



March 13, 2020

The Honorable Pat Toomey  
Chairman  
Subcommittee on Health Care  
Committee on Finance  
U.S. Senate  
219 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Debbie Stabenow  
Ranking Member  
Subcommittee on Health Care  
Committee on Finance  
U.S. Senate  
219 Dirksen Senate Office Building  
Washington, DC 20150

Dear Chairman Toomey and Ranking Member Stabenow:

On behalf of the National PACE Association (NPA), please accept this letter in response to the February 11, 2020 Senate Finance Subcommittee on Health Care request for suggested policy solutions to improve the care and quality of life for those living with Alzheimer's Disease and related dementias (AD/RD) as well as their families.

NPA is a national organization representing 114 operating Programs of All-Inclusive Care for the Elderly (PACE) organizations in 28 states, and numerous additional entities pursuing PACE development and supportive of PACE. PACE organizations (POs) serve among the most vulnerable of Medicare and Medicaid populations—medically complex older adults over age 55 who are State certified as requiring a nursing home level of care. The objective of PACE is to maintain the independence of program participants in their homes and communities for as long as possible. POs currently serve over 53,000 participants nationwide. Today, almost half of all those enrolled in PACE (46 percent) experience dementia.

While individual care needs will vary, people age 65 and over have a 68 percent probability of either experiencing cognitive impairment or requiring assistance with at least two activities of daily living (ADLs). And this population is growing. According to MedPAC, approximately 10,000 baby boomers turn 65 and become eligible for Medicare daily. In 2020, across the U.S., there are an estimated 5.8 million older Americans (65≤) with AD according to the Alzheimer's Association- representing one out of every ten in this age cohort. Those aged 65-74 represent 17 percent or one million, 75-84 represent 47 percent or 2.7 million, while the oldest old (85 ≤) represent 36 percent or 2.1 million. By 2025, the number of elders with AD is predicted to climb to 7.1 million and to 13.8 million by 2050, absent advancements in prevention and treatment.

Fully integrated, POs provide program participants with AD/RD and other medically complex conditions with all needed medical and supportive services, including the entire continuum of Medicare- and Medicaid-covered items and services. POs coordinate and render care, as determined by each individual participant's care plan, around the clock, 7 days a week, every day of the year, across all settings. Participants may be Medicare beneficiaries, Medicaid beneficiaries, dually eligible beneficiaries, Department of Veterans Affairs beneficiaries or private pay. In exchange for monthly capitated payments, PACE organizations assume full financial risk for the full range of community-based and, as needed, institutional services they

are responsible for providing, either directly or through contracts with other community-based providers, hospitals, nursing homes, etc.

The hallmarks of this unique model of care are the broad scope of services, the interdisciplinary team (IDT) and the PACE center. The person-centered PACE care model combines excellence in clinical care and care coordination from a dedicated staff of providers with the focus on quality and efficiency. The IDT is comprised of primary care providers, nurses, social workers, physical and occupational therapists, recreational therapists or activity coordinators, dietitians, PACE center managers, home care coordinators, and drivers and personal care aides or their representatives. These individuals holistically assess participants' care needs, then develop and implement comprehensive, fully integrated care plans providing many services directly in the PACE center and participants' homes. Additional necessary services are provided through POs' contracts with other providers. Given the extensive health care, LTSS and other needs of participants, POs interact with participants and their family caregivers on a regular and frequent basis, often daily. Accordingly, PO staff are frequently in participants' homes and involved in all aspects of their care due to the intensity of participants' needs.

The scope of services provided by PACE spans all Medicare Parts A, B and D benefits, all Medicaid-covered benefits, and any other services or supports deemed necessary by the IDT to maintain or improve the health status of participants. Under PACE, typically fragmented health care financing and delivery systems come together to serve the multifaceted needs of these frail, elderly and disabled patient populations.

Outside of PACE, the status quo of decentralized and disconnected care and services is especially detrimental for those living with AD/RD. The U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) recently reported that [t]he traditional health care system is not well suited to meeting the complex needs of people with dementia. . . . The sheer number of health and social service providers that serve this population, including physicians' offices, outpatient clinics, emergency departments, hospitals, rehabilitation facilities, residential care facilities, adult day centers, home care, and community organizations, also makes coordinated communication challenging."

The PACE care model is distinctive within the American health care system as it uniquely unites care determinations, provision and payment. The fully comprehensive, capitated payment provides a strong incentive for POs to avoid duplicative or unnecessary services while encouraging the use of acute care, preventive care, maintenance therapy and other appropriate community-based alternatives to hospital and nursing home care as well as long term care services and supports (LTSS). Care decisions are provider-led through the IDT in consultation with the participant and their family. This construct empowers the PACE model of care to achieve the Triple Aim of better care and patient experience, better population health and lower costs. For those living with AD/RD, ASPE noted "[t]ypical fee-for-service reimbursement policies do not incentivize providers to coordinate medical care, and LTSS are not well integrated with health care delivery systems."

PACE also enables older Americans to receive care at home-- their preferred environment. In 2018, AARP found that 86 percent of those 65 and older surveyed either strongly or somewhat agreed that they want to remain in their current home for as long as they can. Though all PACE participants meet their State's criteria for needing a nursing home level of care, at enrollment, all live in the community due to the support of the PACE organization's services and over time ninety-five percent are able to remain living in the community-- including those with AD/RD.

Living at home, while highly preferred, often depends on the willingness of family caregivers to facilitate that situation. Family caregivers have similar preferences as older Americans on this issue; in fact, the Alzheimer's Association found that the primary reason (65 percent) family caregivers assume the role is to enable their loved one to remain at home. Family caregivers, when available, play a vital role in the overall success and wellbeing of participants besides their sense of independence.

Supporting caregivers in addressing the needs of their loved ones is central to one of the core tenets of the PACE model of care, providing participant-centered care. When the PO IDT conducts an initial assessment of a participant upon enrollment, evaluation of the preferences of both the participant and family caregiver(s) for care are required. This assessment also evaluates the capability of the caregiver(s) and identifies any need for caregiver training or support from the PO to ensure that the needs of participant are met. Care provided by a caregiver is identified in the participant's care plan and, as a result, monitored by the IDT continuously.

The extent to which an individual participant relies on a caregiver for care is personal and individualized. Since the role of caregivers may change over time, so as the IDT reassesses a participant's needs, the IDT also reassesses the status of the caregiver(s). These reevaluations happen on a routine basis, as part of each participant's required semi-annual reassessment and ensuing care planning updates, as well as in response to any changes in status of either the participant or caregiver or to requests for services. Moreover, the IDT is required to remain alert to pertinent information shared by participants and caregivers which may precipitate a change in roles or identify new care and/or support needs.

The choice to be a family caregiver comes at a greater sacrifice for AD/RD family caregivers than for most others, since dementia caregivers have shown to be one of the groups shouldering high levels of burden, according to a recent study on dementia caregiving authored by the National Alliance for Caregiving and the Alzheimer's Association (NAC/AA). The same study reports close to 50 percent of dementia family caregivers are in the high burden category and overall, the average level of burden is much greater for this population of caregivers as compared to others.

Additionally, the duration of bearing this burden lasts over a year for close to 70 percent of family caregivers of those living with dementia, with more than 30 percent providing care to their loved one in excess of five years, and 15 percent for ten years or more. These figures reflect the varying survival rates of those over 65 living with AD/RD, four to eight years on average according to the Alzheimer's Association. Further estimates show that an older person with AD/RD aged 70, who lives for another ten years, will experience the severe stage

of the disease for 40 percent of that time, most of which will be at the nursing home level of care. In this circumstance and for any other person living with AD/RD at the nursing home level of care 55 and older, the PACE model meets the needs of both the loved one and the caregiver by allowing the elder to remain at home through the provision of our comprehensive care and services, while supporting the family caregiver and alleviating some of the burden.

Research conducted by NPA demonstrated that 58 percent of family caregivers experienced lower burden levels after their loved one enrolled in PACE. Similarly, for those enrolled in PACE, more than 50 percent of all surveyed family caregivers reported that they had more time for themselves and were less stressed about meeting other responsibilities. This finding is key since NAC/AA found that two thirds of the dementia caregivers who were employed noted that being a family caregiver impacted their work and that this group of caregivers also had a three times higher incidence of losing job benefits. PACE addresses many of the needs of both the loved one living with AD/RD and the family caregiver. By combining care need determination, coordination and execution of care delivery 24/7/365, and constant communication along with financing, PACE successfully facilitates family caregivers being able to work outside the home—without sacrificing the amount or quality of care received by their loved one.

The Chief Operating Officer of the PACE Organization of Rhode Island, Joan Kwiatkowski, recently shared a case study illustrating how PACE program enrollment facilitated significant improvements in a family caregiver's life in the June 2019 edition of the Rhode Island Medical Journal.

*AltaGracia is a 90-year-old old Hispanic woman with Alzheimer's dementia and severe end-stage COPD, requiring continuous oxygen. She lives with her daughter who works full-time. She had multiple falls and behavioral symptoms of dementia with aggression and frequent night-time awakenings. Like most of our participants, she was at the brink of a nursing home placement. Her daughter was exhausted from stress and worry.*

*With PACE, she attends the day center six days a week, participating in our memory care program and purposeful activities, as well as receiving CNA supports at home both in the morning and at night. She receives geri-psych follow up at the PACE center, which has led to a decrease in dementia-related behavioral symptoms. Her daughter gets respite care services so she can go on occasional vacations and get some personal time while keeping her mother at home and minimizing while keeping her mother at home and minimizing strain. (pp 30-32)*

Other examples of the success of the PACE model serving those older Americans living with AD/RD may be viewed via videos posted to the NPA website. The [first video](#) shares the story of family caregiver Khaadija Shabazz, whose mother experiences dementia and has been enrolled in the PACE Southeast Michigan program in Detroit. The [second video](#) features another caregiver, Charles Laughery, who along with his wife and three daughters, cares for his mother with dementia in San Diego in conjunction with St. Paul's PACE.

PACE also serves those living with AD/RD who choose to live alone. The Alzheimer's Association reports that in 2020 approximately 70 percent of those with AD/RD live in the community, and of that population, more than a quarter (26 percent) reside by themselves. The individualized, comprehensive, coordinated and integrated care delivered to eligible elders with AD/RD enrolled in the PACE model of care enables them to remain at home alone safely.

Given the expressed preference of both older Americans and their caregivers to remain at home, in the future PACE and other alternatives to nursing homes will be in great demand. For those elders living with AD/RD, several studies have shown the probability of nursing home admission is considerably higher and that costs incurred during those stays are significantly higher. Other studies have found that for those with living with severe AD/RD who have experienced either skilled nursing facility or assisted living placements there is a correlation with poorer quality of life and increased costs. PACE may allow some of these older Americans, and others, to either delay entering a nursing home or avoid this institutional setting altogether.

The Commonwealth Fund found that 83 percent of adults of any age with high needs had public health insurance— 20 percent were dually eligible for Medicare and Medicaid; 50 percent were Medicare beneficiaries and 13 percent were Medicaid beneficiaries. Analogously, only four percent of all Medicare beneficiaries without AD/RD live with at least five chronic conditions, the incidence of that categorization is more than 6 times higher (26 percent) for Medicare beneficiaries with AD/RD, according to the Alzheimer's Association. The same study also found that Medicare beneficiaries with AD/RD along with at least one comorbid condition had higher per beneficiary expenditures for most health care services than those beneficiaries without AD/RD experiencing the same specified condition. Considering this significant reliance on Medicare and/or Medicaid among those with high health care needs, it is critical for our nation to encourage increased use of evidence-based, proven, cost-effective care models, such as PACE.

A recent study by Mathematica Policy Research determined that PACE costs to the Medicare program are comparable to the costs of other Medicare options, while delivering better quality of care for an extremely frail, complex population. PACE rates are also considerably lower than nursing home rates. In 2019, the Medicare per member, per month rate averaged \$2,574, while the mean Medicaid per member, per month rate was \$3,933. In contrast, the 2019 monthly average rate for a semi-private room in a nursing home was \$7,513 a month, while the rate for a private room was \$8,517 a month according to Genworth Financial. Increased enrollment in PACE enables high need Medicare beneficiaries to access a broad spectrum of medical care and services economically, thereby slowing their spending over time and possibly preventing Medicaid eligibility.

A recent Health Affairs study found that approximately 700,000 older Americans, who ordinarily would not meet the income and asset eligibility limits for Medicaid, became eligible due to the costs of medical and other necessary care. States pay PACE programs 13 percent less on average than the cost of caring for a comparable population through other Medicaid services, including nursing homes and community-based waiver programs.

Aside from controlling expenditures for this high cost, high need population, PACE attains the desired outcomes of fewer unmet needs, improved chronic care management, better functional support and higher quality of life for participants and their families. Thus, anticipating greater demand for PACE going forward, NPA recommends the following policy changes to best position this innovative model of care for growth.

### **Issue 1: Direct CMS to Move Forward on PACE-specific Pilots**

Current eligibility requirements restrict PACE access to individuals aged 55 or over and require a nursing home level of care. The PACE Innovation Act of 2015 (P.L. 114-85) authorized CMS to test the PACE model with new populations, such as younger people with disabilities, individuals at risk for needing nursing home care and others. While CMS took action in 2016 and 2017 toward implementing PACE-specific pilots, progress has stalled.

CMS released Requests for Information (RFIs) in December 2016 and July 2017 regarding the initiation of PACE-specific pilot for people living with mobility deficits across the lifespan. However, the agency still has not issued a Request for Applications (RFA) in follow up to the responses submitted to the RFIs or taken any action on other PACE- specific pilots. Most recently, the Center for Medicare and Medicaid Innovation (CMMI) has indicated strongly that rather than proceed with PACE-specific pilots, it is encouraging PACE organizations to test serving new populations through other primary care-focused pilots, such as Direct Contracting.

NPA is gravely concerned that pilots not based on the PACE care model are inappropriate to test PACE innovations, which could help serve new medically complex populations, such as those living with AD/RD under 55 at nursing home level of care and those with AD/RD across the lifespan not yet at the nursing home level of care. While the population at present impacted by early-onset AD/RD is approximately 131,000 commercially insured Americans between the ages of 30 and 64, diagnosis rates have jumped by 200 percent from 2013-2017, according to a new report by the Blue Cross Blue Shield Association, entitled "Early-Onset Dementia and Alzheimer's Rates Grow for Younger Americans." The report states "[t]hese health trends indicate a need for a focus on appropriate care and support for individuals with either form of dementia and support for their caregivers as the disease progresses."

The designs of the other CMMI primary care initiatives do not fully incorporate the integrated coverage, enrollment and financing features of the PACE model, namely:

1. the all-inclusive nature of the PACE benefit package, which extends beyond primary care to include acute care, preventive care and LTSS;
2. the combined Medicare and Medicaid capitation payments for enrollees eligible for both programs (dual-eligibles);
3. the provider-based delivery system embodied by PACE, which is very different from either fee-for-service care management or general managed care; and
4. the multi-year, long-term needs of the high-cost, high- need PACE population that extend beyond a single episode of illness or post-acute care.

By not reflecting these critical PACE features, the CMMI primary care initiatives do not embody the authorization Congress provided to pilot PACE for new populations.

***Recommendation 1: Direct CMMI to Resume Efforts on PACE-specific Pilots***

NPA requests that Congress urge CMMI to issue PACE-specific pilots as permitted by the PACE Innovation Act soon. PACE-specific pilots will provide valuable opportunities to understand how this proven model of care can be adapted to serve new populations living with complex care needs. Why should those with AD/RD now ineligible to be cared for by PACE under the current paradigm be denied this opportunity by CMS? Many community providers who serve these new populations are ready to move forward with PACE pilots but cannot under the existing CMS pilots, including the Primary Care First Initiative. Organizations across the nation should be able to build on and adapt the PACE model to serve new populations, offering these people a chance to experience an effective, integrated, community-based care option that supports their independence and quality of life. Exploring new alternatives for the delivery and financing of community based LTSS is an important task in planning for our nation's care needs, especially those living with AD/RD.

**Issue 2: The Current PACE Application Process Restricts Growth and Expanded Access to PACE Services**

While NPA appreciates that CMS has undertaken efforts to streamline the PACE application process, we believe important opportunities remain to enhance the efficiency and effectiveness of the PACE application process, particularly as it relates to expansion applications.

***Recommendation 2: Allow for a PO to have more than one New PACE Center or Service Area Expansion application under CMS review at a time***

NPA thanks CMS for providing POs the opportunity to submit Service Area Expansion applications, including both applications to expand a PO's service area and applications to add a new PACE center within an existing service area, on a quarterly basis. However, this frequency remains insufficient to address the needs POs face as providers of care to expand their service capacity and serve Medicare and/or Medicaid beneficiaries in new service areas. In many cases, it is very difficult for a PO to coordinate the submission of an application involving a new PACE center and completion of that PACE center in a way that minimizes the length of the application process. Often the reasons for this are outside the PO's control, e.g., delays in construction, delays in state licensing/certification processes, etc.

Hence, if there is a need for a new PACE center within an existing service area or a new opportunity to expand its service area while an existing application is pending CMS review, a PO may not be able to act for an extended time period. Depending on the circumstance, during this period, the PO may have less than optimal PACE center capacity in an existing, approved service area or miss out on an opportunity to provide beneficiaries in a new service area access to its services. For this reason, NPA recommends Congress direct CMS to reconsider its current policy of limiting POs to one application pending CMS review at a time and allow for multiple pending applications of all types.

### **Issue 3: Increased Accessibility and Affordability Needed for Medicare-only PACE Participants**

Despite being a benefit under both Medicare and Medicaid, most PACE participants (90 percent) are dually eligible for Medicare and Medicaid, while less than 1 percent are eligible only for Medicare. Barriers currently exist for Medicare-only beneficiaries preventing them from readily accessing PACE. NPA believes that this lack of access is a critical equity issue with respect to Medicare-only beneficiaries who now are disadvantaged with respect to PACE access. Given that the need for care will continue to increase along with the rapidly rising numbers of older Americans, eliminating these impediments is prudent public policy.

#### ***Recommendation 3: Allow Medicare-Only PACE Participants to Enroll in Standalone Part D Prescription Drug Plans***

Since PACE is required to provide all Medicare and Medicaid benefits to a participant, each PO establishes and manages a Part D plan. Unlike dually eligible beneficiaries, Medicare-only beneficiaries must pay a monthly premium to POs for their Part D coverage. As such, Medicare-only beneficiaries should have the freedom to select the Part D plan of their choice. Greater selection and flexibility are critical so that Medicare beneficiaries may choose the Part D coverage best suited to their medical and financial needs. In our experience, unaffordable Part D premiums in PACE force many otherwise eligible Medicare-only beneficiaries to forego PACE as an option. Given that PACE Part D plans must establish monthly premiums inclusive of deductible and cost-sharing amounts that are based on notably higher drug and administrative expenditures, PACE Part D premiums differ greatly from those for marketplace Part D plans. In 2020, the national average monthly premium for PACE Part D plans is \$893.17, in contrast to the national average monthly premium of \$42.05 for marketplace plans.

However, less than 1 percent of the more than 53,000 PACE participants are Medicare-only beneficiaries in 2020; the remainder are either Medicaid-only or dual-eligible beneficiaries for whom Part D premiums and co-payments are subsidized. Addressing the high cost of Part D premiums for Medicare-only beneficiaries seeking to enroll in PACE by allowing participation in marketplace prescription drug plans in lieu of PO-operated Part D plans, would increase access to this innovative model of care.

Prior to the enactment of the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003 (P.L. 108-173), POs used a portion of the funds provided through its per participant, per month capitation rates to cover the cost of all prescription drugs for their enrolled participants. The MMA requires that PACE participants obtain Part D prescription drug benefits through a Part D plan operated by their POs (42 USC 1395w-131(f)). For a variety of reasons, Part D premiums charged to Medicare-only PACE participants are substantially higher than premiums charged by standalone Part D plans. First, POs' Part D plans only can enroll PACE participants, all of whom are high-cost, high-need individuals. Second, because POs are prohibited from charging participants any deductible and copayment amounts (42 USC 1395eee(b)), all beneficiary Part D costs are reflected in their Part D premiums. Since PACE participants do not incur out-of-pocket costs, they cannot access manufacturer discounts in the coverage gap, and POs cannot access catastrophic reinsurance. Other factors contributing to the high cost of PACE Part D plans include higher drug acquisition costs due to the small size of these plans in comparison to other Part D plans

and the small size of PACE Part D plans resulting in higher per capita administrative costs. For Medicare-only beneficiaries, the current mandate that PACE participants obtain their Part D benefits through POs' Part D plans renders PACE an unaffordable option, especially for those with low-to-moderate incomes.

***Recommendation 4: Allow PACE Organizations More Flexibility in Determining the Premiums Charged to Medicare-Only Beneficiaries***

Part of the continuum of care provided by PACE to all participants is coverage for and delivery of care under Medicare Parts A, B and D. PACE also covers and provides wrap-around LTSS as needed to maintain or improve the health of participants enrolled in the program. A Medicare-only beneficiary pays a monthly premium to the PACE program for these wrap-around LTSS services and others that in the case of a dually eligible beneficiary would be covered and paid for by Medicaid. However, under current federal regulations the fee a PACE program is required to charge a Medicare-only beneficiary for all Medicaid-covered services must be equal to the average amount paid to PACE by state Medicaid programs for their enrolled dually eligible beneficiaries. Except for New York and Wisconsin, the state Medicaid rates for PACE are averages and do not account for the health status of an individual. Moreover, even in the aforementioned states that adjust payment for health status, the adjustment is to the average rate paid by Medicaid to the PO, not individual beneficiary rates. Nationally, the mean Medicaid rate per participant, per month is \$3,933.

Requiring PACE to charge an average monthly rate based on the Medicaid rate of a state results in Medicare beneficiaries paying a "one size fits all" rate. Medicare beneficiaries who are paying out of pocket for PACE should be able to pay a rate that reflects their individual health status and corresponding level of need. In comparison to PACE Medicaid rates that do not account for health status, allowing for PACE health status rate adjustments may result in lower monthly costs for some Medicare beneficiaries. Allowing Medicare beneficiaries to pay a capitation rate consistent with their health status will better align their needs with their costs and result in improved affordability of PACE services.

***Recommendation 5: Allow PACE Organizations to Establish Two-Way Agreements***

At present, 32 states have amended their Medicaid plans to offer PACE as an optional benefit. Correspondingly, POs also must participate in three-way program agreements along with the state and Centers for Medicare and Medicaid Services (CMS). Thus, Medicare-only beneficiaries do not have access to their PACE benefit in the states without a PACE state plan amendment.

The existing three-way program agreement requirement for POs prevents Medicare beneficiaries from being able to access PACE in the states that do not offer PACE—denying them access to part of their Medicare benefit. Access to community-based alternatives to nursing homes will be critical to meet the needs of Medicare beneficiaries in the coming years as these older Americans with cognitive and functional impairments seek community based long term care options.

In closing, NPA holds that it is in the best interests of not only our nation, all Americans living with AD/RD and their families, but also the Medicare and Medicaid programs, for Congress and CMS to collaborate in increasing access to and affordability of PACE, a program that

would, in many cases, improve both quality of care and life as well as decrease expenditures for high cost beneficiaries in the preferred community setting.

NPA appreciates the consideration of our comments; should you need additional information, please contact Francesca Fierro O'Reilly, Vice President, Advocacy, at either [FrancescaO@npaonline.org](mailto:FrancescaO@npaonline.org) or 703-535-1537.

Sincerely,

A handwritten signature in blue ink, appearing to read "Shawn M. Bloom". The signature is stylized and fluid.

Shawn M. Bloom  
President and CEO