

AMERICAN MENTAL HEALTH POLICY

SERIOUS AND PERSISTENT MENTAL ILLNESS

By

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Abstract: This lecture is about policy to meet the needs of Americans with serious and persistent mental illness (SPMI) who are unable to manage in the community without substantial assistance from family, friends, communities, and/or government. People with SPMI, like all people, need a decent place to live, income for basic necessities, improved health care to promote increased longevity, satisfying family and social relationships, activities that they find engaging and meaningful, and access to mainstream society. For many, spiritual experience is a critical need. In addition, this population needs good mental health treatment that goes beyond the provision of medication and verbal therapy and also includes day programs, psychiatric rehabilitation, and case/care management. Although incremental changes over the past 60 years, especially the development of the Community Support Program (CSP), have resulted in improvements in the lives of people with psychiatric disabilities, 35% of them (more of people of color) still do not get treatment and community supports fall short of the need. Additional improvements are needed both for people with SPMI and their families.

It has become customary for those of us who advocate for improved mental health policy to claim that 1 in 5 American adults has a diagnosable* mental illness and that 1 in 4 has a mental illness and/or a substance use disorder. Half, we typically say, will have a mental or substance use disorder in their lifetime.

Our claims are more or less supported by epidemiological research. However, they are misleading because most people equate mental illness with its most severe forms. Homeless people dressed in rags pushing shopping carts with all their belongings or people tormented by angry, domineering voices or people whose depression is so deep that they can't

* A diagnosable mental illness is a condition that would be diagnosed as a mental illness by a competent mental health professional if they did a diagnostic assessment. A large proportion of people with "diagnosable" mental illnesses have never actually been diagnosed. The number of such people is determined via epidemiological studies in which a random sample of individuals is interviewed using structured questionnaires through which mental illness can be inferred.

get out of bed in the morning or people who relive terrifying experiences over and over again or people who are addicted to alcohol or drugs and whose lives have fallen into disarray as a result. These are the kinds of images that typically come to mind when people mention mental illness, and it is simply not the case that 20% or more of Americans are so profoundly disturbed.

Mental illness can be “mild”, “moderate”, or “serious”. Some serious mental illness (which is sometimes called “severe”) occurs once or twice and doesn’t recur, and some comes and goes for many years. Some mental illness is referred to as “serious and persistent” (sometimes called “severe” and “persistent”) because it lasts for many years with a mix of acute psychotic episodes and chronic states of limited functioning. Most mental illness is not serious and persistent. Epidemiological studies report as few as 1% and as many as 3% of American adults have SPMI, as it is often called.

This lecture is about adults with SPMI.* Next week’s lecture is about adults with mental illnesses that are not serious and persistent. The difference, from my point of view, is that some mental illnesses are severely disabling, and some are not. By “disabling” I mean that because of their illness some people are not able to manage in the open community without significant help from their family, friends, communities, and/or the government. This definition of “disability” is arguable and in some contexts incorrect, but from the standpoint of mental health policy, it is very important to distinguish between people with mental illness who can muddle through more or less independently and people with mental illness whose lives would literally be in danger if they did not have a lot of help.

The survival of people with severe, long-term, disabling mental illnesses, is historically the core responsibility of the American mental health system. From the end of the 18th century until the middle of the 20th century, this responsibility was met primarily by providing custodial care in state asylums and hospitals. After World War II, a gradual shift began to support this population in the community. There were changes both in mental health policy and, perhaps more importantly, in policy regarding public assistance,

* Diagnostically, people with SPMI have schizophrenia, bi-polar disorder, treatment resistant severe depression, disabling anxiety disorders, etc. For some people the onset of mental illness is in childhood or adolescence and continues into adulthood. But for many people, especially those with schizophrenia, the illness first emerges in late teens or early 20s. People of great promise seemingly suddenly develop psychotic symptoms including hallucinations and delusions. They lose their grasp of reality in some ways, find it difficult to concentrate, experience deeply disturbing and labile emotions, and become dysfunctional in many ways. Some severe mental illnesses emerges later, some even in late life (45 or later).

which became available to people with psychiatric disabilities early in the 1950's.¹ Reliance on state hospitals peaked in 1955, when at most 1/3 of people with severe, long-term mental illness were in state hospitals. Since then, there has been significant growth of mental health services for people with severe, long-term mental illness. Nearly 2/3 of them now get treatment and other services, mostly outside of state hospitals.

Nevertheless, about 35% of people with serious mental illness do not get any treatment,^{2,3} more among people of color.⁴ And there are significant problems with the quality of treatment they do get. It frequently is not even "minimally adequate",⁵ and it is often fragmented and chaotic.

People with severe and persistent mental illness often have difficult lives. Their life expectancy is 10-25 years less than the general population⁶ in large part because they often have poor health and have limited access to decent health care.⁷ They frequently have co-occurring substance use disorders. They often live in poverty, in squalid and sometimes dangerous housing, and in conditions that we would find unacceptable for ourselves. They have limited access to the mainstream—even to houses of worship.⁸ They frequently experience homelessness at some point in their lives.⁹ They are disproportionately among those incarcerated in jails and prisons.¹⁰ They have high rates of suicide.¹¹ They are mostly unemployed.¹² And so on.

Despite this overall bleak picture, a considerable portion of the population of people with severe, long-term mental illness have lives that they find satisfying and meaningful and, in that sense, have experienced what has come to be called "recovery".¹³ Notably, some people with serious mental illness are now working as peer specialists,¹⁴ and there are some who have emerged as advocacy leaders and as managers of mental health organizations.

What does it take for people with SPMI to have satisfying lives in the community? The answer is not difficult, because people with SPMI are first and foremost people, and all people have the same fundamental needs:

- A decent place to live
- Income to pay for food, other necessities, and a bit of fun
- Health and longevity
- Satisfying family and social relationships
- Satisfying and meaningful activities such as work or art or advocacy
- A sense of connection and belonging in a community they value
- Spiritual opportunities.

Because of the severity of their mental disorders, people with SPMI also need more support from family, friends, community, and government than

people without disabilities. This includes psychiatric treatment, psychiatric rehabilitation, care management, humane crisis intervention, outreach to find them and connect with them before they are in crisis, a more just criminal justice system, and respect for their rights as human beings.

I think that there is widespread agreement about all this, but there are significant details that are incredibly complicated and controversial. For example, and most prominently, there is disagreement about whether more people with SPMI need inpatient hospital care and about whether coercive interventions should be used more extensively for people reluctant or unable to use organized mental health services. Some argue in favor of increased coercion so as to reduce homelessness and incarceration. Some maintain that increased outreach and engagement and expansion of community support services, especially housing, would be far more effective.

Unfortunately, the dispute between those who favor more hospitalization and coercion and those who oppose it dominates the headlines about mental health policy. As I've said, there is considerable agreement about the need for more and better treatment, rehabilitation, and community support services, and I have argued for many years that the mental health community should unify around these areas of agreement so as to become a more effective advocacy force.¹⁵

But unity is difficult to achieve in large part because of differences in fundamental perspectives about SPMI. Many advocates and providers have a "treatment-oriented" perspective. Others, I among them, have what has come to be called a "recovery-oriented" perspective.¹⁶ The difference is that from one perspective the primary question is what services (especially treatment services) people with SPMI need. From the recovery perspective, the key question is what people with SPMI need to lead satisfying lives in the community. The answers to the two questions overlap, but the services-oriented perspective emphasizes the need for treatment, rehabilitation, supportive housing, care management and the like while the recovery-oriented perspective emphasizes, to say it again, the need for a decent place to live, income for necessities, good physical health, satisfying family and social relationships, meaningful activity, and spiritual life in addition to mental health services.

One way to think about this difference in perspectives is that typically mental health policy focuses, quite understandably, on needs due to abnormality. The alternative is to focus as well on the humanity of people with SPMI, on the needs and desires they share with others, on their normality.

In what follows, I will comment on what it takes for people with SPMI to lead satisfying lives and make some observations about policy needs to help them have such lives.

A Decent Place To Live

Obviously, people with SPMI, like all people, need a place to live. Unfortunately, they have limited access to mainstream housing, unless they live with family, as a great many do. This is in part due to cost and in part due to discrimination against people with mental illness because of stigma¹⁷, which results in generally unwarranted fear that they will be violent or unsanitary or just unpleasant.

Over the years there have been a variety of efforts to provide greater access to mainstream housing including anti-discrimination laws such as the Fair Housing Act,¹⁸ the Americans with Disabilities Act,¹⁹ and the Olmstead Decision.²⁰ In addition, rent subsidies are available for people—including people with disabilities—who cannot afford market rates, even in neighborhoods where poor people live. Section 8 housing subsidies²¹ pick up rental costs over 30% of income. But there aren't enough subsidies for people with disabilities generally, and they are particularly hard to come by for people with mental illness or substance use disorders.

Policy Need: Additional subsidized housing.

In addition to efforts to enhance access to mainstream housing, mental health policy has focused on developing supportive housing²² specifically for people with serious mental illness. There are several forms of supportive housing including “supervised”, “transitional”, “permanent”, “supportive”, “supported”, etc.

The approach to providing supportive housing for people with severe and persistent mental illness has undergone considerable change over the years. The initial model was “transitional”—discharge from a hospital to a closely supervised community residence and then, when ready, discharge to a “supportive” rather than a supervised residence, (a “halfway house”) then to scatter-site apartments, and then to independent living.²³ This model has proved to be largely unsuccessful because it assumes straight line recovery, like from a broken leg, whereas many, perhaps most, people with severe and persistent mental illness experience frequent ups and downs. Periods of acute illness can result in re-admission to hospitals, loss of homes in the community, and having to start the transitional process all over again. The model also ignored the stress of moving and its impact on psychological condition. And often community residences were structured like college dorms—roommates, shared chores, etc. This is not an experience well-suited

to people who are paranoid, very shy, or—for that matter—who experience themselves as independent adults.

In response to the general failure of the transitional model, other models emerged stressing rapid movement from hospital to a **permanent** home where people could get support when they needed it and very importantly where they could return if they needed a brief stay in a hospital. Some permanent housing is in “supportive” group residences, and some is in “scatter-site” apartments.

There are issues about supportive housing for people with mental illness that are still matters of debate. For example, is it better to provide housing in “mixed-use” places, i.e., places where both people with and people without mental illness live?

Another ongoing debate is about “readiness” to live outside of a hospital. Some community residences, for example, will not admit people with a history of substance use disorder until they’ve been abstinent for 6 months outside the hospital. Such a standard of readiness effectively bars some people having a chance to live in a community residence at all. An alternative model known as “Housing First”²⁴ has proved much more effective.

There has been a similar debate about whether the goal for people with histories of, or current, substance use disorders should be lifetime **abstinence** from drugs and alcohol or limited use designed for **harm reduction**.

Since overcoming homelessness became a priority in this country roughly 40 years ago, it has been easier for people who are homeless **and** severely mentally ill to get supportive housing than for people who are severely mentally ill but live with family or “independently” in mainstream housing. There are even occasions in which people who have housing are advised to become homeless so that they can qualify for the supportive housing that is available.*

For the most part, mental health housing has been designed with physically able, working age adults in mind. As a result, it has not worked well for people with chronic illnesses that require complex medical management, such as taking multiple medications, and/or for people with physical disabilities, which becomes increasingly common as people age. For people

* This is a cruel consequence of humane concern for people who are homeless. But such consequences are unavoidable. Whenever a policy is created to benefit one type of person, people in need are left out. That is the nature of “categorical” policy.

with complex physical health needs and those who need assistance with day-to-day activities, nursing homes have been the primary recourse. So a significant number of older people are forced out of the mental health system and into the “long-term” care system, which, of course, is not generally designed for people with serious mental illness and where their care is often inadequate.

In addition, what seems on paper to be a simple move from mental health housing to a nursing home, in reality ruptures important human relationships and results in tremendous loss. There has been talk about “continuity of care” since the advent of community mental health, but that goal has proved elusive in general and particularly so when it comes to forced moves from program to program and system to system.

Policy Need: More permanent supportive housing especially using the Housing First model and especially for people with complex medical as well as mental health needs.

Although housing policy focuses on organized supportive housing, the fact of the matter is that a great many individuals live with caregiving family members including parents and siblings. **Family caregivers are at high risk for burn-out and need support** themselves, including respite, counseling, mutual support groups, and especially financial assistance. In addition to recognizing their needs, it is important to **recognize family caregivers as members of the service team**, as important or even more important in their way as mental health professionals.

Policy Need: Additional support for family caregivers.

Public Assistance Benefits

Living in a community setting rather than in an institution requires steady income to cover rent, food, clothing, a bit of fun, etc. And the transition from an institution-based to a community-based mental health system would not have been possible without a change in public assistance policy. In its original form, the Social Security Act did not provide financial assistance for people with disabilities. That changed in the mid-1950s, making it possible to discharge people from state hospitals without jobs or other sources of income to support themselves in the community. Now Social Security Disability Insurance (SSDI) provides (arguably enough) income to cover life’s necessities. This was less of a change in some states than in others because at that time some states provided some cash assistance for people with disabilities through their state general welfare programs. But it was not

until the early 1970s that the federal government underwrote Supplemental Security Income (SSI) to cover people with disabilities who were not eligible for SSDI throughout the country. Even now not all states provide general welfare benefits for single adults without children even if they are “unemployable.”²⁵

SSDI and SSI have both contributed to progressive change regarding people with disabilities including psychiatric disability. But both are also problematic in several ways including major problems (1) establishing eligibility and waiting for cash assistance to begin, (2) creating disincentives to work, (3) threats to the viability of the Social Security Disability Trust Fund, and (4) the need for the equivalent of financial guardians to help some people to control their spending.

Eligibility problems include difficulty filling out forms, getting documentation of disability, and getting through interviews that demonstrate the applicant’s incompetence. During conservative administrations, such as Ronald Reagan’s, eligibility reviews have been used to reduce the number of people receiving SSDI benefits, with disastrous consequences for a great many people who became homeless as a result.

Policy Need: Improve the process of establishing eligibility for SSDI and SSI to reduce the number of instances in which findings of ineligibility have to be reversed on appeal.

Disincentives to work are also a troublesome outcome of SSDI and SSI. If a person with a disability goes to work, they not only can lose their cash assistance, which in theory they shouldn’t need if they are working, but also their health insurance coverage via Medicare or Medicaid. Some people with psychiatric disabilities readily acknowledge that they reject work that does not provide income security or reliable health insurance coverage. As a result, various efforts have been made to eliminate disincentives to work. SSDI, for example, allows a certain amount of income without having to give up income from SSDI. People who go to work can also keep Medicare up to a certain income. And more.^{26,27}

Policy Need: Continue efforts to overcome disincentives to work.

Risks to the viability of the Disability Trust Fund also threaten SSDI from time to time. Now projected to be depleted by 2035,²⁸ Congress must make adjustments to protect the viability of the fund for the foreseeable future.

So far, such adjustments have always been made, but often at the last minute with an impending sense of crisis.

Policy Need: Stabilize the Social Security Disability Trust Fund for the foreseeable future.

Because SSDI and SSI provide monthly checks to be used to cover all expenses, individuals who do not control their spending often run out of money by the end of the month or may even be evicted due to lack of payment of rent. In my view there is nothing surprising about this. Quite the contrary, it is hard to imagine how people can resist celebrating the arrival of their monthly check with a bit of partying, a gift for a friend, or an indulgence for themselves. Pointing to their inability to live within their budget as a kind of personal flaw is, in my view, a prime example of blaming the victim. But there are people who really need someone to help them manage their finances, and it is possible for a “representative-payee” to be appointed to receive the monthly checks, pay the rent, and dole out cash. Guardianship, however, is a two-edged sword. It can be life-saving; it can also be infantilizing and interfere with the process of recovery. It can also result in “financial abuse” and/or theft. Oversight of the representative-payees is, therefore, critical.

Policy Need: Assess the adequacy and safety of guardianship and the representative-payee program for people with SPMI. Make changes as needed to preserve the autonomy of people with disabilities to the extent possible.

In addition to cash benefits, the American social welfare system provides various in-kind benefits such as food stamps, rent subsidies, heating discounts, and so on. It also provides tax credits to some people with disabilities who are working.

Policy Need: Ongoing assessment of the adequacy of social welfare provisions for people with SPMI.

Health and Life Expectancy²⁹

People with serious long-term mental illness generally have poorer health and lower life expectancy (10-25 years less) than the general population.³⁰

Policy Need: Make improving health and increasing life expectancy a major priority for people with SPMI.

The primary causes of death for this population are—as they are for others—physical diseases^{31,32}, especially cardiac conditions, cancer, respiratory diseases, and diabetes. But the differences in rates of death are associated not only with greater prevalence of physical illnesses but also with suicide³³.

Increased risks of physical illness undoubtedly reflect high rates of smoking^{34, 35} and obesity³⁶. Obesity can be a consequence of poor nutrition and lack of exercise, but also of some anti-psychotic medications. This leads to much speculation that taking these drugs to ameliorate psychotic symptoms may contribute to lower life expectancy. However, there is at least one study that concludes that consistently taking second generation anti-psychotic medications prescribed properly and in safe doses actually prolongs life because it contributes to other improvements in how people live³⁷.

It also seems likely that the higher death rate of people with serious, long-term mental disorders is related to high rates of substance misuse and to the consequences of significant periods of life on the streets³⁸, where living conditions are harsh and dangerous. People who are homeless and living with mental illness frequently suffer from physical health conditions that can become extremely serious if not treated early on.³⁹ And they are also frequent victims of physical and sexual assault⁴⁰, which can result in long-lasting physical and psychological damage. In addition, they have high rates of sexually transmitted diseases⁴¹ including being HIV+, the transmission of which is related to a combination of factors, including unsafe sexual behavior, sexual assault, and IV substance use.

It is also clear that people with serious, long-term mental disorders are less likely to get good primary health care⁴². In part this reflects the reluctance of some people with serious, long-term mental disorders to seek health care, but it also reflects the reluctance of many primary care and specialty providers to serve this population.

Lack of dental care is also a significant problem for many people with SPMI.⁴³ Losing teeth without replacement creates gaps in smiles, and many experience a sense of humiliation about their appearance.

Significant efforts are currently being made to **reduce health disparities and the mortality gap**. Most focus on improving **access to high quality health care**, promoting **integration of physical and behavioral healthcare**, and the development of “**wellness**” initiatives that focus on smoking cessation, improved nutrition, exercise, and weight control⁴⁴.

Policy Need: Expand efforts to reduce the high incidence of illness and injury among people, to increase access to good health care, and to promote wellness among people with SPMI.

In addition to improving physical health, it is important to develop more effective measures to **reduce the incidence of suicide**. People with serious mental illness, especially those with schizophrenia, are at much higher risk of suicide than the general population.^{45,46} For people with SPMI, suicide is most likely at younger ages, especially shortly after the first psychotic break, when many people experience a sense of hopelessness about ever achieving the promise that they had before they became psychotic. Therefore, efforts to provide comprehensive intervention during and immediately after the first break seem critical to the effort to reduce the incidence of suicide in this population.⁴⁷ In addition, there is widespread belief that screening for suicide risk in primary care might avert some suicides (even though there is little evidence to support this)⁴⁸ and that measures such as safety plans⁴⁹ for those who acknowledge suicide ideation can be helpful. Access to good psychiatric treatment also may reduce the incidence of suicide.⁵⁰

Limiting access to the means of suicide, particularly to guns, could reduce the rate of suicide in the United States. Guns are the most lethal means of attempting suicide, and more than half of Americans who complete suicide do it with a gun.^{51,52} In fact, recent efforts at gun control focus on background checks including a history of involuntary inpatient commitment due to mental illness and dangerousness. It may seem just a matter of common sense that people with mental illness not be allowed to own guns, but it’s really very complicated. Are people with a history of mental illness and dangerousness, mentally ill forever? Dangerous forever? And, if there is a right in this country for people to own guns, don’t people with mental

illness—the vast, vast majority of whom never are violent—have this right too?

Policy Need: Enhance efforts to reduce the incidence of suicide among people with SPMI with intensive treatment and support after the first break, with treatment for co-occurring substance use disorders, and removal of guns when people are psychotic.

Living in the Community

Living more or less independently in the community requires quite a number of skills that are unnecessary for people who live in institutions. These include maintaining a safe and clean home, shopping for and preparing food, personal hygiene, filling out paperwork to get and keep getting income supports and health care coverage, managing money, paying rent on time, managing medication, keeping appointments, using public transportation, finding and maintaining friends, participating in recreational activities, finding an accepting house of worship, and more.

In the early days of deinstitutionalization, it came as a bit of a surprise that people discharged after decades in state hospitals did not know how to manage because there was over-optimism about the promise of the new medications. But it quickly became apparent that people who had lived in institutions for long periods of time became “institutionalized” people⁵³ and suffered from losses of skills sometimes characterized as “social breakdown syndrome”⁵⁴. We learned quickly that people need help preparing to live in the community. Very quickly after that it became clear that for many people the skills they developed via training prior to discharge often did not generalize from place to place. So, a person who learned to shop in a mock super market in a rehabilitation facility might well be thrown into confusion when shopping in the super market near where they later lived in the community.

Helping people to learn to manage shopping, public transportation, social opportunities, etc. in the specific community where they lived became a significant challenge. For example, I developed a program at the Bridge in about 1975, which I called the “Community Living Program”, that included exercises in shopping in local stores, finding and going to cheap movie theatres, finding free activities, learning how to have social conversation, etc. We also put out a weekly newsletter, a what-to-do and where-to-get-it guide for people with serious mental illness who lived on the Upper West Side of Manhattan. The newsletter not only provided what we thought would be useful information but also required work skills that the members of the program might be able to use for paying work eventually.

I'm sorry to report that this was not a very successful program and even sorrier to report that according to Cochrane—the organization that identifies evidence-based practices—organized skill training programs of this kind have not worked very well in comparison to simpler approaches such as peer support groups or just getting experience.⁵⁵

Fortunately, there are community-based interventions to help people with serious mental illness to manage in the real world.⁵⁶

Policy Note: Development of community living skills is a crucial element of psych-social rehabilitation, but how to provide support and skills development best is still not clear. Continued efforts and research are needed.

Family Relationships

A great many adults with SPMI live with their family—with parents, siblings, and others who provide care and support essential for survival in the community.* In addition, many people with SPMI who live apart from family rely on parents and/or siblings for companionship, assistance navigating their worlds, and financial support.

Providing financial support can be legally tricky because it can jeopardize eligibility for governmental income supports and health insurance. Some people receiving SSDI or SSI pay rent to their parents or siblings in order to retain benefits and, of course, to provide some financial assistance to family caregivers.

Policy Need: Provide local guidance to family caregivers regarding how to negotiate the system to get maximum financial help.

Caregiving parents are commonly concerned about what will happen after they, the parents, become disabled or die. They often want to leave money for their disabled adult children as a legacy. Trusts are a common way to do this.⁵⁷ These are also legally complex, and laws vary from state to state.

Policy Need: Assure that legal assistance is available to families that want to provide support for family members with disabilities without jeopardizing entitlements.

* In addition, some people with serious mental illness live with spouses, other intimate partners, or friends but on different terms than living with a caregiving relative.

There are some organizations that help families to set up and to manage such trusts.

Family relationships are, of course, complex. Ties of affection and obligation are usually very strong. Both love and anger can run deep. In addition, there is often a struggle between the parental instinct to protect and provide care and adult desires for independence and self-reliance. Issues that arise include privacy and the right to make one's own decisions. Should patient records be confidential even from parents? Should people with SPMI have the same rights to choose or to reject treatment as people without mental illness? Should their families have a say?

Families tend to tilt in the direction of coercive interventions to protect their loved ones from themselves. Adults with serious mental illness generally want to be able to make their own decisions. The tension between protection and autonomy contributes to significant policy disputes regarding privacy, confidentiality, the right to reject treatment, etc.

These policy disputes have led to the formation of different advocacy organizations representing families of people with serious mental illness or representing the people themselves. The National Alliance on Mental Illness (NAMI), which primarily represents families, has become a major advocacy force.* A variety of groups composed of, and led by, people with histories of mental illness have become politically influential as well.

It is very important to recognize that family caregiving is extremely **burdensome** to families. Often they make personal and financial sacrifices in order to provide care. They are at high risk of stress-related physical and mental disorders—especially depression and anxiety. The family support they need is often not readily available. These needs include respite, counseling, mutual aid, and—very importantly—financial help.

Respite can either be relief for a few hours, like babysitting, or relief for days, weeks, or longer. Longer respite can be provided either by people who move into the home temporarily or in temporary community residences.

Counseling is often difficult because family caregivers are often too busy and not available when counseling is. Hopefully, the increased use of tele-mental health will help make counseling more accessible to family caregivers.

* NAMI originally represented family members almost exclusively and heavily tilted towards coercive interventions and greater use of inpatient care. Over the years it has become much more “consumer-friendly”, has many members with histories of mental illness, and has become more “recovery-oriented.”

Mutual aid support groups have proved to be very helpful. NAMI and other local organizations provide them. Again, availability can be an issue. Support groups on Zoom and the like may become increasingly helpful.

Efforts to provide financial help to families have not gone very far. Tax relief is often on progressive, rarely on conservative, political agendas. But there are some tax benefits for caregivers. Best to get expert advice on this.

One very interesting benefit that I believe has been under-used is "self-directed care".⁵⁸ This allows people with serious mental illness who are cared for by family members to designate them as their formal caregivers so that they can get paid for the work they do.

Policy Need: Expand various forms of family support, including financial support.

One final note about family relationships. Some people with serious and persistent mental illness are themselves parents and family caregivers. Many SPMI with children do not live with their children, who may be living with other family members or in foster care because the parent with SPMI is not able to provide adequate care. Some children, however, are in foster care because merely having a serious mental illness can be used as evidence of being unable to care for a child even if there has never been an episode of abuse or neglect or it is long in the past. Sadly, this leads many people with SPMI who have children living with them to avoid having their children removed.

Policy Need: Assist people with SPMI who are parents and want to raise their children to do so while also taking appropriate precautions to protect the children from abuse and neglect. This is a very tough balance to achieve. Each state should review its current polity. In addition, psychiatric rehabilitation programs should recognize parenting as a personal goal that is as important as work. Regulations governing these programs should require this.

In addition to having children to take care of, people with SPMI sometimes become caregivers for their own parents or siblings when they become disabled. Some manage this adequately; others cannot, creating considerable jeopardy to the people being cared for.

Policy Need: Provide training for adult protective services and other providers regarding appropriate intervention when disabled family members are providing care for disabled relatives.

Social and Intimate Relationships

Although there may be some people who really prefer to be alone, the vast majority of us want and need to have relationships with other people. This includes friends, intimate partners, and people with whom we have more casual, hopefully pleasurable relationships.

Having social relationships can be difficult for people with SPMI. Many have lost the friends of their childhood and adolescence, from the time in their lives before they developed visible mental illness and lost some of their social skills. Sadly, they are frequently shunned.

Developing new social relationships can be difficult in part because it requires social skills but also because people with SPMI are frequently not welcome in places in mainstream society where they might meet new people. Even houses of worship are sometimes not hospitable to people whose appearance and manner can mark them as different.

Many people develop new relationships through school or work. But most people with SPMI do not work or go to school, vastly limiting their opportunities for social engagement. Of course, those who go to programs for people with SPMI meet people there and develop what can be very important relationships.

These programs include day treatment, psychiatric rehabilitation, sheltered work (mostly gone now), and some very interesting social programs that are often called "social clubs". Some of these are simply opportunities to hang out and socialize. Some of these are "clubhouse" programs⁵⁹ that are a mix of vocational and social rehabilitation. Fountain House⁶⁰ is the original model.

For all of these programs, funding can be problematic. Day treatment⁶¹ is generally funded with Medicaid and to a limited extent by Medicare. To receive this funding day programs must meet criteria as "medical" programs. So, for example, activities in day "treatment" programs are usually referred to as "therapy"—art therapy, dance therapy, etc. The same activities in non-medical day programs are just referred to as art, dance, etc.

The need to use a medical model for rehabilitative activities in order to get funding creates problems for some programs, such as clubhouse programs, that have non-medical program philosophies.

Policy Need: Modify requirements of “medical need” to include services that are needed by people with serious mental illness but are not medical services.

The desire for social relationships leads many people into bars. People with SPMI are no exception. This can be quite problematic because the mix of alcohol and psychiatric medications can contribute to problems of physical health, to addictions, and very importantly to running out of money every month. Social club programs are in part designed to be alternatives to bars, places to go for fun without alcohol. But this is not an easy sell to grown-ups who would prefer to be in mainstream society rather than in segregated programs for people with mental illness with supervisors to oversee the programs and the people who use them.

It is important to note that the use of some illegal drugs—especially marijuana—is also part of a normal social life for many Americans. It should come as no surprise that people with SPMI use drugs as part of their social lives.

Policy Need: Revise America’s drug use policies to avoid criminal penalties for recreational use. Focus on harm reduction policies for people with serious mental illness and others.

It’s also important to note that, as it is for most people, sex is very important to people with SPMI. Unfortunately, there is apparently more unprotected sex among people with mental illness, leading to high rates of sexually transmitted diseases.

Policy Need: Licensing and accreditation requirements should include programmatic efforts to promote social life and safe sex.

As I hope is apparent, there is considerable tension between organized programs to help people with SPMI satisfy their social desires and needs and the natural desire of adults to lead normal, independent lives in mainstream society. How to mediate this tension is a huge challenge for the mental health system. One approach that has emerged over the years is the provision of dating services for people with mental illness and/or other disabilities.⁶² I have no idea whether these services are heavily used or

whether they work. And I wonder whether the dating services that are designed for the general population are helpful to people with serious mental illness as well.

Activity

For people with SPMI, as for all people, having something to do that is satisfying and/or meaningful is a key element of a satisfying life.

Work and Education: Most adults find this in large part through **work or education**, which, as I've noted, is less common among people with SPMI. But work and/or education is an important for most. Therefore, promoting work and/or education for people with serious mental illness is a key element of mental health policy. This is generally referred to as "rehabilitation" even though that word is somewhat misleading. It is true that the challenge for many people with serious and persistent mental illness is to recover what they once had but have lost due to illness, but it is also true that many the challenge is to develop skills that they have never had (sometimes referred to as "habilitation").

Rehabilitation has 3 core elements: (1) helping people to develop necessary skills, (2) arranging for or mandating environmental accommodations, and (3) providing support to help people maintain work or education.

Unfortunately, in my view, efforts to help people with SPMI regarding work or education too often focus on skills development on the assumption that the reason for lack of work is primarily lack of skills. Skills are important, but so are personality traits such as dedication to work. And, environmental adaptations and support can also help people without some skills to do their job or get an education.

Policy Note: Rehabilitation should be understood as a combination of skills development, environmental accommodations, and support.

There is also a widespread belief that people with disabilities need to be ready for work before getting a job. That way of thinking about work neglects newer ideas about "**work first**" with on-the-job skills development and supports to maintain the job.

Policy Note: Governmental support for vocational rehabilitation should give priority to programs that do not demand "readiness" for work.

Among the greatest environmental obstacles to getting and keeping jobs is discrimination against people with histories of serious mental illness. This is

largely driven by myths about unreliability and even violence, i.e., by what is referred to as “stigma”.⁶³

Because stigma is a major contributor to limited access to mainstream society, overcoming it is, and has been, a major goal of mental health policy for many years. This is difficult to accomplish because attitudes and misbeliefs about mental illness are deeply entrenched in all cultures.

There are, in my view, two fundamental ways to think about overcoming stigma.⁶⁴ One is to attempt to change widespread attitudes and beliefs that result in lack of community acceptance. Public education about mental illness is touted as a way of doing this, though its effectiveness is open to question. The other way to overcome stigma and to increase community participation is similar to measures taken to overcome racism since the middle of the 20th century. Anti-discrimination laws and regulations, for example, have forced schools and more to integrate even though racist attitudes remain entrenched.

The Americans With Disabilities Act of 1990 (ADA)⁶⁵ addressed this by outlawing discrimination in hiring. This is hard to implement in practice, but has definitely made a difference. The ADA also requires employers, and others, to provide “reasonable” accommodations to make work possible. For example, flexible work hours, time off for breaks or to go for treatment, etc. can make it possible for some people with serious mental illness to get and keep work.*

Policy Need: USE LEGAL MANDATES TO PROHIBIT DISCRIMINATION AGAINST, AND TO PROMOTE ACCOMMODATIONS FOR, PEOPLE WITH SERIOUS MENTAL ILLNESS IN WORK AND EDUCATION. ACTIVELY ENFORCE SUCH MANDATES.

In addition to efforts to overcome discrimination, there are a variety of supports that have been developed to help people get and keep work. These include some remarkable programs where job support counselors visit people at work to help them to handle the challenges on the job.

* Some employers go much further to make work possible. For example, many years ago—before there were computers—I worked at a large agency which relied heavily on statistical typists. The best typist that we had actively hallucinated and from time-to-time erupted into screaming episodes with her voices. To keep her, we built a soundproof enclosure where she could work. Then no one could hear her yelling, so she was not disruptive and continued to be a fabulous worker.

There are also mutual support groups for people with serious mental illness who have jobs and help each other manage through conversation about their experiences.

Policy Need: Include job and education support as a required element of rehabilitation programs.

Perhaps the most important development with regard to work for people with serious mental illness has been **the creation of jobs for “peers”** within the mental health system. There are peer advocates, counselors, “bridgers”, and more. Some peers have even become CEOs and other high level administrators, some have become significant players in the advocacy community, etc.

Policy Need: PROMOTE EMPLOYMENT OF PEERS IN THE MENTAL HEALTH SYSTEM.

Recreational, Communal, and Creative Activities: Of course, work is far from the only source of meaningful activity. People with SPMI can participate in all sorts of community activities from chess to exercise to politics to religious life and more.

Obviously, there are often difficulties related to access to mainstream society, some of it driven, as for jobs, by stigma (discussed above). In addition to mandating non-discriminatory access to public facilities, fundamental to opening the mainstream to people with SPMI is work with various community organizations to make room for, or better yet to welcome, people with mental illness. For example, Y’s and other community centers will sometimes open their facilities to people with serious mental illness. Some mainstream gyms also accept members with serious mental illness thus helping both to provide something to do and contributing to improved health. It is particularly important for programs serving people with SPMI to develop working relationships with houses of worship to facilitate access and a friendly reception.

Policy Need: Mental health programs should be expected to build relationships with community organizations to build access to people with serious mental illness and also to provide mental health support to these organizations.

Meaning/spirituality

For most people meaning is critical to a sense of well-being.⁶⁶ Having meaning is often identified with having a purpose. But there are many other ways to experience meaning—being useful and making a contribution, for example, or feeling that you are helpful, mean something to, or are loved by other people. Particularly important, in my view, are (1) feeling part of something larger than yourself and your immediate world and (2) a sense of a transcendent reality with which you can have a spiritual connection. So, people, including people with SPMI, find meaning in work; in accomplishment; in recognition; in connections with other people; in having a sense of belonging with communities and nations; and in transcendental experience.*

I think it's particularly important to recognize the empirical fact that both participation in religion and spirituality can make a significant contribution to a sense of well-being among people with serious mental illness, just as they can for people without significant mental illness.⁶⁷ And, for this reason, I think promoting access to organized religion can be extremely helpful to people with SPMI.

Many years ago, when I was Deputy Commissioner of Mental Health in NYS, I proposed the creation of a "chaplains without walls" program, which would have been available to people with serious mental illness living in the community. The chaplain would function like a minister, priest, Rabbi, or Iman and provide an opportunity for a religious relationship. The chaplain also would facilitate membership and belonging in houses of worship. The proposal was rejected because it was seen as violating Constitutional requirements related to "church and state". But it seemed me then, and still does, that this simply a logical part of deinstitutionalization. State hospitals, after all, have chaplains for inpatients. Why not extend it to outpatients? Of course, the principle of separating church and state makes governmental policy to support religious participation and spirituality legally very tricky. Still, I think that if a primary goal of mental health policy is to promote satisfying lives for people with SPMI, promoting participation in religion and spirituality has to be part of it.

Policy Need: The mental health system should facilitate religious and spiritual experiences and connections for people with serious mental illness.

* To describe an experience as transcendental is not to claim that there is a transcendent dimension of reality. As William James pointed out in *The Varieties of Religious Experience* at the turn of the 20th century, the **feeling** of metaphysical truth is not the same as metaphysical truth.

Formal Treatment and Rehabilitation Services

In this lecture I have emphasized what people with serious and persistent mental illness need to achieve a modicum of well-being, (known these days as “recovery”). This approach takes us well beyond the question of what formal mental health services—both treatment and support—are needed to help this population manage in the community. As I’ve said, for policy purposes I think it is very important to focus on non-clinical needs—for a place to live, for income, for health, for family and friends, for engaging activity, and for a sense of meaning. But, of course, it is also important to focus on mental health services that are provided formally—for treatment, rehabilitation, supports such as housing, case management, and more.

The combined need for treatment and support services was recognized in the late 1970’s under the rubric of the “Community Support Program” (CSP). I discussed this in a previous lecture on the history of mental health policy.⁶⁸

Each component of CSP is complex. I will merely touch on the nature of needed services and issues related to them.

Treatment includes a variety of modalities such as medication, verbal therapies, day programs, electro convulsive shock therapy (ECT), and others. Each is controversial in its own way.

Does psychiatric medication have side effects that require more caution than is commonplace? Obesity, premature death, lethargy, loss of sexual function, etc., all are potentially serious issues in the lives of people struggling to experience well-being.

Are verbal therapies effective for people with serious mental illness? Do they result in improvements in clinical condition? Do they have other value such as providing individualized support that may not be available through group oriented programs?

Are day programs preferable to clinics? Are day programs structured and financed in ways that call for patients/clients/members to spend a full day at the program most days of the week thus discouraging more individualized activities?

Is ECT safe and effective? Originally ECT often resulted in damage to memory and other cognitive functions. Extreme portrayals of the experience in films such as *One Flew Over the Cuckoo’s Nest* showed ECT being used punitively. The impression formed that ECT is very dangerous. But over the years, ECT has been refined and presumably has become safe and often effective, although in general it is used only as a last resort.

Policy Need: Ongoing review of the safety and effectiveness of various forms of psychiatric treatment.

Integrated Treatment for co-occurring severe, long-term mental and substance use disorders is more effective for the many people who have co-occurring disorders than is separated treatment for mental illness and for substance misuse. But it is rarely used.

Policy Need: Make integrated treatment a standard feature of the mental health treatment system. This requires more than coordination between the mental health and substance misuse service systems. It requires integration of the two systems at the service delivery level.

Psychiatric Rehabilitation

There are also various forms of psychiatric rehabilitation. Some emphasize skills development, drawing on the model of rehabilitation that is often effective for people with physical losses such as damaged limbs and immobility. This model is used less and less for people with psychiatric disabilities, for whom recovery often has very different meaning.

Early in the era of deinstitutionalization sheltered workshops were a popular way of providing rehabilitation for people with serious mental illness. Originally created for people with developmental disabilities who were not expected to develop additional skills, sheltered work offered something to do during the day with a bit of pay as well as an opportunity to meet people and develop social relationships. Over time many of the politically active parents of people with serious mental illness became critical of these programs because they did not offer hope for a “normal” life. They began to favor other sorts of rehabilitation programs that offered hope that their mentally ill children could ultimately have normal work lives. Sheltered workshops for people with mental illness have almost totally disappeared.

Two types of rehabilitation models emerged over time—(1) clubhouse programs and (2) individualized rehabilitation. There is some tension between the two, but both continue to dominate the field. Whether one is more effective than the other remains a matter of debate.

Policy Need: Psychiatric rehabilitation should be regarded as a critical component of a continuum of care for people with serious mental illness. Since it is not clear what forms of psychiatric rehabilitation are most effective, ongoing research about the effectiveness of psychiatric rehabilitation is a critical need.

Mental Health Housing organized for people with serious mental illness also has several forms: supportive, supported, transitional, permanent, supervised, scatter-site, mixed, etc. I have discussed issues regarding these types of housing elsewhere in this lecture.

Policy Need: In addition to continued expansion of permanent housing, research is needed about which forms of special housing provide the best long-term experience for people with SPMI.

Case Management, too, has multiple models. Some case managers help their clients to find the services they need. Some do that but also are available in times of crisis. Some provide counseling either formally or informally. Some case managers are called “care managers” and provide follow up and support for patients in clinical treatment. Some make decisions on behalf of managed care organizations about what services will be paid for.

Policy Need: Individuals who provide ongoing efforts to link people with SPMI to needed services of all kinds and to help service providers coordinate care (aka “case” or “care” managers) are vital components of a system of care. Research about, and continued refinement of, case/care management models would be useful.

“Assertive Community Treatment”: Because a significant portion of people with serious and persistent mental illness either choose not to, or are unable to, use mental health programs, efforts to reach out to and engage them where they are in the community have become recognized as a critical component of the community mental health system. The best known form of this is “assertive community treatment” (ACT). ACT teams consisting of a mix of mental health professionals meet with their clients wherever and whenever they can—in their homes, in homeless enclaves or shelters, in houses of worship, on park benches, etc. This often results in people getting a range of services that benefit them including psychiatric treatment,

individualized rehabilitation, physical health care, etc. Many agree to use service programs once they are connected with providers they come to trust.

Policy Need: Expanded assertive community treatment.

It is worth noting that the mental health system overall is built on the assumption that people with mental illness will go to settings at specified times to see mental health professionals and engage in structured mental health programs. This fundamental assumption neglects a very large number of people.

Policy Need: Reorient the mental health system overall from a place-based service system to a system that provides services in home and community-based settings. This would include shifting from licensing and accrediting facilities to licensing and accrediting service capacity.

SOME SPECIAL ISSUES

Criminal Justice: Even though estimates of the proportion of people with mental disorders who are arrested and incarcerated and of the proportion of crimes that are committed by people with mental disorders vary from study to study, there is widespread agreement that U.S. prisons and jails incarcerate a disproportionate number of people with current or past mental health conditions and that facilities are not meeting the need for treatment.⁶⁹ There is also agreement that people with serious mental illness are often mistreated at the point of arrest, pre-trial, at trial, while incarcerated or serving suspended sentences, and at the point of discharge/release. As a result, people with serious mental illness often experience an exacerbation of their condition while involved with the criminal justice system. Others develop mental disorders in reaction to their treatment. Exposure to violence, lack of freedom and dignity with regard to the most basic human functions, and such practices as solitary confinement can have a profound, negative impact on mental health.

Policy Note: Extensive reform of the criminal justice system is needed to avert its harmful effects. (I discuss this in the lecture devoted to criminal justice and mental health.)

Racial disparities: Although people of color are no more likely than Whites to have diagnosable mental disorders, they are more likely to be diagnosed with severe disorders such as schizophrenia, to be perceived as dangerous, and to be hospitalized for long periods of time. That is true even now after decades of efforts to address these well-known disparities, efforts that began

after the passage of the Civil Rights Act in 1964. Anti-discrimination has resulted in the end of racial segregation in hospitals and other facilities for the most part, but it remains true that people of color are less likely to get mental health services and also less likely to be mental health professionals, to have leadership roles, and to play a significant role in the development of the mental health system.

Policy Note: Extensive efforts are still required to overcome racism and racial disparities in the mental health system. I discuss these in more detail in the lecture on race and mental health.

Aging: The mental health system appears to have been designed on the assumption that people with serious and persistent mental illness will not survive into old age with serious mental illnesses. Some mental health planners appear to believe that most of this population will recover over time—a partial truth—while others seem to believe that they will not live long enough to need services when they are old.

As designed, housing and rehabilitation programs especially do not work well for older adults, who are (1) likely to have chronic physical conditions and/or dementia and (2) likely to have personal goals that are different from those of younger adults. The unfortunate result is that a substantial portion of older people with SPMI get moved from the mental health system to the long-term care system, especially to nursing homes and other residential facilities that are not designed to serve people with serious mental illness. In the process, they are cut off from friends and caregivers of many years as well as from service providers and programs that understand their needs.

Policy Note: The mental health system should be redesigned to take into account the needs of older adults with SPMI for physical health care, treatment for dementia, and programming responsive to their personal goals as they age. In addition, substantial improvements are needed in the long-term care system, both in residential and in day programs, to address the needs of older adults with behavioral health conditions.

AN AGENDA FOR CHANGE

Throughout this lecture I have noted needs for policy improvements to make it more possible for people with serious and persistent mental illness to lead lives that they find satisfying and meaningful. These changes include:

- Enhanced Housing
- Stabilized Public Assistance
- Improved Health and Health Care Resulting in Increased Life Expectancy
- Criminal Justice Reform
- Increased Service Capacity and Access
- Improved Quality of Care and Enhanced Integration of Services
- Increased Continuity Of Care, Especially During Transitions From One Level Of Care To Another
- Increased Outreach And Engagement Efforts
- Increased Family Support
- Enhanced Workforce Including More Extensive Use Of Peers
- Continued Efforts To Reduce Stigma
- More Extensive Efforts To Address Racism And Racial Disparities
- Modify The Mental Health Service System To Enhance Service For Older Adults With SPMI
- More Extensive Psycho-Social Research
- More Appropriate Funding Models And Increased Funding

Daunting challenges for your generation of mental health reformers.

¹ Frank and Glied *Better But Not Well*, Chapter 4.

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