

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

July 10, 2018

Representative Frank Pallone
Minority Leader, Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, D.C. 20515

Dear Representative Pallone,

Justice in Aging submits the following comments in response to the discussion draft of *The Medicare Long-Term Care Services and Supports Act*, released on May 2, 2018. We appreciate your leadership on long-term care and are grateful for this opportunity to provide feedback on your proposal to address the important issue of providing a federal long-term care benefit to older adults and people with disabilities.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults. We use the power of law to fight senior poverty by securing access to affordable health care, economic security and the courts for older adults with limited resources. We have decades of experience advancing policies that ensure Medicare and Medicaid meet the needs of low-income beneficiaries, especially those dually eligible for both programs. We bring our expertise in Medicaid long-term care and Medicaid's intersections with Medicare to our advocacy for expanded access to home and community based services (HCBS) for older adults and people with disabilities.

As the number of older adults increases and a growing share of them are aging into poverty, the need for publicly financed long-term care is also rising. Ensuring that we have a system that can sustain this growth and meet the needs of the changing demographic is critical. We greatly appreciate your recognition of this enormous need and, more importantly, your initiative to address it. We support the framework and principles outlined in the *Medicare Long-Term Care Services and Supports Act* ("the Act") as a significant and important step that we must take to address our nation's growing long-term care needs.

Our comments first address specific sections of the Act, followed by additional concerns and recommendations for achieving long-term care solutions.

I. Specific Provisions in the *Medicare Long-Term Care Services and Supports Act*

A. Section 1. Purpose

We strongly support the concept of adding a long-term services and supports (LTSS) benefit to the Medicare program. As the Act outlines, including an LTSS benefit in Medicare would help older adults and people with disabilities maintain their independence, while addressing unmet

WASHINGTON

1444 Eye Street, NW, Suite 1100
Washington, DC 20005
202-289-6976

LOS ANGELES

3660 Wilshire Boulevard, Suite 718
Los Angeles, CA 90010
213-639-0930

OAKLAND

1330 Broadway, Suite 525
Oakland, CA 94612
510-663-1055

long-term care needs and protecting individuals and their families from unbearable out-of-pocket costs. Two out of five older adults who have difficulty with activities of daily living or instrumental activities of daily living or probable dementia report not receiving any assistance. About a third of dual eligible beneficiaries and half of persons of color and older adults who live alone say they do not have help.¹

We also agree with prioritizing the need to alleviate the enormous burden unpaid family caregivers face because we do not have a sufficient long-term care system in this country. Currently, nearly half of Medicare beneficiaries who have high LTSS needs rely solely on unpaid caregivers for help; even those beneficiaries who have some paid help rely on family caregivers.²

So while we urge you to consider ways to address these long-term care issues for all populations, we recognize that addressing them for the Medicare population is a significant undertaking that is both necessary and important. And we agree with doing so through the Medicare program itself.

B. Section 2. Establishment of Long-Term Care Services and Supports Program as Part of Medicare

Eligibility & Certification Process. As noted above, we fully support creating an LTSS benefit in Medicare and agree that all individuals who are eligible for Medicare should also be eligible for this benefit if they are determined to need LTSS. We urge giving more consideration to the assessment process. This component must be designed carefully to ensure that the process properly assesses the wide array of functional limitations persons needing LTSS experience. In particular, we are concerned that the assessment process be designed to fully include individuals with developmental, mental health, and cognitive disabilities such as early stages of dementia.

Self-Directed Cash Benefit. We strongly support the proposal's self-directed cash and counseling model. This approach best supports person-centered care and has been successful in the Medicaid context. Making this a self-directed benefit would also facilitate its integration with Medicaid. Individuals who are dually eligible for Medicaid and Medicare could more easily use a cash benefit to fill in necessary services and supports that are not already covered and avoid having duplicative coverage.

Benefit Amount. We support the proposed benefit floor being the financial equivalent of 5 hours a day of a home health aide. While we recognize that for cost purposes, there will likely need to be a ceiling, we would urge seizing the opportunity to make the benefit generous and flexible enough to meet even the highest needs without the constraints of budget neutrality requirements. We recommend clarifying that the maximum benefit amount for the highest

¹ Commonwealth Fund, Use of Paid and Unpaid Personal Help by Medicare Beneficiaries Needing Long-Term Services and Supports (Nov. 15, 2017), available at www.commonwealthfund.org/publications/issue-briefs/2017/nov/use-paid-and-unpaid-personal-help-medicare-beneficiaries-needing.

² *Id.*

benefit level scaled to functional ability should be no lower than the local average cost of a nursing facility. We also recommend providing for an exceptions process to allow higher benefit amounts for those few individuals who may have LTSS costs exceeding the average cost of a nursing facility. This is especially important to ensure that individuals with very high-cost needs are not forced into institutions because the benefit does not adequately cover their costs to remain in the community.

Waiting Period. Justice in Aging opposes a waiting period or deductible for low-income individuals with LTSS needs. Low-income individuals who are not Medicaid-eligible cannot afford the cost of LTSS or long-term care insurance. Even a modest cash deductible would be a significant strain on a family with income below 250% of the federal poverty level. Right now, many low-income families make significant sacrifices to care for a parent or other family member, and a waiting period or deductible would inhibit relief and perpetuate the economic and health care inequities that these individuals and their families, especially women caregivers, face.

If a waiting period or deductible is necessary to contain costs, we recommend that it be scaled to income and not exceed two years for any income level. Individuals whose household income is less than 250% FPL and who are not eligible for full Medicaid should have no waiting period or deductible. Those with incomes between 250% and 400% FPL should have no more than a one year waiting period.

We also note that some individuals might not apply for the benefit for months or years after onset of their functional limitations. We recommend that the waiting period start on the first day of the month following the eligibility determination date or 90 days after the onset of qualifying functional limitations, whichever is earlier. Such a provision would protect individuals who were not aware of the Part E program. It would also help address issues for individuals who apply when the benefit is first introduced. Social Security policy with respect to determining onset date for disability determinations could be used as a guide. The benefit itself would start after the waiting period ends (or as of the eligibility date if the waiting period was completed before application).

Payment of LTSS Benefits.

- ***Use of Amounts in Account.*** We support the broad range of services and supports the benefit can be used for. In particular, we agree with allowing it to be used for the types of services that Medicaid does not traditionally cover, such as home modifications, that allow individuals to remain in their homes or transition back to their homes after a hospitalization or stay in a nursing facility. We recommend specifying that the benefit could be used for the range of services and supports allowed under the Medicaid Money Follows the Person program, including first month's rent and security deposits for those who are transitioning out of an institution.

We also support the explicit authorization of funds to pay family caregivers for the home care services they provide. One area of concern that we explain more fully below

is ensuring that the availability of family caregivers is not used to diminish the level of benefits an individual is eligible for under Part E or Medicaid.

- **Authorized Representatives.** We agree with including a procedure for allowing authorized representatives to access an individual's benefits and appreciate the explicit requirement that such representatives provide quality services, do not have conflicts of interest, and do not misuse benefits. Justice in Aging has [expertise](#) with the Social Security representative payee program. Particularly relevant to this discussion, we have recently written an issue brief³ about the challenges that arise when nursing facilities or other creditors are the representative. Based on these experiences, we recommend making the Act more explicit as to who can be an authorized representative and the types of beneficiary protections the Secretary must include. For example, we recommend requiring auditing of authorized representatives (see the Strengthening Protections for Social Security Beneficiaries Act of 2018⁴). We are happy to provide further recommendations as you continue to develop this proposal.
- **Supplement, Not Supplant Other Health Care Benefits.** We support the Act's aim to have Part E supplement and not supplant Medicaid benefits for those who are dually eligible. We are concerned, however, about if and how eligibility for Part E benefits would impact Medicaid service planning. For example, individuals eligible for Medicaid may have difficulties showing the necessity of Medicaid services if the Part E benefit is available. As Medicaid is the payer of last resort and considering how Medicaid service authorizations currently operate, it is not clear that Medicaid would automatically disregard the availability of Part E benefits for purposes of Medicaid service planning.

The Act includes explicit disregards for purposes of financial eligibility. We recommend mirroring this explicitness for how Medicaid programs should disregard all or part of Part E benefits in service planning. It is important that this issue be addressed precisely because otherwise Medicaid programs are likely to cite Part E benefits as justification for denying or limiting Medicaid coverage for long-term services and supports. In an analogous situation, for example, Medicaid programs frequently (but improperly) limit benefits by ruling that the needed assistance should be provided by a family member or friend for free, even if the family member or friend is not able or willing to provide the assistance. Justice in Aging has discussed this problem in an issue brief,⁵ and we are available to discuss how to address the issue in this proposal.

³ Justice in Aging, *Skilled Nursing Facilities and Other Creditors Acting as Representative Payees* (Jan. 2018), available at www.justiceinaging.org/wp-content/uploads/2018/01/Skilled-Nursing-Facilities-and-Other-Creditors-Acting-As-Representative-Payees.pdf.

⁴ See Social Security Admin., *Social Security Legislative Bulletin: President Signs H.R. 4547, Strengthening Protections for Social Security Beneficiaries Act of 2018* (Apr. 24, 2018), www.ssa.gov/legislation/legis_bulletin_042418.html.

⁵ Justice in Aging, *Voluntary Means Voluntary: Coordinating Medicaid HCBS with Family Assistance* (May 2016), available at www.justiceinaging.org/wp-content/uploads/2016/05/Voluntary-Means-Voluntary-Coordinating-Medicaid-HCBS-with-Family-Assistance.pdf.

Eligibility for Other Benefits. We agree that the cash benefits paid under Part E should be disregarded when determining eligibility for other federal, state or locally funded assistance programs. We appreciate that the Act makes this explicit, particularly for Medicaid. We note that in addition to the programs listed in Section 2(c)(6)(d), programs such as the Low-Income Home Energy Assistance Program (LIHEAP) and the Lifeline discount phone service program also provide critical support to low-income older adults and families.

We are also concerned about eligibility for locally funded programs such as discount bus passes or other transportation programs. While eligibility is often based on income tax filing, this may vary widely by jurisdiction. Therefore, we recommend further consideration of the interaction between existing Medicaid cash and counseling benefits, as well as other forms of federal cash assistance, and eligibility for state and locally funded assistance. Please let us know if you would like to discuss this issue further.

Advice and Benefit Management Counseling. We want to emphasize the importance of one-on-one counseling accompanying this benefit and strongly support the proposal to assign a counselor to each beneficiary. We also support having the Administration on Community Living be responsible for oversight of the counseling program and coordinating with CMS. We recommend clarifying whether a new LTSS counseling program will be created or whether an existing program or entity will assume this role. We also caution that this kind of counseling about managing money, managing employees, etc. is significantly different from and more involved than helping individuals with their Medicare coverage options. Therefore, a volunteer model, such as the State Health Insurance Assistance Program (SHIP), may not be well-suited. Rather, we recommend Part E follow the best practices in Medicaid cash and counseling models and utilize entities such as Aging and Disability Resource Centers that are specifically trained to provide person-centered counseling in the long-term care context. We also note that counselors will need to have a very strong working knowledge of the state's Medicaid program to help dual eligible beneficiaries coordinate their services.

Aligning Part E with Medicaid. We note discrepancies between the draft Act and the summary document in terms of how much of the Part E benefit would apply towards Medicaid LTSS costs. We agree with the proposal outlined in the summary that dual eligible beneficiaries residing in nursing facilities retain 5 percent of the Part E benefit as a personal needs allowance. With respect to HCBS, the Act states that the beneficiary retains 25 percent of the benefit (p. 25), while the summary states the individual retains 75 percent. Recognizing that an individual living in the community is likely to need to pay for LTSS that Medicaid may not cover such as home modifications or respite care, we recommend that the beneficiary retain a minimum of 50 percent of their Part E benefit to pay for these services.

We also recommend aligning the personal needs allowance amount for beneficiaries enrolled in a PACE program who are not living in an institution with the HCBS amount, not the nursing facility amount. The PACE program falls under the HCBS umbrella and we therefore believe it should be treated similarly for purposes of determining Part E benefits going towards Medicaid LTSS costs.

Finally, we support the Consortium for Citizens with Disabilities recommendation to specify in the Act that all HCBS settings must be in compliance with the Home and Community Based Services Settings Final Rule.

C. Section 3--Financing.

To put LTSS benefits on equal footing with other Medicare benefits, we recommend financing Medicare Part E benefits through an increased Medicare payroll tax and general revenue. We also support consideration of an estate tax as Part E would financially benefit estates, and reinstating other taxes that were rolled back in the Tax Cuts & Jobs Act.

II. Other Concerns

A. Appeals

We recommend that the Act explicitly provide that the right to appeal applies both to the eligibility determination and the benefit level determination. As we have experienced with Part B outpatient observation status, an absence of explicit appeal rights in the statute can mean beneficiaries do not have adequate means to challenge benefits determinations within the existing Medicare appeals processes. We ask for clarification that the appeals process will be incorporated into current Medicare appeals structures, including the full appeals route available for all other Medicare determinations. (The current draft of the Act (p. 4) appears to provide for redetermination and no further steps.) It also is essential that beneficiaries have timely access to the appeals system. Currently the Office of Medicare Hearings and Appeals (OMHA) is underfunded and understaffed, often resulting in waits for Administrative Law Judge hearings that exceed regulatory requirements. OMHA would need additional resources to accommodate these additional responsibilities.

B. Ombuds

We recommend creating an ombuds to help beneficiaries resolve issues with their Part E benefit and to identify and help solve systemic problems. Our experience with the dual eligible financial alignment demonstrations and other programs has shown that having external, unbiased beneficiary support is especially important and useful when launching a new system, as the Act does. Ombuds can also facilitate early resolution of issues, limiting the burden on the appeals system. We further recommend that the ombuds be state-based given the significant amount of coordination that will need to occur between Part E and state Medicaid programs.

C. Interaction with Medicare Advantage

Given that more than one in three Medicare beneficiaries are enrolled in Medicare Advantage (MA) plans, it is important to fully consider how to administer the Part E benefit for these individuals. Although incorporating Part E benefits into an MA plans' responsibilities would allow for coordination with other Medicare services, there is an inherent tension between genuinely self-directed services and managed care plan oversight. In Medicaid, the cash and

counseling model has been employed primarily in the fee-for-service context. We are not aware of models where a full cash and counseling model has operated under the umbrella of a managed care plan.

In states with both Medicaid managed care plans (MCOs) and self-directed care models, current practice varies. California, which has the largest Medicaid personal care program in the nation, represents one end of the spectrum. The state completely carves out its personal care services program, called In-home Supportive Services (IHSS), from the control or administration of the MCOs. IHSS is entirely administered by state and county agencies.

In contrast, many of the financial alignment demonstrations overseen by the CMS Medicare-Medicaid Coordination Office incorporate personal care services within managed care with varying levels of self-direction, though all significantly more restrictive than the proposed fully self-directed cash and counseling model. (See for example the Massachusetts Three-Way Contract.⁶)

CMS approved New York State's Section 1115 Medicaid waiver⁷ to incorporate a self-directed personal assistance program into an HIV Special Needs Plan (HIV-SNP) model. The participants' authority in that model is broad and includes recruiting and hiring staff, verifying staff's ability to perform identified tasks, scheduling staff, evaluating staff performance, verifying time worked and approving time sheets, and discharging staff. The participant does not, however, directly pay providers.

In light of the limited experience, we would urge caution in determining how the cash and counseling model would operate for MA plan participants. We suggest that the Act allow flexibility for experimentation both with carving out the benefit and with incorporating the model within MA. CMS could develop best practices through demonstrations. For any model that permits MA plans to administer Part E benefits for their members, strong safeguards must be included to ensure that standards for assessments and redeterminations are the same as for beneficiaries in Original Medicare. Further, it would be important to ensure that the MA member is able to use Part E benefits to supplement, rather than merely substitute for, needed Part A and B benefits provided by the MA plan. As MA plans have recently received authority to offer a wider range of "supplemental benefits" to members, we may be able to draw upon that experience to develop safeguards to apply to the Part E context.

⁶ U.S. Dept. Health & Human Servs., Contract between HHS Centers for Medicare & Medicaid Servs. In Partnership with The Commonwealth of Mass. and XXX, at 101 (Dec. 28, 2015), available at www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/MAContract12282015.pdf.

⁷ Centers for Medicare & Medicaid Servs., Section 1115 Of the Social Security Act Medicaid Demonstration, New York Medicaid Redesign Team (MRT) Waiver Number 11-W-00114/2, available at www.health.ny.gov/health_care/managed_care/appextension/docs/2016-12-07_renewal_stc.pdf.

D. Oversight of suppliers

While we support the broad range of services and supports this benefit could pay for, we note that this brings along with it the potential for fraud by suppliers. In Medicaid, self-direction has mostly been limited to directing personal care aides—hiring them, training them, deciding what tasks they will do, and paying them. With the Medicare Part E benefit, individuals could use the benefit to pay for things like durable medical equipment and home modifications. Given the wide range of items and services covered, requiring suppliers to enroll with Medicare seems impractical. It would severely limit beneficiaries' access if they could not hire a handyman to install grab bars or purchase those grab bars at the local hardware store.

Therefore, we do not propose a provider enrollment system beyond that already in place in Medicare but, instead, recommend that the proposal include standards and auditing procedures to check for fraud, including through the counseling provided to beneficiaries. Most importantly, beneficiaries and benefits counselors will need to be educated. An ombuds, as recommended above, could help beneficiaries resolve issues with suppliers and identify and help solve systemic problems.

III. Additional Long-Term Care Solutions

We appreciate the proposal's explicit recognition that a Medicare LTSS benefit is not intended or expected to provide LTSS coverage to every population and that Medicaid and many other programs that currently exist would both support and be supported by such a benefit. We agree that Medicaid will remain vital to individuals who do not qualify for Medicare Part E as well as for those who are dually eligible for Medicare. Therefore, we ask that you consider, alongside creation of this benefit, measures to strengthen Medicaid and ensure that it can continue to provide comprehensive coverage and financial protection for those with the lowest incomes and the greatest needs.

First, we recommend ensuring that states use Medicare Part E funding received for providing LTSS to dually eligible individuals to improve and expand their Medicaid HCBS. We see this as an opportunity to further ongoing efforts to reduce Medicaid's institutional bias and strengthen HCBS infrastructure. While Money Follows the Person, the Balancing Incentives Program, Community First Choice, and other programs have helped states enhance access to HCBS, the progress has been slower among older adults at the same time the need has been increasing. The vast majority of older adults say they want to age in place, but the HCBS capacity is not yet there to meet this need.

Therefore, we support the Consortium for Citizens with Disabilities' recommendation that the Act incentivize states to provide more and better HCBS by tying receipt of Part E benefit dollars to meeting HCBS standards. For example, states could be required to cover HCBS through state plan options to eliminate waiting lists in order to receive Part E dollars. Additionally, states that implement Community First Choice program standards for all HCBS could receive a higher share of the benefit.

Second, we recommend that spousal impoverishment protections be made permanent for all individuals regardless of whether they are receiving care at home or in an institution. The Affordable Care Act's extension of impoverishment protections to spouses of individuals receiving HCBS has helped many low-income older adults avoid having to choose between getting necessary community-based LTSS and keeping their spouse out of poverty. It is critical to make sure this protection continues so that dually eligible individuals with the greatest LTSS needs can remain in their own homes and communities without jeopardizing the financial well-being of their spouse.

Third, Medicaid should be able to pay for the services and supports individuals need to move out of institutions and into the community by making the Medicaid Money Follows the Person program permanent. While the proposed Medicare benefit should assist with these transitions, it is important that all individuals, including those who are only eligible for Medicaid, living in institutions can return to the community.

Finally, while we realize this proposal is designed to complement other mechanisms for providing long-term care, we are concerned that limiting eligibility to those who are entitled to (or enrolled in) Medicare Part A and those who are entitled to Social Security Disability Insurance (SSDI) would not cover some individuals who already have difficulty accessing LTSS because they are not eligible for many state and federal programs and cannot find or afford long-term care insurance. This includes low-income individuals without sufficient work history who do not qualify for Supplemental Security Income (SSI) or Medicaid, such as immigrants who have not met permanent residency requirements. We recommend considering ways to provide a federally supported LTSS to these individuals, through, for example, expanding Medicaid buy-in.

IV. Conclusion

Thank you again for your leadership and the opportunity to submit comments on this important proposal. We look forward to continuing the discussion and working with you to expand and improve LTSS to serve everyone in need, especially low-income older adults. If any questions arise concerning this submission, please contact me at jgoldberg@justiceinaging.org.

Sincerely,



Jennifer Goldberg
Directing Attorney