

NAELA Comments on the [2022 National Strategy to Support Family Caregivers](#)

Submitted via ACL.gov

What are the three most important topics/issues for the Advisory Councils to focus on moving forward?

We, the National Academy of Elder Law Attorneys (NAELA), are committed to advancing holistic, person-centered services to meet the needs of older adults, people with disabilities, and their caregivers. From this perspective, we ask the Advisory Councils to focus on:

- 1) Ensuring that all stakeholders (including caregivers) have access to high-quality education and resources necessary for making important and difficult decisions about their or their loved ones' future.
- 2) Educating all stakeholders on policy changes needed to better support caregivers and achieve the goals outlined in the strategy.
- 3) Ensuring accountability and transparency as the strategy is being developed and refined.

Are there issues that are not covered in this component that should be addressed in future updates?

In future updates, the Advisory Councils should address, to a greater degree, the issue of decision-making, including guardianship and various less-restrictive alternatives. Guardianship should be a last resort. Caregivers and other stakeholders need access to educational materials regarding alternatives to guardianship, including supported decision-making, durable powers of attorney, advance directives, default health care decision maker provisions in state law, trusts, representative payee arrangements, and other available legal and social mechanisms for decision-making. States should be encouraged to establish a task force, including judges, advocates and consumers, to review state laws and make recommendations regarding needed revisions to state guardianship laws to encourage limited rather than plenary guardianship orders, require the alleged incapacitated person to be involved in decisions or supported decision making to the greatest extent possible, and to evaluate other strategies to maximize the alleged incapacitated person's autonomy and independence. State courts should develop training materials for judges regarding the need to limit the scope of guardianship orders to address the particular needs of the alleged incapacitated person and to grant the guardian powers only in those areas in which the alleged incapacitated person lacks decision making capacity.

Additionally, the Councils should expand on their current discussion of affordability in long-term care by focusing on Medicaid eligibility and enrollment issues. Long-term care (other than through Medicaid) is unaffordable to the vast majority of Americans. Compounding the problem, people who are eligible for Medicaid are too frequently denied due to procedural deadlines and requirements that are difficult, if not impossible, to meet. These issues are well-documented. NAELA has recommended that CMS take several steps to ensure fairness in eligibility determinations and redeterminations, including but not limited to:

- 1) Expand the deduction of prospective expenses for medically needy eligibility
- 2) Align Non-modified adjusted gross income (MAGI) enrollment and renewal requirements with MAGI Policies
- 3) Expand beneficiary protections and timeliness requirements for acting on changes in circumstances
- 4) Extend the length of time that beneficiaries have to respond to requests for additional information needed for eligibility determinations and redeterminations
- 5) Create additional protections around returned mail
- 6) Improve fairness in information requests by providing clarity on the standard of proof needed to verify eligibility.

Moreover, we ask the Councils to devote attention to the need to end Medicaid estate recovery – an unfair policy that prevents families from achieving upward mobility and disproportionately affects people of color, while offering only modest benefits for states.

Finally, the Councils should devote additional attention to the importance of Medicaid home-and community-based services (HCBS) and ending Medicaid’s institutional bias. 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:

- 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.
- 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 in order to promote individual choice to receive HCBS, while still ensuring that spouses are cared for.
- 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.

If you have additional comments on any aspect of the Strategy, please provide them below

As advocates for older adults, people with disabilities, and their families, we strongly support the goals, actions, and key outcomes outlined in the National Caregiving Strategy. We share ACL’s commitment to strengthening the care infrastructure and ensuring that caregivers are supported. In addition to our written comments, we welcome the opportunity to engage with you on these issues. If you have any questions or would like to set up a discussion, please contact Michael Knaapen.

