

**ADVOCACY PRIORITY:
HOME AND COMMUNITY-BASED SERVICES AND
LONG-TERM SERVICES AND SUPPORTS**

Preserve and enhance the dignity, independence, and resources of individuals in need of long-term services and supports (LTSS) by making home and community-based services (HCBS) under the Medicaid program available to every beneficiary and by promoting accountability for long-term care facilities that serve beneficiaries choosing institutional care.

Description

Medicaid is the [primary payer](#) for LTSS, which encompass both institutional care and HCBS. According to the [U.S. Department of Health and Human Services \(HHS\) Assistant Secretary for Planning and Evaluation \(ASPE\)](#), LTSS includes “a range of assistance individuals need to meet their health or personal needs over an extended period. Most LTSS is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called activities of daily living (ADLs), which include such tasks as bathing, dressing, toileting and eating. Health insurance does not cover LTSS costs, and Medicare, the major public insurance program for older Americans, does not cover most LTSS expenses.”

Institutional care offered in nursing homes is an original Medicaid benefit, specified in the enabling statute in 1965. This Medicaid “institutional bias” (i.e., a bias toward institutional care) is rooted in the program’s history and underlying statute. Few vehicles for coverage of LTSS existed outside of an institution until the enactment of Section 1915(c) HCBS waiver authority in 1981. With this option, and the addition of other pathways authorized by Congress, interest in HCBS programs grew. The U.S. Supreme Court’s 1999 decision in *Olmstead v. L.C.* marked a tipping point in efforts by Congress, the states, and the Centers for Medicare & Medicaid Services (CMS) to increase the share of LTSS provided in the home and community.

This policy priority addresses NAELA’s belief that the Medicaid program should eliminate its historic “institutional bias” by maximizing the availability of HCBS. To fully achieve this goal, the income cap and service limitations in Medicaid’s HCBS state plan benefit should be eliminated. This policy priority also calls for “full inclusion in the community,” which can be realized through enforcement of the landmark [Olmstead decision](#), as well as civil rights laws such as the [Americans with Disabilities Act](#) and [Section 504 of the Rehabilitation Act](#).

For individuals who would choose institutional care such as in a skilled nursing facility to obtain LTSS, this priority aims to advocate for public policies that promote accountability for nursing homes in their practices, including those related to payments owed, privacy laws, long-term care ombudspersons, and nursing home admission contracts.

Rationale

HCBS account for only half of all Medicaid LTSS spending — much lower than the demand. Despite slow and steady progress giving states numerous pathways to offer HCBS, 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, states facing budget constraints are more likely to reduce HCBS, 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 exist 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. HCBS waitlists limit access to HCBS, especially for seniors. [According to KFF](#), there are close to 700,000 people on HCBS waiting lists or interest lists in 2023 — a statistic that has not changed materially since 2016.

KFF [estimates](#) that 1.6 million Medicaid beneficiaries use LTSS in institutional settings. To protect the rights of residents and their families, additional accountability measures and oversight are needed for certain practices. For example, according to a recent [Consumer Financial Protection Bureau Report](#), on which NAELA provided comments, some nursing homes require a friend or family member of the resident to sign an admissions contract as a “Responsible Party” during the admissions process. Despite federal and sometimes state laws that prohibit a nursing home from requiring a person other than the resident to assume personal responsibility for any cost of the resident’s care, some nursing homes request, refer to collections, or sue to recover unpaid balances based on these “Responsible Party” contract clauses. These policies intersect with the following areas of elder and special needs law:

- **Elder Justice:** Ensuring access to HCBS promotes elder justice by allowing older adults to receive care in their preferred setting, reducing the risk of abuse and neglect associated with institutional care.

- **Long-Term Care:** HCBS are a key component of long-term care, offering alternatives to nursing homes and institutional settings.
- **Medicaid:** Medicaid funding is crucial for providing HCBS to eligible beneficiaries, making it essential to advocate for expanded access to these services.
- **Health Care Access:** HCBS provide health care access to individuals with disabilities, allowing them to stay in their home.
- **Managed Care:** An increasing number of states are using managed care models to provide HCBS. Managed care allows states to have budget certainty and expand services and populations while achieving efficiencies, but also requires monitoring and oversight by stakeholders.
- **Older Americans Act:** The OAA, if reauthorized and funded, is one strategy to enhance HCBS to beneficiaries through Title III-B of the OAA.
- **Special Needs Planning:** Expanded HCBS provide opportunities for more individuals with special needs to live in the community, and practitioners must consider Medicaid eligibility rules and the availability of HCBS waiver programs when advising and drafting relevant planning documents for individuals with special needs.

Value to NAELA Members and Their Clients

- Advocating for policies that result in reduced waitlists for HCBS will increase attorneys' ability to secure enrollment in these programs for their clients.
- Advocating for improvements to hospital and nursing home privacy policies on disclosing information to third parties about a potential discharge may assist individuals with disabilities should they need their supporter to help in understanding their options for community-based vs. institutional-based treatment settings. If improvements are made to the disclosure process for information provided to third parties, attorneys can more quickly assist clients in securing their preferred care setting.

Legislation and Regulations

- [42 U.S.C. § 1396 et seq.](#): Medicaid statute generally. Also:
 - [42 USC § 1396t](#): Home and community care for older individuals who are functionally disabled
 - [42 USC § 1396u](#): Community supported living arrangements services
- [42 U.S.C. § 1396n](#): Section 1915(c) HCBS waivers.
- [Home and Community-Based Services \(HCBS\) Settings Rule](#)

Recent NAELA Advocacy

- Endorsed [H.R. 7573](#) (Rep. Schakowsky), which bans Medicaid estate recovery; [H.R. 8110](#) (Rep. Dingell), which makes permanent the state option to extend protection against spousal impoverishment for recipients of HCBS; and [H.R. 8109](#) (Rep. Dingell), which makes permanent the Money Follows the Person (MFP) rebalancing demonstration.
- Submitted statement for the Congressional Record for April 30, 2024, House Energy and Commerce Subcommittee on Health [hearing](#), “Legislative Proposals to Increase Medicaid Access and Improve Program Integrity,” which considered H.R. 7573, H.R. 8110, and H.R. 8109.
- Submitted comment letter to House Energy & Commerce Committee in response to 2022 request for information, “Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion,” that discussed a wide range of requests such as making HCBS a mandatory Medicaid benefit; additional federal support for state investments in HCBS programs; making permanent the MFP program; considering the role of presumptive eligibility in reducing institutionalization; extending Medicaid spousal impoverishment protections in promoting individual choice to receive HCBS; and targeted approaches to address LTSS and HCBS workforce challenges, strategies to promote access to affordable housing, and efforts to support shifts in cultural norms and increase awareness among Medicaid beneficiaries and providers about HCBS options.
- Submitted comments in response to recent Ensuring Access to Medicaid Services [final rule](#) to support HCBS reporting and advisory committee standards.

Future Opportunities

- Lobby for legislation making permanent spousal impoverishment protections (e.g., H.R. 8110) for recipients of HCBS, which will expire in 2027.
- Lobby for legislation making MFP demonstration permanent (e.g., H.R. 8109), which will expire in FY 2027.
- Lobby for legislation banning or significantly limiting the number of families that may be subject to Medicaid estate recovery.

The above opportunities represent the most likely advocacy opportunities during this period of a heavily divided (and at times non-functioning) Congress and the last year of the Biden administration. Should the political environment swing toward one end of the political spectrum vs. another, NAELA may either be able to push for more ambitious measures such as an extension of pandemic-relief-era enhanced HCBS funding (set to expire in March 2025), or conversely, need to focus on more “defensive” measures.