls program as part of deinstitutionalization in NYS. It was rejected.)

- Working with the aging services system to make people with SPMI welcome in senior centers and other places where older adults congregate.
- Confronting racial discrimination
- Confronting discrimination against people with serious and persistent mental illness.

Without doubt, more **research is needed to guide the development of an adequate mental health services and policy** regarding older adults with psychiatric disabilities. Research also needs to be diversified, with increased attention to epidemiological, clinical, services, and systems research.

All of this, of course, requires both **increased and restructured financing**. The major funding sources, particularly Medicaid and Medicare, are too linked to the medical model—i.e., to treatment rather than to psychosocial interventions. This has been improving with some Medicaid, for example, now being used for housing and peer support services. But there is a long way to go to move beyond the medical model.

In essence what is needed is **a system that is clinically, culturally, and geriatrically competent**.

By a culturally competent *system*, I mean one not only a system in which direct interactions between the helpers and the helped are linguistically fluent and culturally informed. I also mean a system in which people of color have professional jobs, in which they can rise to supervisory positions, in which they can become executives, in which they can have influence on the development of program models, on systems planning, and on legislation and regulation.

Winning greater attention to geriatric mental health in local, state, and federal agencies is critical because currently meeting the mental health needs of older adults is a very low priority, barely on the radar screen, as it were. Advocacy strategies include calling for the development of:

- Dedicated leadership in governmental agencies and
- Multi-year inter-agency plans to meet the behavioral health challenges of the elder boom.

But after several decades of trying to get it, how to build greater political interest in the behavioral health needs of older adults frankly remains a mystery to me. It's easy to say we need more media attention. How to get it is another thing. I would welcome your thoughts.

I am sure you find my list policy initiatives more than a little daunting. It might be best for you to think about it piecemeal, as a list from which you could draw for any number of advocacy or research projects that you could pursue as you begin your careers.

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I want to return now to the question I noted earlier about the possible need for more inpatient facilities.

In truth there is no way to know whether there is a need for more hospital beds because **need depends not just on mental condition but also on the range of alternatives to hospital beds that is available**.

The lack of an empirically based needs methodology has led to **a major and counterproductive ideological debate** within the mental health advocacy community**.**

As I am sure you all know, the current status of people with serious and persistent mental illness reflects the transition in American mental health policy that took place in the middle of the 20th century—a transition from institution-based to community-based policy. That's a cumbersome way of saying that a decision was made to vastly reduce the use of state hospitals and to replace them with local systems of care.

The first phase of this process is known as deinstitutionalization; and, even though it resulted in better lives for many people, there was inadequate investment in the development of community-based services with catastrophic consequences for many people. In response, with leadership from NIMH, largely from two Marylanders—Neal Brown and Steven Sharfstein—community support programs began to be developed throughout the United States. 45 years later that is still in process.

The slow roll out of community support programs contributed to (but did not cause) the rise of homelessness, of the incarceration of large numbers of people with SPMI in jails and prisons, and in part to transinstitutionalization from state hospitals to nursing homes. And many mental health advocates bemoan deinstitutionalization and argue insistently that it was a mistake and that we need much greater inpatient capacity in general hospitals or even in revitalized state hospitals and that involuntary treatment should be more widespread. Other mental health advocates focus on the horrors of life in state hospitals (if you want a description, ask me). These advocates insistently call for more housing, rehabilitation, outreach, case management, and outpatient treatment as well as criminal justice reform. They oppose efforts to expand inpatient care and involuntary commitment as the violation of civil rights.

In my opinion, and to quote myself, these

"Vituperative ideological divisions among mental health advocates impede us from achieving major improvements in our mental health system.

Some advocates would limit the rights of people with serious mental illnesses for their own good and for the safety of society. They believe in expanding the use of coercive interventions, especially involuntary outpatient treatment, which they usually refer to as "assisted outpatient treatment." They also generally believe that deinstitutionalization went too far and that many people with serious mental illness would be better off in hospitals than in jails and prisons, or homeless on the streets. They, therefore, advocate for increasing the use of both short and long-term psychiatric hospitalization.

Opposing advocates argue that to protect people with serious mental illness from homelessness, we need more housing, and that to keep them out of jails and prisons we need extensive criminal justice reform. These advocates maintain that there would be little need for coercive interventions if there were expanded outreach and engagement efforts. In addition, they often point to the horrendous history of abuse that occurred in state hospitals and argue that if more "recovery oriented" and "person-centered" community-based services were available, fewer people would need inpatient services.

No doubt, both perspectives are well-meaning and have some merit. Unfortunately, in the battles to get major legislative changes, advocates with these different ideological convictions neutralize each other. At best, we end up with incremental improvements. Often, we get window dressing—such as new administrative structures—or compromises that are largely self-defeating—such as getting expanded Medicaid coverage of psychiatric hospitals, but only for relatively short stays. Major change is rare.

Despite the ideological divide, there is a remarkable degree of agreement among mental health advocates about needed improvements."

http://michaelbfriedman.com/mbf/images/Put_Ideological_Differences_Aside_Final.pdf

The list of policy recommendations I have given is an example of the broad agreement that exists about how to improve American mental health policy, in this case for older adults with SPMI. Getting bogged down in the question of whether we need more inpatient capacity, especially long-term inpatient capacity, distracts from building the **unity we need to bring about major changes that could improve the lives of people with mental disorders, including older adults with SPMI.**