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Tracking Health Reform

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

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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. While it makes an insignificant dent in state budgets, Medicaid estate recovery nonetheless can 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 longstanding 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 also has 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 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, Sabo, and Vespa 2020). By 2050 the proportion of the population aged 65 and older will almost double what it was in 2010, those aged 80 and older will triple, and the proportion aged 90 and older will quadruple (US

Census Bureau 2020; Neuman, Cubanski, and Damico 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 prior 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, Meschede, and Osoro 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 upwards 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 like bathing, dressing, cooking, and medication management and take place in a variety of settings like nursing homes, assisted living facilities, adult daycare 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

circumstances¹, 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 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 co-finance the program and are thus incentivized to constrain spending. The 1993 Medicaid estate recovery policy requires states to recoup some costs of LTSS. Enacted in response to the rising costs in state Medicaid programs and increasing demand for LTSS, the policy requires states to seek repayment for Medicaid debts accrued for adults age 55 and older for the use of LTSS (Sabo 1993; Williams 2020; Zieger 1997). When a Medicaid beneficiary uses Medicaid LTSS, either home and community-based services or long-term custodial nursing home care, the state considers the beneficiary in debt for using these services. It consequently expects to be repaid upon the beneficiary's death.

For a policy that is over three decades old, little research exists to understand the reach, effectiveness, and impacts of Medicaid estate recovery. This article investigates the 30-year plus 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

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

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, including the 1935 Old-Age Assistance (OAA program), medical vendor payments in 1950, and Medical Assistance to the Aged (MAA) 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. Building on the OAA and medical vendor payments, the Kerr-Mills Act introduced 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 assistance related to illness from becoming 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 of 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 (30% and 48% less likely respectively) than their non-Hispanic white counterparts, adjusted for need and sociodemographic resources (Thomeer, Mudrazija, and Angel 2015). However, they comprise a disproportionate share of the Medicaid population, with Black and Hispanic adults representing about half of Medicaid beneficiaries in 2023 (18.4% Black adults; 31.5% 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 Medicaid-eligible (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 like 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 like California and New York being the most lenient.

Medicaid Estate Recovery

Congress established Medicaid estate recovery 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; Sabo 1993). While states were authorized to implement estate recovery
programs as early as 1965, when Medicaid was first enacted, prior to 1993 just 22 states
(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) had implemented such a
policy. 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
(Summers 2013; OIG 1995; GAO 1989).

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."

(360) States are required under the 1993 law 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 – fourteen years after the policy was originally enacted – that all 50 states and the District of Columbia implemented their version of the policy (Greenhalgh-Stanley 2012). Table 1 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 here]

Under guidance established by the Centers for Medicare & Medicaid Services (CMS), every state is required to acknowledge situations where estate recovery may cause undue hardship for the Medicaid beneficiary. However, the definition and criteria for what constitutes undue hardship varies by state (Sabo 1993). 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, Sabatino, and Wood 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, where 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 into 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 the level of consciousness of the policy among Medicaid beneficiaries, signaling that their assets are at risk (Greenhalgh-Stanley 2012). Consequently, they 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 elder law attorney 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), 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, Danziger, and Schoeni 2013). Although Medicaid estate recovery has important implications for the financial health of older adults due to delayed

or avoided care and their families due to recoveries reducing 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 the policy facilitates a shift from taxpayer burden to the estate 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 Medicaid estate recovery is the only incentive for people with resources to spend it on their care.

Conversely, critics of the estate recovery policy, including policy analysts at the Medicaid and CHIP Payment and Access Commission (MACPAC), advocacy groups like Justice in Aging, and legal scholars such as Jim Schuster (2023), say that estate recovery may disincentivize Medicaid-eligible individuals with high care needs to seek long-term care, which

can lead to poor health outcomes (Kapp 2006; Schuster 2023; Justice in Aging 2021; MACPAC 2021). Their collective research argues heirs of deceased Medicaid beneficiaries will suffer the loss of inherited property and be unable to meet their own needs (Kapp 2006; Justice in Aging 2021; Schuster 2023; MACPAC 2021). 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, Sabatino, and Wood 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 all 50 states and the District of Columbia, recovering nearly 20,000 estates in a single year from one-fifth of states that vary in policy leniency, suggests the vast scope of Medicaid estate recovery when accounting for more aggressive state recovery strategies.

Only two prior studies have investigated the implementation of estate recovery policies (MACPAC 2021; Karp, Sabatino, and Wood 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" (Karp, Sabatino, and Wood 2005, 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 financial impact of the policy on the state. In 2004, 30 states had enough data to report their administrative costs, which ranged from \$30,000 to over \$1 million (Karp, Sabatino, and Wood 2005). The survey also found inconsistent practices around hardship waiver applications, where 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 (Karp, Sabatino, and Wood 2005, 34).

The second study, a 2021 Medicaid and CHIP Payment and Access Commission (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 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 (MACPAC 2021; Karp, Sabatino, and Wood 2005).

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 restrict inheritances and asset transfers, as a way to reduce costs for states. Initially designed to ensure

those with resources to pay for LTSS were using them to do so, research finds 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 no less important to maintaining familial wealth and may include connections to an elder law attorney who can navigate a Medicaid application to circumvent look-back periods or estate recovery programs and a family network who instills the importance of estate planning with completion of a trust long before LTSS are needed. Medicaid estate recovery may contribute to disparities in intergenerational wealth transfers—adult children of well-resourced Medicaid beneficiaries continue to inherit property and those with limited assets forfeit them to recovery upon their death. Because there are a significant number of wealthy families not subject to estate recovery policies benefiting from proactive estate planning and access to clever elder law attorneys, states are only recouping a fraction of the cost of Medicaid LTSS while their budgets remain strained.

Outside of socioeconomic and marital status, indicated by Medicaid enrollment and program eligibility, not all states collect detailed demographic data on whose estates were recovered. No known research has been able to leverage granular data like 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 (HRS), Greenhalgh-Stanley found state adoption of estate recovery induced older adults to decrease homeownership by 4.6%, with larger effects in rural areas (Greenhalgh-Stanley 2012). Further, they found a 15% decrease in home equity as a result of Medicaid estate recovery implementation and a decrease in homeownership at death by 33% (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 a person's estate 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 advanced 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 (i.e., a Medicaid policy that refers to the period prior to the date someone applies for Medicaid, that subject all financial transactions to review prior to determining eligibility) and Medicaid estate recovery are examples of such policies. Evidence suggests 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 (Koss and Baker 2018; Yung-Ting 2008; Carr 2012; Kelly, Masters, and DeViney 2013; Spishak-Thomas 2024). For example, white, well-educated, married men were more likely to engage in estate planning prior to enrolling in Medicaid (Spishak-Thomas 2024), with white older adults being 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 2 times more likely to have a will at 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 the ability for older adults 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 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 exempts certain people with disabilities whose income exceeds the more traditional Medicaid levels, from estate recovery and restricts the state to conducting recovery for long-term care (e.g., custodial nursing home stays) expenses only (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 (Richard 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. Additionally, North Carolina increased the amount of assets for a qualified undue hardship applicant from \$12,000 to \$25,000 (Richard 2023). Similarly, Georgia instituted changes related to estate value in 2021, waiving the recovery of the first \$25,000 of estates valued over \$25,000 and mandating 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 Janice Schakowsky, a Democrat representing Illinois's 9th congressional district, would repeal the requirement for states to establish a Medicaid estate recovery program and limit the ability for states to place a lien on a Medicaid beneficiary's property (Schakowsky 2024). The bill was first introduced in the 117th Congress by Representative Schakowsky (H.R. 6698) in February 2022, with just 20 exclusively Democrat cosponsors and never made it out of committee. It was then reintroduced in March 2024 with 47 cosponsors, all Democrats, and did not make it out of the Health subcommittee of Energy and Commerce, never receiving a vote. Relatedly, H.R. 8094, sponsored by Republican Thomas Kean in New Jersey's 7th congressional district, would amend title XIX of the Social Security Act to modify certain asset rules, prohibiting states from recovery when a home has been transferred to another person who is Medicaid eligible or has an income below 138% of the federal poverty level (Kean 2024). Kean's bill did not have any cosponsors and did not make it out of the Energy and Commerce subcommittee on Health. While both bills' reforms are consistent with recommendations from the 2021 MACPAC report, 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) (Thomeer, Mudrazija, and Angel 2016; Sergeant, Ekerdt, and Chapin 2010). 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.

More research is needed to understand the scope of estate recovery and its effects on families to inform lawmakers as they reconsider their approach. 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.

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

Medicaid estate recovery may improve the financial circumstances of surviving family members of deceased Medicaid beneficiaries.

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References

- Arora, Kanika. 2016. "How Does Dementia Onset in Parents Influence Unmarried Adult Children's Wealth." *Social Science & Medicine* 152 (March):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 (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* (blog). July 8, 2024. https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/.

- Corbett, Rachel. 2019. "Medicaid's Dark Secret." *The Atlantic*, October 2019. https://www.theatlantic.com/magazine/archive/2019/10/when-medicaid-takes-everything-you-own/596671/.
- Greenhalgh-Stanley, Nadia. 2012. "Medicaid and the Housing and Asset Decisions of the Elderly: Evidence from Estate Recovery Programs." *Journal of Urban Economics* 72 (2): 210–24. https://doi.org/10.1016/j.jue.2012.05.005.
- Grogan, Colleen M. 2006. "Chapter 9. A Marriage of Convenience: The Persistent and Changing Relationship between Long-Term Care and Medicaid." In *Chapter 9. A Marriage of Convenience: The Persistent and Changing Relationship between Long-Term Care and Medicaid*, 202–26. Rutgers University Press. https://doi.org/10.36019/9780813539874-012.
- 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 (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, 2022. https://kffhealthnews.org/news/article/medicaid-nursing-home-payments-care-mandate/.
- Justice in Aging. 2021. "Medicaid Estate Claims: Perpetuating Poverty & Inequality for a Minimal Return." Issue Brief. Washington, DC: Justice in Aging.
- Kapp, Marshall B. 2006. "Medicaid Planning, Estate Recovery, and Alternatives for Long-Term Care Financing: Identifying the Ethical Issues." *Care Management Journals: Journal of Case Management; The Journal of Long Term Home Health Care* 7 (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." AARP Public Policy Institute.
- Kean, Thomas R. 2024. H.R. 8094 To Amend Title XIX of the Social Security Act to Modify Certain Asset Recovery Rules.
- Kelly, Christopher M., Julie L. Masters, and Stanley DeViney. 2013. "End-of-Life Planning Activities: An Integrated Process." *Death Studies* 37 (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 (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, 2024. https://www.bostonglobe.com/2024/09/07/metro/estate-recovery-masshealth-medicaid-tringali-massachusetts/.
- Manatt Health. 2022. "Making Medicaid Estate Recovery Policies More Equitable: State Toolkit."
- 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 (6): e221373. https://doi.org/10.1001/jamahealthforum.2022.1373.
- Medicaid and CHIP Payment and Access Commission (MACPAC). 2018. "Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid." Washington, DC.

- ———. 2021. "March 2021 Report to Congress on Medicaid and CHIP." Washington, DC. https://www.macpac.gov/publication/march-2021-report-to-congress-on-medicaid-and-chip/.
- ——. 2024. "MACStats: Medicaid and CHIP Data Book." Washington, DC.
- Medina, Lauren, Shannon Sabo, and Jonathan Vespa. 2020. "Living Longer: Historical and Projected Life Expectancy in the United States, 1960 to 2060." *United State Census Bureau*, February, 1125–45.
- Modi, Radha, and Alyasah Ali Sewell. 2022. "Unequal Early Adulthoods: Racial and Ethnic Wealth Disparities during the Great Recession." *The Sociological Quarterly* 63 (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, 2021, sec. Opinion. 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." Chicago, IL: Mathematica.
- Neuman, Patricia, Juliette Cubanski, and Anthony Damico. 2015. "Medicare Per Capita Spending By Age And Service: New Data Highlights Oldest Beneficiaries." *Health Affairs* 34 (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 U.S. South." *Social Forces* 90 (3): 713–34. https://doi.org/10.1093/sf/sor021.
- Office of the Inspector General (OIG). 1995. "Medicaid Estate Recovery Programs." Washington, DC: U.S. Department of Health and Human Services. 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 (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." *The ANNALS of the American Academy of Political and Social Science* 650 (1): 98–123. https://doi.org/10.1177/0002716213497452.
- Richard, Dave. 2023. "State Plan Amendment Title XIX, Social Security Act." *North Carolina Department of Health and Human Services Division of Health Benefits*, no. 23 (January).
- Sabo, Martin O. 1993. *H.R. 2264 Omnibus Budget Reconciliation Act.* https://www.congress.gov/bill/103rd-congress/house-bill/2264.
- Schakowsky, Janice D. 2024. H.R. 7573 Stop Unfair Medicaid Recoveries Act.
- 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." *National Academy of Elder Law Attorneys* 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 (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.
- Shapiro, Thomas M., Tatjana Meschede, and Laura Sullivan. 2010. "The Racial Wealth Gap Increases Fourfold." Brandeis University: Institute on Assets and Social Policy.
- Spishak-Thomas, Amanda. 2024. "Medicaid Enrollment and Intergenerational Transfers of Wealth Among Older Adults." *The Gerontologist* 64 (7): 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 Comment." *Penn State Law Review* 118 (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." *The Journals of Gerontology: Series B* 70 (4): 628–38. https://doi.org/10.1093/geronb/gbu114.
- ———. 2016. "Relationship Status and Long-Term Care Facility Use in Later Life." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 71 (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 & World Report*, October 14, 2021. //www.usnews.com/news/health-news/articles/2021-10-14/debt-after-death-the-painful-blow-of-medicaid-estate-recovery.
- United States General Accounting Office. 1989. "Recoveries From Nursing Home Residents' Estates Could Offset Program Costs." Report to Congressional Committees HRD-89-56. Washington, DC. https://www.gao.gov/assets/hrd-89-56.pdf.
- U.S. Census Bureau. n.d. "National Demographic Analysis Tables: 2020." Accessed February 3, 2021. https://www.census.gov/data/tables/2020/demo/popest/2020-demographic-analysis-tables.html.
- Vespa, Jonathan. 2018. "The U.S. Joins Other Countries With Large Aging Populations." U.S. Census Bureau. *The Graying of America: More Older Adults Than Kids by 2035* (blog). March 13, 2018. 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*, Life Cycle Consumption, Housing, and Homeownership, 47 (March):101624. https://doi.org/10.1016/j.jhe.2019.03.002.
- Washington, Anika. 2021. "Estate Recovery Changes." *Georgia Department of Community Health*, December.
- Williams, Kristine. 2020. "The Future of Estate Recovery: An Analysis of Different State Approaches and Changes." *National Academy of Elder Law Attorneys* 16 (April). https://www.naela.org/NewsJournalOnline/Journal_Articles/2020/Spring_2020/EstRecovery.aspx.
- 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 (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.



Table 1 Estate Recovery Policy Mechanisms

Definition
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.
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.
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.
If a Medicaid beneficiary has a surviving spouse, a child who is under age 21 or a child of any age who is blind or has a disability, recovery must be deferred until after their death. Additionally, recovery may be deferred if a sibling lived in the home for at least one year prior to the beneficiary's death or an adult child delayed a beneficiary's nursing home placement by living in the home for at least two 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.
least two 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. 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 estates are of modest value (defined differently by state) or the sole income-producing asset of surviving relatives (e.g., family farms).

Notes: Table 1 contains definitions of the primary policy mechanisms of Medicaid estate recovery (Karp, Sabatino, and Wood 2005; Medicaid and CHIP Payment and Access Commission (MACPAC) 2021).

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	7
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	

Oregon1993Pennsylvania1995Rhode Island1993South Carolina1995South Dakota1995Tennessee2002Texas2005	Oklahoma Oregon	
Oregon1993Pennsylvania1995Rhode Island1993South Carolina1995South Dakota1995Tennessee2002Texas2005	Oregon	
Pennsylvania 1995 Rhode Island 1993 South Carolina 1995 South Dakota 1995 Tennessee 2002 Texas 2005		2002
Rhode Island South Carolina 1995 South Dakota 1995 Tennessee 2002 Texas 2005	Pennsylvania	
South Carolina 1995 South Dakota 1995 Tennessee 2002 Texas 2005		
South Dakota 1995 1995 Tennessee 2002 Texas 2005	Rhode Island	
Tennessee 2002 Texas 2005	South Carolina	
Texas 2005	South Dakota	1995
	Tennessee	
Utah 1993	Texas	
Otan 1993	Utah	
Vermont 1995	Vermon	
Virginia 1993	Virginia	
Washington 1993	Washington	
West Virginia 1995 1995	West Virginia	1998
Wisconsin 1993 1995	Wisconsin	1993
Wyoming 1995 200	***	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.