# Schizophrenia in Later Life: Public Policy Issues in the United States

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Abstract: This chapter recommends a broad range of public policy changes to promote increased life expectancy and quality of life among older adults with schizophrenia and other serious, long-term psychotic conditions. Needed changes include: (1) comprehensive efforts to reduce the mortality gap, (2) securing the future of the Social Security Trust Fund, (3) expanded community housing and non-institutional residential care, (4) expanded capacity to provide high quality, integrated behavioral health and medical services as well as recovery-oriented psychosocial interventions, (5) restructuring Medicaid and Medicare to assure funding is available for psychosocial interventions—especially housing, outreach and engagement, off-site services, rehabilitation, case management, and family support—as well as for traditional treatment interventions, (6) addressing problems of capacity and quality among service providers including the VA, (7) enhancing public education and anti-stigma campaigns, (8) addressing workforce inadequacies in both size and competence, (9) increasing and diversifying research to emphasize improving services and translating evidence-based practices into practice, and (10) enhancing coordination and geriatric mental health leadership of federal and state agencies that oversee the behavioral health and other systems that serve this population.

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Without doubt, life for older adults with schizophrenia and other long-term psychotic disorders is better now than it was in the days when hundreds of thousands of old people were warehoused in state asylums. But even more than half a century after the shift from an institution-based to a community-based mental health system, this population still faces many serious problems.

This chapter is based on the premise that significant changes in mental health policy could result in improvements in the lives of older people (55+) with schizophrenia and other long-term psychotic disorders. These disorders typically have a terrible impact on both length and quality of life. People with

schizophrenia and other long-term psychotic disorders die 10-20 years younger than the general population.[1] They are likely to be disabled and to rely on public financial assistance[2] to live in the community. They are more likely to be homeless[3] or to have unstable housing[4]. Although widely feared, they are in fact more likely to be victims rather than perpetrators of violence[5], except violence towards themselves. They are far more likely to complete suicide than the general population[6,7]. In addition, they are unlikely to be welcomed in mainstream society, and this affects access to housing and good health care, job prospects, family and social life, recreational opportunities, access to houses of worship, and more.

Although the psychological condition of people with schizophrenia tends to improve over time[8], additional problems are likely to emerge as they grow older. They are at even higher risk than other older adults to have chronic physical conditions such as diabetes, cardiac conditions, respiratory problems, among others[1,9]. They may also be at slightly higher risk of developing dementia[10]. In addition, they are more likely to suffer the residual effects of hard lives that often include periods of homelessness and substance abuse.

As they age, older adults living with long-term psychotic disorders are less likely to get competent psychiatric treatment, in part because there is a tremendous shortage of geriatric psychiatrists and other mental health professionals, and in part because the side-effects and increased risk of premature disability and death associated with anti-psychotic medications make them more difficult to manage for older adults than for younger[11]. In addition, psychosocial supports for people with schizophrenia are generally designed for younger adults and not often adjusted for older adults. For example, rehabilitation programs focus heavily on vocational goals rather than goals more appropriate to older adults, such as socialization and recreation.

Most importantly, special housing programs for people with serious mental illness, which are in short supply for younger populations, rarely have the capacity to care for people with co-occurring serious, long-term physical and behavioral conditions. As a result, older adults with serious long-term psychiatric disabilities often live in facilities not suited to their needs, including nursing homes, adult homes, and various supportive housing programs designed for younger, physically healthier populations.

In addition, some older adults with psychiatric disabilities live with parents, who are likely to be very old[12] and who may be increasingly disabled

themselves, or with other family caregivers, all of whom are hard-pressed to provide needed care and who often need considerable support themselves.

Despite all these challenges, people with schizophrenia who survive into old age can lead lives that they find satisfying and meaningful. A diagnosis of schizophrenia or other long-term psychotic disorder need not doom individuals to terrible lives. The quality of individuals' lives can be better or worse, and which it is depends to a considerable extent not only on the treatment and care that they get, but also on the conditions in which they live.

Public policy matters to this, and in this chapter we will explore how changes in public policy could help people with schizophrenia or other psychotic conditions to lead tolerable lives in old age.

In the sections that follow, we will discuss policy implications related to:

- The mortality gap
- Income supports
- Housing needs
- Treatment issues
- Psychosocial interventions
- Systems coordination and leadership
- Workforce issues and
- Research needs.

## The Mortality Gap

As we noted earlier, people with serious long-term mental illness die 10-20 years younger than the general population[1]. This suggests that the life expectancy of this population in the United States is between 60 and 70 years. In our view, increasing life expectancy to about 80 years should be a major goal of geriatric mental health.

Why is life expectancy so low for people with serious long-term mental illness?

The primary causes of death for this population are—as they are for others—physical diseases[9,13], 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 suicide[1].

Increased risks of physical illness undoubtedly reflect high rates of smoking[14,15] and obesity[16] among this population. 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[12]. 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 live[17].

It also seems likely that the higher death rate of people with serious, long-term mental disorders is related to high rates of substance abuse and to the consequences of significant periods of life on the streets[18], 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.[19] And they are also frequent victims of physical and sexual assault[20], which can result in long-lasting physical and psychological damage. In addition, they have high rates of sexually transmitted diseases[21] including being HIV+, the transmission of which is related to a combination of factors, including unsafe sexual behavior, sexual assault, and substance abuse.

It is also clear that people with serious, long-term mental disorders are less likely to get good primary health care[22]. 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.

What can be done to reduce the mortality gap?

Most efforts currently focus on improving access to high quality health care, promoting integration of physical and behavioral healthcare[23], and the development of “wellness” initiatives that focus on smoking cessation, stress reduction, improved nutrition, exercise, and weight control[24].

In addition, it is important to develop effective measures to prevent suicide. Older adults with schizophrenia attempt suicide more often than the general population[25], but suicide among people with schizophrenia is most likely to take place 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.[26] Therefore, efforts to provide comprehensive intervention during and just after the first break seem critical

to the effort to reduce the incidence of suicide in this population.[27] 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[28]) and that measures such as safety plans[29] for those who acknowledge suicide ideation can be helpful. Access to good psychiatric treatment also may reduce the incidence of suicide.[30]

It also seems likely that limiting access to the means of suicide, particularly to guns, could reduce the rate of suicide in the United States.[31] Guns are the most lethal means of attempting suicide, and as such are the most common method for suicide completion, particularly among older Americans.[32]

Public Policy Implications of the Mortality Gap: What policy changes are needed to increase life expectancy of people with schizophrenia and other psychotic conditions?

- Improved access to quality health care
- Greater integration of physical and behavioral health care services
- Improved integration of mental health and substance abuse treatment
- Greater attention to the risk of suicide among older primary care patients living with psychotic disorders
- Improved mental health and substance abuse treatment, with particular attention to clinically appropriate use of anti-psychotic medications
- Improved intervention during and after a person's first psychotic break with particular attention to the prevention of suicide
- More "wellness" programs to reduce morbidity and mortality associated with physical health problems
- More extensive efforts to reduce homelessness
- Attention to the risk associated with access to firearms for people with serious mental disorders
- Redesign of the Medicare and Medicaid programs to facilitate funding of the measures noted above.

## Income Supports

Public income supports—Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Social Security Retirement Benefits, and the Supplemental Nutrition Assistance Program (SNAP), otherwise known as "food stamps"—are what make it possible for unemployed people with psychiatric disabilities to live in the community.

In general, income supports provide a subsistence level of support, which may or may not be adequate to cover housing costs that in many parts of

the country go up much faster than the annual cost of living adjustment.[33] This makes maintaining stable housing in the community difficult for many people with long-term psychiatric disabilities and undoubtedly contributes to homelessness.

Income supports are also used to pay for various forms of residential care, including: 1) community residences, 2) supportive housing, 3) senior housing, 4) assisted living, and 5) nursing homes.

Unfortunately, income supports are in jeopardy in the long-term. Social Security Disability and Retirement benefits are funded out of the Social Security Trust Fund, and, as of this writing, the disability portion of the Trust Fund is projected to be depleted in 2022 and the overall Fund in 2034[34]. In addition, SSI, SNAP, and general welfare benefits are always subject to the vicissitudes of politics.

Public Policy Implications of Reliance On Income Supports

It is widely agreed that it is critical to modify America's current Social Security system to make it financially viable for the foreseeable future. But conservatives generally argue for reducing benefits by, for example, raising the retirement age or toughening standards of disability, while liberals generally argue for increasing income to the fund by, for example, raising the cap on taxable income. Both approaches may be necessary to preserve the Fund, but compromise is politically difficult given the ideological divide in the United States today.

In addition, it is a problem that income supports are generally not adjusted for local housing costs. A change in this regard could make it more possible for people living with long-term psychiatric disabilities to maintain safe and stable housing.

## Housing and Residential Care

Stable, safe, and appropriate housing and high-quality residential care are critical for older adults living with schizophrenia or other psychotic conditions. But they are difficult to obtain.

This is an extremely complex matter because older adults with severe, long-term psychiatric disabilities live in many different settings. Some live independently. Some live with caregiving family or friends. Some get formal residential care in senior housing, supportive housing, community residences, assisted living, adult homes, nursing homes, or homeless shelters. Some are literally homeless and live "on the streets". And some are incarcerated in jails or prisons.

Independent Living: People with serious, long-term mental disorders encounter several difficulties living independently. First, it is a struggle to pay the rent when cost of living adjustments to public assistance do not keep pace with rising housing costs. Those with housing subsidies, such as Section 8, that cover rents that are over 30-40% of income[35] are protected from this, but relatively few people have such subsidies. Second, people can lose their housing if they have extended hospitalizations. Third, in-home services such as home healthcare and psychiatric services that may be necessary to be able to remain at home are often not available. Fourth, and very importantly, living independently can result in social isolation that contributes to—or is a consequence of—increasing levels of depression.

Living With Family: People with serious, long-term mental disorders who live with caregiving family and friends also may encounter difficulties remaining at home. Caregivers typically experience great stress resulting in high rates of physical and mental disorders and increased placement of disabled family members in residential care[36]. In addition, as caregivers age, they are more likely to become disabled themselves or to die, leaving the person who needs help to remain in the community without needed care. Unfortunately, Adult Protective Services, which are supposed to step in when adults cannot live safely in the community are of notoriously uneven quality and are hampered by the lack of appropriate alternatives.

Living in Supportive Settings: Older adults with serious, long-term mental disorders who live in settings that provide support or care often do not get services that they need.

Community residences and other specialized mental health housing programs are generally designed for younger adults who are physically healthy. Those who have co-occurring disorders often cannot get admitted to these facilities or, if they do, cannot get appropriate medical care.[37] This is particularly true for those who develop dementia.

Those who live in other residential care facilities such as assisted living, senior housing, supportive housing, homeless shelters, and nursing homes generally cannot get appropriate treatment for mental or substance use disorders even when they can get decent physical health care or care for dementia.

Living In Jails Or Prisons: The number and proportion of older adults in jails and prisons in the United States is rising rapidly and will continue to grow as the elder boom gathers force[38]. Although estimates regarding mental illness among incarcerated older adults vary, the rate is clearly much higher than in the general population[39]. Needless to say, they generally fare very badly.

Whether older adults with severe mental disorders and/or dementia who are not dangerous to others should serve their full terms in prisons is controversial. Those who believe that the purpose of imprisonment is punishment generally oppose early release. Those who believe that the purpose is rehabilitation and public safety generally support early release.[40]

Public Policy Implications of Residential Issues Problems

Public policy changes are needed to:

- Provide protection from eviction due to unaffordable rent increases or extended stays out of the home due to hospitalization or imprisonment
- Provide funding for renovations that are needed to live safely at home
- Modify Medicaid and Medicare to fund in-home health and mental health services
- Provide access to activities that counter social isolation including those in senior centers, social adult day care, medical day care, psychiatric rehabilitation, day treatment, and partial hospitalization
- Provide support for family caregivers including respite, counseling, support groups and tax relief
- Develop residential care alternatives that provide as much freedom and access to the community as possible while still providing appropriate care and treatment for people with co-occurring physical and behavioral disorders[*]
- Avoid incarceration in, or early release from, jails and prisons for older adults with severe, long-term behavioral disorders who are not currently a danger to society.

## Treatment issues

Most accounts of the needs of older (and younger) adults with schizophrenia or other psychotic conditions focus on psychiatric treatment and then note ancillary, useful interventions such as rehabilitation. Our view is that people with schizophrenia and other psychotic conditions need a comprehensive array of interventions including inpatient and outpatient treatment but also

[*] The current public policy assumption that it is preferable for people with disabilities to live independently if at all possible needs to be examined in light of the risks of social isolation.

including housing, income supports, rehabilitation, other community supports, physical health care, and case management.

This section of this chapter focuses on clinical treatment.

What forms of treatment help?

In this day and age of community-based mental health policy, outpatient treatment is primary. Inpatient treatment is regarded as a treatment of last resort and, when at all possible, it is provided in local, general hospitals rather than in state or private psychiatric hospitals. The treatment goal usually is to stabilize an acute psychotic flare-up while keeping the person as close to his or her community and family as possible.

This stance about inpatient treatment is controversial, with some considerable advocacy for a return to increased use of long-term hospitalization so as to reduce the number of people with serious, long-term mental illness who are homeless or who have been transinstitutionalized to adult homes, nursing homes, or prisons.[41] Advocates for community-based treatment argue in response that if there were enough outpatient treatment and housing for people with serious mental illness, there would be little need for long-term inpatient care.[42]

Unfortunately, however, there is not enough outpatient treatment. Geriatric psychiatrists, psychologists, social workers, and nurses are in short supply, and there are very few outpatient programs that have staff who are clinically competent to serve older adults with mental and/or substance use disorders.[43] As a result, treatment for behavioral disorders increasingly falls to primary care providers, who are usually ill-prepared for the job.

It is important to be clear that good treatment includes both anti-psychotic medications and psychotherapy[44] and that both require special skills for working with older adults. Prescribing anti-psychotic medications for older adults is exceedingly difficult because they require lower than usual doses to get a therapeutic effect and to avoid risky side effects such as reduced ability to concentrate, greater confusion, loss of energy, fatigue, and heightened risk of cardiac conditions and of falls, which are the largest cause of premature disability and death in older adults. Prescribers became even more wary of recommending these medications in 2008, when the FDA extended a black-box warning regarding the risk of sudden death in elderly dementia patients to all anti-psychotic medications.[45] Psychotherapy also requires special skills for older adults and, of course, more time than primary care providers have available.

The solution currently being developed is integrated physical and behavioral healthcare. There are several evidence-based models of integrated care.[46] Primary healthcare settings can routinely screen for mental and substance use disorders, provide care coordination and care management, and/or include behavioral health providers at their sites. Mental health and substance abuse centers can include physical health care at their sites. And Medicare and Medicaid are now promoting the use of complex, integrated managed care structures such as "health homes" and "accountable care organizations" through which care managers help patients with serious, complex conditions to get the help they need from a variety of community-based providers.

Barriers To Effective Treatment

In addition to limited capacity, uneven clinical competence, and the slow growth of integrated care, treatment for older adults with psychotic disorders suffers from insufficient research to develop evidence-based treatment methods. Clinical research often does not include older adults at all, and, when it does, it often rules out older adults with co-occurring physical disorders.[43] This vastly limits knowledge about effective treatment for actual older adults with behavioral disorders, most of whom have co-occurring disorders.

The quality of clinical services for older adults is also compromised because of limited cultural competence, especially the lack of bilingual providers. This will be an increasing problem in the future as so-called "minority" populations become the majority of Americans.

In addition, many older adults with schizophrenia do not get treatment at all. Low utilization is due partly to service shortages, but it is also due to problems of access. For example, many older adults have limited mobility and need either in-home treatment or good transportation, both of which are hard to obtain. But low utilization is also due to either ignorance about or reluctance to use mental health services, loosely referred to as "stigma". It is important to distinguish between ignorance about mental illness, the possible effectiveness of treatment, and where to get it on the one hand and shame or embarrassment about using mental health services on the other. Public education campaigns, which are commonly recommended, are more likely to help with issues of ignorance than issues of shame.[47]

Providers

The public mental health system consists of a variety of providers, including: (1) general hospitals, (2) community mental health and health organizations, (3) drug abuse treatment organizations, (4) state psychiatric

centers, (5) the Veterans' Administration (VA), and (6) private organizations that accept Medicare and Medicaid or that work in partnerships with non-clinical providers, especially nursing homes. All providers encounter problems related to capacity, funding, and regulation.

Funding of Treatment

Inadequate funding is often cited as a major barrier to treatment. Problems include lack of coverage, lack of parity, failure to cover non-traditional interventions such as care management, outreach and engagement, and offsite services.[48]

Coverage issues are less significant for people with schizophrenia and other long-term psychotic conditions who live in the community than for other people with mental or substance use disorders. Even before the passage of the Affordable Care Act (ACA), only 7% of this population were uncovered by the government health insurance. The vast majority (93%) were covered by Medicaid or Medicare (85%), and/or the Veterans' Administration (7%).[49] It seems safe to assume that some who were uncovered in 2010 gained coverage through the health exchanges or expanded Medicaid under the ACA (now in jeopardy). However, mostly this coverage is for medication, office-based psychotherapy, and day treatment.[50] Other forms of intervention, such as housing and case management, remain difficult to fund through Medicaid or Medicare.

Policy Implications of Problems Related to Treatment

Policy changes needed to deal with low utilization and uneven quality of treatment services for people with schizophrenia or other long-term psychotic conditions include:

- Resolution of the debate about the need for increased inpatient services

- Expanded outpatient treatment

- Building a larger clinically and culturally competent workforce

- Improved quality of care through:

    - Enhanced clinical and cultural competence of primary care and behavioral health providers
    - Increased integration of physical and behavioral health services
    - Regulatory controls, advisories, oversight, and education regarding appropriate use of anti-psychotic medications for older adults

    - Evaluation of health homes and accountable care organizations and the like
    - Enhanced clinical research regarding older adults and translation of research into practice

- Funding for outreach and engagement, for off-site/in-home services, and transportation

- Funding for care coordination and care management services in outpatient physical and mental health programs

- Full implementation of parity requirements

- Enhanced public education and anti-stigma campaigns.

## Psychosocial interventions

In addition to treatment, psychosocial interventions are of vital importance to the survival and quality of life of older adults with schizophrenia and other long-term psychotic conditions. As previously discussed, housing is most important. Other psychosocial interventions include recovery-oriented psychiatric and substance abuse rehabilitation; case/care management; assertive community treatment; programs to counter inactivity and social isolation; peer support and advocacy; wellness programs including anti-smoking and weight management; access to mainstream social, recreational, and religious opportunities; and family support. The most recent Patient Outcomes Research Team (PORT) findings also recommend supported employment—which is applicable to some but far from all older adults—skills training, and token economies for those in long-term hospital or residential care.[44]

### Recovery Oriented Rehabilitation

Various studies indicate that full recovery from schizophrenia, i.e., long-term remission of symptoms, is rare.[8,10] Despite this fact, a belief in recovery has become a powerful component of psychiatric and substance abuse rehabilitation. The concept, however, has been redefined. It no longer means "cured." Instead, it means that it is possible for people with severe mental and/or substance abuse disorders to lead lives that they find satisfying and meaningful despite the continuing to have the disorder,[51] which can include continuing to have prominent symptoms such as hallucinations and delusions.

Psychiatric rehabilitation has a number of key components: skills development, ongoing support, and environmental modifications, all of which contribute to creating places of belonging and access to mainstream opportunities.

There are many different models of psychiatric rehabilitation, some of which are reimbursable by Medicaid and some of which are not. Most emphasize vocational rehabilitation, which may or may not be relevant to older adults with schizophrenia.

Outreach and Assertive Community Treatment

Many people with schizophrenia and other long-term psychotic conditions, particularly those who have had bad experiences with the mental health system or who abuse substances, are extremely reluctant to go to formal mental health settings for treatment. For this sub-population, outreach and engagement efforts are critical. Assertive community treatment, which includes a broad range of treatment, rehabilitation, medical services and dedicated case management, is a proven method for engaging people who otherwise reject care.[52]

Access to Mainstream Society

Older adults with schizophrenia and other long-term psychotic conditions are not readily accepted in mainstream society, especially when their dress and demeanor make it apparent that they have a serious behavioral problem. It is therefore important to help people to develop appropriate social skills, but it is also important to try to build community acceptance. For example, supported employment programs work not only to prepare people for jobs but to find employers who are willing to make appropriate accommodations. Building acceptance at houses of worship is particularly important because spiritual experience and participation in a religion is exceedingly important to many people with serious mental illness, just as it is to people who are not mentally ill.[53]

Despite efforts over many years to outlaw discrimination in housing, work, and access to public places, people with severe and persistent mental illness frequently continue to feel unwanted and then withdraw or turn to organized programs.

Programs To Counter Isolation and Inactivity

There are a number of different kinds of programs that address isolation and inactivity. Many psychiatric rehabilitation programs provide places where clients can go for social interaction and activities. Clubhouses, for example, provide lifetime membership and opportunities for volunteer work and socialization.[54] Alternatively, there are psychiatric day treatment programs that also offer opportunities for socialization and activity in the guise of group therapeutic activities.

Outside of the mental health system, older people with psychiatric disabilities not infrequently are served in adult medical day care programs, which are primarily designed for people with dementia and/or physical disabilities. But placid older adults with serious and persistent mental illness often fit into these programs and can be attractive to the programs because they are all Medicaid eligible. These programs also provide medical services that can be beneficial to people with co-occurring physical and mental disorders.

Drift From The Mental Health System To Long-Term Care

There is a kind of drift from the mental health system to the long-term care system for many older adults with serious and persistent mental disorders. This drift also occurs with residential care as people move from community residences, supportive housing, and the like to nursing homes.

While in the abstract it may make sense for people to move from one system to another and one program to another, in fact it means fracturing relationships that often have lasted for years and are central to the lives of the people being shifted to new programs. This is particularly troubling when it happens towards the end of life, when program staff and clients may be the only important relationships and they may not be able to visit and spend time with their friend as s/he is dying.

In addition, long-term care programs are generally not competent treatment providers for schizophrenia and other long-term psychotic conditions. Nursing homes, for example, which are primarily funded by Medicaid, are not adequately reimbursed to cover mental health treatment as a core service. Instead, they generally have arrangements with mental health providers (individuals or groups) in private practice that bill separately for the services they provide. While some of these groups are quite good,

others are reputed to do little more than prescribe medications of questionable value and to have brief contact with patients.[55,56]

Wellness Programs

Poor health is a major reason for the low life expectancy of people with schizophrenia and other long-term psychotic conditions. Smoking, obesity, and poor physical conditioning are among the major reasons for poor health and drive up the costs of care. For this reason, wellness initiatives that emphasize smoking cessation, nutrition, and exercise have been expanding. Some of these programs are organized at local community centers, which helps to connect people who often are isolated with the mainstream. Whether wellness programs are readily available for those who also have physical limitations is an open question.

Case/Care Management

Since the late 1970s, when public policy regarding people with serious and persistent mental illness began to emphasize comprehensive community mental health systems with a broad range of community supports as the antidote to the shortfalls of deinstitutionalization, case management has been seen as the connective tissue of the mental health system. Case managers have direct relationships with clients who move among a variety of service programs and who occasionally become disconnected from service. The job of case managers is to keep them in appropriate services and to be available to provide support, especially in times of crisis.

Case management (sometimes called "care" management) is also at the core or various managed care initiatives, such as "health homes," that have emerged for people with co-occurring serious, long-term behavioral and physical health disorders.[57,58,59] This is the population most likely to experience frequent and very costly crises.

Another form of care management has proven very effective in primary care practices for patients who have been diagnosed with mental disorders and been prescribed medication. Care managers provide follow-up care that includes helping patients to adhere to treatment plans. In some cases, these care managers also provide problem-solving therapy, which is particularly effective for dealing with depression.[60]

Family Support

Many people with schizophrenia and other long-term psychotic disorders live with family members or friends who serve as their primary caregivers. Serving as a caregiver is, as previously noted, extremely demanding and stressful. Many people burn out and arrange placement out of the home—often in institutional settings such as nursing homes. Research regarding family support for caregivers of family members with dementia[61] indicates that providing family support services, such as crisis intervention, support groups, and counseling at convenient times and places results in reduced depression, anxiety, and physical disorders and delayed placement out of the home by as much as 18 months. Other family support measures include respite—both for a night out and for vacations—and tax relief to help cover the costs of having a disabled person live at home.

Policy Implications of The Value of Psychosocial Interventions

Needed policy changes include:

- Shifting Medicare and Medicaid from a medical only model for funding to include funding to support rehabilitation and recovery models of intervention

- Regulatory changes to support outreach and engagement.

- Medicaid and Medicare funding for wellness initiatives and family support.

- Tax relief for families who provide care for disabled family members

- Avoiding the disruption that occurs with the shift from the mental health system to the long-term care system due to medical complications by:

    - building capacity to manage physical health issues into mental health programs and vice versa
    - by providing continuity of relationships, especially as death approaches.

- Continuing and increasing the fight against stigma and discrimination through advocacy, political action, and litigation.

## COORDINATION OF SYSTEMS AND LEADERSHIP

A recent Government Accountability Office report noted that there are over 100 poorly coordinated federal agencies and programs dealing with behavioral health issues.[62] These include the National Institutes of Mental

Health (NIMH), Drug Abuse (NIDA), Alcohol Abuse (NIAAA), as well as the Substance Abuse and Mental Health Services Administration (SAMHSA), The Health Resources Services Administration (HRSA,) The Agency on Healthcare Research and Quality (AHRQ), the Administration on for Community Living (ACL) the Social Security Department, the Centers for Medicare and Medicaid (CMS), The Centers for Disease Control (CDC), The Department of Housing and Urban Development (HUD), Department of Justice, and more.

Because of concerns about poor coordination among these agencies, the 21st Century Cures Act of 2016 includes a provision to create an Assistant Secretary of the Department of Health and Human Services who heads SAMHSA and oversees and coordinates the efforts of the various federal agencies and programs dealing with behavioral health.[63]

There is similar fragmentation at the state level even though in many states the department that handles behavioral health is part of a larger department of health. Despite that, there are frequent failures of communication and coordination, as well as disputes between behavioral health leadership and leadership of state Medicaid agencies, public health leadership, and staff in Governors' offices, especially budget staff.

In addition, geriatric behavioral health tends to be at best an afterthought in federal and state agencies that address behavioral health.

Public Policy Implications of Issues of Coordination and Leadership

Clearly, there is a need to raise the visibility and priority of geriatric behavioral health in relevant federal and state agencies. Appointing a lead in each relevant agency at a high enough level to have some clout could help geriatric mental health emerge from the shadow of other priorities and interests. In addition, at the federal level it might be helpful to have a Deputy Assistant Secretary for Geriatric Behavioral Health in the new Office of the Assistant Secretary.

## Workforce challenges

Fundamental to developing an adequate system of care for older adults with schizophrenia and other long-term psychotic conditions is addressing the inadequate size and competence of the current workforce. There are far too few geriatric psychiatrists, psychologists, social workers, and nurses; and, this situation is not likely to improve in the foreseeable future.[43]

One frequently offered solution is to expect increasing amounts of treatment to be provided by primary care professionals—a solution that runs the risk of decreased quality of care.

Another approach, which appears to be gathering support is to diversify the workforce with non-professional staff including "health coaches and lay community health workers trained to provide screening and brief interventions for geriatric mental health and substance use disorders."[43] It is argued that this approach would also make it possible to engage more older adults and diverse groups of lay people as providers, a diversification that probably would contribute to generational and cultural competence. In addition, the use of peers as care coordinators, care managers, home visitors, and medical escorts, could be of great assistance to -professionals who are often office-bound because of the size of their caseloads and because of inadequate reimbursement for off-site services.

In addition, there are technological solutions to the workforce shortage including telemedicine and Internet based applications.[43]

Public Policy Implications of the Inadequacy of The Workforce

Needed public policy changes include:

- Enhanced efforts to recruit, educate, and train a high-quality professional workforce with incentives such as loan forgiveness
- More education regarding older adults and regarding mental and substance use disorders in professional schools
- Development of non-professional alternatives emphasizing the use of older adults and people with a history of schizophrenia or other severe mental or substance use disorder("peers")
- Modifying regulations regarding funding of telemedicine to make it more widely available
- Encouraging innovation in the use of the internet-based interventions.

## Research

Research regarding older adults with schizophrenia or other long-term psychotic disorders is not nearly as abundant as research for younger populations.[64] This probably reflects the facts that 1) historically, older

adults have been a small proportion of the American population and 2) psychiatrists and other mental health professionals have had relatively little interest in geriatric psychiatry, preferring other areas of practice and research.

Now, however, the older adult population is in the process of growing to be 20% of the American population, equal to the population of children under the age of 18.[65] The number of Americans with serious, long-term mental or substance abuse disorders will grow accordingly. It is past time for there to be as much attention to geriatric behavioral health as to other populations.

What should be the focus of future research?

This is a matter of great controversy. NIMH, which is the primary source of funding for research on mental illness, and NIDA and NIAAA, which are the primary sources of research on substance abuse, are all heavily focused on biomedical research. Pharmaceutical companies, which are also large funders of research, focus on discovering new and hopefully better patent protected medications.

It is certainly true that this sort of research has borne some fruit, but not nearly as much as has been promised over the past quarter century when major breakthroughs, or even cures, have appeared to be close at hand. Sadly, there have been no major breakthroughs, and there is very little reason to believe that there will be any time soon.

That suggests that it is time to focus more research on how to increase life expectancy and quality of life for adults with schizophrenia and other serious, long-term behavioral disorders. This would include additional clinical research on the effectiveness and safety of anti-psychotic medications, additional research on the treatment of depression in this population, additional research on the effectiveness of psychotherapy, and more.

But beyond clinical research, it is important to explore psychosocial interventions that promote enhanced survival and quality of life, including housing options, prevention of homelessness, recovery-oriented rehabilitation, case/care management, family support, and more. This should include possible preventive interventions including suicide prevention, relapse prevention, and wellness promotion.

Evidence-based findings regarding effective interventions unfortunately are not effectively translated into practice. Thus, additional research on how to move from the laboratory to the field is very important.

Evaluation of reorganized systems is also extremely important during the period where there is widespread belief that the integration of physical and behavioral health services will result in better outcomes for patients and as well as overall reduced costs. Will the new initiatives such as health homes and accountable care organizations work? Will they work for older adults as well as younger?

In addition, public education and anti-stigma efforts are high on most agendas. Whether they are effective and how they can be effective is an important topic for future research.

Public Policy Implications of Future Research Needs

- Develop a federal research plan for older adults with serious behavioral disorders that:
    - Coordinates research in various federal agencies—NIMH, SAMHSA, HRSA, AHRQ, and others
    - Rebalances research priorities by reducing the dominance of biomedical research and increasing clinical and services research, especially regarding psychosocial interventions

- Protect research funding in the Federal budget from cuts that have been proposed by the current administration.

## Summary

Promotion of increased life expectancy and quality of life should be the fundamental goals of public policy regarding older adults with schizophrenia and other serious, long-term psychotic conditions. This calls for:

1. Addressing the mortality gap via improved access to improved health care, enhanced integration of physical and behavioral health services, increased wellness activities, suicide prevention, reduced homelessness, and more.

2. Securing the future of the Social Security Trust fund and modifying income support measures to assure stable housing.

3. Expanding community housing programs and non-institutional residential care programs specifically for older adults with co-occurring behavioral and physical health conditions, including those who are homeless and those incarcerated in jails and prisons.

4. Expanding the capacity to provide high quality, integrated behavioral health and medical services to this population including both treatment services and recovery-oriented psychosocial interventions.

5. Restructuring Medicaid and Medicare to assure that funding is available for psychosocial interventions—especially housing, outreach and engagement, off-site services, rehabilitation, case management, and family support—as well as for traditional treatment interventions.

6. Addressing problems of capacity and quality among service providers including the VA, which has an infamously troubled track record serving veterans who have made great sacrifices in service to the nation.

7. Enhancing public education and anti-stigma campaigns.

8. Addressing workforce inadequacies—both size and clinical and cultural competence—through enhanced training, diversification of the workforce, and pursuing technological alternatives.

9. Increasing and diversifying research to emphasize improving services and translating evidence-based practices into practice.

10. Enhancing coordination of federal agencies and of state agencies that oversee the behavioral health and other systems that serve this population and ensuring that each system has leadership specifically regarding geriatric mental health.

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