Tracking Health Reform

Lots of Pain for Little Gain: Three Decades of Medicaid Estate Recovery

Amanda Spishak-Thomas
Rutgers University

Emma Sandoe
Oregon Health Authority

Heather Howard
Princeton University

Abstract Since Congress enacted Medicaid estate recovery into law in 1993, there have been few changes to the policy and little research to investigate its effectiveness. Under Medicaid estate recovery—a response to the rising and uncertain costs associated with long-term custodial care among a rapidly aging American population—states have the right to track former Medicaid beneficiaries' assets and seek recovery from their estate after their death. Although it makes an insignificant dent in state budgets, Medicaid estate recovery can nonetheless have a lasting impact on the lives of families subject to its repayment requirements. For low-income families where homeownership is their primary source of wealth, policies aimed at homeowners may exacerbate long-standing disparities in wealth and disproportionately burden Black and Hispanic families. Recently, some states have initiated policy changes to address problems with Medicaid estate recovery, and similar legislation has also been introduced in Congress. Such reforms, if more widely adopted, may improve the financial circumstances of surviving family members of deceased Medicaid beneficiaries.

Keywords Medicaid, Medicaid estate recovery, long-term care, financing, disparities

The Medicaid estate recovery program has long been an esoteric and overlooked policy. Yet its impacts—and its potential to overwhelm many families' finances—are increasing as the country ages. The US population is growing older as a result of people living longer and having fewer children coupled with the mid-20th century baby boom (Medina et al. 2020). By 2050 the proportion of the population aged 65 and older will almost double what it was in 2010, the proportion of those aged 80 and older will triple, and the proportion aged 90 and older will quadruple (US Census Bureau n.d.;

Journal of Health Politics, Policy and Law, Vol. 51, No. 1, February 2026
DOI 10.1215/03616878-12166749

Neuman et al. 2015). By 2060, almost one in four Americans will be 65 and older (Vespa 2018).

Older adults today have less access to resources with lower rates of savings and fewer pensions to pay for medical care and long-term care compared to previous cohorts of the elderly (Pearson et al. 2019). While families, especially adult children, are usually treated as the first line of defense in providing care for aging parents, a combination of burnout and the need for skilled care often overtakes family members' abilities to manage caretaking without the support of long-term care facilities (e.g., nursing homes) (Arora 2016). Access to wealth can keep households out of poverty and offers older adults the power to make choices about the way they age (Shapiro et al. 2013; Shapiro, Meschede, and Sullivan 2010). However, people often impoverish themselves trying to pay for long-term care, whether in nursing homes (estimated cost in 2023 upward of $116,800 annually) or at home (2023 estimates range from $62,400 to $68,640 dependent on level of need) (Chidambaram and Burns 2024).

Consequently, many people, especially those in the middle class, will quickly spend down their savings and thereby qualify for Medicaid to finance their long-term care needs. In 2019, approximately 34% of all Medicaid spending was allocated for long-term services and supports (LTSS) (Murray et al. 2021). LTSS describes the range of medical and personal care services that assist with activities of daily living, such as bathing, dressing, cooking, and medication management, and that take place in a variety of settings, such as nursing homes, assisted living facilities, adult day-care programs, and professional or informal home health aide services at home (Chidambaram and Burns 2024).

Medicare, which insures older adults as well as persons who receive Social Security Disability Insurance or have end-stage renal disease, covers LTSS only in limited circumstances,[1] despite the fact that such services are a need that most people cannot afford. For low- and middle-income Medicare beneficiaries, Medicaid picks up where Medicare leaves off, providing supplemental coverage of Medicare premiums, covering out-of-pocket costs associated with gaps in Medicare plans (i.e., cost sharing), and home- and community-based and long-term custodial care services, making the program a vital payer for older adults with increased care needs (McInerney

1. Medicare provides some coverage (up to 100 days per benefit period) for skilled nursing home care in the event of a qualifying hospital stay as well as home health services for people who demonstrate a need for short-term, part-time, or intermittent skilled services. Medicare home health includes nursing; physical, speech, and occupational therapy; and home health aide services (Chidambaram and Burns 2024).

et al. 2022). The two programs therefore often work in tandem to provide comprehensive health coverage: 12.2 million Americans are dually eligible for both Medicare and Medicaid (MACPAC 2018). The aging of America's population creates additional financial strains on state Medicaid budgets, given its structure as a joint federal and state partnership.

Medicaid's design ensures that states administer and cofinance the program and are thus incentivized to constrain spending. The 1993 Medicaid estate recovery policy requires states to recoup some costs of LTSS. The policy, which was enacted in response to rising costs in state Medicaid programs and increasing demand for LTSS, requires states to seek repayment for Medicaid debts accrued for the use of LTSS by adults age 55 and older (Omnibus Budget Reconciliation Act, Pub. L. No. 103-66, 1993; Williams 2020; Zieger 1997). When a Medicaid beneficiary uses Medicaid LTSS for either home- and community-based services or long-term custodial nursing home care, the state considers the beneficiary in debt for using these services, and it consequently expects to be repaid upon the beneficiary's death.

For a policy that is more than three decades old, little research exists to understand the reach, effectiveness, and impacts of Medicaid estate recovery. This article investigates the 32-year history of Medicaid estate recovery. First, we provide an overview of how Medicaid came to cover LTSS as well as the origins of Medicaid estate recovery and its major features. Next, we explore the existing literature, highlighting the impacts of Medicaid estate recovery on state budgets as well as the relationship between estate recovery policies and older adults, with implications for disparities in health and wealth. Lastly, we explore current reforms and reflect on the future of Medicaid estate recovery.

Medicaid and Long-Term Care

Medicaid is the largest funder of long-term care for older adults in the country. Established in 1965 as America's health insurance program for the poor (Grogan 2006), Medicaid crucially strengthens the social safety net for older adults in the United States by extending beyond traditional health insurance to include home- and community-based care and custodial nursing home care (Grogan 2006). Long before Medicaid's inception, public policies such as the 1935 Old-Age Assistance program, medical vendor payments in 1950, and Medical Assistance to the Aged under the Kerr-Mills Act in 1960 financed nursing home care for some older adults (Grogan 2006). Most notably, medical vendor payments ushered in a system of

federally financed cash payments to older adults living in nursing homes. The Kerr-Mills Act built on the Old-Age Assistance program and medical vendor payments by introducing the concepts of medical indigency and means testing for older adults in need of nursing home care. Medical indigency was introduced to protect older adults who needed illness-related assistance because they had become impoverished as a result of that illness. When Medicare was enacted in 1965, it did not contain a nursing home benefit, reflecting concerns about the high costs such a benefit could entail (Grogan and Patashnik 2003; Vladeck 1980). In contrast, Medicaid—enacted alongside Medicare as part of the 1965 Social Security Amendments—continued the precedent of Kerr-Mills payments for long-term care and in fact mandated state coverage for such services. Medicaid thus solidified itself as the primary payer for older adults in need of long-term nursing home care.

Today, Medicaid covers the cost of residential care for 6 in 10 nursing home residents (Jaffe 2022). Black and Hispanic older adults are less likely to move into a nursing home than their non-Hispanic white counterparts (30% and 48% less likely respectively), adjusted for need and sociodemographic resources (Thomeer et al. 2015). However, they constitute a disproportionate share of the Medicaid population, with Black and Hispanic adults representing about half of Medicaid beneficiaries in 2023 (18.4% for Black adults; 31.5% for Hispanic adults) (MACPAC 2024). The overrepresentation of Black and Hispanic Medicaid beneficiaries exacerbates the uneven impacts of policies like Medicaid estate recovery.

While some individuals who require LTSS qualify for Medicaid when they enter nursing facilities, many nursing facility residents and people requiring LTSS begin as private pay, quickly spending down their assets until they become eligible for Medicaid (Grogan 2006). Unlike Medicare, Medicaid eligibility is means-tested; to qualify, individuals must meet strict state-determined asset and income requirements (Greenhalgh-Stanley 2012). Beginning in 1966 with New York, state policy makers carved out several exemptions. Exemptions included a beneficiary's primary vehicle and owner-occupied housing assets followed by federal protections against spousal impoverishment in 1988, in an effort to prevent illness from causing impoverishment of both the beneficiary and their spouse (Grogan 2006; Stevens and Stevens 1970). The updated exemptions were in line with the original medical indigency provisions baked into the Kerr-Mills Act. Thus, individuals may transfer ownership of their remaining assets, vehicle, or home to their adult children to preserve inheritances while appearing as if they are spending down the entirety of their wealth to qualify for Medicaid.

Like other aspects of Medicaid, states vary in the degree to which they tolerate these transfers, with states such as California and New York being the most lenient.

Medicaid Estate Recovery

Congress established Medicaid estate recovery as a part of the 1993 Omnibus Budget Reconciliation Act, with the aim of preventing Medicaid enrollees from transferring assets to heirs while benefiting from taxpayer funds intended to assist low-income individuals and families (Williams 2020). Although states were authorized to implement estate recovery programs as early as 1965 when Medicaid was first enacted, before 1993 just 21 states and the District of Columbia had implemented such a policy (Alabama, California, Connecticut, District of Columbia, Florida, Georgia, Hawaii, Illinois, Indiana, Maryland, Massachusetts, Minnesota, Missouri, Montana, New Hampshire, New Jersey, New York, North Dakota, Oregon, Rhode Island, Utah, Vermont). States with early estate recovery programs benefited from key resources like a robust and well-trained staff and diligent records on Medicaid beneficiaries and surviving spouses, which simplified the process of recovery (OIG 1995). As a result, these states likely stood to recover higher-than-average amounts relative to the cost of establishing and carrying out recovery (GAO 1989; OIG 1995; Summers 2013).

Estate recovery policies are structured such that "the cost of medical assistance covered by Medicaid becomes a debt of the recipient's estate or the estate of the recipient's spouse" (Zieger 1997: 360). The 1993 law requires states to seek repayment for these Medicaid debts accrued mostly through the usage of long-term care benefits for individuals age 55 and older (Zieger 1997). This practice puts at risk the homes surviving relatives might otherwise expect to inherit. Many states opposed and initially refused to enforce the new policy, to avoid impoverishing surviving relatives. It was not until states faced the loss of federal Medicaid funding in 2007—14 years after the policy was originally enacted—that all 50 states and the District of Columbia implemented their own versions of the policy (Greenhalgh-Stanley 2012). Table A1 lists policy implementation by state and year. States were granted some latitude in designing their policies in terms of cost-effectiveness standards, benefits pursued for recovery, liens, and hardship waiver policies (table 1).

Under guidance established by the Centers for Medicare and Medicaid Services (CMS), every state is required to acknowledge situations where estate recovery may cause undue hardship for the Medicaid beneficiary.

Table 1 Estate Recovery Policy Mechanisms

Policy mechanisms	Definition
Definition of estate	At minimum, states are required to attempt to recover all property and assets that pass to heirs under state probate laws, but states vary in their definition of an estate and the priority of Medicaid's claims against an estate's other creditors.
Liens	A state can choose to place a lien on the home of a Medicaid beneficiary while they are still alive, signaling that their assets are at risk of recovery upon their death.
Cost-effectiveness thresholds	This is the point at which an individual's estate is deemed worthwhile to recover relative to the administrative costs of recovery. States may waive recovery in cases where it is not cost-effective for them to recover an estate.
Deferrals	If a Medicaid beneficiary has a surviving spouse, a child who is younger than age 21, or a child of any age who is blind or has a disability, recovery must be deferred until after the spouse or child's death. Additionally, recovery may be deferred if a sibling lived in the home for at least 1 year before the beneficiary's death, or if an adult child delayed a beneficiary's nursing home placement by living in the home for at least 2 years before admission to the nursing home. States can also choose to exempt those estates from recovery rather than pursue them after the death of a spouse or eligible child (i.e., younger than 21, or any age with a disability).
Hardship waivers	States are required to establish procedures for waiving estate recovery requirements due to hardship, including a definition of what constitutes hardship using criteria established by CMS and the Department of Health and Human Services. CMS suggests states waive recovery in instances where an estate is of modest value (defined differently by each state) or is the sole income-producing asset of surviving relatives (e.g., family farms).

Sources: Karp, Sabatino, and Wood (2005); MACPAC (2021).

However, the definition of and criteria for what constitutes undue hardship vary by state under 1993's Omnibus Budget Reconciliation Act. CMS provides an example definition that states may consider, but there are no standardized criteria, resulting in significant state variation. CMS suggests states give special consideration in cases where a home is of modest value, or if the estate claim endangers the sole income-producing asset of surviving relatives, like a family farm (Karp et al. 2005). Functionally, states determine the scope of their program by defining what constitutes a hardship and who is

eligible to apply for a hardship waiver (Manatt Health 2022). States also vary in the amount of time given to complete a hardship waiver application upon the death of a Medicaid beneficiary, ranging from 30 to 90 days. The creation of hardship waivers signals an understanding of the strain estate recovery can cause a family. Hardship waivers offer a way out for families who would otherwise lose assets to estate recovery in the wake of the death of a loved one.

Enacted as a part of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, the TEFRA lien is one of the most common components of estate recovery, whereby a lien can be placed on the Medicaid beneficiary's home while they are still alive (Greenhalgh-Stanley 2012). As of 2022, 26 states have adopted liens as part of their Medicaid estate recovery policies (Greenhalgh-Stanley 2012; MACPAC 2021). Seemingly counter to Medicaid asset exemptions that had been previously established in the program, a TEFRA lien does not mean that the beneficiary must sell their home. Instead, a lien ensures that if a home is sold, either before or after the Medicaid beneficiary dies, it cannot be sold for less than fair market value. Moreover, if the home is transferred to an individual not protected by the law (see table 1 for more information) as a part of the deceased beneficiary's estate, that individual must first satisfy the lien to receive the title of the property (Summers 2013). Widely considered a more aggressive approach to the enforcement of estate recovery, liens may raise awareness of the policy among Medicaid beneficiaries, signaling that their assets are at risk (Greenhalgh-Stanley 2012). Consequently, liens may create a sense of urgency to engage in estate planning in an effort to protect remaining assets, an option that may only be available to families with access to resources and the ability to hire an attorney specializing in elder law to navigate the legal process (Greenhalgh-Stanley 2012).

Medicaid estate recovery has the potential to negatively impact the financial stability of families across generations given its unique ability to seek repayment long after a Medicaid beneficiary has died. In low-income families homeownership is the primary source of wealth (Wainer and Zabel 2020), so policies aimed at homeowners may exacerbate longstanding disparities in family wealth. Moreover, inheritance of familial wealth through parental homeownership can have lasting intergenerational impacts and provide a safety net for low-income individuals in adulthood (Modi and Sewell 2022; Pfeffer et al. 2013). Although Medicaid estate recovery has important implications for the financial health of older adults as a result of delayed or avoided care and their families because of recoveries that reduce inheritances, few studies have assessed Medicaid estate recovery, and there is a dearth of research on its impact and scope.

Impacts of Medicaid Estate Recovery

After three decades, the impact of Medicaid estate recovery on state Medicaid budgets and American families remains uncertain. What's more, interviews with key informants suggest awareness of Medicaid estate recovery among program beneficiaries is limited (MACPAC 2021). There is an ongoing debate among policy analysts and politicians about the effectiveness of Medicaid estate recovery in recouping costs associated with long-term care (Corbett 2019; True 2021). Proponents of estate recovery, including long-term care reformists and policy analysts such as Steve Moses and Brian Blase (2021), highlight the strain of LTSS costs on Medicaid and suggest that the policy facilitates a shift in the burden from taxpayers to the estates of deceased beneficiaries (Kapp 2006; Moses and Blase 2021). In other words, taxpayers get relief from rising taxes used to support cash-strapped states because of the cost of Medicaid programs, while surviving relatives of Medicaid beneficiaries are faced with little to no inheritance after assets are seized in repayment to the state (Kapp 2006). Recovered assets can then be used to preserve state Medicaid programs and continue to finance long-term care for low-income adults. Proponents also argue that for people who have the means to spend resources on their care, Medicaid estate recovery is the only incentive for them to do so.

Conversely, critics of the estate recovery policy, including policy analysts at the Medicaid and CHIP Payment and Access Commission (MACPAC), advocacy groups such as Justice in Aging, and legal scholars such as Jim Schuster (2023), say estate recovery may disincentivize Medicaid-eligible individuals with high care needs to seek long-term care, which can lead to poor health outcomes (JIA 2021; Kapp 2006; MACPAC 2021; Schuster 2023). Their bodies of research argue that heirs of deceased Medicaid beneficiaries will suffer the loss of inherited property and be unable to meet their own needs (JIA 2021; Kapp 2006; MACPAC 2021; Schuster 2023). Evidence suggests that recovery attempts as a result of estate recovery policies have increased dramatically in recent years. According to an AARP state survey, 42 states and the District of Columbia attempted recovery from a total of 3,242 estates in 2004 (Karp et al. 2005). Within a 15-year period, this number increased sixfold; MACPAC (2021) identified states that represented a range of estate recovery policies and collections and found that 19,697 estates were recovered by just 10 states in 2019. Although there is no complete database containing estate-recovery data on all 50 states and the District of Columbia, the recovery of nearly 20,000 estates in a single year from one-fifth of states, all of which vary in

policy leniency, suggests the vast scope of Medicaid estate recovery when accounting for more aggressive state recovery strategies.

Only two earlier studies have investigated the implementation of estate recovery policies (MACPAC 2021; Karp et al. 2005). The first, a 2004 AARP survey of state estate recovery programs, found that policies and practices vary significantly between states and concluded that the lack of data and research hinders a thorough assessment (Karp, Sabatino, and Wood 2005). The report notes that while most states generally give notice about estate recovery when individuals apply for Medicaid, these notices vary significantly in "readability, print size, and the extent to which they are readily understandable as well as the inclusion of vital information" (5). Cost-effectiveness thresholds (i.e., whether the administrative costs associated with recovery efforts outweigh the actual amount recovered) inform whether the policy is efficient; however, data for administrative costs are incomplete and raise uncertainty about the policy's financial impact on the state. In 2004, 30 states had enough data to report their annual administrative costs, which ranged from $30,000 to more than $1 million (Karp et al. 2005). The survey also found inconsistent practices around hardship waiver applications; although a majority of states reported giving some kind of notice of the availability of hardship waivers "at the time recovery is under way," at least 13 states indicated no standard process or form for applying for a hardship waiver (34).

The second study, a 2021 MACPAC report to Congress, used data from a survey of 10 states to assess estate recovery policies over three years, concluding with recommendations for Congress to amend the original legislation to make estate recovery optional and to set minimum standards for hardship waivers under the program. It found that recovery from the estates of low-income families recoups little money compared to the total cost of LTSS spending for state Medicaid programs: only 0.55% of total fee-for-service LTSS spending (MACPAC 2021). The MACPAC report found that the average amount recovered from estates varied significantly, from a low of $2,768 in Missouri to a high of $71,556 in Alaska. Both studies on estate recovery stop short of identifying who is targeted by estate recovery and the policy's impact on intergenerational transfers of wealth (Karp, Sabatino, and Wood 2005; MACPAC 2021).

A Driver of Disparities in Wealth

LTSS is prohibitively expensive for both families and states. For decades, policy makers have sought policies like Medicaid estate recovery

and Medicaid look-back periods—which evaluate whether a Medicaid applicant has transferred assets to others within a certain period of time before applying for Medicaid—as a way to reduce costs for states. Although Medicaid estate recovery was initially designed to ensure that those with resources to pay for LTSS were using them to do so, research finds that low-income families may be disproportionately impacted by Medicaid estate recovery, and those with greater resources are less affected by these policies (MACPAC 2021). Beyond wealth itself, some resources are less easily measured but are no less important to maintaining familial wealth, such as connections to an elder law attorney who can navigate a Medicaid application to circumvent look-back periods or estate recovery programs, or a family network that instills the importance of estate planning with completion of a trust long before LTSS is needed. Medicaid estate recovery may contribute to disparities in intergenerational wealth transfers because adult children of well-resourced Medicaid beneficiaries continue to inherit property, and those with limited assets forfeit such assets to recovery upon their death. A significant number of wealthy families are not subject to estate recovery policies and are benefiting from proactive estate planning and access to clever elder law attorneys, so states are only recouping a fraction of the cost of Medicaid LTSS, while their budgets remain strained.

Not all states collect detailed demographic data on whose estates were recovered, other than socioeconomic and marital status, which are indicated by Medicaid enrollment and program eligibility. No known research has been able to leverage granular data such as race, ethnicity, or gender to investigate the impact of Medicaid estate recovery on specific groups. Only one causal study has investigated the impact of Medicaid estate recovery on behavioral decisions of older adults, namely housing and asset decisions. Using data from the Health and Retirement Study, Greenhalgh-Stanley found that state adoption of estate recovery induced older adults to decrease homeownership by 4.6%, with larger effects in rural areas (Greenhalgh-Stanley 2012). Furthermore, they found that implementation of Medicaid estate recovery caused a 15% decrease in home equity and a 33% decrease in homeownership at death (Greenhalgh-Stanley 2012). Importantly, Greenhalgh-Stanley concludes that the use of trusts and equivalent estate-planning mechanisms increased with the intention of protecting assets for inheritance (Greenhalgh-Stanley 2012).

Estate planning describes the process of making arrangements for the estate of a person who is still living, in preparation for their eventual death or incapacity. It can include drafting a will or a trust as well as designating

decision-makers through advance care directives. Completing a will or trust can protect assets from certain Medicaid policies with implications for intergenerational transfers of wealth. Medicaid look-back periods and Medicaid estate recovery are examples of such policies. Evidence suggests that some individuals may circumvent Medicaid policies through savvy estate planning and that a number of sociodemographic factors, including race/ethnicity and homeownership status, may be predictors of such behavior (Carr 2012; Kelly et al. 2013; Koss and Baker 2018; Spishak-Thomas 2024; Yung-Ting 2008). For example, white, well-educated, married men were more likely than women, Black, or Hispanic people, unmarried individuals, and those with low educational attainment, to engage in estate planning before enrolling in Medicaid (Spishak-Thomas 2024), and white older adults were four times more likely to engage in estate planning than their Black counterparts (Koss and Baker 2018). Using data from the Wisconsin Longitudinal Study, Carr (2012) found homeowners were nearly twice as likely to have a will at the end of life, and Yung-Ting (2008) concluded that people with higher net worth and educational attainment were more likely to have participated in financial end-of-life planning. These findings suggest significant disparities exist in older adults' ability to navigate estate planning. States trying to capture Medicaid repayment through policies like Medicaid estate recovery make it more difficult for low-income families to accumulate wealth and move into the middle class.

Future of Medicaid Estate Recovery

Medicaid is the most critical source of financing for LTSS in the United States, and given the means-tested nature of the program, a majority of Medicaid enrollees have few assets to begin with (Arora 2016). Since Congress enacted Medicaid estate recovery more than 30 years ago, there have been few changes in the policy and little research to investigate its effectiveness. Recently, some states have initiated policy changes, opting for improved strategies that consider the ratio of administrative costs to collections (e.g., cost-effectiveness strategies), higher home value minimums, and income caps. For example, in 2024 Massachusetts enacted legislation that provides estate recovery exemptions for certain people with disabilities whose income exceeds the more traditional Medicaid levels and that only allows the state to conduct recovery for expenses for long-term care (e.g., custodial nursing home stays) (Laughlin 2024). North Carolina also made changes to their policy as of 2023, increasing the estate value

threshold from $5,000 to $50,000 and the Medicaid claim threshold from $3,000 to $10,000 (CMS 2023). In other words, the deceased beneficiary's estate must be worth at least $50,000, and the amount of Medicaid benefits a beneficiary used on LTSS must be at least $10,000, before estate recovery can be implemented. Additionally, North Carolina increased the amount of assets for a qualified undue hardship applicant from $12,000 to $25,000 (CMS 2023). Similarly, Georgia instituted changes related to estate value in 2021, waiving the recovery of the first $25,000 of estates valued at more than $25,000 and mandating that Medicaid beneficiaries receive notice of Medicaid estate recovery at both the initial Medicaid application and each subsequent renewal (Washington 2021).

Beyond individual state action, Democrats in Congress have introduced legislation to reform Medicaid estate recovery, but it has not been enacted into law. Notably, the Stop Unfair Medicaid Recoveries Act (H.R. 7573)—sponsored by Democrat Janice Schakowsky, who represents Illinois's ninth congressional district—would repeal the requirement for states to establish a Medicaid estate recovery program and would limit states' ability to place a lien on a Medicaid beneficiary's property. Schakowsky first introduced the bill in the 117th Congress (H.R. 6698) in February 2022; with just 20 cosponsors (all Democrats), the bill never made it out of committee. It was then reintroduced in March 2024 with 47 cosponsors, again all Democrats, and did not make it out of the health subcommittee of the Energy and Commerce Committee, so it never received a floor vote. Relatedly, H.R. 8094 (To Amend Title XIX of the Social Security Act to Modify Certain Asset Recovery Rules), sponsored by Republican Thomas Kean in New Jersey's seventh congressional district, would prohibit states from recovery when a home has been transferred to another person who is eligible for Medicaid or has an income below 138% of the federal poverty level. Kean's bill did not have any cosponsors and did not make it out of the health subcommittee of Energy and Commerce. Both bills' reforms are consistent with recommendations from the 2021 MACPAC report, but their history of few cosponsors and little bipartisan support suggests they have gained little traction in Congress thus far.

Meanwhile, policies such as those included in the 2021 American Rescue Plan Act (ARPA) indicate policy makers are seeking ways to rebalance long-term care and incentivize home- and community-based services (HCBS). ARPA provided state Medicaid programs with the funding to expand the use of HCBS in lieu of custodial nursing home care. This shift to HCBS was intended to attenuate the high risks of COVID-19 infections in congregate

care settings for older adults. Fortunately, this is also in line with the preferences of most older adults, who prefer to remain in their homes as long as possible (i.e., age in place) (Sergeant et al. 2010; Thomeer et al. 2016). However, housing remains a key piece of the puzzle. Housing is essential to satisfy the preferences of older adults who wish to age in place and to support state initiatives aimed at rebalancing the proportion of older adults from nursing homes to HCBS. It is even more concerning, then, that Medicaid estate recovery puts housing at risk.

To inform lawmakers as they reconsider their approach to estate recovery, more research is needed to understand the policy's scope and its effects on families. Specifically, future research should explore the consequences of Medicaid estate recovery for older adults and their families as well as the socioeconomic and demographic patterns of who is impacted by this policy. Future work should investigate the impact of estate recovery on Medicaid enrollment and long-term care planning, to understand the potential level of awareness of older adults targeted by the policy. Lastly, little research has been done to characterize the variation in Medicaid estate recovery programs, including differentiation in policy levers such as hardship waiver policies or cost-effectiveness and claim thresholds. Cataloging state variation alongside existing data on collections could establish a baseline of state policy aggressiveness and corresponding impacts on state budgets.

Although estate recovery makes an insignificant dent in a state's budget, it nonetheless may have a lasting impact on the lives of families targeted by it. Changes would allow states to minimize the policy's negative effects. Access to wealth can keep households out of poverty, and inherited wealth can facilitate economic security for an adult child (O'Connell 2012; Shapiro et al. 2013; Shapiro, Meschede, and Sullivan 2010). Reforms to Medicaid estate recovery may improve the financial circumstances of surviving family members of deceased Medicaid beneficiaries.

■ ■ ■

Amanda Spishak-Thomas is an assistant research professor with the Center for State Health Policy at Rutgers University. She studies how Medicaid provides scaffolding for low-income families, focusing on the intersection of long-term care and intergenerational transfers of wealth. She is also a principal investigator on New Jersey's Medicaid 1115 Waiver Demonstration, leading the Managed Long-Term Services and Supports and Maternity portfolios.
a.spishak.thomas@ifh.rutgers.edu

Emma Sandoe is the director of Oregon's Medicaid Division within the Oregon Health Authority. She leads employees and programs that support Oregon Health Plan, the state's Medicaid program that serves approximately 1.4 million members. Before coming to the Oregon Health Authority, she served as North Carolina's deputy director of Medicaid policy, where she was the primary liaison to the state's tribal nations and to CMS. She helped direct the passage and implementation of the state's Medicaid expansion, which brought health coverage to more than 550,000 people.

Heather Howard is a professor of the practice at Princeton University's School of Public and International Affairs, where she codirects the Global Health Program. She is also director of the State Health and Value Strategies program, a Robert Wood Johnson Foundation–funded program focused on helping states transform their health care systems to be affordable, equitable, and innovative. She served as New Jersey's commissioner of the Department of Health and Senior Services during 2008–10. She also has significant federal experience, having worked on the White House Domestic Policy Council and in the US Senate and US House of Representatives.

Acknowledgments

The authors are grateful to Frank Thompson and Jonathan Oberlander for their very helpful comments.

References

Arora, Kanika. 2016. "How Does Dementia Onset in Parents Influence Unmarried Adult Children's Wealth?" *Social Science and Medicine* 152: 156–65. https://doi.org/10.1016/j.socscimed.2016.01.042.

Carr, Deborah. 2012. "The Social Stratification of Older Adults' Preparations for End-of-Life Health Care." *Journal of Health and Social Behavior* 53, no. 3: 297–312. https://doi.org/10.1177/0022146512455427.

Chidambaram, Priya, and Alice Burns. 2024. "10 Things About Long-Term Services and Supports (LTSS)." KFF, July 8. https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/.

CMS (Centers for Medicare and Medicaid Services). 2023. "State Plan Amendment (SPA) #: 23-0001." April 25. https://www.medicaid.gov/medicaid/spa/downloads/NC-23-0001.pdf.

Corbett, Rachel. 2019. "Medicaid's Dark Secret." *Atlantic*, October. https://www.theatlantic.com/magazine/archive/2019/10/when-medicaid-takes-everything-you-own/596671/.

GAO (US General Accounting Office). 1989. "Recoveries from Nursing Home Residents' Estates Could Offset Program Costs." Report to congressional committees HRD-89-56. March 7. https://www.gao.gov/assets/hrd-89-56.pdf.

Greenhalgh-Stanley, Nadia. 2012. "Medicaid and the Housing and Asset Decisions of the Elderly: Evidence from Estate Recovery Programs." *Journal of Urban Economics* 72, no. 2: 210–24. https://doi.org/10.1016/j.jue.2012.05.005.

Grogan, Colleen M. 2006. "A Marriage of Convenience: The Persistent and Changing Relationship Between Long-Term Care and Medicaid." In *History and Health Policy in the United States*, edited by Rosemary A. Stevens, Charles E. Rosenberg, and Lawton R. Burns. Rutgers University Press.

Grogan, Colleen M., and Eric M. Patashnik. 2003. "Universalism Within Targeting: Nursing Home Care, the Middle Class, and the Politics of the Medicaid Program." *Social Service Review* 77, no. 1: 51–71. https://doi.org/10.1086/345704.

Jaffe, Susan. 2022. "Medicaid Weighs Attaching Strings to Nursing Home Payments to Improve Patient Care." *KFF Health News*, June 10. https://kffhealthnews.org/news/article/medicaid-nursing-home-payments-care-mandate/.

JIA (Justice in Aging). 2021. "Medicaid Estate Claims: Perpetuating Poverty and Inequality for a Minimal Return." April. https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf.

Kapp, Marshall B. 2006. "Medicaid Planning, Estate Recovery, and Alternatives for Long-Term Care Financing: Identifying the Ethical Issues." *Journal of Case Management* 7, no. 2: 73–78. https://doi.org/10.1891/cmaj.7.2.73.

Karp, Naomi, Charles P. Sabatino, and Erica F. Wood. 2005. "Medicaid Estate Recovery: A 2004 Survey of State Programs and Practices." June. AARP Public Policy Institute. https://digirepo.nlm.nih.gov/master/borndig/101256282/2005_06_recovery.pdf.

Kelly, Christopher M., Julie L. Masters, and Stanley DeViney. 2013. "End-of-Life Planning Activities: An Integrated Process." *Death Studies* 37, no. 6: 529–51. https://doi.org/10.1080/07481187.2011.653081.

Koss, Catheryn S., and Tamara A. Baker. 2018. "Where There's a Will: The Link Between Estate Planning and Disparities in Advance Care Planning by White and Black Older Adults." *Research on Aging* 40, no. 3: 281–302. https://doi.org/10.1177/0164027517697116.

Laughlin, Jason. 2024. "In a Win for Seniors and People with Disabilities, Massachusetts Curtails Estate Recovery Practices." *Boston Globe*, September 7. https://www.bostonglobe.com/2024/09/07/metro/estate-recovery-masshealth-medicaid-tringali-massachusetts/.

MACPAC (Medicaid and CHIP Payment and Access Commission). 2018. "Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid." January. https://www.macpac.gov/wp-content/uploads/2020/07/Data-Book-Beneficiaries-Dually-Eligible-for-Medicare-and-Medicaid-January-2018.pdf.

MACPAC (Medicaid and CHIP Payment and Access Commission). 2021. "March 2021 Report to Congress on Medicaid and CHIP." March. https://www.macpac.gov/publication/march-2021-report-to-congress-on-medicaid-and-chip/.

MACPAC (Medicaid and CHIP Payment and Access Commission). 2024. "MACStats: Medicaid and CHIP Data Book." December. https://www.macpac.gov/publication/macstats-medicaid-and-chip-data-book-2/.

Manatt Health. 2022. "Making Medicaid Estate Recovery Policies More Equitable: State Toolkit." State Health and Value Strategies. April. https://www.shvs.org/wp-content/uploads/2022/04/Medicaid-Estate-Recovery-State-Toolkit.pdf.

McInerney, Melissa, Grace McCormack, Jennifer M. Mellor, and Lindsay M. Sabik. 2022. "Association of Medicaid Expansion with Medicaid Enrollment and Health Care Use Among Older Adults with Low Income and Chronic Condition Limitations." *JAMA Health Forum* 3, no. 6: article ID e221373. https://doi.org/10.1001/jamahealthforum.2022.1373.

Medina, Lauren, Shannon Sabo, and Jonathan Vespa. 2020. "Living Longer: Historical and Projected Life Expectancy in the United States, 1960 to 2060." US Census Bureau, February. https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1145.pdf.

Modi, Radha, and Alyasah Ali Sewell. 2022. "Unequal Early Adulthoods: Racial and Ethnic Wealth Disparities During the Great Recession." *Sociological Quarterly* 63, no. 1: 21–47. https://doi.org/10.1080/00380253.2020.1865115.

Moses, Steve, and Brian Blase. 2021. "Using Medicaid to Protect Inheritances." *The Hill*, June 10. https://thehill.com/opinion/finance/557675-using-medicaid-to-protect-inheritances/.

Murray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. 2021. "Medicaid Long-Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019." Mathematica, December 9. https://www.mathematica.org/publications/medicaid-long-term-services-and-supports-annual-expenditures-report-federal-fiscal-year-2019.

Neuman, Patricia, Juliette Cubanski, and Anthony Damico. 2015. "Medicare per Capita Spending by Age and Service: New Data Highlights Oldest Beneficiaries." *Health Affairs* 34, no. 2: 335–39. https://doi.org/10.1377/hlthaff.2014.1371.

O'Connell, Heather A. 2012. "The Impact of Slavery on Racial Inequality in Poverty in the Contemporary US South." *Social Forces* 90, no. 3: 713–34. https://doi.org/10.1093/sf/sor021.

OIG (Office of the Inspector General). 1995. "Medicaid Estate Recovery Programs." US Department of Health and Human Services. March. https://oig.hhs.gov/oei/reports/oei-07-92-00880.pdf.

Pearson, Caroline F., Charlene C. Quinn, Sai Loganathan, A. Rupa Datta, Beth Burnham Mace, and David C. Grabowski. 2019. "The Forgotten Middle: Many Middle-Income Seniors Will Have Insufficient Resources for Housing and Health Care." *Health Affairs* 38, no. 5. https://doi.org/10.1377/hlthaff.2018.05233.

Pfeffer, Fabian T., Sheldon Danziger, and Robert F. Schoeni. 2013. "Wealth Disparities Before and After the Great Recession." *Annals of the American Academy of Political and Social Science* 650, no. 1: 98–123. https://doi.org/10.1177/0002716213497452.

Schuster, Jim. 2023. "Medicaid Estate Recovery: A Failed Program Based on an Invalid 19th Century Philosophy Is Harming Our Ability to Meet the Challenges of the 21st Century." *NAELA Journal* 19: 45–61.

Sergeant, Julie F., David J. Ekerdt, and Rosemary K. Chapin. 2010. "Older Adults' Expectations to Move: Do They Predict Actual Community-Based or Nursing Facility Moves Within 2 Years?" *Journal of Aging and Health* 22, no. 7: 1029–53. https://doi.org/10.1177/0898264310368296.

Shapiro, Thomas M., Tatjana Meschede, and Sam Osoro. 2013. "The Roots of the Widening Racial Wealth Gap: Explaining the Black-White Economic Divide." Institute on Assets and Social Policy, February. https://heller.brandeis.edu/iere/pdfs/racial-wealth-equity/racial-wealth-gap/roots-widening-racial-wealth-gap.pdf.

Shapiro, Thomas M., Tatjana Meschede, and Laura Sullivan. 2010. "The Racial Wealth Gap Increases Fourfold." Institute on Assets and Social Policy. May. https://heller.brandeis.edu/iere/pdfs/racial-wealth-equity/racial-wealth-gap/racial-wealth-gap-fourfold.pdf.

Spishak-Thomas, Amanda. 2024. "Medicaid Enrollment and Intergenerational Transfers of Wealth Among Older Adults." *Gerontologist* 64, no. 7: article ID gnae074. https://doi.org/10.1093/geront/gnae074.

Stevens, Rosemary, and Robert Stevens. 1970. "Medicaid: Anatomy of a Dilemma." *Law and Contemporary Problems* 35: 348–425.

Summers, Katie L. 2013. "Medicaid Estate Recovery: To Expand, or Not to Expand, That Is the Question." *Penn State Law Review* 118, no. 2: 465–88.

Thomeer, Mieke Beth, Stipica Mudrazija, and Jacqueline L. Angel. 2015. "How Do Race and Hispanic Ethnicity Affect Nursing Home Admission? Evidence From the Health and Retirement Study." *Journals of Gerontology: Series B* 70, no. 4: 628–38. https://doi.org/10.1093/geronb/gbu114.

Thomeer, Mieke Beth, Stipica Mudrazija, and Jacqueline L. Angel. 2016. "Relationship Status and Long-Term Care Facility Use in Later Life." *Journals of Gerontology Series B* 71, no. 4: 711–23. https://doi.org/10.1093/geronb/gbv106.

True, Sarah. 2021. "Debt After Death: The Painful Blow of Medicaid Estate Recovery." *US News and World Report*, October 14. //www.usnews.com/news/health-news/articles/2021-10-14/debt-after-death-the-painful-blow-of-medicaid-estate-recovery.

US Census Bureau. n.d. "National Demographic Analysis Tables: 2020." Updated April 11, 2024. https://www.census.gov/data/tables/2020/demo/popest/2020-demographic-analysis-tables.html.

Vespa, Jonathan. 2018. "The Graying of America: More Older Adults Than Kids by 2035." US Census Bureau, March 13. https://www.census.gov/library/stories/2018/03/graying-america.html.

Vladeck, Bruce C. 1980. *Unloving Care: The Nursing Home Tragedy*. Basic Books.

Wainer, Allison, and Jeffrey Zabel. 2020. "Homeownership and Wealth Accumulation for Low-Income Households." *Journal of Housing Economics* 47: article ID 101624. https://doi.org/10.1016/j.jhe.2019.03.002.

Washington, Anika. 2021. "Estate Recovery Changes." Georgia Department of Community Health, December 21. https://www.ezelderlaw.com/wp-content/uploads/2021/09/Estate-Recovery-Changes-Memo.pdf.

Williams, Kristine. 2020. "The Future of Estate Recovery: An Analysis of Different State Approaches and Changes." *NAELA Journal* 16, special issue. https://naela.informz.net/NAELA/data/images/NewsJrnl2020/NAELAJournalSpring2020Williams.pdf.

Yung-Ting, Su. 2008. "Looking Beyond Retirement: Patterns and Predictors of Formal End-of-Life Planning Among Retirement Age Individuals." *Journal of Family and Economic Issues* 29, no. 4: 654–73. https://doi.org/10.1007/s10834-008-9130-y.

Zieger, Jon M. 1997. "The State Giveth and the State Taketh Away: In Pursuit of a Practical Approach to Medicaid Estate Recovery." *Elder Law Journal* 5: 359–93.

Appendix

Table A1 Medicaid Estate Recovery Policies by State and Year of Adoption

State	MER	TEFRA
Alabama	1993	1993
Alaska	1998	
Arizona	1995	
Arkansas	1993	
California	1993	1993
Colorado	1993	1995
Connecticut	1993	1995
Delaware	1995	1998
District of Columbia	2000	
Florida	1993	
Georgia	2006	
Hawaii	1993	1995
Idaho	1993	1995
Illinois	1993	1995
Indiana	1993	2004
Iowa	1995	
Kansas	1993	
Kentucky	1995	
Louisiana	1995	
Maine	1993	
Maryland	1993	1993
Massachusetts	1998	1998
Michigan	2007	
Minnesota	1993	1995
Mississippi	2000	
Missouri	1995	1995
Montana	1993	1995
Nebraska	1995	
Nevada	1995	1995
New Hampshire	1993	1993
New Jersey	1993	
New Mexico	1995	
New York	1993	1995
North Carolina	1998	
North Dakota	1993	
Ohio	1995	
Oklahoma	2002	2002
Oregon	1993	

Table A1 (*continued*)

State	MER	TEFRA
Pennsylvania	1995	
Rhode Island	1993	
South Carolina	1995	
South Dakota	1995	1995
Tennessee	2002	
Texas	2005	
Utah	1993	
Vermont	1995	
Virginia	1993	
Washington	1993	
West Virginia	1995	1998
Wisconsin	1993	1993
Wyoming	1995	2004

Notes: Appendix Table A1 contains a list of all 50 states and the District of Columbia and the years in which they implemented Medicaid estate recovery (MER). Additionally, it contains information on whether a state implemented a Tax Equity and Fiscal Responsibility Act (TEFRA) lien and if so, what year it was implemented.