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COGNITIVE AND BEHAVIORAL HEALTH IN LATE LIFE: POLICY CHALLENGES AND CONTROVERSIES

A Presentation to
The Division of Geriatric Psychiatry and Neuropsychiatry
Johns Hopkins School of Medicine
October 7, 2022

I am grateful to Gwenn Smith for inviting me to organize a series of presentations on geriatric cognitive and behavioral health policy. She did that, I think, because I so often ask presenters at these Friday Noon meetings what the policy implications of their research are. This is a question I urge all of you to ask about your research, which very often has implicit policy implications that are worth making explicit.

Today I will provide an overview of policy issues. Quincy Samus, a member of the faculty who also chairs the Maryland Council on Alzheimer's Disease and Related Disorders, will make a presentation next week (October 14) on the Council's recent recommendations. On October 21, Gary Kennedy, who is Director of The Division of Geriatric Psychiatry at Montefiore Hospital in NYC, will report on research related to hoarding. And on October 28, Thomas Cudjoe, from the Department of Geriatric Medicine, will talk about social isolation and needed policy changes to address it.

Today I will provide a brief overview about major policy challenges related to the cognitive and behavioral health needs of older adults. My observations will be from 50,000 feet above the ground. There are a horde of policy issues on the ground or, as we sometimes say, in the "weeds". I will not say much about those issues today. Secondly, I will suggest an arguable agenda for policy change, and then I will make some observations about several major policy controversies. Finally, I will provide a bit information about the Ad Hoc Group of Experts on Geriatric Cognitive and Behavioral Health, which is co-chaired by Kostas Lyketsos and myself and includes several members of the Hopkins faculty. Let me or Kostas know if you'd like to join us.

(1) Geriatric Cognitive and Behavioral Health Challenges

In our ageist society there is widespread belief that serious mental decline is inevitable as people age and that older people are unavoidably a burden on

society. That is not true. Most older adults do not have cognitive or behavioral disorders. But there certainly are reasons for concern. About 1 in 10 people 65 and older have some form of dementia, most likely Alzheimer's disease. At 85 and over, it's approaching 4 in 10.[1] In addition, about 1 in 7 [2] (the NIMH estimate) or perhaps 1 in 5 [3] (the CDC estimate) of older adults have mental illnesses such as anxiety disorders, mood disorders, or psychosis. 1 in 25 suffer from addiction,[4] and as many as 1 in 5 misuse alcohol and medications.[5] And, many older adults experience emotional distress in response to challenging life circumstances such as the pandemic, social isolation, economic instability, racism, poor health, the need to adapt to common changes in old age, etc. Troubling emotional responses—which unquestionably increased during the pandemic—include grief, loneliness, demoralization, stress, agitation, and more. All of this contributes to a host of problems, including personal and familial dysfunction, premature disability and death, avoidable institutionalization, high rates of suicide, and very high costs of care.

So serious mental problems are a significant risk in later life, but—to say it again—far from inevitable. In fact, mental well-being is more common than mental disability. The numbers make this clear. If 10% of older adults have dementia, 90% do not. If 20% of older adults have mental disorders, 80% do not. If 5% suffer from addictions and 20% from misuse of alcohol and medications, the vast majority do not. It is important to understand that older people are not just people who need help; many of us can provide help, who can make significant contributions to our families, communities, and nation.

Nevertheless, the consequences of poor mental health* are significant. Dementia was the 7th leading cause of death in the United States in 2020[6]. Prior to the pandemic it was 5th. Research about the burden of various diseases in the US concludes that "neuropsychiatric" disorders are the leading cause of disability, accounting for nearly 20% of all years of life lost to disability and premature mortality. [7]

Mental and substance use disorders ("behavioral health" conditions) also can be dangerous, resulting in illnesses and injuries that contribute to premature disability and death. For example, people with serious mental illness die 10-25 years younger than the general population, in large part because they have high rates of obesity, diabetes, and heart disease.[8] Depression contributes to high suicide rates among older adults, and suicide is now the 11th leading cause of death in the United States.[9] It was 10th prior to the pandemic. Anxiety contributes to social isolation and rejection of help. Misuse of alcohol often leads to illnesses and accidental injuries, especially

* Unfortunately, the term "mental health" has come to refer to a limited subset of problems and disorders of the mind. When I use the term, I am sometimes referring to that subset and sometimes more broadly to any and all problems of the human mind whether developmental, cognitive, psychiatric, or substance misuse.

falls and automobile accidents, which can result to premature disability or death. Between 2015 and 2019, there were about 140,000 alcohol related deaths per year.[10] Misuse of illegal substances and the policy of criminalization contribute to homelessness, the over-population of prisons, the spread of contagious diseases, disruption of work and family life, violence in the home and in the community—especially in poor communities of color—and more.

In addition, cognitive and behavioral health conditions, because they can be disabling and often co-occur with significant physical illnesses, are major drivers of the very high health care costs in America. This includes the costs of long stays in hospitals due to medical complexities, the costs of high use of emergency rooms, and the costs of long-term residential care. Investing in improving the cognitive and behavioral health of older adults can improve health outcomes and help to contain health care costs at the local, state, and national levels.

For all of these reasons, it is very important to address the needs of those people who do experience mental problems in old age. It is all the more important because **America is aging rapidly**.[11] Over the next few decades, the proportion of adults 65 and older will come to exceed the proportion of children under 18—an historic first.[12] And as the number of older adults grows from approximately 56 million today to more than 95 million in 2060, so will the number of older adults with cognitive impairment, mental and/or substance use disorders, developmental disabilities,[*] and emotional distress. Unless there are long hoped for breakthroughs in treatment and in preventive interventions, the number of people with dementia will grow from about 6 million to about 10 million. The number of people with mental illnesses will grow from about 10 million to about 20 million. And the number of people with substance use disorders will grow from about 5 million to about 10 million.[**]

The United States is **not prepared to meet the challenges of supporting mental well-being in older adults.** The services that are currently available in the health, long-term care, mental health, substance use, developmental disabilities, and aging services systems **fall very short of meeting the need** and are **dysfunctionally fragmented**. Many older people are **not able to live where they would like to live**, whether the family home or a retirement community because they cannot get the services and supports that they need. Recent studies document that **people**

[*] People with developmental disabilities, who used to have a life expectancy no greater than 40, now have a life expectancy just a bit lower than those without developmental disabilities.

[**] These numbers are calculated by applying prevalence estimates to the Census Bureau's population projections.

with cognitive impairment living in the community have a **range of unmet needs** including "**neuropsychiatric behavior management**, **caregiver support**, daily/meaningful activities, safety screening", and more.[13] Those living **in nursing homes and assisted living** facilities often **get inadequate treatment** for cognitive and behavioral health disorders, which are highly prevalent among residents in these facilities**.[14] Fewer than half of older adults with mental or substance use disorders get any treatment at all**[15] because of **limited service capacity and access**. (These are not the same thing although they are often lumped together.) As a result, treatment for mental illnesses is too often provided by **primary care physicians without adequate training or by mental health professionals without geriatric expertise**.[16] According to the NCS-R, overall, only about 1 in 3 people who get treatment get even "minimally adequate treatment."[17] And very importantly, **systems of care are plagued by racial and economic disparities** in prevalence of disorders, access to care and treatment, and rates of death.

The challenges are particularly great for certain high risk populations including:

- **Black and Latino older adults,** who are more likely to have dementia than their White counterparts and less likely to get the treatment they need for behavioral health conditions.[18]
- **Women,** who outlive men and are increasingly likely to experience social isolation as they age and who are more likely than men to develop cognitive impairment or mental illnesses.[19]
- **People who are poor or struggling with economic insecurity**, who are more likely to experience symptoms of anxiety and depression, to misuse substances, and to develop cognitive impairment than are affluent populations.[20,21]
- **People with disabilities** (about 25% of older adults), who according to CDC "report experiencing frequent mental distress almost 5 times as often as adults without disabilities".[22]
- **Family caregivers,** who frequently experience anxiety, depression, and burn-out[23]
- **People in nursing homes or assisted living**, who commonly have poorly treated behavioral health conditions as well as dementia[24]
- **People who are socially isolated and/or lonely**, who have a 50% increased risk of dementia and higher rates of depression, anxiety, and suicide[25]
- **Victims of trauma/abuse**, who are at higher risk of anxiety (including PTSD) and of depression.[26]
- **People who are LGBT+**, who report the highest levels of distress in response to the pandemic[27] and have higher rates of anxiety, depression, and substance use disorders.[28]

- **Veterans**, who have high rates of anxiety disorders, such as post-traumatic stress; depression; substance use disorders; and suicide.[29]

The unmet cognitive and behavioral health needs of older adults are daunting, particularly during this period of rapid population growth—the "elder boom". But the opportunities to experience mental well-being in later life are also great. So the advocacy agenda needs to include a combination of care and treatment of cognitive and behavioral problems and the promotion of psychological well-being.

Here is an arguable action agenda for policy changes that will contribute to improved mental well-being for older adults.

(2) An Action Agenda for Improved Policy Regarding Mental Well-Being In Late Life

- Provide services to enable older adults with cognitive or behavioral health conditions to **live where they prefer**, generally in the community rather than in institutions. (This is often misleadingly referred to as "aging in place".)

- **Improve long-term care** including nursing homes, assisted living, and home and community-based services.

- **Enhance support for family caregivers.**

- Increase cognitive and behavioral health **service capacity** to keep pace with the growth of the older population and to address current shortfalls.

- Enhance **access to care** particularly with **extensive use of telehealth** and **increased outreach and engagement** efforts such as ACT teams**.**

- **Improve quality of care and treatment** emphasizing clinical, cultural, and geriatric competence in service design and delivery.

- **Increase and improve** the professional and paraprofessional workforce in primary care, long-term care, behavioral health, and aging services.

- **Enhance integration of care** within and between service systems—dementia care, behavioral health care, primary care, long-term care, and aging social services.

- Address **social "determinants" of behavioral health** such as racism, poverty, and social isolation.

- Address **racial and economic disparities**

- **Increase "preventive" interventions** so as to reduce the incidence of cognitive and behavioral disorders, relapse, institutionalization, and suicide

- **Promote mental well-being in old age** via assistance preparing for retirement, the empty nest, maintaining and developing new relationships, finding engaging activities, living with chronic illness, tolerating dependency if necessary, achieving reconciliation with one's past, and dealing with mortality.

- Improve **public and professional education**.

- Develop a better balance between biomedical and other forms of **research**, including epidemiological, clinical, and systems research

- Improve **epidemiological data** and develop a publicly accessible **data dashboard** for planning purposes.

- Increase and redesign **funding** to meet the needs of older adults.

(3) <u>Controversies</u>

A hell of an agenda! And, as I noted a few minutes ago, it is an arguable agenda. In fact, there are huge controversies about how to improve policy to promote mental well-being in older adults. Here are a few of the bigger issues.

- What has been the psychological fallout of the pandemic on older adults? Will it continue, get worse, or dissipate after the pandemic ends? Resilience or persistent emotional distress?

- Is it generally preferable for older adults to live independently in the community or does this often lead to isolation and unhappiness? Should there be more emphasis on developing high quality residential services using the Greenhouse model and the like?

- Should cognitive and behavioral health services and research tilt towards the biomedical or the psychosocial? Currently, they tilt heavily towards the biomedical. It is particularly striking that the primary goal of the National Alzheimer's Planning Advisory Council[30] is to find a cure or surefire preventive intervention by 2025. Many of us, who are skeptical about this "moonshot" approach, believe that it results in the neglect of millions of people who need care and treatment now.

- Should the focus of policy be mostly on the provision of care and treatment, as it is now, or on life satisfaction? The treatment perspective emphasizes the need for more and better care and treatment for mental conditions. The perspective of life satisfaction leads to greater attention to such basic needs as housing, income, medical care, avoiding social isolation, engaging in meaningful activities, etc.

- Did deinstitutionalization go too far? There is an ideological dispute within the mental health community about the shift that began in the 1950s from institution-based policy to community-based policy. Has this resulted in inadequate care for people with serious mental illness, too many of whom are homeless or in jails and prisons? When applied to people with dementia, does it result in excessive efforts to keep people in the community, where they are often cut off from other people and from engaging activities?

- Is there a need for more psychiatric hospital beds, especially for long-term beds? Limited capacity of inpatient care and backups in emergency rooms lead many to argue for adding hospital beds and extending lengths of stay. But others argue that if there were more community-based services, including residential services, additional hospital beds would not be needed.

- Is there a need to change criteria for involuntary inpatient and outpatient commitment? Again, some argue that current standards of dangerousness are too stringent and that many people are allowed to make choices that have dreadful consequences. Others argue that people with mental disorders have rights and that the hazards of liberty are the unavoidable price we pay for freedom. Similar questions arise about when people with dementia should no longer be permitted to make decisions for themselves.

- Should there be greater integration of medical model geriatric cognitive and behavioral health services with aging services? Both hospital-based and freestanding psychiatric services are generally provided separately from social services with reliance on referrals or, at best, care coordination. Do we need new models to integrate programs?

- Is tough regulation the best way to press for improvements in care and treatment? Consumer advocacy organizations tend to advocate for more extensive regulation to deal with shortfalls in quality of care. Providers tend to argue against unfunded mandates and the creation of bureaucratic regulatory requirements that interfere with providing good care.

- Guns are used in 70% of suicides among older adults vs. 50% for the general population. Should gun control be a key element of geriatric mental health advocacy? For some the answer is obviously yes. For others the issue is too political and/or beyond the legitimate scope of mental health professionals.

- Does early diagnosis of dementia have harmful consequences such as increased suicide ideation and rates of completed suicide? Several studies indicate that this is the case,[31,32] but others indicate that knowing that one has dementia helps people to make plans for the future.[33]

- To what extent should the geriatric mental health agenda focus on the so-called "social determinants" of mental health. One question is whether to call them "social drivers" or "social contributors" rather than "social determinants", since they don't in fact *determine* anything. More important is the question of how much time and effort mental health professionals can put into addressing large social issues like racism, poverty, community violence, etc. Are these issues beyond their responsibility?

- Should overcoming racial and economic disparities in systems of care be the number one priority of policy today?

- What images should be used in doing advocacy for improved policy regarding cognitive and behavioral health? For example, there is a debate about whether to take advantage of the widespread erroneous belief that people with serious mental illness are violent and dangerous in order to argue for more resources. There is a similar question about how to portray people with dementia—as dysfunctional people sliding into inevitable helplessness or as people who have continuing capabilities who decline slowly over time but who can experience satisfaction and make familial or even social contributions before reaching the end stage.

- Given the limited state of our knowledge, should more effort be put into preventive interventions? Do we know enough to make investments that will pay off in reduced incidence and prevalence of cognitive and behavioral disorders? And to what extent should the mental health professions focus on the promotion of well-being in addition to providing care and treatment?

- Is the current division of mental problems and interventions in separate and distinct fields with very limited communication, coordination, and cooperation a dysfunctional way of conceptualizing the broad arena of mental well-being? Given the vast co-occurrence of cognitive, mental,

substance use, and developmental problems should we attempt to shift from multiple "silos", as they are called, to greater focus on the unity of the human mind, to "one mind" policies. [34]

- There are also questions that verge on the metaphysical but are really questions about what to fund with the limited resources provided for health care. Are many of the mental and emotional problems of old age really diseases or just the normal vicissitudes of aging. For example, is sadness and loss of hope when nearing death a major depressive disorder or an ordinary human reaction?[35] And which of these problems should Medicare, Medicaid, and commercial insurance cover?

- Currently financing experiments based on managed care and profit sharing are underway with the noble goals of cost containment, improved access, improved quality, and reduced disparities. Are they working? Should we return to simpler fee-for-service structures?

Policy and Funding

This brings me to what I believe is the single most important thing to know about policy. **There is no real policy without funding, just rhetoric and empty promises**. Want to improve policy? Have a brilliant idea? Always ask: how much will it cost, who will pay for it, where will the money come from, and how will they pay.

(4) The Ad Hoc Group of Experts

During the Legislative session in 2021, Kostas and I gathered a few members of the faculty at Hopkins to support a proposal for the state of Maryland to develop a cognitive and behavioral health plan. To everyone's surprise the state budget included a planning mandate, with a deadline 6 months out to provide a report to the General Assembly including an assessment of the cognitive and behavioral health needs of older adults in Maryland and a plan to address them. We worked closely with the staff member in the Department of Health who was assigned to write the report, and to our surprise again, a report was delivered to the General Assembly before the end of October 2022. That report did a pretty good job of identifying need but, as it acknowledged, fell short with regard to developing a substantive plan because there was not enough time or resources to get the job done. The report asked for resources to do it. In addition, a preliminary effort was made to establish an interagency task force to develop the plan. That process was slowed by the demands of the 2022 legislative session, but it began with training provided by Susan Lehmann on behalf of our Ad Hoc Group. She did a magnificent job. But progress has ground to a halt (1) because we were not successful in getting the funds

needed to develop a plan, (2) because of staff shortages, and (3) because the election has overshadowed pretty much everything.

While we were pressing for the development of a cognitive and behavioral health plan, the Department of Aging released a draft 4-year plan to address the needs of older adults in Maryland. It contained little about dementia and other cognitive impairments and nothing about behavioral health conditions—mental and substance use disorders. We advocated—unsuccessfully, I'm afraid—for greater attention to cognitive and behavioral health in the aging plan. The current leadership of the Department does not see that as part of their responsibility. This is something we will return to when a new administration is in place.

During this period, the ADRD Council, which is chaired by Quincy Samos, who will report about it next week, issued a draft document to which we responded by noting that the draft inadequately addressed the fact of the very frequent co-occurrence of cognitive and behavioral health disorders. The final report included many of our suggestions.

Subsequently, the state supplemental budget added $3.5 million on a non-recurrent basis to implement recommendations of the ADRD Council. We have weighed in with our suggestions, which emphasize using the new funds as seed funding for projects that will generate ongoing funding. We do not yet know what decisions have been made.

In addition, because the report to the General Assembly regarding a geriatric cognitive and behavioral health plan called for a review of advisory councils in Maryland relevant to geriatric cognitive and behavioral health, we have written a draft report about the councils with recommendations for changes to their mandates and improvements in their communication and coordination with each other. It is our hope that there will be a thorough review of the councils once the new administration is in place.

So, the Ad Hoc Group has been busy and anticipates more such work in the coming year. Again, please let me know if you'd like to participate.

Let me end where I began by encouraging you to ask what the policy implications of your research are and by encouraging you to take on research that would help to resolve the controversial issues I noted earlier. Policymaking, as I'm sure you know, is more political than rational, but research can make a difference.

Thank you for attending today.

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