

September 22, 2023

The Honorable Debbie Stabenow United States Senate Washington, DC 20510

The Honorable Roger Wicker United States Senate Washington, DC 20510

The Honorable Linda Sanchez US House of Representatives Washington, DC 20515

The Honorable Darin LaHood US House of Representatives Washington, DC 20515

The Honorable Shelley Moore Capito United States Senate Washington, DC 20510

The Honorable Robert Menendez United States Senate Washington, DC 20510

The Honorable Doris Matsui US House of Representatives Washington, DC 20515

The Honorable Gus Bilirakis US House of Representatives Washington, DC 20515

Re: Letter of Support for the Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act

Dear Senators and Representatives,

On behalf of the Milken Institute Alliance to Improve Dementia Care, we thank you and your colleagues for addressing the growing public health crisis of Alzheimer's disease and related dementias (ADRD) through the reintroduction of the bicameral, bipartisan *Concentrating on High-Value Alzheimer's Needs to Get to an End* (CHANGE) Act (S.2379 / H.R.4752). This legislation presents a critical step forward to strengthen health-care providers' capacity to detect ADRD earlier in the disease course through the Welcome to Medicare Visit (WMV) and the Annual Wellness Visit (AWV) and better prepare families for the dementia-care journey.

As background, the <u>Alliance to Improve Dementia Care</u> (Alliance) was established in July 2020 to transform and improve the complex health- and long-term-care systems that people at risk for and living with dementia must navigate. With a diverse membership of over 120 organizations and leaders across government, health systems, industry, philanthropy, community-based organizations, research, and advocacy, as well as people with lived experience, our Alliance champions advancing health and economic equity, building workforce and system capacity, and scaling comprehensive dementia-care models to improve outcomes for individuals living with dementia and their caregivers. In May 2021, the Alliance released a report, <u>Building Workforce Capacity to Improve Detection and Diagnosis of Dementia</u>, generating six recommendations to improve the dementia-capable health-care workforce. Among them was a specific recommendation to improve the Medicare AWV by embedding a structured cognitive impairment detection tool to assess for cognitive impairment as part of the visit, citing the previous reintroductions of the CHANGE Act in the 115th and 116th Congresses.ⁱ

In April 2023, I co-authored an article alongside other national experts in the field titled "Expanding the Use of Brief Cognitive Assessments to Detect Suspected Early-Stage Cognitive Impairment in Primary Care," which was published in the peer-reviewed Alzheimer's & Dementia journal. We formulated three strategies for policymakers and third-party payers, along with recommendations to implement each

strategy, to promote the broader integration of brief cognitive assessments (BCAs) within the primary care setting. These include:

- 1. Provide primary care clinicians with accessible, affordable, suitable BCA tools;
- 2. Integrate BCAs into routine workflows; and
- 3. Revise or update reimbursement policies to encourage the adoption of BCAs.

Cognitive Impairment Detection Tool Administration and Documentation in the Medicare Annual Wellness Visit and Initial Welcome to Medicare Visit

The Alliance is confident that the CHANGE Act's requirement of a structured cognitive impairment detection tool identified by the National Institute on Aging (NIA) during the WMV and subsequent AWVs will improve the rates of early detection and diagnosis of dementia in primary care. Currently, administering a validated detection tool during these visits is not required by the Centers for Medicare & Medicaid Services; rather, clinicians may rely on "direct observation" and insight from the patient, family, and/or caregiver. While these are components in assessing cognitive status, they provide no concrete, quantitative baseline upon which to measure and log change over time if symptoms materialize and progress. Fewer than one-third of Medicare beneficiaries having an AWV report receiving a structured cognitive screening during their visit. This increases the risk of a missed or later-stage diagnosis, disqualifying an individual from being eligible for the newly approved amyloid-reducing therapies targeted for mild cognitive impairment and early-stage Alzheimer's disease.

Further reinforcing the significance of this legislation is the prevalence of underdiagnosed dementia. Research estimates that a substantial population—between 40 to 60 percent—of adults with probable dementia remain undiagnosed. Particularly concerning is the delayed detection and diagnosis of cognitive impairment experienced by people of color and those from low-resourced communities. The importance of health equity in the early detection and diagnosis of dementia cannot be overstated as the United States undergoes a substantial demographic shift characterized by a growing and increasingly diverse aging population.

Projections indicate that racial and ethnic minorities are on track to become the new majority. ^{vi} Black and Hispanic adults are at disproportionate risk of a missed dementia diagnosis relative to White adults despite being twice and 1.5 times as likely, respectively, to have dementia. ^{vii} According to the NIA, Black participants in Alzheimer's disease research studies were 35 percent less likely to be diagnosed with ADRD than White participants. ^{viii} Moreover, Asian Americans and Pacific Islanders (AAPIs) represent the fastest-growing racial and ethnic minority in the nation, with an older adult cohort projected to increase by 145 percent between 2010 and 2030. ^{ix} However, AAPIs are also confronted with an elevated risk of underdetected cognitive impairment, delayed diagnosis, suboptimal dementia care management, limited research, and exclusion from clinical trials.

Recommended Refinement To Enhance Equity and Primary Care Capacity for Early Detection

To address and correct these disparities, the Alliance proposes the validation of cognitive impairment detection tools in diverse, representative populations, considering factors such as education levels, cultural differences, multiple languages, and disability levels. As this legislation continues to be refined, the Alliance strongly advocates for examining and prioritizing NIA-identified tools that account for these socioeconomic and demographic variances to prevent populations at heightened risk from being left behind and ensure equity-oriented care delivery. Additionally, we recommend involving all members of an individual's interprofessional care team—such as the primary care provider, nurse practitioner, physician associate, and clinical social worker—who can also receive training to administer NIA-identified tools.

Conclusion

An early diagnosis allows individuals with dementia and their families the crucial first step to begin advance care planning, prioritize modifiable risk factors like physical activity, nutritious eating, and social

engagement,* seek out opportunities to participate in clinical trials, and obtain community-based services to prolong quality of life. Cognitive screening during the WMV and AWV can also allow providers to differentiate between mild cognitive impairment (MCI) and dementia, provide information about reversible and addressable causes such as vitamin B12 deficiency, hearing loss, sleep apnea, thyroid disorders, nutritional deficiencies, and medication side effects, and reassure individuals that testing positive for impairment is not a death sentence. Thus, the CHANGE Act's updated requirement presents a critical opportunity to improve the rates of dementia detection and diagnosis embedded in patients' medical records and equip interprofessional care teams to deliver personalized care according to patients' unique cognitive status.

Thank you for the opportunity to comment on the reintroduction of the CHANGE Act and for considering the Alliance's support of this legislation. The Milken Institute welcomes the chance to provide additional detail on the information above and serve as a resource as you continue to refine the legislation.

Sincerely,

Diane L. Ty

Senior Director, Center for the Future of Aging Director, Alliance to Improve Dementia Care

Milken Institute

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iii https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/preventive-services/medicare-wellness-visits.html

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viii https://www.nia.nih.gov/news/data-shows-racial-disparities-alzheimers-disease-diagnosis-between-black-and-white-research

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^{*} https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext