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## MEETING THE COGNITIVE AND BEHAVIORAL HEALTH NEEDS OF OLDER ADULTS IN MARYLAND

A Presentation To
The Asian American and Pacific Islander Committee of AARP Maryland
By
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Thank you for the invitation to speak to you today about cognitive and behavioral health in old age. I am particularly looking forward to the conversation I hope we will have after my remarks.

To prevent myself from talking on and on, I have divided my remarks into 12 points. And, with apologies, I'm going to read them to you so that I don't ramble into a digression that I might find more fascinating than you do.

1. As the older population grows about 30% in Maryland over the next 10 years and grows far more over the next few decades so will the population of older adults with cognitive or behavioral health problems.

About 25% of older adults per year (50% in their lifetimes) have

- cognitive impairments such as dementia,
- mental disorders such as depression and/or anxiety,
- substance use disorders and other addictions, or very commonly
- combinations of these.

(It is worth noting that Asian-Americans are less likely to have cognitive and/or behavioral disorders than other racial groups.)

In addition, many older adults have difficult emotional reactions to life circumstances such as the pandemic, poverty, racism, community or family violence, disappointments in love or work, illness, loss, social isolation, etc.

And almost all older adults experience some emotional struggle while coming to terms with the vicissitudes of the aging process, which include

role changes such as retirement,

- losses of family and friends,
- diminished physical and mental abilities,
- the increased likelihood of disability, and
- the inevitability of death.
- 2. Contrary to oversimplified reports of survey findings, older adults as well as younger people have suffered from the psychological fallout of the pandemic. Older adults are a bit less likely to experience symptoms of depression and anxiety than younger people in part because they are survivors and in part because they have developed coping skills with age. But they are more likely to come face-to-face with mortality, to grieve the loss of people they care about, and to become socially isolated. The pandemic was particularly difficult for older adults in nursing homes or assisted living facilities, where social isolation was often extreme and death commonplace. In addition, older adults have needed to deal with difficulties regarding access to food and medication, and they have had to adjust to new supportive roles as grandparents.

So, like younger people, older adults have needed help to deal with emotional distress during the pandemic.

- 3. Cognitive and behavioral health disorders have serious consequences for older adults. In addition to avoidable mental suffering, this includes
  - High family burden
  - Overuse of institutions
  - High suicide rates
  - Higher risk of health complications and of premature disability or death
  - Very high overall health care costs
- 4. Some populations are more vulnerable than others. High risk populations include:
  - Family caregivers
  - People of color
  - Women
  - People experiencing economic instability
  - Socially isolated people
  - People with disabilities including cognitive and/or psychiatric disabilities
  - Victims of abuse or other traumas
  - Veterans
  - Lesbians, gay men, those who are non-binary, and especially transsexuals, who have experienced the highest level of emotional distress during the pandemic.

- 5. Older adults, as well as younger people, are **un**likely to get adequate care and treatment.
  - Fewer than 50% of older adults with behavioral health conditions get treatment at all and this varies by race. People of color are less likely to get treatment than are Whites. Asians are by far the least likely to get treatment.
  - Most get it from primary care physicians who, over 85% of the time, fail to provide even minimally adequate treatment.
  - Older adults with dementia typically do not get a diagnosis as early as possible. And studies done here in Maryland indicate that they have substantial unmet needs for daily meaningful activities, for improved physical health care, support of their family caregivers, and for "neuropsychiatric behavior management" among other things.
- 6. Inadequate care has complex causes. Some people cannot get care because of inadequate service capacity due to workforce shortages and inadequate funding. Some people cannot get care because of limited access to care due to unaffordable cost, limited hours and locations of service, language barriers, and more. And some people do not seek, or reject treatment, due to denial of mental illness, a sense of shame or embarrassment, bad prior experiences with the providers of care and treatment, or preference for culturally-based alternative sources of help.
- 7. In addition, to problems getting treatment, the unfortunate fact is that quality care is usually less than "minimally adequate" because of limited clinical, cultural, and geriatric competence and because of overreliance on primary care physicians who are not appropriately trained.
  - In addition, so-called "systems" of care are fragmented. I.e., they suffer from poor communication and very limited coordination and cooperation.
  - Fragmentation is exacerbated by the organization of policy and programs into separate fields, often called "silos", for "Alzheimer's Disease and dementia", for "mental illness", and for "substance use disorders". These silos exist despite how commonly disorders co-occur. For example, over 95% of people with dementia will also have a mental or substance use disorder at some point along the way.
- 8. Cultural incompetence and racial health inequities have become particularly critical problems because (1) the population of people of color is growing rapidly; they will be the majority of the American population in roughly 20 years and (2) because of racial and ethnic health disparities that have always existed have been made unavoidably obvious during the pandemic.

Cultural competence is easy to call for but far from simple to achieve—for several reasons. (1) Cultures are complicated. What are typically identified as single cultures—Black, Latino, Asian, etc.—are not. For example, there is no Asian culture or language; there are Asian cultures and languages. In addition, (2) cultural competence cannot be achieved just by matching color/race/ethnicity, nationality, or language or providers and recipients of care and treatment; there are issues of class, education, political belief, etc. as well. And (3) cultural competence is not just clinical; it is systems competence as well, including the participation of people of color in the power structure of America's systems of care—ranging from promotion to supervisory and management positions to board membership to governmental leadership.

9. On the more positive side, it is important to note that much is known about how to provide care and treatment for people with cognitive and/or behavioral health conditions effectively. There is no cure for dementia despite hopes of breakthroughs, but much is known, if not adequately used, about psycho-social supports for people with dementia and their families. For behavioral health conditions, there also have not been long promised breakthroughs. But there are psychotherapies as well as medications that can help. Very importantly, the expansion of telehealth during the pandemic has made services far more accessible. In addition, we know that coordinated care management in primary care practices vastly improves the outcomes of treatment by primary care physicians. Use of this and similar integrating structures seems to be spreading as primary care practices become larger and more diverse.

In addition, we know that a healthy lifestyle, staying connected with people one enjoys, and staying active do help to prevent illness, deterioration, and disability.

- 10. We also know that, contrary to the ageist perspective of our society, psychological well-being is not just possible; it's usual. Not only can older people achieve considerable personal satisfaction; they can be, and are, contributors to society. Older adults are not, as the ageist perspective has it, only people in need of help; they are people who can give help. Promoting psychological well-being, promoting lives of connection, engagement, belonging, and meaning, can result in a vastly stronger society.
- 11. To address the cognitive and behavioral health needs older adults, AARP of Maryland and other organizations have been advocating for a multi-year, inter-agency plan that draws from sound data regarding demographics, epidemiology, service provision, and financing.

A primary goal of such a plan is to assure that cognitive and behavioral health services **keep pace with population growth**, which, as I said earlier, is projected to be 30% for older adults in Maryland in the coming decade alone—an average of 3% per year.

Beyond keeping pace with population growth, the plan needs to address a daunting range of issues.

Perhaps most important is helping older people with cognitive or mental disorders to live where they prefer, usually in the community, by providing increased support their family caregivers and housing alternatives to institutions. This is often referred to, somewhat misleadingly, as "aging in place".

It is also critical to move past 50 years of talk to real **improvement of** the full array of **long-term care** services including nursing homes, assisted living, and home and community services.

Helping older adults with cognitive and/or behavioral health problems also requires increasing both the **capacity** of and **access** to home and community-based services. **Sustaining tele-health** services after the pandemic is critical to this.

**Improving** the **quality** of both community-based and institutional services is also a key goal. It is especially important to build a larger and more clinically, culturally, and geriatrically competent behavioral health and long-term care **workforce**—paraprofessionals as well as peers. This should include the use of older adults themselves as treatment and care providers. Improving quality also depends on **overcoming fragmentation** and enhancing integration of physical, cognitive, and behavioral health services and of health and aging services.

A comprehensive cognitive and behavioral health plan also needs to improve **public education** and address stigma, significant misunderstanding of cognitive and behavioral health disorders, and widespread ignorance about why and how to seek services.

A comprehensive plan also needs to address **social determinants** of behavioral health disorders, including social isolation, economic hardship, food insecurity, dangerous living conditions, and systemic racism

Ultimately it will be important to re-organize how services for people with cognitive and/or behavioral health disorders are financed so that **funding structures** align with service needs.

And all of this will depend on having the data to do "data-based" planning. We are recommending the development of a transparent "data

**dashboard**" that can be used by policy makers as well as advocates and journalists.

12. There has been progress. The General Assembly included a mandate in the 2021 budget for the Departments of Aging and of Health to submit a report that includes an analysis of the cognitive and behavioral health need of older adults and an assessment of Maryland's response to the need as well as a multi-year plan. The departments' report noted substantial unmet need and called for completion of a substantive data-driven plan. The report also suggested a review of existing councils and advisory groups on aging, behavioral health, and long-term care and establishing the expectation that they all will pay attention to the cognitive and behavioral health needs of older adults. None of them currently does that. Some focus on behavioral health, but not among older adults. Some focus on aging but not on behavioral health issues. Some focus on cognitive decline, but not on behavioral health issues that arise in the lives of people experiencing cognitive impairment.

Will the report to the General Assembly lead to needed improvements? Not without investment in management personnel who can do the heavy lifting that will be needed to translate dreams into realities. And not without investing public and private resources into the development of a "data dashboard". And, most importantly, not without investment in service growth and redesign.

We sought \$250,000 this year to provide the resources just to develop the plan. It was NOT provided. But \$3.5 million was added to the supplemental budget for Alzheimer's Disease and related disorders. What it will be used for was not specified, but we expect that some will fund a Director of Brain Health Services for the state.

So, there has been progress. But **without ongoing advocacy**, the recommendations included in the report will become little more than a bunch of digits languishing in a cloud. We need continuing advocacy for a substantive plan and for real change.

We hope that your organizations will join the ongoing advocacy effort. If you would like to help, please contact me at <a href="mailto:mbfriedman@aol.com">mbfriedman@aol.com</a>.