March 13, 2020

The Honorable John Cornyn    The Honorable Robert P. Casey Jr.
Chair       Ranking Member
Subcommittee on Health Care    Subcommittee on Health Care
Committee on Finance     Committee on Finance
United States Senate     United States Senate
219 Dirksen Senate Office Building   219 Dirksen Senate Office Building
Washington, DC 20510     Washington, DC 20510

RE: Feedback Regarding Actions to Address Alzheimer’s Disease

Dear Chairman Cornyn and Ranking Member Casey:

The American Academy of Nursing (Academy) is pleased to offer the following comments in response to the February 11, 2020, request for additional input and recommendations regarding policy solutions that make meaningful improvements to the detection, education, treatment, and support for patients and families affected by Alzheimer’s disease and related dementias. The Academy is appreciative of the Subcommittee’s effort to preemptively seek out feedback and solutions surrounding the care and treatment of Alzheimer’s patients. Our comments will focus on three areas identified in the Subcommittee’s request for feedback in the areas of Care Coordination in Federal Health Care Programs, Improving Detection and Care, and Protecting Vulnerable Patients.

The Academy serves the public and the nursing profession by advancing health policy and practice through the generation, synthesis and dissemination of nursing knowledge. It’s more than 2,800 fellows are nursing’s most accomplished leaders in education, management, practice, research, and policy. They have been recognized for their extraordinary contributions to the promotion of the public’s health through evidence and innovation.

Care Coordination in Federal Health Care Programs
The Academy has a strong history of supporting efforts to improve the quality of care and services for older adults. Granting Advanced Practice Registered Nurses (APRNs- including nurse practitioners, certified registered nurse anesthetists, certified nurse-midwives, and clinical nurse specialists) the ability to practice to the full extent for their education and training would allow APRNs\(^1\) to meet the critical care needs of Alzheimer’s patients, especially in rural and underserved areas. Moreover, an estimated 45 million Americans are living with one or more chronic conditions that limit physical function and quality of life and are likely to progress in severity over the course of one’s lifetime.\(^2\) The National Academy of Medicine (NAM) has called for the expansion of community-based models to effectively provide health care to Americans with chronic health conditions.\(^3\)

We call on the Subcommittee to take up and pass the Home Health Care Planning Improvement Act of 2019 (S. 296). Home health is an area where APRNs are especially relied upon for their expert clinical skills. Yet, as it currently stands, Medicare law prohibits APRNs from certifying Medicare patients for home health benefits and from signing home health plans of care. The Home Health Care Planning
Improvement Act would allow nurse practitioners, certified nurse-midwives, and clinical nurse specialists to certify these services, ultimately reducing delays in care among those with Alzheimer’s.

**Improving Detection and Care**

The Academy Edge Runner program recognizes nurse-designed models of care and interventions that impact cost, improve healthcare quality and enhance consumer satisfaction. One Edge Runner model for consideration is the UCLA Alzheimer’s and Dementia Care (ADC) Program. This program designed, by APRNs, is a collaborative practice in which patients retain their primary care provider, while both patients and their families receive dementia care from nurse practitioner Dementia Care Managers (DCMs). The goals of the ADC program are to maximize patient function, independence, and dignity while minimizing caregiver strain and unnecessary costs. The UCLA ADC has emerged as a national model for dementia care.

As of November 2019, the program has served over 2,750 patients and their caregivers. Prior to entering the ADC program, UCLA Health found that many caregivers were poorly informed about dementia caregiving and felt they were fighting this battle alone. The ADC Program found that one-third had high stress and more than 10 percent were depressed. By the end of a year in this program, UCLA Health found that confidence in handling problems and complications of Alzheimer’s disease and dementia improved by 72 percent as well as a reduction on caregiver strain, distress and depression. Although the program cannot prevent the progression of dementia, the program noted that persons with dementia had fewer problem behaviors (agitation, irritability, apathy, nighttime behaviors) and depressive symptoms after one year in the program. Moreover, the program reduced emergency department visits, days spent in the hospital, admissions to nursing homes for long-term care and overall Medicare costs.

The Academy further recommends the Subcommittee consider the needs of the “sandwich generation” i.e. those working individuals who are caring for their children as well as their older loved ones in the development of action to address Alzheimer’s care. The NAM report on family caregiving estimates that about half of the nation’s caregivers for older adults are employed. “Working caregivers—especially those who care for people with dementia or with substantial personal care needs—are at risk of significant economic costs: loss of income; out-of-pocket cost for the care recipient; and lower lifetime earnings, savings, and retirement benefits.”

**Protecting Vulnerable Patients**

Mistreatment of vulnerable patients results in diminished well-being and quality of life. Unfortunately, this mistreatment can occur anywhere—in the home, in care and residential facilities, and in the community. The Academy makes the following recommendations to protect Alzheimer’s patients. First, reimbursement should be expanded in Medicare and Medicaid to better cover screening and basic first level mental health services by primary care provider staff. This will enhance inclusion of routine screening for mistreatment, substance use and mental health problems as part of the annual Medicare health promotion visit. Secondly, the Academy recommends more support for the Administration on Aging’s National Center on Elder Abuse (NCEA). The NCEA heightens awareness and serve as a resource for policy makers, social service and health care practitioners, the justice system, researchers, advocates and families.
In summary, the Academy shares your goal in ensuring that future legislation regarding Alzheimer’s make meaningful improvements to the detection, education, treatment, and support for patients and families affected by Alzheimer’s disease and related dementias. Thank you for the opportunity to provide our comments and recommendations, and I hope you will contact us for assistance in any efforts to address these issues or policies. Within our membership are leading experts in this area. If you have any questions or need additional information, please feel free to contact the Academy’s Senior Director of Policy, Christine Murphy, at cmurphy@aannet.org or 202-777-1170.

Sincerely,

Eileen Sullivan-Marx, PhD, RN, FAAN
President

5 UCLA Health, 2019.
9 “Elder justice: Preventing and intervening in elder mistreatment,” 2015
10 “Elder justice: Preventing and intervening in elder mistreatment,” 2015