

May 5, 2023

Jessica Schubel
Special Assistant to the President for Health Care
Domestic Policy Council
Eisenhower Executive Office Building
1650 Pennsylvania Avenue, NW, Room 464
Washington, DC 20501

Via email to: jessica.l.schubel@who.eop.gov

Dear Ms. Schubel:

The National Academy of Elder Law Attorneys are national leaders in advocacy for older adults, people with disabilities, and their families. We are writing to express our support for the President's April 18 "Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers," and to encourage swift implementation of the of the directives outlined therein.

The National Academy of Elder Law Attorneys (NAELA) is the only professional, non-profit association of attorneys that conditions membership on a commitment to the Aspirational Standards for the Practice of Elder and Special Needs Law Attorneys. Extending beyond the benchmark set by the American Bar Association's Model Rules Professional Conduct, these standards recognize the need for holistic, person-centered legal services to meet the needs of older adults, people with disabilities, and their caregivers. Supporting the dignity and independence of these vulnerable populations is at the center of what we do.

NAELA firmly agrees with the Biden-Harris Administration that high quality long-term care is critical to our nation's economic growth and security, and essential to helping older Americans and people with disabilities live, work, and participate in their communities with dignity. We also strongly agree that supporting both professional and family caregivers through improved job quality and better access to supports and resources is central to the goal of enhancing access to high-quality long-term care.

This letter reflects the subject matter expertise of our members, particularly the Federal Advocacy Committee and Board. Although NAELA supports the overall aims of the Executive Order, the comments below are particularly relevant to NAELA's mission, with a focus on advocacy for older adults and persons with disabilities.

Medicaid Home-and Community-Based Services

NAELA strongly supports the directives aimed at improving access to Medicaid home-and community-based services (HCBS). These include a directive to the Secretary of the U.S. Department of Health and Human Services (HHS), through the Centers for Medicare & Medicaid Services (CMS) Administrator, to issue guidance to states on ways to use enhanced funding to better connect HCBS workers who provide services to Medicaid beneficiaries; as well

as a directive to the Secretary to consider rulemaking to improve access to Medicaid HCBS and, as part of any such rulemaking, taking steps to support provider participation in Medicaid HCBS programs.

Medicaid HCBS are among the most important supports offered to older adults and people with disabilities. Today, HCBS accounts for half of all Medicaid LTSS spending and there are numerous pathways available for states to offer these services. Despite this progress, the underlying Medicaid statute – which allows HCBS as an optional benefit but requires nursing facility services as a mandatory one – still biases the program toward institutional care. For example, as the Committee notes, states facing budget constraints are more likely to reduce HCBS services, cap participation (i.e., institute waitlists) or otherwise ration HCBS benefits rather than reducing mandatory services such as institutional care.

As a result, individuals often fail to qualify for HCBS, find that no or inadequate HCBS exists in their area if they do qualify, or the process to get HCBS takes too long to prevent unnecessary institutionalization. Too many individuals with disabilities and older adults end up in institutional settings when they could otherwise receive services in, and remain valued members of, their home or their community.

We acknowledge and appreciate the Biden-Harris Administration's commitment to improving access to HCBS, and the numerous actions it has taken to advance this goal. For example, we firmly support many of the proposals in CMS's recently released notices of proposed rulemaking (NPRMs), *Ensuring Access to Medicaid Services (Access NPRM)* and *Managed Care Access, Finance, and Quality (Managed Care NPRM)*. Even so, we believe that more can be done to remove barriers that keep people with disabilities from living up to their full potential and contributing to their communities. We have identified several opportunities to do so, which we ask the Council and HHS to consider as they contemplate future policy on this issue.

- 1) Streamline complicated spend-down rules to provide increased access to HCBS. Several states have complicated spend-down rules that make it impossible for seniors and individuals with disabilities to access HCBS without bankrupting themselves.
- 2) Make HCBS services a mandatory Medicaid benefit and end the institutional bias.
- 3) Offer additional federal support for state investments in HCBS programs, coupled with strong program integrity safeguards.
- 4) Make permanent the Money Follows the Person program to support individuals that want to transition out of a nursing home back into the community.
- 5) Expand the role of presumptive eligibility in reducing institutionalization.
- 6) Permanently extend Medicaid spousal impoverishment protections to balance the rights of the beneficiary to choose their care setting (institution or home/community) with the financial needs of the community spouse.
- 7) Consider additional policies that have been identified as likely to advance HCBS, including targeted approaches to address workforce challenges, strategies to promote affordable housing, and efforts to increase awareness among Medicaid beneficiaries and providers about HCBS options.

Supporting Family Caregivers

NAELA additionally supports the Executive Order's directives aimed at supporting family caregivers of beneficiaries of Federal health care programs and services. These include a

directive to the Secretary of HHS to “take steps to ensure that hospitals are actively involving family caregivers in the discharge planning process...including by promoting best practices such as partnerships with community-based organizations and using resources from the Administration for Community Living and the Agency for Healthcare Research and Quality;” and a directive to “increase beneficiary communications and support family caregivers by increasing promotion of the option for Medicare beneficiaries to choose to give family caregivers access to their Medicare information via 1-800-MEDICARE and the State health insurance assistance program networks.”

[AARP reports that unpaid family caregivers provided \\$600 billion worth of care in 2021](#). NAELA believes that the involvement and empowerment of family caregivers is essential to ensuring the quality of care provided to beneficiaries of federal health programs. Caregivers and other stakeholders need access to educational materials regarding available health care options, decision-making tools, available supports, and other resources. Unpaid family caregivers not only play critical roles in administering day-to-day task-based care, but they are also involved in healthcare and financial decision-making that demands greater support, resources, and education to fulfill these responsibilities.

Stakeholder Engagement

Finally, NAELA strongly supports the Executive Order’s directive to the Secretaries of relevant agencies to prioritize engagement with family caregivers, guardians, and other relatives with care responsibilities; individuals receiving long-term care; State and local care experts; care providers and workers; employers; labor unions; and other key stakeholders. We firmly agree with the Biden-Administration that prioritizing the voices of those most directly involved will help improve the delivery and design of Federal care assistance and ensure that programs work better for families, the care workforce, and people seeking care.

Conclusion

We thank the Biden-Harris Administration for its commitment to ensuring that high-quality long-term care is available and accessible, and that caregivers are supported, and for its thoughtful consideration of the important issues discussed in the Executive Order. We appreciate this and future opportunities to work with the Biden-Harris Administration. We welcome the opportunity to engage with you on our policy suggestions and priorities moving forward. If you have any questions or would like to set up a discussion, please reach out to Michael Knaapen, NAELA’s Director of Public Policy and Alliance Development, at MKnaapen@naela.org.

Sincerely,

Marielle Hazen, esq.
Shari Polur, esq.
Co-chairs of the NAELA Federal Advocacy Committee