Dear Acting Administrator Slavitt,

The Alzheimer’s Association appreciates the opportunity to offer feedback on the Centers for Medicare & Medicaid Services’ (CMS) potential reforms and policy options to accelerate the provision of home- and community-based services (HCBS) through the Medicaid program.

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s disease care, support, and research. Today, there are more than 5 million Americans living with Alzheimer’s disease, and it is the only cause of death among the top 10 without a way to prevent, cure, or even slow its progression. Twenty-nine percent of older persons with a form of dementia who have Medicare also have Medicaid coverage\(^1\) and caring for these individuals will have cost $236 billion in 2016 with Medicare and Medicaid bearing $160 billion--68 percent--of that figure.\(^2\) An estimated 58 percent of older adults with Alzheimer’s disease and other dementias live in the community\(^3\) and many of those individuals rely on Medicaid HCBS. As the size and proportion of the United States population age 65 and older continue to increase, the number of Americans with Alzheimer’s disease and other dementias will grow,\(^4\) as will the need and demand for HCBS.

Our specific responses to the RFI follow, but first we thank you again for issuing the recent FAQs on Wandering and Exit-Seeking Behavior in HCBS Settings. The guidance is clear and helpful in its examples of promising practices while emphasizing the person-centered approach at the heart of all Medicaid HCBS. HCBS will become increasingly important to persons with dementia and we look forward to our collective efforts to improve the lives of these beneficiaries and those of their families.

\(^2\) Ibid.
\(^3\) Ibid.
\(^4\) Ibid.
What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid LTSS system to meet the needs and preferences of beneficiaries?

The Alzheimer's Association respectfully requests that CMS clarify its reading of § 1919(a) of the Social Security Act, which defines “nursing facility.” In the RFI, CMS states that “a nursing facility must be primarily engaged in providing skilled care and rehabilitation to residents with medical necessity for those services.” While this is consistent with § 1919(a)(1)(A) and (B), CMS seems to suggest that the statute limits facilities to delivering only skilled and rehabilitation services. The RFI then states that “In contrast [emphasis added], nursing facilities are delivering health-related care and services...to individuals...who require care and services...which can be made available to them only through institutional facilities.” The use of “in contrast” implies that this practice is inconsistent with the § 1919(a) definition. However, § 1919(a)(1)(C), the clause that immediately follows (A) and (B), defines a nursing facility as primarily engaged in providing to residents “on a regular basis, health-related care and services to individuals who because of their mental or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities [emphasis added], and is not primarily for the care and treatment of mental diseases.”

We are confused by the RFI’s implication that current nursing facility practice is inconsistent with the statutory definition when, in fact, the practice of delivering health-related care and services that are not necessarily skilled or rehabilitative is entirely consistent. We appreciate any clarification CMS can offer. In the meantime, we discourage CMS from considering a narrow definition that would restrict an institutional benefit only to persons whose needs cannot be met via HCBS. Limiting individual choice is contrary to CMS’s person-centered approach to HCBS and such a reinterpretation could dramatically disrupt a system caring for the most vulnerable beneficiaries.

What actions can CMS take, independently or in partnership with states and stakeholders, to ensure quality of HCBS and beneficiary health and safety?

The Alzheimer’s Association supports CMS’s efforts to strengthen HCBS quality measurement and improvement. Many of the most commonly known and understood metrics of health care quality are based on the improvement of an individual’s condition. It is, however, just as important that the quality of care and life of individuals with degenerative conditions be continuously measured, evaluated, and improved.

We encourage CMS to ensure that quality improvement activities in state plans and waiver programs are consistent with the numerous efforts underway at the national level, such as those conducted by the National Quality Forum and within the implementation of the Quality Payment Program. With regard to persons with dementia, the Alzheimer’s Association respectfully requests that CMS consider the following as it works with states to establish consistent, high-quality care for this growing population of beneficiaries:

- Prioritize measurement of the quality of care for persons with cognitive impairment.

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5 Social Security Act § 1919(a), 42 U.S.C. 1396r.
Ensure that measurement efforts allow for proxy responses. Persons with dementia who are not capable of reporting are often excluded from measurement because caregivers are not allowed to serve as proxies.

Because current and future HCBS measures involve different populations—older adults, people with multiple chronic conditions, and people with disabilities—we encourage CMS, states, and measure developers to determine which populations use particular services and in what settings to better inform and shape quality measure development. For example, if many HCBS recipients reside in a memory care setting with a secured perimeter, then measures in certain domains should be constructed in such a way that reflects the safety needs and cognitive impairment of residents.

Finally, CMS should implement dementia and abuse prevention training requirements for HCBS consistent with those in the recently-finalized long-term care facility reforms. Studies show staff trained specifically in dementia care are able to provide better quality of life for residents and have increased confidence, performance, and job satisfaction. At a minimum, curriculum used for the initial training should cover dementia and its progression and symptoms, strategies for providing person-centered care, communication, techniques for understanding and approaching behavioral symptoms, and aspects of care and safety (e.g. pain, food and fluid, wandering). Additionally, dementia training should be appropriate for the population served, include cultural competency, and provide ongoing learning opportunities, support, and mentoring.

What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste, and abuse in HCBS?
The Alzheimer’s Association appreciates CMS’s efforts to protect beneficiary safety and we support the development and implementation of federal standards. Persons with dementia are particularly vulnerable to abuse, neglect, and exploitation because the disease may prevent them from reporting abuse or recognizing it.

We support the use of background checks and written policies and procedures that prohibit abuse and neglect and describe how to report incidents. We also note for CMS’s reference the Administration for Community Living’s Voluntary Consensus Guidelines for State Adult Protective Service Systems issued in Fall 2016.

As previously noted, the Alzheimer’s Association supports the implementation of dementia training standards for any HCBS personnel. We do not believe that the mere possession of such knowledge, discussed above, can interfere with the delivery of person-centered service and can, in fact, improve the safety of this growing population of HCBS beneficiaries. To this point, we believe that state home care

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registries could play an important role in *improving* individualized services rather than interfering with them if they track the right data, such as the types of training workers receive.

Thank you for the opportunity to comment. Please contact Laura Thornhill, Manager of Regulatory Affairs, at 202-638-7042 or lthornhill@alz.org if you have questions or if we can be of additional assistance.

Sincerely,

Robert Egge
Executive Vice President, Government Affairs