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November 30, 2022

Alison Barkoff
Acting Administrator and Assistant Secretary
for Aging
Administration for Community Living
330 C St SW
Washington, DC 20201

SUBMITTED ELECTRONICALLY VIA <https://acl.gov/CaregiverStrategy/Comments>

Dear Acting Assistant Secretary Barkoff:

On behalf of ADvancing States, I am writing to provide comments on the first-ever National Strategy to Support Family Caregivers. ADvancing States is a nonpartisan association of state government agencies that represents the nation's 56 state and territorial agencies on aging and disabilities. We work to support visionary state leadership, the advancement of state systems innovation, and the development of national policies that support home and community-based services for older adults and persons with disabilities. Our members administer a wide range of services and supports for older adults and people with disabilities, including overseeing Older Americans Act (OAA) programs and services in every state. Together with our members, we work to design, improve, and sustain state systems delivering long-term services and supports (LTSS) for people who are older or have a disability and for their caregivers.

We wish to extend our congratulations to the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving and Supporting Grandparents Raising Grandchildren (SGRG) Advisory Councils, the Administration for Community Living (ACL) Office of Supportive and Caregiver Services, and everyone else who supported this accomplishment. After reviewing the Strategy among our staff and with our members, we have compiled the most important topics we believe the Advisory Councils should focus on and offer recommendations for the next iteration of the Strategy. We are appreciative of the opportunity to submit comments; they are organized by component document, followed by global comments.

First Principles

We agree that to foster consistency in policy change, certain measures must be viewed as foundational. We support the thoughtful inclusion of the four cross-cutting considerations across the Strategy's outcomes. Having essential practices for person-centered/family-centered planning, trauma-informed care, diversity, equity, and inclusion (DEI), and workforce challenges organized in a concise, accessible manner to reference will be useful as states develop any future policy or program concerning care recipients and caregivers, including plans on aging and integrated care systems.

It should be of no surprise that workforce issues are of particular concern to our members. States continue to grapple with a direct care workforce crisis that intersects with all aspects of family caregiving. It is critical to recognize all the different factors involved in meeting the needs of family caregivers. Overall caregiver wellbeing is inextricably linked to the improvement of conditions, pay, and career pathways for paid caregivers, and bold leadership is crucial at this moment.

Federal Actions

- Good policy is informed by robust evidence. ADvancing States strongly encourages the Administration for Community Living (ACL) to expand funding to grow the evidence base for caregiver supports, especially respite. Presently, there is a need for further research into access, quality, and efficacy of both formal and informal respite. Considering the COVID-19 pandemic and ongoing direct care workforce crisis, an expanded evidence base on informal respite is especially needed.
- We additionally encourage Congress to provide appropriations of no less than \$50M to support the Older Americans Act (OAA) Research, Demonstration, and Evaluation Center. The 2020 OAA reauthorization increased research and evaluation capacities and responsibilities at ACL. Our members were very supportive of this proposal, as we believe that the true value and outcomes of OAA services are often challenging to demonstrate with current available research. However, the reauthorization did not provide a dedicated source of funds for the new research center at ACL.
- ADvancing States strongly recommends that Congress continue to expand investments into the OAA's National Family Caregiver Support Program. Over the coming decades the number of caregivers is set to increase considerably. Not only is the caregiver population growing, it is also getting younger. Expanding and sustaining the program will have generational effects.
- Additionally, as states continue to develop State Plans on Aging, further support would be welcomed by state agencies. Guidance from the ACL on how states can incorporate elements of the Strategy to align with their plans on aging and other caregiver initiatives,

including support establishing public-private family caregiver coalitions, would be appreciated.

- A crucial component of a national strategy must be a more comprehensive picture of caregivers and the caregiving experience in the United States. For this reason, states are strongly supportive of federal efforts to update the Behavioral Risk Factor Surveillance System (BRFSS) Caregiving Module, and of submitting BRFSS caregiving questions to other national surveys by 2024.
- For the next iteration of the Strategy, we encourage the Department of Health and Human Services (HHS) to expand participation by federal agencies. For example, encouraging the adoption of caregiving-friendly practices is in line with the goals of the Department of Commerce's 2022-2026 Strategic Plan. The Department of Agriculture's (USDA) cooperative extension program has considerable reach and could be used in a national awareness campaign. Additionally, we support the inclusion of a national campaign to raise awareness about caregivers, but little detail is provided in the 2022 Strategy on what funding is necessary and who should be leading that effort.
- We also ask HHS to consider what state level Medicaid and OAA initiatives or innovations might be able to be expanded at the federal level into demonstration programs and potentially scaled across the country.
- We urge the Centers for Medicare and Medicaid Services (CMS) to expand Medicaid 1115 waivers that allow supports to unpaid caregivers, using Washington State's Tailored Supports for Older Adults (TSOA) as a template. TSOA provides limited, targeted, services to unpaid caregivers of individuals who are at risk of needing more comprehensive LTSS. TSOA also establishes a new eligibility category to ensure that preventive benefits are available for individuals who would not otherwise receive Medicaid supports.
- We also ask CMS to provide states with the option to waive estate recovery for LTSS participants, as this policy can result in individuals delaying enrollment into HCBS and placing more strain on family members. Estate recovery should be an option, not a mandate, for states to implement.
- Another important consideration for caregiver supports is that Medicaid is not the primary source of care for many older adults and people with disabilities and other sources of funding, such as the OAA and the Caregiver Respite Program, are limited programs without sufficient resources to meet the need of all participants. We encourage HHS to expand the availability of caregiver supports beyond these current targeted options. Examples of how this could be accomplished include CMS expanding Medicare's Supplemental Benefits for the Chronically Ill (SSBCI) to include important caregiver supports in order to delay or prevent enrollment in Medicaid LTSS. We further encourage CMS to expand SSBCI to individuals in fee-for-service Medicare in addition to Medicare Advantage. Similarly, HHS should work with private health insurers to encourage and,

where possible, look to include regulatory language to increase provision of supports to caregivers in commercial plans. One such option could be through leveraging the rehabilitation and habilitation benefits within the Essential Health Benefits package to support a caregivers' efforts to assist their loved one regain lost or obtain new functionality.

- We believe that regulatory complexities in Medicaid are also creating unnecessary barriers and delays to care for caregivers. For example, CMS currently requires that participants exhaust all state plan services before accessing any HCBS waiver services. Unfortunately, due to the structure of programs, processes for provider enrollment, service authorizations, and regulatory requirements, this can create significant gaps in coverage and barriers to care. For example, Medicaid state plan personal care services are statutorily barred from reimbursing family members for care; however, waiver services are not. This can create barriers as individuals must demonstrate that they do not have any available providers prior to accessing supports from a family caregiver. Similarly, state plan services can only provide emergency and nonemergency medical transportation, whereas waivers can provide nonmedical transportation. Coordinating across multiple transportation providers based on the nature of the destination created unnecessary stress on caregivers and barriers to services.
- Finally, we suggest CMS expand the option to pay family members who provide personal care services under section 1905(a)(24) of the Social Security Act. Current policy allows states to pay for extraordinary care delivered by legally responsible individuals in 1915(c), (i), (j), and (k) programs but prohibits payment under 1905(a). This creates fractured delivery systems and confusion amongst participants and their caregivers. A coordinated policy for paying family members, regardless of the section of the Act that authorizes the personal care, would improve program delivery.

Global Comments

- As you know, pre-pandemic there were growing challenges for the paid direct care workforce that is critical to serving older adults and individuals with disabilities in their homes and communities. The pandemic greatly exacerbated these challenges and structural issues, and it is not catastrophizing to say that the situation has reached crisis levels. We urge the federal government to consider what flexibilities or tools it can leverage to support states, community-based organizations, providers, and ultimately direct care workers during these difficult times.
- At time of submission of these comments, numerous states reported they are still dissecting and analyzing the various Strategy documents, and so direct state feedback was somewhat limited. In the future, ADvancing States recommends opening the comment

period up following a longer wait period after the release of the Strategy. This would allow for more robust feedback from States and their stakeholders.

- The Strategy represents an important first step and a call to action. It is unclear, however, who will lead this effort. A national strategy should include a leader within the federal government charged with implementing the Strategy; it is less clear at this point who that might be. Additionally, federal funding of state-level caregiver support leadership positions — similar to ombudsmen — could be impactful in coordinating a national strategy while preserving state autonomy.
- USAgings and Advancing States were both left off of the Focus Groups and Key Informant Interviews section of report, despite both participating in some of these efforts and working closely with the National Academy for State Health Policy (NASHP).

Once again, we offer our congratulations on the completion of this important and historic first step. We appreciate the opportunity to offer comment and look forward to continued partnership on these issues. If you have any questions regarding this letter, please feel free to contact Adam Mosey at amosey@advancingstates.org or 202-499-5951.

Sincerely,



Martha Roherty
Executive Director
Advancing States