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“Improving the Medicaid Program for Beneficiaries”

House Energy and Commerce Committee
Subcommittee on Health
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Executive Summary

Mr. Chairman, Ranking Member Green, and members of the committee, thank you for hosting today's hearing on the *PACE Innovation Act* and these other important bills. I am Tim Clontz, and it is my honor to testify today on behalf of the National PACE Association, the 115 PACE organizations operating in 32 states, and the 35,000 participants we serve.

The Program of All Inclusive Care for the Elderly (PACE program) is a proven care model that provides high-quality, integrated care to some of our nation's frailest, most vulnerable citizens – those needing a nursing home level of care. Studies show that people receiving care from PACE organizations live longer, in better health, with fewer hospitalizations and more time living in their homes than those receiving care through other programs.

The *PACE Innovation Act of 2015* would allow 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. This much needed legislation would address serious gaps in our current health and long term care delivery system, and would allow PACE organizations to offer high-quality, fully-integrated care that allows vulnerable populations to maintain their optimal health, receive much-needed services, and to live independently in the community.

This non-controversial, bipartisan legislation was scored as revenue neutral by the Congressional Budget Office, and passed the United States Senate by unanimous consent in August 2015. We thank the bill sponsors, Congressman Christopher Smith (R-NJ) and Congressman Earl Blumenauer (D-OR) for their tireless support of PACE, and applaud the committee for its consideration.

We also commend the committee for its consideration of the Medicaid DOC Act. Giving consumers the information they need to choose the right health care coverage for them helps to move the delivery and finance system in the right direction. We believe this principle should apply to all options equally and applaud the Act's requirement to disclose the primary care and specialist physicians accessible to individuals through Medicaid fee for service and primary care case management programs

We look forward to working with committee leaders to advance these bills through committee, to the House floor, and onto the President for his signature.

Overview of the PACE Program

The Program of All Inclusive Care for the Elderly (PACE) is a fully integrated care model that serves some of the most complex and challenging individuals in our health care system – aging seniors who require a nursing home level of care. The PACE philosophy is centered on the belief that it is better for frail individuals and their families to be served in the community whenever possible. Although all PACE participants are eligible for nursing home care, 90 percent continue to live at home.

PACE organizations provide the entire continuum of medical care and long-term services and supports required by frail older adults, including primary care, specialty care, home care, transportation, therapy services, and other benefits. In short, PACE covers all Medicare Parts A, B and D benefits, all Medicaid-covered benefits, and any other services or supports that are medically necessary to maintain or improve the health status of PACE program participants.

PACE serves some of our nation's frailest and most vulnerable citizens – those requiring a nursing home level of care. The average PACE participant is 76 years old, has 4 to 5 chronic conditions and has difficulty performing at least 3 activities of daily living such as eating, bathing, dressing or moving around. Approximately half of PACE participants have a dementia diagnosis, and ninety percent are dually eligible for Medicare and Medicaid.

Despite their frailty and complexity, PACE participants enjoy a high quality of care and quality of life. Several evaluations of PACE have found that participants experience better health outcomes than beneficiaries served in other care models including fewer unmet needs, better access to preventive services such as immunizations and hearing and vision screenings, less pain, less likelihood of depression, and fewer hospitalizations and nursing home admissions.

Moreover, the PACE program has proven to be a good value to taxpayers. A recent study by Mathematica Policy Research determined that PACE costs are comparable to the cost of other Medicare options but that PACE provides better quality of care. The MPR study determined that PACE enrollees had a lower mortality rate than comparable individuals either in nursing facilities or receiving home and community based services (HCBS) through waiver programs.

Perhaps the best way to describe the PACE program is to tell the story of someone who experienced its benefits:

Dennis is a 59 year old diabetic who lives in the foothills of North Carolina. Prior to enrolling in PACE, he suffered a massive stroke, fell and hit his head. He was hospitalized for three months and lost 30 lbs. When he was discharged to a skilled nursing facility for rehab, his blood sugars were out of control, he required moderate assistance with activities of daily living, and walked with a walker.

Dennis enrolled in PACE in February 2014 and now lives with his sister. PACE helped Dennis get his diabetes under control, improved his function to the point that he requires minimal assistance with his activities of daily living, and he uses PACE's gym and Otago Balance Program to help maintain his physical strength. Dennis is a robust member of the PACE community, and serves as President to the Participant Advisory Committee.

Opportunities for PACE Growth -- Eligibility

PACE has seen significant growth in recent years, including a 30 percent increase in the number of people receiving services over the last three years alone. That said, we believe that PACE can play an even larger role in the health and long-term services and supports delivery system, and have identified several policy initiatives that could promote PACE growth and innovation.

PACE eligibility is currently restricted to individuals 55 or older who have been designated by their states as requiring a nursing home level of care. It is our belief, however, that others would benefit from the PACE model of care, including younger individuals with physical disabilities, individuals with intellectual or developmental disabilities, and older individuals who have chronic care needs but are not yet nursing home eligible. The current health care delivery system is ill-equipped to meet the needs for these individuals, resulting in myriad physical, social and attitudinal barriers to quality health care. For

example:

- 31 percent of individuals with disabilities rank their health as fair or poor, compared to 7 percent of people without a disability.ⁱ
- Individuals with disabilities are at far greater risk for chronic diseases such as diabetes, HIV/AIDs and depression.ⁱⁱ
- Individuals with disabilities experience higher incidences of unhealthy behaviors, including obesity, sedentary lifestyle, cigarette use, and substance abuse.ⁱⁱⁱ
- Women with disabilities experience significant physical and attitudinal barriers to routine gynecologic and reproductive health care. According to one study, women with disabilities were 24 percent less likely to have received a Pap test during the previous year than women without disabilities and were nearly three times more likely than women without disabilities to have postponed needed medical care.^{iv}
- Health care providers are poorly trained to meet the needs of individuals with disabilities. They often hold inaccurate or stereotypical perceptions about people with disabilities, make judgments about individuals' quality of life, or fail to make their facilities, clinics, diagnostic tools and exams accessible.

The PACE eligibility restriction is an arbitrary age limit that puts better care out-of-reach for far too many families. To illustrate this point, I wanted to share with you the story, published in a series by the Newport News Free Press, of a family who is struggling at the hands of our inadequate health and long term care system:

Jim G. is a 54 year old Virginia resident who was diagnosed with early-onset Alzheimer's disease. Although Jim was initially enrolled in clinical trials to combat his illness, he recently ceased all treatment as his memory – and his health – deteriorated. He tried to enroll in the local PACE program, but was unable to because Jim did not meet the age requirements.

Jim was hospitalized in 2014 for a lung infection caused by "silent aspiration", which occurs when the swallowing function is weakened by Alzheimer's. A once vibrant athlete, Jim lost almost 40 lbs.

Initially, Jim stayed home alone during the day, where he was isolated and struggled with activities of daily living, such as personal grooming, household chores, and child care.

Karen struggled to care for Jim and tend to her school-aged children, while also holding down a full time job, but eventually had to quit her job to care for him full time. Unfortunately, Karen discovered that his needs were more than she could handle. Following a psychotic break and a week as a psychiatric inpatient, Jim was permanently placed in a memory care unit near their home. Karen had to use "crowd-sourcing" to raise funds for Jim's treatment.

This heartbreaking situation might have been avoided had Jim been able to enroll in PACE. Jim could have received day-time support that would allow him to continue to live at home with his family. He could have received therapies to help him stay physically strong, and primary care to help avoid silent aspiration and other health complications. PACE has significant experience with dementia, and might have been able to avoid or better managed his psychiatric deterioration. And Karen and her family would have received much needed respite services, emotional and social support, and peace of mind, perhaps helping her maintain her employment.

The PACE Innovation Act of 2015 would help Jim and others like him by allowing CMS to test and adapt the PACE model to support individuals with complex chronic illnesses and disabilities by better integrating the health care and long term supports on which they rely. The following are benefits that this model can offer to consumers, families, and policymakers:

- **Access** to team based, disability competent care for an underserved, high cost population.
- Improved **care coordination with timely and accessible primary care** reducing unnecessary emergency, inpatient and long term care utilization.
- **Reduced nursing home utilization** enabling nursing home eligible individuals to live independently in the community.
- **Compliance with Olmstead** by providing new, less restrictive settings for significantly disabled persons.
- Competent, consistent and **quality attendant care services** for activities of daily living.
- **Social network of care** with innovative physical and virtual day programs to enhance independence and employability.
- **Extensive use of adapted technologies** – computing, telehealth, social networking, environmental controls, mobility – to increase independence, provide enhanced abilities at reduced cost.
- **Significant savings to Medicaid and Medicare** – greater than \$20M per year for 300 members of the program.
- **Relocation of individuals from nursing homes** into community setting by partnering with state and local housing organizations to fund development of accessible, affordable and safe housing.

By supporting policies that allow for PACE growth, innovation and expansion, Congress can be assured that they are supporting a proven, cost-effective care model that will help achieve the goal of better care coordination for Medicare beneficiaries with chronic illness.

Opportunities for PACE Growth – Program Development and Operational Flexibility

In addition to the eligibility limitations identified above, PACE's current regulatory framework often stifles PACE development, innovation and growth.

Opening a PACE program involves a lengthy and bureaucratic process, where PACE sponsoring organizations must navigate a complex maze of state and federal requirements and make significant capital investments before it can start enrolling participants. This cumbersome process exists for both the development of new programs as well as the growth of existing programs. In total, the PACE application process takes 18-24 months and can cost \$4 - \$6 million.

Similarly, PACE organizations must adhere to myriad, cumbersome, sometimes vague regulatory requirements. For example, PACE organizations cannot contract with community-based physicians or Alternative Care Settings to provide services. The requirement that participants see only PACE physicians – and therefore leave their family physician – may discourage some beneficiaries from enrolling in PACE. Similarly, if a PACE organization reaches capacity in one location, it must spend \$4 - \$6 million to construct a new PACE center rather than contract with a local adult-day health center or senior center. Other regulatory requirements place similar burdens on PACE organizations, often with little benefit to the beneficiary or the taxpayer.

Unfortunately, PACE regulations have been unchanged since 2006. Although NPA and Congress have sought regulatory changes for many years, CMS has not adhered to its own timeline for updating PACE regulations. In its fall 2012 *Regulatory Agenda*, CMS published that a Notice of Proposed Rulemaking to revise the PACE regulation would be issued in July 2013. Since then, this deadline has been extended to December 2013, again to August 2014, then to spring 2015 and is now set for fall 2015. The lack of a revised PACE regulation constrains PACE organizations' ability to grow, increases costs, and limits PACE organizations' ability to offer beneficiaries access to a proven model of care.

Closing

Simply put, helping people get the care they need at home with the love and support of their family members and friends makes sense. Integrating medical care and community based long term services and supports also makes sense. These are two truths that the PACE program has known and applied for over 25 years to the care of people age 55 and older who need a level of care comparable to a nursing home but who wish to continue their lives at home.

It is time to build on this foundation and extend its effective delivery system to additional people through a pilot program. The PACE Innovation Act does this. Through the act, the PACE model can be adapted to serve people under the age of 55 and people at risk of needing a nursing home level of care. People like a woman with early onset Alzheimer's, or a younger person with physical disabilities, or a person with an intellectual or developmental disability.

While the differences in each of these individual's needs may be significant, the shared challenge of accessing effectively integrated and coordinated medical and long term services and supports is compelling. We can build a more effective delivery and financing system to serve these vulnerable populations. With your support the PACE Innovation Act and the pilots can help to show the way.

Thank you for the opportunity to address the committee on these important matters.

ⁱ Seth Curtis and Dennis Heaphy, Disability Policy Consortium: Disabilities and Disparities: Executive Summary (March 2009).

ⁱⁱ *Ibid.*

ⁱⁱⁱ *Ibid.*

^{iv} National Council on Disabilities "The Current State of Health Care for People with Disabilities."
<http://www.ncd.gov/publications/2009/Sept302009#Health%20Status>