



October 26, 2017

Acting Secretary Eric Hargan
Acting Assistant Secretary John R. Graham
U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation
Strategic Planning Team
Attn: Strategic Plan Comments
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Washington, DC 20201
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Dear Acting Secretary Hargan and Acting Assistant Secretary Graham:

Thank you for the opportunity to provide input on the draft 2018-2022 HHS Strategic Plan. Please note: this public comment letter reflects my own views based on more than 20 years of professional experience in dementia policy and working with many thousands of affected individuals, but does not purport to speak for the views of LEAD Coalition member organizations.

The draft HHS Strategic Plan rightly focuses on improving quality of life and the nation's healthcare system for all Americans – from people living with chronic diseases to caregivers, children to older Americans, consumers to members of the workforce. Many of the objectives and strategies listed in the draft Strategic Plan align well with the LEAD Coalition's focus on accelerating transformational progress in: (1) care and support to enrich the quality of life of those with dementia and their caregivers; (2) detection and diagnosis; and (3) research leading to prevention, effective treatment, and eventual cures. However, there are opportunities for the draft Strategic Plan to be more specific about strategies for diversity in clinical trials and research as well as strategies for improving quality of life among people with Alzheimer's disease and other forms of dementia including vascular disease, Lewy body dementia, and frontotemporal degeneration.

HHS should finalize and work toward implementing the following draft Strategic Plan objectives and strategies, which would have a positive effect on detection, treatment, quality of life, and research on Alzheimer's disease and other forms of dementia:

Objective 1.1: Promote affordable health care, while balancing spending on premiums, deductibles, and out-of-pocket costs

- *Strengthen informed consumer decision-making and transparency about the cost of care:* Test new payment models on alternative approaches to end-of-life care that incentivize patient and family-centered preferences, while respecting religious beliefs and moral convictions, and promote programmatic payment and quality of care options for advance care planning in support of the physician/patient relationship.
- *Incentivize quality and value-based care:* Promote the application of proven clinical preventive services for high impact risk factors and early stage disease detection, through federal guidelines, quality measurement, and partnerships with accrediting organizations, including faith-based and other community organizations.

Alzheimer's and other forms of dementia are among the most expensive diseases facing our nation, both in terms of out-of-pocket personal expenses and burden on the Medicare and Medicaid programs. These diseases will cost the U.S. approximately \$259 billion in 2017.ⁱ Objective 1.1 is an important tool in ensuring that people know their diagnosis at a time when they are most able to make informed and productive choices about current and future care; the objective also promotes more affordable and higher quality care.

Objective 2.1: Empower people to make informed choices for healthier living

- *Promote healthcare access and reduce health disparities:* Develop and disseminate the use of culturally and linguistically competent, accessible approaches to reduce healthcare costs, improve quality of life, and reduce disparities.
- *Ensure people have the information they need to make healthier living choices:* Increase awareness of the importance of healthy lifestyle behaviors among patients and caregivers for risk reduction of chronic conditions and other illnesses, including for those with or at risk of Alzheimer's disease and other dementias, across the lifespan.
- *Expand access to healthier living supports:* Support patient, consumer, and caregiver involvement in care planning, as appropriate, to ensure that care is person-centered, responding to the needs and wishes of those being served, including their religious or conscience needs and wishes.
- *Ensure people have the information they need to make healthier living choices:* Develop tools and resources that improve health department and healthcare setting efficiency in providing education, training, and quality assurance for screening, treatment, services and prevention messages.

Objective 2.1 addresses a number of profoundly important challenges within the dementia community. African Americans are twice as likely to develop Alzheimer's disease than non-Hispanic whites and Latinos are one and a half times as likely to develop the disease as non-

Hispanic whites; roughly two-thirds of people with Alzheimer's disease are women. Additionally, there is strong emerging evidence that disparities in various social determinants of health may impact risk of developing dementia. Nearly all people with dementia have multiple co-morbid chronic illnesses; whether there exists a causal or merely correlative relationship, people at risk for or living with dementia would be far better off if they either prevented or were better able to manage diabetes, vascular disease, and other serious health challenges. Such amelioration of co-morbidities also would reduce significantly both health system utilization and expenditures.

Objective 2.2: Prevent, treat, and control communicable diseases and chronic conditions

- *Support early detection and treatment of communicable and chronic diseases:* Increase access to a core set of clinical preventive services including immunizations and screenings, especially for underserved populations.

As noted in response to Objective 2.1, most people living with dementia have co-morbid conditions; additionally, the cognitive and functional decline inherent in progression of diseases causing dementia also make people living with these conditions more susceptible to communicable diseases. Therefore, Objective 2.2 is of particular importance in meeting the health needs of people living with dementia and in reducing avoidable burden on health system utilization and expenditures.

Objective 3.4: Maximize the independence, well-being, and health of older adults, people with disabilities, and their families and caregivers

- *Strengthen community living supports:* Develop age- and dementia-friendly livable communities to improve quality of life for older adults, families, caregivers, people with disabilities, and the larger community.
- *Improve quality and availability of long-term services and supports, including home and community-based services (HCBS):* Identify opportunities to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers.
- *Reduce disparities in services for older adults and people with disabilities:* Include culturally appropriate, person- and family-centered care planning in federal social and healthcare services for older adults and persons with disabilities to protect individual choice and address a person's current and future economic resources, including advanced care planning needs.
- *Strengthen supports for caregivers:* Expand the availability of, and access to, supports for unpaid family caregivers, to maximize the health and well-being of the caregivers and the people for whom they provide care; Identify research gaps in caregiving and optimize sharing of research findings.
- *Strengthen the workforce:* Educate the healthcare and service professional workforce on the concerns of a geriatric population to ensure awareness of the unique challenges and issues of older adults; Improve and increase competency in the healthcare and direct service workforce in person-centered approaches and cultural competency; Strengthen

the training and capacity of healthcare providers to recognize, assess, refer, connect, and engage caregivers.

Objective 3.4 is poised to capitalize on a number of existing and emerging public-private partnerships (PPPs). For example, Dementia Friendly Americaⁱⁱ is a public-private partnership uniting the power of more than 35 national organizations, resources from a number of federal agencies including grants from ACL, and the on-the-ground capacity of community-based organizations in nearly every state to more effectively support and serve those across America who are living with dementia and their family and friend care partners. Similarly, a strong PPP is guiding both ongoing implementation of the CDC's The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013–2018^{iii,iv} and development of its 2018-2023 Road Map.^v Objective 3.4 also has tremendous capacity to highlight and better address the often distinct challenges and needs of people with intellectual and developmental disabilities who develop Alzheimer's disease or other forms of dementia and of their formal and informal caregivers.

Objective 4.3: Advance basic science knowledge and conduct applied prevention and treatment research to improve health and development

- *Invest in research to reduce the incidence of the leading causes of death:* Support research to prevent the leading causes of death in adults by improving the quality and specificity of reporting causes of death, developing systematic studies and testing interventions to determine and prevent the actual causes of death, thereby increasing both life expectancy and quality of life and reducing healthcare costs.

As detailed below, Alzheimer's disease and other forms of dementia are among the nation's top 10 leading causes of death (and significant under-reporting occurs due to stigma and gaps in understanding by some medical professionals), and alone among the top 10 as having no proven means of prevention, disease-modifying treatment, or cure. While the science is daunting and research funding remains inadequate to the scope and scale of the disease cost, progress is being made and more is on the horizon thanks to significant application of new resources by NIH at the direction of Congress over the past several years. It would be helpful if the HHS draft Strategic Plan specifically noted that Congress requires that NIH annually submit to the President and then to Congress a professional judgment budget estimating "the additional funding, above the base for Alzheimer's and related dementias, needed to effectively treat and prevent these disorders by 2025. The estimate – often referred to as a 'bypass budget' because it is presented without modification through the traditional Federal budget process – also summarizes NIH-funded research and promising research opportunities."^{vi}

While the overall draft Strategic Plan is strong and contains a number of objectives particularly important to the dementia community, the draft Strategic Plan also suffers from some important omissions, particularly in Objective 2.2 and Objective 2.3. Objective 2.2 focuses on preventing, treating and controlling communicable diseases and chronic conditions and specifically calls out measures for diseases like HIV/AIDS, all strains of hepatitis, heart disease and COPD. Objective 2.3, meanwhile, focuses on early detection, prevention and

recovery of mental health disorders and substance abuse. Neither objective mentions Alzheimer's disease or other forms of dementia. **Alzheimer's disease and other forms of dementia should be included in both objectives.** According to work led by the Gerontological Society of America, cognitive impairment in older Americans is severely under detected.^{vii} Timely and accurate diagnosis of dementia – when communicated clearly, compassionately and with referral to community based services – gives the adult and their family or caregiver the opportunity to receive educational resources, support and other services that may lead to improved health-related outcomes and quality of life for the person with dementia and those around them as the disease progresses; it also creates optimal conditions for the diagnosed individual, family members and other caregivers to volunteer for research studies.^{viii}

Furthermore, the draft Strategic Plan should include more objectives surrounding disparities and diversity in clinical trials. African Americans, for example, are less likely to participate in Alzheimer's disease clinical trials than non-Hispanic whites, but nearly twice as likely to have Alzheimer's disease.^{ix,x} To help break down barriers to research participation, HHS should add Objectives to the draft Strategic Plan to:

- Prioritize development of evidence-based interventions that align with population-based health care delivery, that improve care of people with dementia, and that protect the physical and mental health of unpaid family or informal caregivers.
- Prioritize reimagining the status quo clinical trial recruitment and retention system that is unacceptably slow, uncertain, expensive, and burdensome on participants and their caregivers, all of which intolerably delays new means of prevention, detection, diagnosis and cure of Alzheimer's disease and other forms of dementia.

More broadly, the draft Strategic Plan should include greater emphasis on health and health care disparities as well as health challenges often experienced differently by diverse populations. Health disparities are caused by a multitude of factors and are impacted by gender, race, ethnicity, sexual orientation, gender identity, immigration and primary language, among others. This is one reason why the NIH Office of Research on Women's Health, the FDA Office of Women's Health, the HHS Office of Minority Health (OMH), Centers for Medicare & Medicaid Services Office of Minority Health and numerous other OMH divisions within HHS serve critical roles in supporting HHS' Strategic Plan. While the draft Strategic Plan, as noted above, does address disparities and diversity generally, there is ample opportunity and reason to revise and strengthen the Strategic Plan to explicitly reference and remedy disparities among women, racial and ethnic minority populations each of whom are disproportionately affected by Alzheimer's disease and other forms of dementia. Such revisions would make the Strategic Plan more consistent with numerous federal efforts including the HHS Action Plan to Reduce Racial and Ethnic Disparities^{xi}, the first CMS Equity Plan for Improving Quality in Medicare^{xii}, and the 2016 National Health Care Quality and Disparities Report^{xiii} from the Agency for Healthcare Research and Quality. Failure to include more references to the disparities that racial and ethnic minorities, in particular, experience is a marked departure from the 2014-2018 HHS Strategic Plan. HHS should build on previous efforts and use them as a foundation for further disparities elimination.

In at least two other respects, the draft Strategic Plan should be revised to correct omissions relative to previous HHS Strategic Plans. The 2018-2022 draft Strategic Plan appears to remove entirely all reference to the lesbian, gay, bisexual, and/or transgender communities. The mission of the Department of Health and Human Services is “to enhance and protect the health and well-being of all Americans,” so the absence of references to LGBT Americans from the Strategic Plan both neglects their health challenges – including frequently intensified challenges in obtaining formal and informal dementia care supportive services as well as qualification for dementia research studies that require a care partner – and send an unfortunate message of marginalization. In revising and then finalizing the draft 2018-2022 Strategic Plan, **HHS should restore references to the LGBT populations, acknowledge the health disparities faced by these communities, and include strategies that will eliminate those disparities.**

Similarly, the draft Strategic Plan fails to mention HHS’ central role in promoting and carrying out the Affordable Care Act (ACA), which contains a number of provisions of great important to people facing Alzheimer’s disease and other forms of dementia. The LEAD Coalition’s 2017 issue brief *On the Issues: Health Reform and Dementia*^{xiv} details through 13 examples, the ACA expands access to health and social care (including, specifically the Alzheimer’s Disease Initiative and a Medicare benefit to encourage earlier detection and diagnosis of cognitive impairment), supports participation in research and clinical trials, and provides consumer protections essential to quality of life for people with dementia and their caregivers. In revising and then finalizing the draft 2018-2022 Strategic Plan, **HHS should explicitly state its commitment to the ACA and include strategies for expanding outreach to vulnerable populations – including people living with dementia and their caregivers -- whose access to good health and quality healthcare are dependent upon the agency’s robust support for the law.**

There are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer’s disease and other forms of dementia. These conditions impose enormous costs to our nation’s health, prosperity, and social fabric, costs that are skyrocketing.^{xv} Based on the National Institute on Aging’s Health and Retirement Study (HRS), we know that the health system costs of caring for people with dementia in the United States are comparable to, and perhaps greater than, those for heart disease and cancer.^{xvi} A recent analysis of HRS data revealed that average per-person health care spending in the last five years of life for people with dementia was more than a quarter-million dollars, 57 percent greater than costs associated with death from other diseases such as including cancer and heart disease.^{xvii}

Today, more than five million Americans have dementia at an annual cost to our economy exceeding \$259 billion.^{xviii} Alzheimer’s disease contributes to the deaths of approximately 500,000 Americans each year, making it the third leading cause of death in the United States.^{xix} If the current trajectory persists, at least 13 million Americans will have dementia in 2050 and total costs of care are projected to exceed \$1 trillion annually (inflation adjusted 2014 dollars).^{xx} The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs.

The choice before our nation is not whether to pay for dementia; we are paying dearly. The question is whether we will emulate the scientific investment strategies that have led to remarkable progress in fighting other leading causes of death – such as cancer, HIV/AIDS and heart disease – and achieve similar breakthroughs, or spend trillions more than otherwise necessary to care for tens of millions of people. A modernized and more robust research portfolio can help America prevent this catastrophe and move us closer to achieving our national goal of preventing and effectively treating dementia by 2025.^{xxi}

Thank you for your consideration of this public comment and for HHS' commitment to supporting people living with dementia and overcoming all causes of dementia. Please contact me with questions or for additional information. The LEAD Coalition looks forward to continuing to work collaboratively with HHS and other partners throughout the Executive Branch.

Sincerely,

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ⁱ <https://www.alz.org/facts/>

ⁱⁱ www.dfamerica.org

ⁱⁱⁱ <https://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf>

^{iv} <https://www.cdc.gov/aging/healthybrain/roadmap.htm>

^v http://www.leadcoalition.org/?wpfb_dl=227

^{vi} <https://www.nia.nih.gov/about/bypass-budget-proposal-archive>

^{vii} <https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf>

^{viii} <https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf>

^{ix} [http://www.trci.alzdem.com/article/S2352-8737\(16\)30039-7/fulltext#sec3](http://www.trci.alzdem.com/article/S2352-8737(16)30039-7/fulltext#sec3)

^x <http://www.alz.org/facts/>

^{xi} https://minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf

^{xii} https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf

^{xiii} <https://www.ahrq.gov/research/findings/nhqrdr/nhqdr16/index.html>

^{xiv} http://www.leadcoalition.org/wp-content/uploads/2017/03/LEAD-Coalition_Issue-Brief-Health-Reform-March-2017.pdf

^{xv} <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>

^{xvi} <http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>

^{xvii} <http://annals.org/article.aspx?articleid=2466364#>

^{xviii} <https://aspe.hhs.gov/system/files/pdf/257526/NatlPlan2017.pdf>

^{xix} <http://www.neurology.org/content/early/2014/03/05/WNL.0000000000000240>

^{xx} <http://www.alz.org/trajectory>

^{xxi} <https://aspe.hhs.gov/system/files/pdf/257526/NatIPlan2017.pdf>