MENTAL HEALTH POLICY IN THE UNITED STATES

MEETING THE COGNITIVE AND BEHAVIORAL HEALTH CHALLENGES OF LATER LIFE

By
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Abstract: America is aging. Over the next few decades, the proportion of older adults will exceed the proportion of children under 18, and the proportion of working age adults will decline, a major shift in the composition of the American society. As the population grows so will the number of older adults with cognitive and/or behavioral health conditions. This "lecture" provides (1) a review of demographic projections, (2) an overview of cognitive, mental, and substance use disorders in later life, (3) an overview of needed services with comments about barriers to their use, (4) an overview of the psychological conditions necessary to achieve well-being in old age, and (5) a multi-year policy agenda that can serve as the conceptual base for public policy proposals.

America is aging. Over the next few decades, the proportion of older adults will exceed the proportion of children under 18, and the proportion of working age adults will decline, a major shift in the composition of the American society.[1]

This shift raises serious concerns about the future. Will the Social Security system be sustainable? Will the health care system be able to handle increasing numbers of people in need of care? Will there be an adequate workforce to provide care for older people who need care? Will family caregivers burn out?

Unfortunately, there has not been a similar sense of concern about the challenges to mental well-being that will emerge as the older population grows.

There simply is no doubt that cognitive and behavioral health disorders among older adults result in considerable, unnecessary human suffering and premature disability and death. Dementia is the 5th leading cause of death in the United States.[2] And people with mental and/or substance use disorders are at high risk of obesity, diabetes, heart disease, communicable diseases, etc., all of which contribute to early disability and death.[3]

Cognitive and behavioral health conditions also contribute to the high cost of health care in the United States. In part the very high costs arise from the high co-occurrence of cognitive, behavioral, and severe, chronic physical health conditions.[4] In part the high costs arise from the large numbers of people with cognitive and/or behavioral health conditions who are in institutions, especially nursing homes and psychiatric hospitals. [5]

So, addressing issues related to mental well-being will be key to addressing potentially unaffordable health care costs in the United States.

This "lecture" provides (1) a review of demographic projections, (2) an overview of cognitive, mental, and substance use disorders in later life, (3) an overview of needed services with comments about barriers to their use, (4) an overview of the psychological conditions necessary to achieve well-being in old age, and (5) a multi-year policy agenda that can serve as the conceptual base for public policy proposals.

SECTION 1: DEMOGRAPHICS

Population Size: The population of older adults in America is increasing rapidly as the Baby Boom becomes the Elder Boom. It is projected that the number of older adults 65 or over will increase from 56 million to 95 million from 2020 to 2060. The population 85+ will nearly triple from 6.7 to 19 million. [6]

Population Proportion: Very importantly, the proportion of older adults is also growing and is projected to eventually exceed the proportion of children in our nation—a dramatic shift in the composition of our society. Nationally, over the next 40 years the proportion of adults 65+ is projected to increase from about 17% to about 24% of the total population. The proportion of children under 18 is projected to decrease from about 22 to 20% and the proportion of working age adults is projected to decrease by 4%.[7] This raises questions about whether there will be a large enough working population to support our children, our elderly, and our disabled.

Racial/Ethnic Mix: The proportion of older People of Color will also grow dramatically. Nationally from 2020 to 2060, the proportion of older People of Color (65+) is projected to increase from 24% to 45%,[8] heightening the challenges created by the facts that People of Color are at higher risk for dementia than are Whites[9] and that they are less likely to get treatment for behavioral health conditions.[10]

Male-Female Proportions: Currently, there are more older women than men. If the difference in life expectancy between men and women continues to decrease, this difference in the male-female mix will decline slightly. Nevertheless, it is projected that the population of people 65+ will continue

to include more women than men. The proportion of women grows with age. By age 85 there are nearly twice as many women as men,[11] heightening the risk of loss of intimacy in women's lives.

Dependence/Independence: Although the stereotypical picture of older adults is that they are dependent and in need of help to manage from day to day, in fact most older adults function relatively independently. Many work for pay or as volunteers, and it is projected that for the foreseeable future, the number and proportion of older adults working for pay or as active volunteers will continue to grow.[12,13]

But the number of older adults with disabilities and in need of help is also projected to increase. About 25% of older adults 65+ have a disability and need help with activities of daily living. Over the next two decades, this population is projected to increase nationally from about 14 million to 20 million. For those 85+, disability requiring daily help is much more common, about 60% on average and increasing with age. [14]

Again, this raises the specter of a vast shortage of workers to help older adults in need of help. And immigration policy, which has become increasingly restrictive, could make the shortage of helping workers even more severe.

However, it is possible that, as the proportion of older adults working for pay or as active volunteers increases, they may become a significant part of the future helping workforce.

Family Caregiving: Family caregivers currently provide about 80% of care for people with disabilities[15], with an annual economic value of about $500 billion.[16] Families will continue to be the primary caregivers for people with disabilities for the foreseeable future.

Place of Residence: Most older adults live more or less independently in the community. Only about 7% of people 65+ live in institutions such as nursing homes and assisted living facilities.[17] Some others live in other types of supportive care settings.[18]

Social Isolation: Currently 25-30% of older adults live alone, a number that increases with age.[19] It seems likely that a larger proportion of older adults will live alone and not to have family support due to (1) the increased number of people who never marry or who divorce after 50, (2) the growing number of older adults with no children living nearby, (3) changes in family culture regarding care of elder family members, and (4) our failure as a society to adequately address the needs of family caregivers.[20]

Of course, living alone does not necessarily result in social isolation because people may have social connections outside the home, but it seems likely that the growth of single-person households will contribute to greater social isolation and loneliness, both of which create higher risks for physical and mental illness.[21]

Use of the internet has the potential to reduce the isolation of people who live alone and are unable to get out, but older adults are less likely to use the internet than younger adults.[22]

Poverty: Approximately, 10% of older adults live in poverty, ranging from 7% for Whites to 20% for Blacks, a very significant racial disparity.[23] And people who live in poverty are at higher risk of developing dementia and/or behavioral health conditions.[24, 25]

Elder Abuse and Mistreatment and Other Trauma: 10-15% of older adults are victims of mistreatment by people who are supposed to provide care and support. Psychological abuse and financial exploitation are most common. About 2.5% of older adults suffer physical abuse. [26, 27, 28] Elder abuse and other forms of trauma, such as loss of a spouse or partner, can result in post-traumatic stress disorder and other behavioral health conditions.[29]

Veterans: Roughly half of veterans are 65+.[30] They are at higher risk for cognitive and behavioral disorders and of suicide than non-veterans.[31]

Health Status: As the Baby Boom becomes the Elder Boom, the health status of the next generation of older adults will probably change.

- A portion will be healthier than ever before and/or better able to have satisfying lives despite having chronic health conditions.[32]

- But a portion of the next generation will be less healthy, in part because there will be more people living with serious chronic conditions,[33] and in part because the current generation of working-class men 45-54 is at high risk for drug addiction, suicidal depression, and alcohol-related disorders.[34] Those who survive into old age are more likely to have chronic health and behavioral health conditions.

- It is possible, but not at all clear, that there will be shifts in the prevalence and incidence of behavioral health conditions. For example, use of illegal substances is already greater among elder boomers than the prior generation of older adults; but it is mostly marijuana, which is being legalized in more and more states. Will opioid use decline? Will suicide continue to increase? Will more people with serious mental illness survive into old age? Will depression increase? There is no way to know.

- In addition, the long-term impact of the COVID-19 pandemic on physical, behavioral, and cognitive health is unknown.

SECTION 2: COGNITIVE AND BEHAVIORAL HEALTH CONDITIONS IN LATER LIFE

Unless there are long-promised breakthroughs in the prevention and treatment of cognitive and/or behavioral health disorders or the COVID-19 pandemic or other unpredictable disasters have long lasting psychological fallout, the prevalence and incidence of cognitive and behavioral health disorders will probably remain about the same. The prevalence of dementia is about 11% annually according to the Alzheimer's Association.[35] Behavioral health disorders affect 20-25% of the population annually and 50% over a lifetime.[36]

The prevalence of cognitive disorders increases with age.[37] To the surprise of almost everyone in our ageist society, the prevalence of behavioral disorders decreases,[38] in part because of some long-term recovery from serious mental illness[39], in part because people with serious mental or substance use disorders have lower life expectancy than the general population,[40] and in part because many older adults have developed more coping skills with age.

Even if the prevalence does not change over the next few decades, population growth will result in a substantial increase in the number of people with cognitive and/or mental and/or substance use disorders in later life. Given current population projections, between 2020 and 2060 the population of people with dementia probably will grow from about 6 million to over 10 million, and the number of people with behavioral health conditions will grow from between 11 and 14 million to between 19 and 23 million.

A Heterogeneous Population: The population of older people with cognitive and/or behavioral health conditions is heterogeneous, including:

- **People with Alzheimer's disease or other dementias**

  There are various forms of dementia. Alzheimer's Disease is the most common (60-80%).[41] Dementias are characterized by memory loss and diminished cognition. They generally are "progressive" disorders that get worse over time. In early phases, people can function at nearly normal levels and be quite sociable and productive. In the mid-phase, many people continue to enjoy various activities, especially creative activities, and contact with others. Some find satisfaction in living in the moment. Others are often unhappy and frightened. Some, but far from all, develop

behaviors that are difficult to manage such as wandering or emotional outbursts.

Unfortunately, dementia is typically identified with its end stage when memory is extremely impaired, social interaction is very difficult, and help is needed for the most basic day-to-day functions.

Virtually all people with dementia also have **co-occurring behavioral health disorders such as anxiety, depression, psychosis, and/or substance abuse** at some point while living with cognitive decline. [42, 43]

There are no treatments that prevent or cure dementia although there are medications that slow the progression of the disorder for some people. Psychosocial interventions of various kinds can be extremely useful.[44]

Activity of all kinds such as exercise, participation in the arts, etc. can reduce the risk of dementia. Good nutrition, exercise, and having the good fortune to avoid severe trauma may also help.

- **People with serious and persistent mental illnesses such as unremitting schizophrenia or treatment resistant bipolar disorder or depression**

  The proportion of people with serious and persistent mental illness diminishes with age (arguably from about 1.5-2.5% of the population to less than 1%).[45] This reflects both recovery over time[46] and low life expectancy.[47]

  Because considerable effort is now underway to reduce premature deaths among people with serious mental illness,[48] this population may increase in the future.

  Schizophrenia generally begins in late adolescence/early adulthood. But there is some "late onset" (defined as after age 40).[49]

  The lives of people with serious and persistent illness are often very difficult and frequently include periods of homelessness[50] and co-occurring substance abuse.[51]

  This population is at extremely high risk for suicide; the current estimate is that over 5% of people with schizophrenia will take their own lives.[52] This risk is highest when they are young adults and experience despair in the face of the collapse of high hopes.

As the result of high rates of suicide and, mostly, of chronic, serious physical health conditions, the life expectancy of people with serious mental illness is 10-25 years less than the general population.[53]

People with serious and persistent mental illness benefit from various interventions including income supports, subsidized and supportive housing, medication and verbal therapies, psychiatric rehabilitation, case management, socialization and vocational opportunities, and peer support.

Many develop lives that they find satisfying and meaningful despite the continuation of mental illness (referred to as "recovery").[54] Some recover fully.[55]

Stable housing is critical to recovery.[56] Unfortunately, as people with serious and persistent mental illness age and develop typical chronic physical illnesses, the housing that is available to them when they are younger may become inaccessible. Many then drift into nursing homes simply because no other supportive housing is available or affordable.[57]

Similarly, older adults with serious and persistent mental illness may not be able to receive the help they need in programs designed for younger people; many then become part of the long-term care system for day care and other services. Unfortunately, long-term healthcare is not designed to meet the needs of older adults with behavioral health conditions.

- **People with psychotic conditions that develop in late life**

Some older adults develop psychotic conditions in late life.[58] These are characterized by hallucinations, delusions, inability to grasp reality, emotional lability, and sometimes behavioral problems. Such psychotic conditions are often exacerbations of minor conditions earlier in life. For example, a person who was characteristically anxious may develop paranoid delusions. Whether rooted in earlier life or not, psychotic conditions that emerge in later life may be transient, recurrent, or persistent.

Acute psychotic conditions frequently require inpatient hospitalization or some other form of protective residential care. Medication can be helpful in quelling acute symptoms. Both medication and psychosocial interventions can be useful for people whose psychotic conditions persist after acute symptoms have been stabilized.

As with all medications for older adults, dosing can be difficult and side effects, such as falls, are potentially dangerous.[59]

- **People with severe anxiety and/or mood disorders resulting in isolation, dysfunction, behavioral obstacles to living in the community, and high rates of suicide**

  Anxiety disorders are arguably more common (a bit over 11% annually) than major depressive disorders (about 6% annually)[60, 61] and include generalized social anxiety, phobias, obsessive compulsive disorder, non-psychotic paranoia, and post-traumatic stress disorder.

  Major depressive disorder—to the surprise of many—is less common among older than younger adults,[62] but minor depression and symptoms of depression that do not meet criteria for diagnosis of major depression are more common than major depression and can cause considerable dysfunction.[63,64]

  Even if minor depression is included, **depression—contrary to common belief—is not normal in old age**.

  Suicide is a critical problem among adults in later life. Between 2015 and 2019, the middle-aged population (especially those over 50) had the highest rate of any age group (about 20 per 100,000 compared to an average rate of about 14.5). Although the suicide rate of those 65+ was lower than that of middle-aged people, after 65 suicide rates increased with age. The highest rate was for white men 85 or older (48.5 per 100,000).[65]

  For older adults guns are the primary means of completing suicide (70%).[66]

  There are effective treatments for depression and anxiety in older adults, including both pharmacological and non-pharmacological interventions. Treatment of depression and anxiety disorders becomes more complicated with age (1) because the medications that are typically used to treat them can have more adverse side effects for older adults including increased rates of death,[67] and (2) because for those with cognitive impairment the usual forms of psychotherapy may need to be modified.[68]

- **People with less severe, but clinically significant, anxiety and mood disorders**

  Although older adults with mild or moderate mental disorders are generally able to "muddle through", as it were, they often suffer from considerable emotional pain and lost potential, which itself becomes a source of personal disappointment over time.

People with these conditions often can benefit from psychotherapy, especially one or another form of cognitive behavioral therapy, and/or medication,[69] but most do not get treatment.[70] When they do, it is usually from a primary care physician and of inadequate quality.[71] There is strong evidence, however, that providing coordinated care management and other forms of integrated treatment in primary care can improve the outcome of treatment.[72]

- **People with substance use problems or addictions**

Overuse of alcohol is by far the most common substance use problem (other than smoking) among adults in later life.[73] Among people 65+, alcohol addiction is uncommon, but over 15% overuse or misuse alcohol.[74] Some rely on alcohol to deal with loneliness and isolation; many simply do not realize that the body's tolerance of alcohol declines with age. Alcohol misuse contributes to of tens of thousands of premature deaths each year.[75]

Overuse and misuse of prescription painkillers is also common. Much of this is because chronic pain becomes more common as people age.[76]

Older adults 65+ are unlikely to use illegal drugs such as heroin and cocaine[77, 78] perhaps because addictions to these drugs decline with age and perhaps because of the low life expectancy of people with ongoing addiction to street drugs.

However, the use of marijuana, which is now legal in many states, is growing considerably as a recreational drug and as medication for treatment of pain.[79] Whether this is a problem is a matter of debate.

Overall, about 4% of older adults have diagnosable substance use disorders.[80] Co-occurring, diagnosable mental and substance use disorders are common, affecting about 2-3% of the American population.[81] For example, people who have major depressive and/or anxiety disorders frequently rely on alcohol and/or other drugs to quell their feelings of distress.

Gambling addiction is also a problem for some older adults.[82]

Older adults can benefit from various forms of treatment for addiction including detoxification, residential treatment, intensive rehabilitation, behavioral counseling, medication assisted treatment, "dual-diagnosis" integrated treatment, mutual aid groups such as Alcoholics Anonymous, and SBIRT (Screening, Brief Intervention, and Referral to Treatment). [83]

Whether the goal of treatment should be abstinence or harm reduction is a much-debated question.[84]

- **People with co-occurring disorders**

  Cognitive and behavioral health conditions rarely occur in isolation from other physical, cognitive, mental, and substance use disorders.

  Many people with one form or another of dementia also have other forms of dementia, which may not be discovered until after they have died.[85]

  In addition, nearly all people with dementia experience neuro-psychiatric symptoms such as anxiety, depression, or psychosis at some point while they are living with dementia.[86]

  People with mood disorders such as depression very frequently also have anxiety disorders and vice versa. People with psychotic conditions also frequently experience depression and/or anxiety.

  People who misuse substances or who have substance use disorders often also have diagnosable mood or anxiety disorders, people with mood and anxiety disorders are at high risk for misuse or abuse of substances.

  The co-occurrence of physical and mental disorders is common among older adults if only because older adults are more likely to have chronic health conditions than are younger adults.

  In addition, people with serious, long-term mental illness are more likely to have been exposed to violence, contagious disease, and difficult living conditions such as homelessness. Poor health is a common long-term outcome of their often very difficult lives.

  The co-occurrence of mental disorders with chronic health conditions increases the risk that the health conditions will result in premature disability or death.[87,88]

  In addition, the presence of a disabling or life-threatening chronic health condition frequently results in difficult emotional challenges of adaptation such as learning to live without being able to drive, demoralization, and/or a sense of profound hopelessness.[89]

  Integration of physical and behavioral health care is believed to have better outcomes than the usual approach of separating the two.[90] However, the increased reliance on primary care physicians to provide behavioral health treatment can be problematic because most physicians are inadequately trained in behavioral health care.

- **People with significant emotional distress in reaction to difficult life events**

  Much emotional distress arises from, and usually dissipates in response to, life circumstances such as illness, death of people we care about, broken intimate relationships, failures at work, and so forth. In addition, disastrous events such as economic decline, wars, natural disasters, or pandemics can have devastating psychological fallout, some of which is transient, but some of which persists over time.[91] For example, suicide rates tend to go up during bad economic times [92], and veterans who have been in battle have higher rates of depression, anxiety, substance use disorders, and suicide than the general population.[93]

  There are a variety of interventions that can help people experiencing situational distress. Psychotherapy/counseling is useful for many people; but addressing the social determinants of their distress such as economic hardship, isolation, and exposure to disease or violence may be of even greater help to relieve distress. In addition, short-term crisis intervention such as "emotional first-aid" can be very helpful,[94] particularly if it is provided in the context of other efforts people are making to weather the causes of their distress such as getting food, economic benefits, places to live, etc.[95] ("Psychological debriefing", which was a primary form of intervention until early in this century has been shown to result in increases post-traumatic stress disorder and hopefully is no longer used.[96])

  Contrary to the ageist expectations of our society, older adults are less likely to be overwhelmed emotionally by difficult life circumstances and often can be very helpful to others in their family and community.[97]

- **Developmental Challenges Of Old Age** [98, 99, 100]

  Many people experience psychological distress as they move from one developmental stage of human life to another—from childhood to adolescence to young adulthood to parenthood, etc.

  This is, of course, true of the transition from working age to old age, a transition that brings with it a number of psychological challenges. Retirement and other role changes create the challenge of finding new satisfying and meaningful roles to play. Decreasing social connections and increasing social isolation as friends and family die or move away create the challenge of dealing with grief and developing new relationships, including intimate relationships. The likely increase of chronic health conditions, often with increasing pain, creates the

challenge of tolerating declining physical ability and the growing risk of dependency. In addition, there is the ultimate challenge of making peace with one's past despite regrets and disappointments and of coming to terms with death.

Most people are able to manage these challenges more or less successfully, but for many it is not emotionally easy to do. Some develop mental and or substance use problems in the process. Some reach out for professional help, while others seek help from friends or respected family members or from leaders in houses of the worship and other community organizations.

However they do it, what's important to understand is that **most older adults find satisfaction in life despite the typical slings and arrows of aging.**

- **Family caregivers**

Family caregivers of children, adults, and older adults with disabilities are under great stress and are at high risk of developing mental and/or physical disorders, especially depression and/or anxiety disorders.[101] They frequently "burn out", resulting in premature placement of older adults with disabilities in institutions.[102]

Family caregiver support has been shown to reduce mental and physical disorders and burn-out in family caregivers.[103] This includes respite, access to supportive relationships at times and places that work for the caregivers, and providing financial assistance. Support groups can be helpful for caregivers who are able to get to them, but often they are too busy to attend. The increasing use of tele-health may make support groups more accessible.

SECTION 3: SERVICES FOR PEOPLE WITH COGNITIVE AND/OR BEHAVIORAL DISORDERS AND THEIR FAMILIES

People with cognitive and/or behavioral disorders and their families can benefit from a broad range of services including residential care, day treatment and rehabilitation, community support services, case management, and family support as well as psychiatric and/or substance abuse treatment services.

- **Long-term care**

"Long-term care" refers to a group of services for people with physical, cognitive, or sometimes psychiatric disabilities who need assistance with basic activities of daily living (ADLs). Long-term care includes skilled

nursing homes, assisted living facilities, medical day treatment, home health care, and family support services.

Most older adults can manage without substantial help,[104] but a significant number need help with basic ADLs. Since virtually all older adults prefer to remain in their own homes or to relocate to another setting in the community [105] (somewhat misleadingly referred to as "aging in place"), those who need help generally prefer to get it at home.

Although many people in need do get basic help through the long-term care system, many do not. [106] Affordability is an issue, particularly because Medicare does not cover most long-term care services.[107] Ironically, people who are poor and eligible for Medicaid get better coverage for long-term care than people who rely on Medicare or private health insurance.

Quality is also a major concern. Life in many nursing homes is grim, though some have gone through "culture change" and re-modeled to provide quite lovely living settings.[108]

Most long-term care recipients have cognitive and/or behavioral disorders. For example, behavioral health conditions affect at least half of nursing home residents[109], about 2/3 of those in assisted living,[110] and many receiving home health care.

Unfortunately, however, long-term care providers generally do not provide adequate staff training regarding dementia, behavior management, or mental or substance use disorders.

There is widespread agreement that institutional services are over-used and that expansion of home and community-based alternatives could help people live in the community where they prefer, whether in places they have been living or in settings they prefer later in life.

- **Behavioral Health Services**

  Fortunately, **there are effective interventions** for many, though not all, mental and substance use disorders in later life. For mental illness this includes various forms of treatment—medication, verbal therapies, electro-convulsive shock therapy (ECT), etc.—as well as various psychosocial interventions such as residential programs, psychiatric rehabilitation, case management, peer advocacy, etc.[111]

  Services for substance misuse include behavioral counseling, medication assisted treatment, outpatient and residential detoxification and rehabilitation programs as well as mutual aid programs such as

Alcoholics Anonymous.[112] SBIRT is a form of early intervention for substance use disorders that provides screening, brief motivational interventions, and referral to ongoing treatment. [113]

Use Of Treatment For Behavioral Health Disorders

Unfortunately, about half of older adults with mental or substance use disorders do not get treatment. Most who do get treatment for mental illness get it from primary health care providers who are poorly prepared to identify or treat these disorders.[114]

As a result, only about a third of people who get treatment receive even "minimally" adequate treatment. Fewer than 15% of those who get treatment, primarily medication, from primary care physicians will get adequate care. Only about a half of those who get treatment from mental health professionals receive adequate care.[115]

The low use of mental health treatment services[116] reflects problems of:

- Capacity: There simply are not enough clinically, culturally, linguistically, and generationally competent providers.

- Affordability: High fees and limited coverage (often with co-pays) for behavioral health services through employer-based health insurance, privately purchased health insurance, Medicare, and even Medicaid make it difficult for many people to afford treatment.

  In addition, there is a shortage of geriatric mental health professionals who accept Medicare or other forms of health insurance.

- Access: Many treatment programs are in hard-to-reach locations, have service hours that are inconvenient for many people, do not have multi-lingual capacity, etc.

  For older adults with mobility problems, going to a designated place such as a mental health clinic for mental health services can be exceedingly difficult, and there is a tremendous shortage of services in home and community settings.

  The removal of regulatory restrictions on tele-mental health services during the pandemic has improved access to treatment, but it is not clear whether this will continue after the "emergency" ends.

- Stigma, ageism, and lack of awareness about mental illness and the possible effectiveness of treatment result in reluctance to seek or

accept behavioral health services, particularly among those who are very old. Stigma is somewhat less among the baby boom generation.

- Bad prior experience with behavioral health services also results in reluctance to seek services.

- Cultural preferences for help from non-medical sources such as respected elders, spiritual leaders, etc. also result in people who might benefit from treatment not seeking it. Understanding culturally determined "pathways" to help and forming working relationships with the helpers along these pathways can facilitate engagement.[117]

Psychosocial Interventions

As noted previously, older adults with behavioral health conditions can also benefit from a variety of psychosocial interventions and community supports including supportive housing, psychiatric and substance use rehabilitation, case management, peer advocacy/support, mutual aid, and more.

These services tend to be in short supply for older adults. For example, there are very few supportive housing programs that are accessible to people with physical limitations as well as behavioral health conditions. In addition, few rehabilitation or peer support programs are designed with older adults in mind. They are geared to younger adults whose personal goals focus on education and work, not on "retirement."

Some Special Service Issues

- Racial and economic disparities:

  The pandemic has raised awareness about significant health disparities between Whites and People of Color and between people who are medically affluent and those who are largely cut off from high quality health care—including cognitive and behavioral health care. In the long-term overcoming racism and poverty will be essential for achieving health equity. In the meantime, steps need to be taken to assure that People of Color and people living without adequate income or health insurance coverage can get access to high quality care.

- Crisis Services:[118] When older adults experience a psychiatric or substance use crisis, the police are frequently called to intervene, usually uneventfully but sometimes tragically.[119] The development of crisis intervention teams staffed by mental health professionals has become a high priority.

In addition, it is widely recognized that the use of emergency rooms in general hospitals for people in psychiatric crisis can be problematic. Some hospitals have special psychiatric emergency areas, which generally improve care to some extent. Other alternatives to emergency rooms include mobile crisis teams, psychiatric crisis centers, and off-hour response by community-based providers.

Telephonic crisis services are also important. Soon there will be a national three digit number for psychiatric crisis—988—that can be used instead of 911.

- Homelessness or Inadequate Housing: Some adults in later life, particularly those with serious mental or substance use disorders, live in overcrowded, squalid, or unsafe housing or in shelters; some are literally homeless and sleep outdoors or in abandoned buildings. Although more housing has been developed over the past 40 years for people who otherwise would be homeless or on the edge of homelessness, there are still significant numbers of people who need stable housing.[120]

  In addition, there are some people with cognitive or behavioral disorders who have housing but are not able to maintain it. Lack of cleanliness can become a health hazard as can hoarding, a more widespread problem than generally known.[121] In these situations, either the local Department of Health or Adult Protective Services should step in to help. But that frequently is very difficult because of a shortage of adequately trained staff and because there are few alternative resources. As a result, nursing homes and similar institutional facilities become the only viable protective settings.[122]

- Elder Abuse and Mistreatment and Other Forms of Trauma: 10-15% of older adults are victims of mistreatment.[123, 124, 125] By definition, elder abuse or maltreatment is committed by people who have a responsibility to care for a person in need of care—family, friends, or paid caregivers. Abuse can take the form of failure to provide basic assistance with day-to-day needs. Sometimes abuse is emotional. Sometimes it involves outright assault. Often it involves financial exploitation or theft.[126]

  Older adults who have cognitive and/or behavioral health disorders are frequent victims of elder abuse or mistreatment.

  Helping victims of elder abuse can be exceedingly difficult, especially when they live with, rely on, and care about the people who are abusing them. Behavioral health intervention, for the victim or for an abuser, is complicated by the fact that treatment models are designed

for people who can make and keep relatively short appointments and who can do so safely. Elder abuse victims frequently need more time and flexibility than are offered by behavioral health providers; alternative models are needed.[127]

Trauma of other kinds is also common among older adults. Falls a great risk because they can result in severe injuries. Changes in life circumstances such as the loss of a spouse can also be traumatic.

Trauma frequently engenders significant emotional distress, but traditionally behavioral health service providers have not used a "trauma informed perspective." Much effort is underway to correct this.

- Guardianship: Some older adults with disabling cognitive or behavioral disorders are determined to be incompetent to manage their own affairs and are assigned guardians—either public or private. While this frequently works well, there are a significant number of issues that can arise ranging from anger and resentment towards the guardian to abuse or theft by the guardian. There is oversight of public guardianship arrangements, though it is often inadequate. There is no oversight of private guardianships. Assuring adequate protection for older adults from inappropriate assignment of guardians and from abuse and exploitation is an ongoing concern. It may be preferable to avoid guardianship with interventions such as supported decision-making, which preserves legal autonomy as long as possible.[128]

- Criminal Justice Issues: Older adults who have cognitive and/or behavioral health disorders are sometimes caught up in the criminal justice system.[129] If an older adult with a cognitive or behavioral disorder commits a crime, they are likely to go into the same court processes as other adults. Sometimes mental health courts or "treatment alternatives to incarceration"[130] will be available to them, but this may not be the case. They may spend time in jail pre-trial if only because people with limited resources often cannot make bail. The experience of jail or prison contributes to the development or exacerbation of mental illness and is, of course, exceedingly difficult for people with dementia. Few people with dementia at the time of their crime are incarcerated, yet many serving long or lifetime sentences in prison develop dementia while they are in prison.[131] There is a significant debate about whether people sentenced for serious crimes should be released after they develop dementia.

Funding for Cognitive and Behavioral Health Care

People with cognitive and/or behavioral disorders are quite costly to serve. The Alzheimer's Association estimates that people with dementia cost about $355 billion per year for overall health care.[132] Older people with serious mental illness and/or substance use disorders cost an additional $30 billion or so just for behavioral health services[133] and much more for their physical health care. It seems reasonable to estimate that older adults with cognitive and/or behavioral health disorders consume about 10% of overall health care spending in the United States,[134] far exceeding their proportion of the population, which is about 3.5%.[135]

Funding for their health care comes from an incoherent mishmash of public and private funding sources including Medicare, Medicaid, government grants and contracts, commercial insurance, private pay, and philanthropy. Each funding source has its own rules for eligibility for coverage, for what services are covered, and for how much is paid.

For example, Medicare pays for long-term care in nursing homes for up to 90 days. Some people have long-term care insurance to pick up the costs for a time-limited period, but most people do not. So, Medicaid becomes the primary payer for long-term care. But only people who are poor are eligible for Medicaid, forcing many people to divest of the assets and spend most of their retirement income on nursing home care in order to become eligible for Medicaid. In essence, disability creates poverty as a condition of care for disability.

It is widely recognized that funding models create barriers to care. Of particular concern are the use of a medical model and of fee-for-service.

The medical model makes it difficult to address needs related to the social determinants of the difficult lives people with cognitive and behavioral health conditions often lead. For example, some people enter nursing homes because they do not have a non-institutional place to live that would be far less costly, but historically Medicaid would only pay for a nursing home, which is a "medically necessary" service. It would not pay for housing. Fortunately, this is now changing and under some circumstances Medicaid treats housing as medically necessary.

Another example: it is often clear that family members and friends need financial support to be able to handle the caregiving responsibilities they take on voluntarily, but that is not regarded as a medical need and therefore is not covered via health insurance. (One exception to this is that people with disabilities who are eligible for Medicaid can designate a family member or friend to be a paid home health care provider.)

So, it gets wildly complicated, with special provisions being devised to get around the standard of medical necessity. But by and large that standard defines what care will be paid for.

Another fundamental issue with regard to funding is reliance on the fee-for-service model of payment. Generally, this model is perceived as creating an incentive to provide more service than is needed because providers get paid for providing services. One popular alternative is capitation, but this sometimes creates an incentive to provide less service than needed, because providers get paid a flat rate for a period of time and do not get paid more if they provide more services.

Over the past few years, there have been vast efforts to restructure how health care is funded by creating incentives for providers to provide only needed services. For example, accountable care organizations are structured to share savings from prior year costs between providers and payers. In addition, there are efforts being made now to pay on the basis of outcomes rather than on the basis of care provided. This is far easier said than done, and when it comes to people with chronic, progressive diseases it is not at all clear what a successful outcome would be.

In Sum: The availability, quality, and funding of services for people with cognitive and/or behavioral disorders is a matter of ongoing concern.

SECTION 4: ACHIEVING WELL-BEING IN LATER LIFE

Cognitive and behavioral health are not just avoiding or overcoming cognitive, mental, or substance use disorders; they also are essential for achieving well-being in old age. This is referred to with many terms including "aging well", "successful aging", "healthy aging", "active aging", "creative aging", and more.

Later life is widely viewed as a time of winding down. People approaching retirement are finishing their work lives, enjoying (perhaps) an "empty nest", and—hopefully laying the groundwork for a tolerable life in old age.

Old age—in our ageist society—is widely seen as a bleak time in life especially as health becomes compromised. In fact, however, most older adults are satisfied with their lives despite some decline in health and in basic abilities.[136]

It is, therefore, **critical to focus not only on slowing or preventing the typical declines of old age but especially on achieving satisfaction despite them**.

Well-being in old age depends fundamentally on having satisfying relationships and engaging in pleasurable and meaningful activities. It is also correlated with having certain personality traits, including having a positive attitude, optimism, adaptability, and resilience.[137]

Achieving well-being depends on meeting the developmental challenges of old age**,** which, as previously noted, include (1) finding alternative sources of satisfaction and self-esteem after retirement and changes in family roles, (2) finding new sources of meaning, (3) coping with losses of family and friends, (4) tolerating and adapting to diminished physical and mental capacities, (5) living with chronic illnesses that often result in persistent pain and sometimes in disability, (6) learning to accept increased dependency if necessary, (7) reconciliation with one's past, and (8) coming to terms with mortality.[138]

Well-being in old age fundamentally means being at peace with oneself. This includes (1) having a sense of authenticity, (2) accepting the life one has lived despite inevitable regrets, remorse, and disappointments, (3) finding sources of pleasure, and (4) for many older adults finding opportunities to continue to be productive, to make a contribution, and to feel meaningful. For some people, this is achieved through new family roles, such as grandparenting. For others, it is achieved through paid work or community activities as volunteers. For some it is achieved through artistic activities, continuing education, and the cultivation of personal skills ranging from golf to poetry. For many, it is found through spiritual experience.[139]

What most people dread about old age is dementia, the subjective effects of which are largely misunderstood. Most importantly, it is important to understand that people with dementia can experience satisfaction.[140]

This varies from one stage of dementia to another. In early stages some people continue productive activity and meaningful relationships with people. Some, of course, experience considerable emotional pain, especially sadness and fear, and some become behaviorally difficult. But these are frequently problems that can be effectively dealt with, resulting in relief from emotional pain and sometimes improvements in functioning. Some people in early and mid-stages actually become more affectionate, open, and creative than they were earlier in life.[141]

People with dementia in the middle and end stages frequently get considerable personal satisfaction from creative arts, especially visual art and music.[142] In general, even though people with dementia may have starkly limited memory, the satisfaction of being in the moment can be considerable.

Importantly, it is possible for society to take actions to promote well-being in old age. Reducing social isolation is particularly important,[143] as are opportunities for paid and volunteer work, safe spaces for exercise, and access to continuing education and creative activities.[144] Promoting healthy lifestyles earlier in life can contribute to well-being in later life.[145]

The development of "age-friendly",[146] "livable", [147] and "dementia-friendly" [148]communities will be key to supporting successful aging in the next generation.

SECTION 5: COGNITIVE AND BEHAVIORAL HEALTH POLICY GOALS

With the elder boom already well-underway, it is long past time for our nation, states, and local communities (1) to respond meaningfully to population growth, (2) to adequately address the cognitive and behavioral health problems of late life, and (3) to promote opportunities to achieve psychological well-being in old age.

Broad policy goals include:

- **Community Integration ("Aging in Place")**

  Provide supports to enable older adults with major cognitive and/or behavioral health disorders to remain in, or return to, the community and avoid institutionalization. Needed supports include:

  - Safe and supportive housing alternatives to institutions
  - Additional community and home-based cognitive and behavioral health services
  - Improved health care for people with serious cognitive or behavioral disorders
  - In-home healthcare and ADL supports
  - Family caregiver supports (see below)
  - Criminal justice reform.

- **Address Ongoing Neglect of the Long-term Care System**

  The limited quality of congregate care facilities and shortage of services and support to help older people to remain in, or return to, the community reflect the failure of our society to invest in an adequate long-term care system. It is time for our nation and state to assure that appropriate, high quality long-term care is available for people with disabilities who are in need of basic assistance and that their family caregivers get the support they need and deserve. This includes:

- Improving Quality in Nursing Homes and Assisted Living Facilities by:

  - Supporting "culture change" to improve quality of life in institutions
  - Providing adequate cognitive and behavioral health services in nursing homes and assisted living facilities
  - Providing staff training regarding cognitive and behavioral health
  - Generally upgrading the quality of staff
  - Increasing oversight and accountability.

- Improving behavioral health services in adult medical day care.

  In addition to the individuals with dementia and physical disabilities they were designed to serve, adult medical day care programs increasingly serve those with serious and persistent mental illness who have "aged out" of a mental health system designed for younger adults. Medical day care programs need to enhance behavioral health services and to train staff regarding this population.

- Enhancing in-home services for older adults with cognitive and/or behavioral disabilities by training home health staff

- Enhancing family support: This includes respite, access to supportive relationships at times and places that work for the caregivers, and financial assistance.

- Enhancing personal planning to meet long-term care needs: People with dementia frequently do not have enough advanced warning that they will need substantial help over time and often do not know who to turn to for help developing their plans for the future. Early identification of dementia and future care planning should become routine elements of long-term care.

- Improving linkages between the long-term care and behavioral health "systems": It is common for people to "age-out'' of the mental health or substance abuse systems because it is not designed to meet the changing needs of people as they age, particularly in day programs and in residential services. As a result, a significant number of people drift into the long-term care settings—especially nursing homes and adult medical day care—without any coordination between the two systems. There are opportunities for collaboration that would improve care for older adults.

- Creating incentives for the purchase of private, long-term care insurance

- Improving public education about cognitive and behavioral disorders and about long-term care options.

- Addressing laws and regulations that often force people into poverty in order to get coverage for long-term care.

- **Increase Behavioral Health Services for Older Adults** including:

  - Increasing service capacity to keep pace with population growth and to fill unmet needs. This includes addressing the workforce shortage and inadequate funding for service growth.

  - Enhancing access to services including:

    - Making services affordable
    - Preserving the use of tele-health services after the "emergency" period related to the pandemic
    - Providing more services in home and community settings
    - Increasing linguistic competence
    - Expanding outreach and engagement services

  - Addressing high priority problems such as suicide and opioid addiction and overdose deaths.

- **Improve the Quality of Behavioral Health Services for Older Adults**

  Overall, the quality of behavioral, physical, long-term healthcare, and aging services is inadequate. Improving quality of care requires:

  - Enhancing integration of behavioral, physical, and long-term healthcare and aging services

  - Increasing "generational" and cultural competence in all service systems

  - Enhancing the clinical expertise of both the professional and paraprofessional workforce

  - Increasing the use of "evidence-based" practices

  - Improving psychiatric crisis services

  - Improving responsiveness to elder abuse and other forms of trauma

  - Increasing harm reduction approaches to substance abuse

- Reviewing and revising the licensing and accreditation requirements and enhancing inspection and enforcement

- **Workforce Development**

  The workforce that addresses the physical, behavioral, and long-term healthcare needs of older adults is simply too small to meet current need, let alone to keep pace with the increasing percentage of older individuals in the general population. Building a clinically and culturally competent workforce of adequate size requires:

  - Massive efforts at recruitment, retention, education, and training

  - Workforce diversification that expands the roles of paraprofessionals, makes greater use of "peers", and uses older adults both as paid and volunteer staff.

  In addition to shortages of professional providers, there are increasing problems recruiting and maintaining the paraprofessional workforce due to the declining proportion of working age adults and low pay and poor benefits and working conditions.

  In addition, the paraprofessional workforce is in jeopardy due to restrictive changes in immigration policy. Having an adequate workforce in the future will require opening immigration appropriately.

- **Increase and Re-Balance Research**

  Progress in meeting the needs of people with cognitive and/or behavioral disorders depends heavily on the outcome of research. In recent decades research has focused primarily on seeking the organic roots of these disorders and developing medications to prevent and/or cure them.

  While there has been some progress in biomedical research, hope for breakthroughs, which have been promised for 30 or more years, has largely been frustrated. Nevertheless, a heavy tilt towards investing research funds into biomedical research continues.

  In the meantime, despite limited investment, other forms of research have paid some dividends. Clinical research has identified some medications that are somewhat effective for mental and substance use disorders, though not for dementia. Services research has helped to identify psychosocial interventions that help. Systems research has led to imaginative innovations in the structure and financing of service delivery systems. Translational research has helped to promote the use of

evidence-based practices. Epidemiological research has pointed to useful directions for improving practice and helped guide policy developments.

Unfortunately, research specifically about older adults with behavioral health issues has not been prioritized and thus has been limited. It has also been complicated by the fact that research about behavioral health tends to exclude people with significant physical health conditions, making it difficult to find older research subjects and to learn about real life older people. It is critical to invest more in research about older adults with behavioral health conditions and with co-occurring physical and behavioral health disorders.

Research regarding dementia in older adults and about their family caregivers has been much more robust, but it is heavily tilted towards biomedical research in the hopes of a breakthrough. This has resulted in debate between those who support this approach and those who are concerned about the millions of people and families who will suffer from dementia before a biomedical breakthrough takes place.

Achieving an appropriate balance in both dementia and behavioral health research is an ongoing challenge.

- **Provide Public Education And Improved Experience With Services**

  Stigma, ageism, and ignorance about cognitive and behavioral health, its treatment, and how to find resources are major contributors to low utilization of behavioral health services. Public education is needed to reduce stigma about the use of behavioral health services and to combat ageism.

  Information and referral services are also critical to helping people find the services they could benefit from. The establishment of 988 should help to make information easier to find.

  While there is a great deal of information available on-line and in print, much of it is not designed to reach people who are poorly educated or who get information by other means, such as from culturally rooted TV and radio. How to reach the people in greatest need effectively is an important challenge.

  In addition, many people reject services because of bad prior experiences. Understanding and improving the patient/client experience is critical to promoting greater willingness to use cognitive and behavioral health services.

- **Address Social Determinants of Behavioral Health Problems**

  Although dementia and some behavioral health conditions have organic roots, social and economic circumstances contribute to emotional distress and to the struggles many people have when they have dementia or serious mental illnesses. Addressing such circumstances, known as "social determinants", may help to reduce the incidence and prevalence of some illnesses. It certainly can relieve some of the suffering caused by poverty, inadequate health coverage and care, poor housing, social isolation, and systemic racism.

  "Upstream" interventions are important for people with cognitive and serious behavioral disorders and their families. These include:

  - Assuring adequate income and fighting against threats to the Social Security Trust Fund
  - Providing affordable health and behavioral healthcare through adequate health insurance coverage, reasonable prescription drug pricing, and other means
  - Assuring safe and stable housing
  - Reducing social isolation
  - Reducing racism and discrimination.

  Fighting efforts to reduce Social Security or Medicare is critical to helping people manage cognitive and behavioral health disorders.

- **Address racial and economic health disparities**

  The pandemic has made the fact of economic and racial disparities unavoidably obvious. Improving access to cognitive and behavioral health services for those who are relatively poor and for people of color needs to be a priority for future efforts to improve care.

- **Address Cognitive and Behavioral Health Disparities**

  In addition, people with cognitive and/or behavioral disorders suffer disparities that are inadequately addressed. Most obvious is the dramatically low life expectancy of people with serious mental illness. This reflects the hard lives many of them lead, especially those who are or have been homeless. It also reflects the high co-occurrence of substance use disorders. It reflects their high rates of suicide. It reflects high rates of social isolation. And it may reflect the physical side effects of their psychiatric medications, such as obesity, diabetes, and heart disease.

  Addressing the health disparities that affect people with serious mental illness also needs to be a priority for the future.

- **Promote Well-Being in Later Life**

  Despite ageist beliefs, it is possible to achieve well-being in old age. It is important for both the public and the private sectors to contribute to successful aging through assistance with pre-retirement preparation, contributing to adequate retirement income, helping older adults avoid social isolation, and by supporting opportunities for older adults to play meaningful social roles.

  "Age-Friendly"/"Livable"/"Dementia Friendly" Communities are the key to supporting successful aging.

- **Promote Readiness of the Public and Private Sectors**

  Responding adequately to the growing population of older adults with cognitive and/or behavioral health problems calls for significant actions in both the public and the private sectors.

  Government needs knowledgeable leadership with clear responsibility for addressing the needs of this population. Because necessary services and supports will inevitably span several levels of government—federal, state, county, and municipal—and several fields of practice—physical, behavioral, and long-term health care as well as aging services—it is necessary to establish cross agency planning and coordinating structures with the power to bring about change.

  In addition, the private sector will need to enhance employer-based and private market health insurance, affordable long-term care insurance, volunteer and paying work opportunities, retirement planning, and family support.

- **Data-driven, multi-year planning**

  It will be particularly important for the public sector to engage in **data-driven, multi-year planning**.

  Unfortunately, epidemiological research currently falls far short of the needs for information of the kind that can identify gaps in healthy aging. Major improvements in public health "surveillance" are needed to monitor the status of cognitive and behavioral health including the full range of behavioral health conditions and the degree of satisfaction/happiness/well-being experienced by older adults.

  In addition, data regarding service need, utilization, and cost are scattered in various data bases if they exist at all. Each state should

develop a "**data dashboard**" that collects available data in forms that can be used for planning the service system of the future.

I have taken steps in this direction with a compilation of relevant national data. [149]

- **Improve Finance Models and Funding**

  Improvements of the magnitude outlined here will require increased spending on services, research, and administrative activities. However, increases in funding should be accompanied by increased transparency and accountability. It is particularly important to know how much is spent on services, on research, on prevention and health promotion activities, on administration, and on oversight and enforcement. It is also important to know the outcomes of services.

  It is also important to implement financing models that will improve practice and outcomes of care. The office/facility-based, fee-for-service reimbursement model that has dominated healthcare finance for over a century is now in flux. The emphasis is on developing finance models that result in improved outcomes. For older adults, it is important for financing methods to support:

  - Integrated service delivery
  - Coordinated care management and similar structures in primary care
  - Home-based services for people with mobility/transportation problems
  - Tele-health services without the restrictions that were in place prior to the emergency provisions adopted for the pandemic
  - Greater use of documented best practices
  - Increased innovation without facing bureaucratic nightmares
  - Incentives to enhance the workforce

  It is particularly important to find ways to promote continuity of treatment and care from pre-65 to 65 and over, which is often extremely difficult because of the transition from private insurance or Medicaid for working age adults to Medicare at the age of 65.

  The lack of coordination of insurance is particularly problematic for people who have both Medicare and Medicaid. The "dual-eligibles" are often not eligible for innovative funding structures developed either for Medicare or for Medicaid—but not for both.

  The past several decades witnessed massive experiments with financing and organizing health care including managed care, capitation, medical homes, accountable care organizations, all-payer systems, global budgets, and coordinated care management structures. Whether these

designs result in the improved health outcomes or cost savings they promise is open to question and calls for careful review.

Action Now

The cognitive and behavioral health problems faced by older adults are daunting**,** but the need is great and growing. The first half of the elder boom is already in the past. If this is not the time to take on these issues, when will it be?

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