REPORT 5 OF THE COUNCIL ON MEDICAL SERVICE (A-25)
Medicaid Estate Recovery Reform
(Resolution 104-A-24)
(Reference Committee A)

EXECUTIVE SUMMARY

At the 2024 Annual Meeting, the House of Delegates referred Resolution 104, which was sponsored by the Medical Student Section and asked the American Medical Association (AMA) to oppose federal or state efforts to impose liens on or seek adjustment or recovery from the estate of individuals who received long-term services or supports coverage under Medicaid. During the development of this report, the Council reviewed the literature on Medicaid estate recovery, met with an expert, and discussed potential reforms. Of note, the Council's deliberations took place at a time of heightened concern regarding potential reductions in Medicaid funding, which would have deleterious effects on state budgets and Medicaid programs.

Because Medicaid estate recovery is not directly addressed in AMA policy, the Council found that new policy is needed and that, given widespread concerns regarding potential federal Medicaid funding cuts, new policy must allow for state flexibility. The Council's recommendations are thus intended to support and encourage meaningful estate recovery reforms without requiring states to abandon the practice. In some states, the return on investment may not be worth the costs of administering Medicaid estate recovery programs; however, states that recoup the most funds may not want to forego that revenue, especially if federal Medicaid funds are reduced. For these reasons, the Council decided not to oppose estate recovery efforts outright. Instead, this report recommends support for specific reforms intended to help maintain Medicaid as a safety net and ensure that long-term services and supports (LTSS) are provided to people most in need.

To acknowledge the variance in estate recovery efforts and allow states more flexibility than they currently have, the Council recommends that the AMA support making Medicaid estate recovery optional, instead of mandatory. This recommendation allows states to decide whether (or not) to continue their estate recovery programs, which is consistent with longstanding AMA policy allowing states some flexibility in implementing their Medicaid programs. When Medicaid estate recovery is pursued, the Council recommends: 1) limiting recoupment to the costs of LTSS and not for other Medicaid services that were provided; 2) standards for hardship waivers that prohibit claims against a sole income-producing asset of heirs, homes of modest value, and any estate less than a specified threshold value; 3) exempting estates from recovery efforts when the value of the recovery is projected to be less than the cost of recoupment efforts; 4) basing estate recovery on the costs of LTSS care when managed care organizations are utilized, instead of the capitation amount, when the cost of LTSS is lower than the capitation amount; 5) providing education regarding state Medicaid estate recovery requirements; 6) screening patients for hardship waivers and assisting them with filing, if eligible; and 7) collecting and making publicly available important data regarding estates that have been pursued and amounts that have been recovered.

REPORT OF THE COUNCIL ON MEDICAL SERVICE

CMS Report 5-A-25

Subject: Medicaid Estate Recovery Reform (Resolution 104-A-24)

Presented by: Stephen Epstein, MD, MPP, Chair

Referred to: Reference Committee A

At the 2024 Annual Meeting, the House of Delegates (HOD) referred Resolution 104, which was sponsored by the Medical Student Section and asked the American Medical Association (AMA) to oppose federal or state efforts to impose liens on or seek adjustment or recovery from the estate of individuals who received long-term services or supports coverage under Medicaid. The Board of Trustees assigned this item to the Council on Medical Service for a report back to the House of Delegates. This report describes federal Medicaid estate recovery requirements, discusses the pros and cons of estate recovery, and makes policy recommendations for future reforms.

BACKGROUND

Since the Medicaid program's inception in 1965, states have been permitted to try to collect repayments for certain Medicaid services after older enrollees had died. In 1982, the Tax Equity and Fiscal Responsibility Act gave states the option to utilize property liens to prevent Medicaid enrollees from evading estate recovery efforts by transferring their homes to someone else shortly before their death. The Omnibus Budget Reconciliation Act of 1993 (OBRA 93) mandated estate recovery efforts targeting certain deceased enrollees who had used Medicaid long-term services and supports (LTSS), including nursing facility services and home and community-based services (HCBS), while allowing states some discretion in how estate recovery programs are implemented. Under OBRA 93, states must attempt to recover payments from the estates of individuals who received Medicaid LTSS when they were aged 55 or older; enrollees of any age expected to reside permanently in long-term care facilities; and, under certain circumstances, individuals with long-term care insurance.[1]

For the age 55 and older group, federal law stipulates that states must pursue estate payments for amounts that are at least equal to the costs of a patient's nursing facility care, HCBS, and hospital services and prescriptions provided while an enrollee was receiving LTSS. States have the option to also pursue estate recovery for the costs of other Medicaid-covered services, except for Medicare cost-sharing assistance that is provided to individuals who are dually eligible for Medicaid and Medicare. According to KFF, 37 states go beyond minimum federal estate recovery requirements and apply recoupment efforts to optional Medicaid services, including 32 states that try to recover the costs of all Medicaid services (as long as LTSS services were provided); 28 states that target some people under age 55; and five states that focus on certain optional benefits.[2]

Generally speaking, and depending on a specific state's policies, elements of an individual's estate that can be subject to recovery efforts include cash, checking and savings accounts, stocks and bonds, remaining funds in certain types of trusts (e.g., Qualified Income Trust and/or Irrevocable

Funeral Trust) and any other items of value, including an individual's home. Life insurance policies are generally protected unless the beneficiary is the Medicaid enrollee's estate.[3]

Federal law also places some parameters around estate recovery efforts. For example, states are not permitted to seek recovery from the estate of a deceased Medicaid enrollee who is survived by a spouse until the spouse has died, and once the spouse has died, states can waive recovery if they determine efforts will not be cost effective. Similarly, states must exempt or defer recovery from the estates of enrollees who are survived by a child under 21 or a child of any age who is blind or has a disability.[4] As such, states may not try to take the homes of deceased enrollees that are occupied by a surviving spouse, child under 21, child of any age who is blind or has a disability, or a sibling who has an equity stake in that home. However, states are allowed to impose liens on the property of enrollees who are receiving institutionalized care and are not expected to return home, unless the home is occupied by the individual's spouse, child under age 21, child of any age who is blind or has a disability, or sibling who has an equity interest in the home.[5] Once survivors have died or a surviving child has turned 21, states can—and often do—proceed with attempting to recoup payments from estates. Pursuant to court judgments, states are also permitted to impose liens to pay for Medicaid benefits that were incorrectly provided.

OBRA 93 required states to establish procedures for waiving estate recovery due to undue hardships, which the Centers for Medicare & Medicaid Services (CMS) has stated could include: 1) an estate that is the sole income-producing asset for survivors (e.g., family farm); 2) a home of modest value, defined as roughly half the average home value in the county; and 3) other compelling circumstances. Although states are not required to implement these particular hardship examples, most (49) have reported adopting at least one of the three, including 35 states that said they use the "sole income-producing asset" criteria.[6] Notably, only 15 states report waiving estate recovery for homes of modest value.[7]

For Medicaid managed care organization (MCO) enrollees who would be subject to estate recovery under fee for service (FFS), states can seek recoupment of MCO capitation payments rather than the costs of Medicaid services that were provided. In states that pursue estate recovery for all Medicaid services, the total capitation payment for the period the individual was enrolled in the MCO must be sought. If the state applies estate recovery to some, but not all services, the state must pursue recoupment of the part of the capitation payment attributed to those services.[8] According to KFF, 30 states report trying to recoup payments for MCO capitation payments which, notably, can exceed the amount that Medicaid had actually spent on the enrollee.

Medicaid Long-Term Services and Supports (LTSS)

LTSS refers to the broad range of clinical health and related services provided to help people who have functional or cognitive limitations with activities of daily living (ADL) when these individuals need extra care either at home or in a facility. ADLs include eating, bathing, dressing, and instrumental tasks like medication management, house cleaning, and meal preparation. LTSS are intended to help individuals with self-care needs over an extended time period, which differentiates them from post-acute services, such as home health or skilled nursing facility (SNF) care, that are designed to help individuals recover after a hospitalization.[9]

Older adults and people living with chronic illnesses and disabilities are among the estimated nine million users of Medicaid LTSS, a figure that includes the 7.8 million enrollees who received HCBS in 2022 and 1.5 million individuals who received LTSS that year in an institutional setting.[10] The significantly larger share of people receiving HCBS reflects a shift over the years in the provision of LTSS from nursing homes and other facilities to home and community settings. Over half (57

percent) of enrollees receiving Medicaid LTSS are under 65, although—not surprisingly—more than two-thirds of individuals receiving institutional care are 65 and older.[11] Importantly, these statistics exclude individuals receiving unpaid LTSS that is generally provided by family members and friends outside of Medicaid, as well as individuals paying for LTSS (including assisted living or nursing home care) out of pocket. Although more people have private long-term care insurance than was the case years ago, in 2021 only about 80,000 people filed claims for such benefits.[12] Of note, insurance coverage for LTSS is profoundly different than coverage for other health care services in that it is quite limited outside of Medicaid and, within Medicaid, LTSS is only available to people meeting strict eligibility requirements who must spend down their income and assets to qualify.

Although nursing facility services are a mandatory benefit under Medicaid, coverage for most HCBS—other than home health—is optional and, therefore, varies by state. Complex eligibility rules regarding income, assets, and functional limitations also vary significantly by state, as do LTSS eligibility pathways. In general, applicants for Medicaid LTSS must "spend down" their income and assets in order to qualify for LTSS, and "look-back" rules are in place to try to keep people from transferring assets to others to become Medicaid-eligible. Although data are somewhat lacking on this topic, analyses have found that advantaged groups are more likely to engage in estate planning to circumvent "look-back" and estate recovery requirements.[13]

As the largest payer, Medicaid covers the costs of roughly 60 percent of total LTSS expenditures in the United States. Additional payments are made out of pocket by individuals and by private long-term care insurers, the Department of Defense, the Department of Veterans Affairs, and state and local governments.[14] In 2022, Medicaid LTSS spending totaled just over $200 billion, which included $129.4 billion for HCBS and $71 billion for institutional care. The average expenditure per user on institutional care was over $48,000, significantly higher than average per-person spending on HCBS ($16,491).[15] Demonstrating the need for LTSS, approximately 700,000 people are on waiting lists for HCBS.[16] In 2020, CBO estimated that, in 2030, $160 billion will be spent on HCBS and $80 billion on institutional care.[17] Recognizing that people are aging and living longer, which will impact the use of and spending for LTSS, the Council on Medical Service has addressed long-term care in this country and presented reports on LTSS financing reforms (Council Report 5-A-18) and financing structures for HCBS (Council Report 4-N-21).

PROS AND CONS OF MEDICAID ESTATE RECOVERY

The Federal Estate Recovery Mandate was established as a program integrity tool intended to help ensure that Medicaid LTSS recipients use their own resources to cover the costs of their care. Proponents of estate recovery underscore that such efforts are needed to ensure that families are not transferring or otherwise protecting their financial resources in order to qualify for Medicaid LTSS and that Medicaid funds are used to care for the neediest enrollees. Additionally, the recovery of assets may help supplement Medicaid funding in some states and even federally, since a portion of the money recovered must be paid to the federal government for the share of the services that were federally funded. Within federal parameters, states have discretion in how aggressively they choose to pursue estate recovery and, therefore, there is wide variability in how states administer their recovery programs.

Criticisms over the years have highlighted that Medicaid estate recovery primarily targets individuals and families who are poor, that families of color are disproportionately affected, and that the process contributes to wealth inequality and intergenerational poverty. To qualify for Medicaid LTSS in the first place, individuals must have limited incomes and have spent down most of their financial resources, though the value of a person's home and certain other assets are not counted in eligibility assessments. Due to the high cost of long-term care in this country, many middle-income

people also qualify for Medicaid once their savings have been spent down. However, critics also note that middle- and higher-income people frequently use estate planning vehicles (e.g., trusts) to protect their assets and evade recovery efforts, while people who cannot afford estate planning services tend to give up more to the state, thus widening estate recovery disparities. The lack of available data prevents a thorough understanding of how many people shelter assets from state Medicaid programs, but it is not an unusual practice. Notably, the Medicaid and CHIP Payment Access Commission (MACPAC) has concluded from its surveys and interviews that estate recovery is not very effective in recouping money from people who may have the means to cover LTSS themselves.[18]

Advocates concerned about estate recovery efforts have noted that estate recovery programs can dissuade people in need of LTSS from applying for Medicaid services. Critics also argue that very little payment is collected by most states and that recovered dollars represent a small slice of what Medicaid spends on LTSS. In 2019, when an estimated $733 million was recovered overall from estates, only eight states recouped more than one percent of the cost of FFS LTSS and 28 states recovered less than 0.5 percent.[19] Based in part on each state's priorities and program administration, amounts recovered vary significantly by state. For example, in 2019, Iowa recovered over 14 percent of FFS LTSS spending in the state while Hawaii, Louisiana, and West Virginia recovered only 0.02 percent. Moreover, five states with the largest recoveries (Massachusetts, New York, Pennsylvania, Ohio, and Wisconsin) recouped nearly half of all collections in the U.S.[20] As noted by the authors of Resolution 104-A-24, the administrative costs of implementing estate recovery programs can be substantial, thus diminishing the utility of such efforts. Although little data are available on state administrative costs, there seems to be a wide range of spending on estate recovery across states. According to MACPAC's data from five states, the administrative costs of recovery ranged from 3.7 percent to 32.1 percent of the amount collected. MACPAC's research also suggests that states could collect more from estates if their program efforts mirrored those in states that recoup the most money.[21]

REFORM PROPOSALS

At the national level, MACPAC published a thorough analysis of the state-of-play in a 2021 report to Congress on estate recovery reforms. This report recommended that Congress amend the Social Security Act to:

1. Make Medicaid estate recovery optional for the populations and services for which it is required under current law;
2. Allow states providing LTSS under managed care arrangements to pursue estate recovery based on the cost of care when the cost of services used by an enrollee was less than the capitation payment made to an MCO; and
3. Direct the Department of Health and Human Services Secretary to set minimum standards for hardship waivers so that states are not allowed to pursue recovery for: a) any asset that is the sole income-producing asset of survivors; b) homes of modest value; and c) any estate valued under a certain threshold.[22]

Federal legislation from the last Congress includes H.R. 7573, which was sponsored solely by Democrats and prohibits all estate recovery efforts, and H.R. 8094, which was introduced by a Republican House member and would prohibit states from pursuing estate recovery when the individual's home is transferred to someone who is eligible for medical assistance or has an income below 138 percent of the Federal Poverty Level (FPL).[23]

Although states must meet minimum federal requirements for estate recovery, within those parameters, they can implement their own reforms. Examples of recent state activity include legislation in Maine and Massachusetts that scaled back recovery efforts to federal minimum requirements. Additionally, Georgia, Illinois, Massachusetts, and South Carolina have established cost effectiveness thresholds that essentially waive recovery of estates worth less than $25,000.[24] Illinois has also begun requiring the state Medicaid agency to publicly report data on estate recovery. Some states, like Massachusetts, also provide enrollees with more thorough explanations of estate recovery requirements when they are applying for Medicaid LTSS.

RELEVANT AMA POLICY

AMA policy does not specifically address Medicaid estate recovery efforts, although numerous policies focus on long-term care and LTSS. Under Policy H-280.991, the AMA maintains that programs to finance long-term care should:

- Assure access to needed services when personal resources are inadequate to finance care;
- Prevent impoverishment of the individual or family in the face of extended or catastrophic service costs.
- Cover needed services in a timely, coordinated manner in the least restrictive setting;
- Provide coverage for the medical components of long-term care through Medicaid for all individuals with income below 100 percent of the FPL; and
- Provide sliding scale subsidies for the purchase of LTC insurance coverage for individuals with income between 100-200 percent of the FPL.

Although not specific to Medicaid estate recovery, Policy H-290.982 supports increasing investments in HCBS; allowing states to use long-term care eligibility criteria which distinguish between people who can be served in a home or community-based setting and those who can only be serviced in a nursing facility; buy-ins for home and community-based care for people with incomes and assets above Medicaid eligibility limits; and grants to states to develop new long-term care infrastructures and encourage expansion of long-term care financing to middle-income families who need assistance. Policy H-280.945 also supports incentivizing states to expand access to HCBS. Policy D-280.982 directs the AMA to:

- Advocate for business models in long-term care for the elderly which incentivize and promote the ethical and equitable use of resources to maximize care quality, staff and resident safety, and resident quality of life, and which hold patients' interests as paramount over maximizing profit; and
- Advocate for further research into alternatives to current options for long-term care to promote the highest quality and value LTSS models as well as functions and structures which best support these models for care.

DISCUSSION

The Council reviewed the literature on Medicaid estate recovery, met with an expert, and deliberated at length about potential reforms. At the request of the Medical Student Section, which sponsored referred Resolution 104-A-24, the Council limited its study to estate recovery and, therefore, does not make recommendations regarding Medicaid LTSS eligibility requirements (e.g., spend-down rules), which are equally complex and should be addressed separately.

Of note, the Council's deliberations took place at a time of heightened unease among state medical associations, national medical specialty societies, the AMA, and many states and advocacy groups

regarding potential reductions in Medicaid funding, which would have deleterious effects on state budgets and Medicaid programs. At the time this report was written, Congress had not enacted any Medicaid cuts; however, many states were considering how to prepare for federal Medicaid changes. For context, it is also important to point out that the AMA has not received any inquiries or requests for assistance with estate recovery reforms. Still, because estate recovery is not directly addressed in AMA policy, the Council agrees that new policy is needed and that, given the uncertainties around federal Medicaid funding, this policy should retain state flexibility. Accordingly, the Council crafted recommendations that support and encourage meaningful estate recovery reforms without requiring states to abandon the practice or take other immediate actions.

Medicaid LTSS provides a critical safety net for lower-income people who have few resources and need assistance with ADLs, including older adults with chronic illnesses or dementia and younger people living with disabilities. The Council recognizes that demand for critical LTSS services is likely to grow as the U.S. population ages and people live longer, and that Medicaid services should be available to those most in need of LTSS. We do not believe that Medicaid should pay for the long-term care costs of people who have financial means to do so themselves; however, because LTSS is exorbitantly expensive and not covered by most insurers, we understand the challenges of preventing people from sheltering their assets and misusing the system.

As discussed in this report, federal law requires states to perform estate recovery as a condition of their participation in Medicaid. Based on surveys and interviews with key stakeholders, MACPAC reported that states primarily recoup funds from modest-sized estates and that individuals with more financial means often evade recovery efforts, raising equity concerns. We acknowledge these concerns and believe that additional guardrails may be needed. We also recognize that states and other stakeholders, including physicians, hold differing views on the benefits and harms of estate recovery programs. For example, in some states, the return on investment may not be worth the costs of administering estate recovery programs; however, states that recoup the most funds may not want to forego that revenue, especially in a challenging fiscal environment. For these reasons, the Council decided not to oppose estate recovery efforts outright. Instead, we recommend support for specific reforms intended to help maintain Medicaid as a safety net and ensure that, as intended, LTSS are provided to people most in need. To acknowledge the variance in estate recovery across states and allow states more flexibility than they currently have, the Council recommends that the AMA support making Medicaid estate recovery optional, instead of mandatory. This recommendation allows states to decide whether (or not) to continue their estate recovery programs, which is consistent with longstanding AMA policy allowing states some flexibility in implementing their Medicaid programs.

When Medicaid estate recovery is pursued, the Council recommends supporting the following additional reforms:

- First, the Council learned that more than half of states apply recoupment efforts beyond LTSS and attempt to recover the costs of some or all other Medicaid-covered services provided to an enrollee. We do not believe it is appropriate to pursue recovery beyond the costs of LTSS care, and, therefore, recommend that estate recovery be limited to the costs of LTSS and not other Medicaid services that may have been utilized.
- The Council also recommends support for developing standards for hardship waivers that prohibit claims against a sole income-producing asset of heirs; homes of modest value; and any estate less than a specified threshold value. This language mirrors one of MACPAC's recommendations and was also used by CMS to describe sample hardship waiver criteria. The Council discussed recommending a specified threshold value but believe that other stakeholders are better equipped to determine an appropriate threshold amount.

- Relatedly, the Council recommends support for exempting estates when the value of the recovery is projected to be less than the cost of recoupment efforts. We do not believe it makes sense to pursue estate recovery when the return would be so low.
- When MCOs are utilized, the Council recommends basing estate recovery on the costs of LTSS care, instead of the capitation amount, when the cost of LTSS is lower. Similar to the first reform (see above), we do not believe that estates should be pursued for amounts exceeding the cost of care that was provided. Our recommended approach would also be easier for families to understand since they may not know the amount of capitation that was paid for them.
- Similarly, the Council feels strongly that LTSS enrollees and their families must be better educated about estate recovery requirements so they are not surprised by a state's recoupment efforts after the enrollee has died. Although states are required to provide basic information to enrollees, it is not always adequate or easy to find. Accordingly, the Council recommends supporting education at the time of enrollment in LTSS, and during any renewal process, that is appropriate to enrollees' language and health literacy abilities.
- To ensure that available hardship waivers are offered to eligible enrollees, the Council recommends screening patients for hardship waivers and assisting them with filing such waivers, if eligible.
- Finally, the Council also recommends supporting data collection and public reporting on estate recovery programs. We found data to be lacking and believe more information is needed to accurately evaluate the impacts and effectiveness (or not) of estate pursuits.

RECOMMENDATIONS

The Council on Medical Service recommends that the following recommendations be adopted in lieu of Resolution 104-A-24, and that the remainder of the report be filed:

1. That our American Medical Association (AMA) oppose federal or state efforts to impose liens on or seek adjustment or recovery from the estate of individuals who received long-term services or supports coverage under Medicaid. (New HOD Policy)

2. That our AMA support the following when Medicaid estate recovery is pursued:

    a. Limiting recoupment to the costs of long-term services and supports (LTSS) and not for other Medicaid services that were provided;
    b. Establishing standards for hardship waivers that prohibit claims against a sole income-producing asset of heirs; homes of modest value; and any estate less than a specified threshold value;
    c. Exempting estates from recovery efforts when the value of the recovery is projected to be less than the cost of recoupment efforts;
    d. Basing estate recovery on the costs of LTSS care when managed care organizations are utilized, instead of the capitation amount, when the cost of LTSS is lower than the capitation amount;
    e. Providing education regarding state Medicaid estate recovery requirements at the time of enrollment in LTSS, and during any renewal process, that is appropriate to enrollees' language and health literacy abilities;
    f. Screening patients for hardship waivers and assisting them with filing, if eligible; and
    g. Collecting and making publicly available important data regarding estates that have been pursued and amounts that have been recovered. (New HOD Policy)

Fiscal Note: Minimal - less than $1,000.

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