



September 27, 2023

Dear Senator :

We sincerely thank you and your colleagues for recognizing and decisively responding to the challenges of Alzheimer's disease and other forms of dementia (including vascular, Lewy body dementia, frontotemporal degeneration, and Creutzfeldt-Jakob disease). Congressional determination to make dementia a national priority has been evident, powerful, and effective. From passage of the National Alzheimer's Project Act to historic funding increases for research, and legislation that improves quality of life for those facing dementia while strengthening the scientific enterprise, Congress has recognized overcoming dementia as a budgetary necessity, an economic priority, and a health and moral imperative. In furtherance of this Congressionally established national priority, **we ask you to become a co-sponsor of the bicameral, bipartisan *Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act* ([S.2379](#) / [H.R.4752](#)).**

The CHANGE Act strengthens dementia detection, in turn catalyzing improved care, promoting health equity, and accelerating science to prevent, effectively treat, and eventually cure Alzheimer's disease and related forms of dementia. Specifically, the CHANGE Act directs the Centers of Medicare and Medicaid Services (CMS) to require professionals providing the Medicare Annual Wellness Visits (AWV)ⁱ and Welcome to Medicare Visits (WMV) to use cognitive impairment detection tools identified by the National Institute on Aging (NIA). Use of these tools will allow clinicians to better detect mild cognitive impairment and other early symptoms of Alzheimer's disease and related forms of dementia.

CMS currently encourages, but does not require, providers to use a brief validated structured cognitive assessment tool. Consequently, many providers use "direct observation," rather than a validated tool, to assess patients' cognitive health. We know of no authoritative source or evidence-based rationale supporting use of direct observation as a means of adequately detecting early cognitive impairment. In fact, direct observation is the least useful and least appropriate tool, all too often contributing to under-diagnosis, delayed diagnosis, misdiagnosis, and non-disclosure of diagnosis. Such failure carries extraordinary potential to harm any patient and to deepen existing health disparities for women, people of color, rural populations, economically disadvantaged people, and

adults with pre-existing cognitive conditions (such as autism, Down syndrome, intellectual disability, severe psychiatric diagnoses, etc.). Recent studies showed that among patients aged 70 years or older, seen in primary care settings, cognitive impairment goes unrecognized in more than 50% of cases. Among older Latino adults, approximately 40% have undiagnosed cognitive symptoms for three years or more. Underutilization of validated assessment tools delays detection and diagnosis, resulting in decreased opportunities for people to access timely treatment options, including clinical research participation.

Providers need not rely on direct observation alone. Free, easy-to-use, validated assessment tools exist, and a number of these tools are listed on the NIA website.ⁱⁱ The CHANGE Act requires Medicare to equip providers to use the NIA tools, which will improve care for millions of families currently facing Alzheimer's disease. When people receive a timely and accurate diagnosis, they have improved opportunities to make informed and productive medical, financial, legal, and spiritual choices to strengthen both their own quality of life and that of their family caregivers.

The CHANGE Act would help providers detect Alzheimer's sooner, which is increasingly important in light of new FDA-approvedⁱⁱⁱ and Medicare-covered^{iv} therapies that are for use in early-stage Alzheimer's disease and as Medicare prepares to launch its nationwide comprehensive dementia care model.^v As research increasingly focuses on intervening at the earliest point in the disease trajectory, shortcomings in disease detection impede progress toward breakthrough therapies. The CHANGE Act strengthens providers' readiness to conduct timely and accurate cognitive assessment, convey diagnosis, and document this in a patient's record.

The CHANGE Act comes at a time of deepening urgency and expanding opportunity. While the need never has been greater, Congress and federal agencies are taking unprecedented action to build comprehensive, integrated, and transformative solutions.

Please contact Dana Richter (dana_richter@capito.senate.gov) with Senator Capito or Amy Brown (amy_brown@stabenow.senate.gov) with Senator Stabenow regarding any questions about or to become a CHANGE Act co-sponsor.

Thank you for considering our views and for your commitment to overcoming Alzheimer's disease and other forms of dementia. For any questions or additional information about this or other policy issues, please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (the LEAD Coalition),^{vi} ikremer@leadcoalition.org.

Sincerely,

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ⁱ <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/preventive-services/medicare-wellness-visits.html> (see: Annual Wellness Visit Health Risk Assessment, Detect any cognitive impairment patients may have)

ⁱⁱ <https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>

ⁱⁱⁱ <https://www.fda.gov/news-events/press-announcements/fda-converts-novel-alzheimers-disease-treatment-traditional-approval>

^{iv} <https://www.cms.gov/newsroom/press-releases/statement-broader-medicare-coverage-legembi-available-following-fda-traditional-approval>

^v <https://innovation.cms.gov/innovation-models/guide>

^{vi} <https://www.leadcoalition.org> Leaders Engaged on Alzheimer's Disease ([the LEAD Coalition](#)) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, large health systems, and biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its causes -- including Alzheimer's disease, vascular disease, Lewy body dementia, frontotemporal degeneration and Creutzfeldt-Jakob disease -- and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.