

**ADVOCACY PRIORITY:
MEDICAID AND SUPPLEMENTAL SECURITY INCOME**

Advocate for policies that strengthen Medicaid and Supplemental Security Income (SSI), that ensure equitable access to quality health care while safeguarding financial security for individuals with disabilities of all ages, and that limit unfair and inequitable recoveries of benefits.

Description

The continuation and strengthening of Medicaid and SSI eligibility and benefits for NAELA member clients and limiting Medicaid estate recovery is critical to effectively serving clients' financial and health care needs. This priority has three components. First, it focuses NAELA's advocacy on policies that protect continued Medicaid coverage and SSI benefits for older adults and individuals with disabilities of all ages, a population whose medical and daily living needs depend on long-term services and supports available through the Medicaid program and whose financial security often depends on SSI. Second, it focuses on working constructively with policymakers to strike a balance between the importance of continued forward progress on ensuring equitable access to quality health care while protecting existing programs and benefits that individuals with disabilities of all ages rely upon. Third, it focuses on limiting the harm of unfair and inequitable recovery policies on beneficiaries and their families, including Medicaid estate recovery.

Rationale

Protecting Continued Medicaid Coverage and SSI Benefits

"Churn" is an ever-present aspect of the Medicaid program, since covered individuals generally must be redetermined by their state's Medicaid program annually. Today, however, continuation of Medicaid eligibility is particularly challenging (and advocacy all the more important) because state Medicaid programs are working through an 18-month process (known as "Medicaid unwinding") of redetermining eligibility for 90 million individuals nationally after a pause in redeterminations occurred from March 2020 to April 2023. According to KFF, since the start of Medicaid unwinding, more than 21 million people have been disenrolled from Medicaid as of early May 2024, with states reporting renewal outcomes for two-thirds of enrollees so far.

Similarly, certain rules regarding SSI benefits remain outdated, punitive, and overly burdensome on beneficiaries. One example is SSI financial rules governing in-kind support and maintenance (ISM).

ISM rules are unique to the SSI program. No other federal program counts ISM when setting benefit levels.¹ ISM policies are not only administratively burdensome for both the Social Security Administration (SSA) and claimants, they have been identified as a leading cause of overpayments and underpayments by the SSA and others.² The need to reexamine ISM policies has been echoed by the bipartisan Social Security Advisory Board (SSAB), which unanimously recommended simplifying ISM rules, noting that, “Research indicates that these computations significantly complicate administration and lead to many over- and underpayments. For that reason, we suggest a thorough reexamination of the way in which the agency adjusts benefits for ISM.”³

Ensuring Equitable Access to Quality Care While Safeguarding Financial Security for Individuals With Disabilities of All Ages

NAELA is supportive of a broad array of policies that would improve equitable access to quality care across the board. At the same time, NAELA’s primary focus remains protecting the financial security of individuals with disabilities of all ages. Any efforts to expand access to coverage or care, for example, must be done only by taking a “do no harm” approach that safeguards the coverage and access to care that already exists for older adults and people with disabilities and their families.

Advocating for policies reflecting this priority increases the number of individuals with disabilities who can attain supports and quality care while remaining a valued part of their community.

One important example includes NAELA’s advocacy for Medicaid spousal impoverishment protections. The cost of long-term care and the need to spend-down resources and income in order to qualify for Medicaid can rapidly deplete the income and resources of older couples. Spousal impoverishment protections prevent the spouse who is still living at home in the community from being left with little or no income or resources and allow them to live out their lives with independence and dignity. These protections are permanently authorized for those whose spouses reside in a long-term care facility but are set to expire in 2027 for those whose spouses reside in home or community-based settings. NAELA continues to advocate for making these protections permanent, and for other policies that safeguard and strengthen the pathways

¹ SSA Social Security Bulletin, Vol. 74, No. 3. “Source, Form, and Amount of In-kind Support and Maintenance Received by Supplemental Security Income Applicants and Recipients”
<https://www.ssa.gov/policy/docs/ssb/v74n3/v74n3p39.html>.

² SSA’s FY 2022 Agency Financial Report.

³ Social Security Advisory Board Statement on the Supplemental Security Income Program: The Complexity Of In-Kind Support And Maintenance.

to eligibility we have today for older couples and couples of all ages in which one member is disabled.

The breadth of this priority also encompasses discrete advancements in access-related policies, such as reporting and transparency requirements for person-centered care plans, which help NAELA members and their clients enforce and hold accountable the very programs that are intended to serve individuals with disabilities.

Examples of additional access and quality-related topics for ongoing monitoring include:

- Access-related policies specifically relevant to Medicaid home and community-based services (HCBS) or long-term services and supports (LTSS), such as network adequacy monitoring in Medicaid managed care for home health, private duty nursing, and specialist services.
- State access plans and network adequacy requirements for Medicaid managed care more generally.
- Quality metrics and quality reporting systems, including those related to health equity.
- Prescription drug and durable medical equipment affordability.
- Access and quality topics related specifically to the Medicare program.

Unfair and Inequitable Recoveries

Medicaid estate recovery is a congressionally required responsibility under 42 U.S.C. §1396p on state Medicaid programs to seek repayment of specified Medicaid benefits (nursing home care or equivalent HCBS), yet the policy is an anomaly and has several fundamental flaws that harm NAELA member clients. First, it is an [anomaly](#) because no other public benefit program requires that correctly paid benefits be recouped from deceased recipients' family members. Second, the revenue generated by estate recovery is [modest](#) and is far outweighed by the burdens it places on low-income families and communities of color, preventing families from building wealth through home ownership and being able to live safely and securely in their communities. Third, the scope and enforcement of state policies for Medicaid estate recovery vary substantially across states, exacerbating these inequities.

Another recovery policy that may harm NAELA member clients is recovery of overpayments in the SSI program. Overpayment of SSI benefits occurs when a beneficiary receives more benefits than they are entitled to. The overpayment is then recovered in the form of withheld funds from current benefits, often creating substantial financial hardship and uncertainty for clients. Overpayments are common in the SSI program because of the many factors that go into

determining the benefit amount (i.e., income or resource changes, changes in ISM, marriage, becoming temporarily institutionalized in a jail or nursing home, etc.). Often, miscalculations or benefit determinations that are based on incomplete or outdated information are not the fault of the beneficiary; however, recoveries of current benefits can create profound hardship for individuals who depend on those benefits. The SSA has [recently enacted](#) several policy changes which will reduce the harm of SSI recoveries, including reducing the withholding rate so that only 10% (rather than 100%) of the current benefit is withheld, and making it easier for beneficiaries to request and receive hardship waivers.

In NAELA's view, advocating against unfair and inequitable recoveries, raising the SSI asset limit, and improving due process in connection with SSI recoveries can help narrow or eliminate the scope of SSI recoveries or dramatically decrease SSI overpayments in the first place.

This priority intersects with nine areas of elder and special needs law:

- **Elder Justice:** Ensuring access to Medicaid promotes elder justice by allowing older adults, particularly those with limited incomes and from underserved communities, to receive health care services to live with dignity and as much independence as possible.
- **Guardianship:** Medicaid benefits are often managed by guardians for individuals with disabilities, making it important to ensure continuity and prevent unfair recoveries that could disrupt care.
- **Health Care Access:** Medicaid plays a vital role in providing health care access to individuals with disabilities, including funding for essential services and supports.
- **Long-Term Care:** For most Americans who need long-term care, Medicaid is the only affordable option. Therefore, maintaining Medicaid coverage is key to receiving long-term care benefits.
- **Managed Care:** Now that managed care enrolls a far greater number of beneficiaries than traditional fee-for-service Medicaid, it is important to understand the delivery system and how to navigate it effectively for beneficiaries and their caregivers. Managed care plans are also involved in Medicaid estate recovery efforts.
- **Medicaid:** Advocating for continued Medicaid benefits aligns with this priority, as Medicaid is the primary source of health care coverage for many individuals with disabilities.
- **Medicare:** Advocating for policies that improve equitable access to high-quality care aligns with this priority, as Medicare is the primary source of health care coverage for older adults.
- **Supplemental Security Income and Social Security Disability Income:** Advocating for policies that strengthen SSI is a central component of this priority.

- **Special Needs Planning:** Special needs planning documents can allow individuals to continue to qualify for Medicaid. Public policies that allow special needs planning instruments to be used responsibly are key to maintaining Medicaid (and other public benefits).

Value to NAELA Members and Their Clients

- By promoting policies that streamline eligibility and enrollment policies for older adults and people with disabilities of all ages, NAELA ensures that its members can continue to provide valuable legal services without the burden of navigating complex, burdensome, and often lengthy eligibility determination, renewal, or re-enrollment processes.
- By actively supporting policies to eliminate or narrow Medicaid estate recovery and other unfair recovery policies, NAELA helps safeguard client assets from unjust estate recovery claims, preserving their estates for their intended beneficiaries. This advocacy enhances the financial security of both clients and practitioners, reinforcing NAELA (and by extension its members) as a champion for the health and economic well-being of older adults, individuals with disabilities, and their families.

Legislation and Regulations

Title XVI of the Social Security Act Governs the SSI Program

- **Section 1631(b)** governs SSI overpayments and recoveries.
- **20 CFR 416.1130 - 416.1147. In-kind support and maintenance.** Consideration of ISM in determining the SSI benefit amount was part of the SSI program's enactment in the Social Security Amendments of 1972 (P.L. 92-336). Various statutory amendments have been made over time, and the Social Security Administration also periodically makes administrative changes to how it calculates ISM.

Title XVIII of the Social Security Act Governs Medicare

Title XIX of the Social Security Act governs Medicaid

- [42 U.S.C. §1396p](#). **Liens, adjustments and recoveries, and transfers of assets.** Medicaid estate recovery was made mandatory for all states by provision of the Omnibus Budget Reconciliation Act of 1993 pursuant to 42 U.S.C. §1396p(b).

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](#), “Legislation to Increase Medicaid Access and Improve Program Integrity,” which considered H.R. 7573, H.R. 8110, and H.R. 8109.
- Commented on CMS’s November 2023 proposed rule to remove “comparability mandate” (42 CFR 435.601(d)) that would have provided state Medicaid programs with flexibility to adopt income and/or resource disregards in determining Medicaid financial eligibility for individuals excepted from the application of financial methodologies based on MAGI (“non-MAGI” methodologies). CMS did not finalize this proposal in the [April 2024 final rule](#), partially in response to comments from NAELA.
- Commented on SSA’s [August 2023 proposed rule](#) on “Expansion of the Rental Subsidy Policy for Supplemental Security Income (SSI) Applicants and Recipients” in support of applying nationwide the ISM rental subsidy exception that is currently in place for SSI applicants and recipients residing in seven states.
- Commented on CMS’s May 2023 [proposed rule](#) on “Ensuring Access to Medicaid Services” in support of policies that would create enhanced access reporting requirements and strengthen the person-centered care planning process.
- Provided a letter of support for the President’s April 2023 “Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers.”
- Commented on SSA’s February 2023 proposed rule on “Omitting Food from In-Kind Support and Maintenance Calculations” in support of the policy to omit food from ISM calculations.
- Commented on CMS’s September 2022 proposed rule to streamline several aspects of federal requirements regarding Medicaid applications, eligibility determinations (and redeterminations), enrollment, and renewal processes. CMS [finalized](#) many proposals NAELA and others supported.
- Responded to the U.S. House of Representatives Committee on Energy and Commerce (E&C) Republicans September 2022 report and request for information, “Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion,” regarding ways to eliminate waiting lists for HCBS, make coverage options more affordable, and ensure continued access to long-term services while doing no harm to current Medicaid beneficiaries.

Future Opportunities

- With affiliate NAELA Foundation, execute grant from Robert Wood Johnson Foundation that funds research, education, and advocacy on Medicaid estate recovery, beginning August 2024 through April 2026.
- Lobby for legislation banning or significantly limiting the number of families that may be subject to Medicaid estate recovery.
- 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 that would narrow or eliminate the use of ISM in calculating SSI benefits.

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.