

Expanding Exemptions from Medicaid Estate Recovery in Illinois

By Rebecca Rieckhoff, Ngeindaloh Smith, and Meghan P. Carter
February 16, 2022

Overview:

Under Section 1917(b)(1) of Title XIX of the Social Security Act, states are required to seek recovery from the estates of certain Medicaid beneficiaries to recoup payments made for long-term services and supports (“LTSS”) and related benefits.¹ States have discretion as to whether to pursue recovery for other Medicaid services. While estate recovery for LTSS is mandatory for some beneficiaries, there are some exemptions built into federal law, including exemptions to estate recovery where the beneficiary has a surviving spouse, a child under age 21, a child of any age who is blind or has a disability, or, in some circumstances, a sibling or child who lived in the beneficiary’s home and provided care to the beneficiary. States must also establish procedures for waiving estate recovery in cases where recovery would present an undue hardship. Defining the parameters of these undue hardship exemptions is largely left to the states.²

The theory behind estate recovery may be to keep funds available for future Medicaid beneficiaries, but in reality, these programs recoup only a small percentage of states’ Medicaid LTSS expenditures. And this cost is high: estate recovery unduly burdens low-income families and communities of color.

Recognizing the shortcomings of Medicaid estate recovery programs, the Medicaid and CHIP Payment and Access Commission (“MACPAC”)³ made several recommendations for expanding mandatory exemptions to estate recovery on the federal level in its March 2021 *Report to Congress on Medicaid and CHIP*.⁴ In its report, MACPAC noted that Medicaid beneficiaries with sizeable assets are more likely to engage in estate planning to legally shield those assets from recovery.⁵ Accordingly, most estate recovery comes from beneficiaries of modest means. MACPAC also noted that state Medicaid estate recovery programs may also disproportionately affect people of color.⁶ Justice in Aging has similarly found that Medicaid estate recovery

¹ 42 U.S.C. § 1396p; *see also* 42 U.S.C. § 1396a, requiring that state plans for medical assistance comply with the provisions of section 1396p.

² Centers for Medicare and Medicaid Services, State Medicaid Manual § 3810. The State Medicaid Manual sets out the outer bounds of state options for undue hardship exemptions, but states are left with significant discretion to set their undue hardship exemption parameters.

³ MACPAC is authorized under 42 U.S.C. § 1396 to serve as a non-partisan legislative branch agency that provides policy and data analysis and recommendations to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states on issues affecting Medicaid.

⁴ These recommendations are featured in Chapter 3 of MACPAC’s March 2021 report, *Medicaid Estate Recovery: Improving Policy and Promoting Equity*, available at <https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf>.

⁵ *Id.* MACPAC noted in its report that “[E]state recovery does not appear to be effective in recouping assets from the estates of beneficiaries with substantial means. Instead, the modest average recovery amounts reported in our survey and comments from stakeholder interviews suggest that states primarily collect from estates of modest size.” *Id.* at 92.

⁶ *Id.* at 73.

programs disproportionately burden lower income families and communities of color and erect barriers to creating generational wealth through homeownership.⁷

In recognition of the potential for estate recovery programs to unduly burden people of lesser means, the MACPAC commissioners voted 15-1-1 in favor of a recommendation to implement federal minimum hardship waivers, including waivers for income producing assets (such as family farms, daycares, barbershops, and other family businesses), homes of modest value, and estates that do not meet minimum cost-effectiveness thresholds. These hardship minimums would supplement the existing carve-outs for estate recovery in federal law. These recommendations are consistent with guidance the Centers for Medicare & Medicaid Services (“CMS”) has issued to states regarding estate recovery waivers.⁸ CMS’ guidance notes that undue hardship exemptions should be made for income-producing assets, homes of modest value, and other compelling circumstances, consistent with the legislative history of Section 1917 of Title XIX of the Social Security Act.⁹

Expanded federal exemptions, if adopted, would help to alleviate some of the hardship Medicaid estate recovery programs impose on beneficiaries of moderate means, but states *already* have the ability to implement these much-needed exemptions into their own estate recovery programs. In fact, many states already provide undue hardship exemptions for homes of modest value and for income-producing assets. States have also implemented exemptions to recovery for estates that do not meet prescribed cost-effectiveness thresholds.

In recognition of the burden that estate recovery places on disadvantaged groups, and to bring Illinois into alignment with MACPAC and CMS recommendations, as well as with the actions of many other states, this paper recommends expanding the categories of state-recognized Medicaid estate recovery exemptions.

Illinois should expand its existing undue hardship exemptions to include homes of modest value and for income-producing assets. Additionally, Illinois should set a minimum cost-effectiveness threshold for estate recovery actions, and not attempt to recover from estates that are valued at less than \$25,000. Finally, to ensure that beneficiaries who are eligible for these exemptions understand their rights, Illinois should develop a more user-friendly notice process and web-based interface where eligible heirs can learn about how to apply for these recovery exemptions. And to ensure transparency, Illinois should publicly report on its estate recovery activities.

Expanding Illinois’ Current Hardship Exemption Criteria:

⁷ *Medicaid Estate Claims: Perpetuating Poverty & Inequality for A Minimal Return*, Justice in Aging (Apr. 2021), <https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf>. Critiques of Medicaid estate recovery have been made since the Federal government expanded required Medicaid recovery in 1996. Writing in 1997, Jon Ziegler noted that states should “do more to distinguish between well-off recipients who are simply hiding assets and poor recipients who have managed to hold on to only a small core group of assets accumulated over a lifetime such as their homes.” Jon M. Zieger, *The State Giveth and the State Taketh Away: In Pursuit of A Practical Approach to Medicaid Estate Recovery*, 5 Elder L.J. 359, 386–87 (1997).

⁸ *State Medicaid Manual* at § 3810.C.1.

⁹ *Id.*

Illinois' current Medicaid estate recovery exemptions are laid out in Ill. Admin. Code tit. 89, § 102.210. The state's Medicaid estate recovery program is administered by the Illinois Department of Healthcare and Family Services (HFS). Illinois has chosen to pursue estate recovery for medical assistance paid out:

- A. at any time for a permanently institutionalized recipient whose real property is subject to the Department's lien; or
- B. except the costs of Community Care Program (CCP) services, prior to October 1, 1993, for a recipient 65 years of age or older; or
- C. on or after October 1, 1993, for a recipient 55 years of age or older; or
- D. for Medicare cost sharing expenses (Part A and B premiums, deductibles, coinsurance and copayments) made on behalf of persons described in 42 USC 1396a(a)(10)(E), when a request for payment of those expenses was received by the Department prior to January 1, 2010. Requests for payment of Medicare cost sharing expenses made after January 1, 2010 are exempt from estate recovery.¹⁰

Illinois defines "Estate" for Medicaid recovery purposes as "all real and personal property within an individual's estate as provided in Illinois probate law."¹¹ Illinois recognizes the current federal exemptions to estate recovery and, per federal requirements, defines an "undue hardship" exemption. Under this undue hardship exemption, the state will waive its right to recover:

if pursuing recovery would cause an heir or beneficiary of the estate to become or remain eligible for a public benefit program, such as SSI, TANF or Food Stamps. The [state] may limit the scope of its waiver to that portion of the estate that the heir or beneficiary would receive and pursue recovery against the balance of the estate, if any. The [state] will not waive recovery despite undue hardship if payment of the claims of other estate creditors that are equal or inferior in priority to the [state's] claim will exhaust the estate and defeat the purpose of the waiver.¹²

Illinois should broaden this exemption. To require that an heir or beneficiary become or remain eligible for public benefits in order to avoid estate recovery sets a very low threshold; individuals who remain just above the cutoff for public benefits could still benefit significantly from even a small inheritance. Per MACPAC, the most recent available data suggests that average estate recovery is only \$8,116. While this small average recovery may not make a significant difference to the state's budget, it can make a significant difference to a family living just above the public benefits cutoff.

Illinois' current hardship exemption is drafted too narrowly. Expanding Illinois' current estate recovery hardship exemption could help to decrease financial instability among the heirs or beneficiaries of some deceased Medicaid beneficiaries. However, this reform alone will not make a significant enough impact. In failing to also adopt other categorical exemptions to Medicaid estate recovery, Illinois lags behind federal guidance from CMS and MACPAC and likely pursues estate recovery from individuals who would significantly benefit from receiving inherited assets. Adding new categorical exemptions to estate recovery, in addition to broadening

¹⁰ Ill. Admin. Code tit. 89, § 102.210.

¹¹ *Id.*

¹² *Id.*

the state's existing undue hardship exemption, is an important step toward advancing social and racial justice in Illinois.

Creating a Modest-Value Homes Undue Hardship Exemption:

Illinois should create a categorical undue hardship estate recovery exemption for homes of modest value. This change would be in line with many other states who already recognize such an exemption and would comply with CMS guidance.¹³ In California, for example, the state waives estate recovery where the homestead is of modest value.¹⁴ In Texas, where the value of a beneficiary's home is less than \$100,000¹⁵ and the home would be inherited by siblings or lineal heirs of the beneficiary, all of whom have a family income under 300% of the Federal poverty level,¹⁶ the state will grant a hardship exemption to recovery.¹⁷ Virginia views the modest value of a home as a special consideration when choosing whether to pursue estate recovery as well.¹⁸ Michigan similarly will not pursue estate recovery against "the proportion of the value of the [beneficiary's] homestead that is equal to or less than 50% of the average price of a home in the county in which the . . . homestead is located as of the date of the [beneficiary's] death."¹⁹

Setting either an absolute minimum home value threshold (like Texas's \$100,000) or a relative home value minimum threshold (like Virginia and Michigan's 50% relative value thresholds) for estate recovery against a Medicaid beneficiary's home would bring Illinois in line with the many other states who recognize the importance of passing along family homes. CMS guidance supports creating an undue hardship exemption for homes of modest values, noting that "a homestead of 'modest value' can be defined as fifty percent (50%) or less of the average price of homes in the county where the homestead is located, as of the date of the beneficiary's death."²⁰ The ability to devise a family home not only provides immediate housing stability for heirs, but also can help those heirs to build intergenerational wealth and secure long-term financial stability for their families.

Implementing an Income-Producing Assets Undue Hardship Exemption:

Many states include exemptions to estate recovery for income-producing assets. In Texas, for example, the state will not pursue recovery where:

¹³ *State Medicaid Manual* at § 3810.C.1.

¹⁴ Cal. Welf. & Inst. Code § 14009.5. California has not created a definition for "modest value."

¹⁵ As measured by the tax appraisal district value. Where the home's value exceeds \$100,000, but all other conditions are met, the first \$100,000 of the tax appraisal district value for the most recent tax year at the time of the beneficiary's death is exempt from estate recovery. 1 Tex. Admin. Code § 373.209.

¹⁶ 1 Tex. Admin. Code § 373.209. Where not all heirs qualify for the hardship waiver, only the percentage of the home that corresponds to the qualifying heir(s) share is exempt from recovery. *Id.*

¹⁷ Texas also offers other hardship exemptions, which function similarly to Illinois' existing hardship exemption. 1 Tex. Admin. Code § 373.209.

¹⁸ 12 Va. Admin. Code 30-20-141. In Virginia, a home of modest value means a home that is worth 50% or less of the average or median price of homes in the county or city where the homestead is located as of the date of the Medicaid beneficiary's death. *Id.*

¹⁹ Mich. Comp. Laws Ann. § 400.112g.

²⁰ *State Medicaid Manual* at § 3810.C.1.

The estate property subject to recovery has been the site of the operation of a family business, farm, or ranch at that location for at least 12 months prior to the death of the decedent; is the primary income producing asset of heirs and legatees, and produces 50 percent or more of their livelihood; and recovery by the State would affect the property and result in the heirs or legatees losing their primary source of income.²¹

California, Georgia, and Michigan will not pursue estate recovery for property that serves as the primary income source for an heir, including family farms and businesses.²² Washington similarly may waive estate recovery where the property subject to recovery is the sole income-producing asset of an heir.²³ Virginia also gives special consideration to income-producing assets, such as family farms and family businesses when evaluating whether to pursue estate recovery.²⁴

Illinois should join the many states that recognize the value of devising income-producing assets to heirs. Family farms, home-run businesses, and other income-producing assets all offer heirs an opportunity to build on the efforts of prior generations and to achieve long-term financial stability. The state may see small financial benefit to reclaiming an engine repair business run out of a beneficiary's garage or a small-scale family farm operation, but the cost borne by the heirs denied the opportunity to realize the lifelong value of those assets is far greater than any benefit to the state. Accordingly, Illinois should expand its exemption categories to include income-producing assets, bringing the state in line not only with the many other states already granting these exemptions but also with federal MACPAC and CMS guidance.²⁵

Implementing a Cost-Effectiveness Threshold:

Illinois should also introduce a clear cost-effectiveness threshold for Medicaid estate recovery actions. CMS guidance supports states' ability to create a cost-effectiveness threshold, which stands apart from a states' undue hardship exemptions.²⁶ Under CMS guidance, states are allowed to adopt their own definition of cost effectiveness.²⁷ By setting a clear minimum value for estate recovery, Illinois would be able to streamline administrative processes and avoid using

²¹ 1 Tex. Admin. Code § 373.209.

²² California will not pursue estate recovery where the property to be recovered is "part of an income-producing business, such as a working farm or ranch, and recovery of medical assistance expenditures would result in the [relevant heir] losing his or her primary source of income." Cal. Code Regs. tit. 22, § 50963; Georgia will grant an undue hardship exemption where "the asset to be recovered is an income producing farm and sole income source of one or more of the Heirs and the annual gross income is limited to \$25,000 or less and is not merely rental income." Ga. Comp. R. & Regs. 111-3-8-.08; Michigan will grant "[a]n exemption for the portion of an estate that is the primary income-producing asset of survivors, including, but not limited to, a family farm or business." Mich. Comp. Laws Ann. § 400.112g.

²³ Wash. Admin. Code 182-527-2750.

²⁴ 12 Va. Admin. Code 30-20-141.

²⁵ CMS notes that undue hardship exemptions for income-producing assets for heirs with limited incomes. *State Medicaid Manual* at § 3810.C.1.

²⁶ CMS has indicated that states "may waive adjustment or recovery in cases in which it is not cost effective for you to recover from an individual's estate. The individual does not need to assert undue hardship. You may determine that an undue hardship exists when it would not be cost effective to recover the assistance paid. You may adopt your own reasonable definition of cost effective." *Id.* at § 3810.E.

²⁷ *Id.*

time and resources to collect from estates that have very little recoverable value. Not only is this in line with MACPAC and CMS guidance, but Illinois would also be following the model of a number of other states which set out predefined cost effectiveness thresholds for estate recovery. Illinois should look to those states as a model when drafting their own exemptions.

Massachusetts, for example, recently implemented a cost-effectiveness threshold for estate recovery. Under this exemption, the state will not pursue recovery where the total assets of the beneficiary's estate are valued at \$25,000 or less.²⁸ Georgia similarly has chosen to waive any and all estate recovery claims against the first \$25,000 of a Medicaid beneficiary's estate.²⁹ Texas will not pursue estate recovery where an estate is valued at \$10,000 or less, where the amount of recoverable Medicaid costs is \$3,000 or less, or where the cost involved of the sale of the property would be equal to or greater than the value of the property.³⁰ Virginia regulations provide that the state will not pursue estate recovery where it would not be cost effective to recover from the estate, but has not set a threshold cost-effectiveness value.³¹ The state weighs the costs of staff time, litigation costs, expert witness fees, deposition expenses, travel expenses, office supplies, postage, advertising, and publishing costs when performing a cost-effectiveness evaluation.³²

Illinois should implement a cost-effectiveness threshold in line with Massachusetts and Georgia, providing exemptions for estates worth less than \$25,000. Creating a clear threshold would provide a clean administrative framework for HFS. It would also ensure that the state is not pursuing recovery at a net loss to the state and would ensure that families of modest means are not bearing the majority of the weight of the state's estate recovery program. It also shifts the burden off the individual family to request a waiver and instead to the state to first evaluate whether pursuing the estate would be worth the state's resources. Establishing a threshold is fair, efficient, and long overdue.

Expanding Available Information for Beneficiaries Subject to Estate Recovery:

States are required to provide notice to all Medicaid applicants explaining their estate recovery policies.³³ However, providing clear and accurate information about estate recovery exemptions when the state initiates the recovery process is important as well. As noted in a 2007 report on Medicaid estate recovery,

Public information on Medicaid estate recovery is essential to Medicaid applicants, enrollees, and their families. Effective information and outreach can heighten public awareness about recovery . . . Conveying clear information at the outset about the recovery program, how it affects individual estates, and procedures for review can minimize stress and decrease misperceptions. Clarity

²⁸ 130 Mass. Code Regs. 515.011. This exemption is in addition to Massachusetts' hardship exemption, which functions similarly to Illinois' existing hardship exemption, codified in 130 Mass. Code Regs. 515.011.

²⁹ Ga. Comp. R. & Regs. 111-3-8-.04.

³⁰ 1 Tex. Admin. Code § 373.215.

³¹ 12 Va. Admin. Code 30-20-141. For estate recovery purposes in Virginia, "cost effective" means that "both the dollar amount of the medical assistance payments (claim) and the value of the estate at least exceed the administrative costs of recovery." *Id.*

³² *Id.*

³³ *State Medicaid Manual* at § 3810.G.1.

and readability of the information is particularly essential because Medicaid enrollees and survivors may have modest education, lack legal representation, have poor vision, or be under severe stress, any of which may affect their ability to read and understand the information presented. Public information also can help to ensure smooth operation of the recovery program and foster public confidence.³⁴

In Illinois, current regulations note that “[t]he [state] will provide written notice to heirs and beneficiaries known to the [state] of the opportunity, time frame and method to request a waiver of estate recovery based on undue hardship.”³⁵ However, as of January 2022, the Illinois Department of Healthcare and Family Services offers only one webpage related to estate recovery which provides only that:

A claim may not be filed against your estate if recovery would cause an heir or beneficiary undue hardship. To waive recovery, the heir or beneficiary must show that the recovery would cause them to become or remain eligible for programs such as Supplemental Security Income (SSI), Temporary Assistance for Needy Families (TANF) or Food Stamps.³⁶

The webpage does not provide beneficiaries with clear information on how to apply for exemption, nor does it provide beneficiaries with information about what materials they will need to provide the state in order to prove qualification for exemption. Beneficiaries are merely instructed to write to the Department’s Bureau of Collections for further information.

Many states offer brochures, websites, training materials, and toll-free telephone numbers and some offer multi-lingual options for these resources.³⁷ Massachusetts, for example, has a website dedicated to Medicaid estate recovery which explains in plain language the reasons for the state’s recovery program and the process by which the state pursues recovery.³⁸ Applications for waiver are available on the website in English and Spanish, along with English and Spanish fact sheets and FAQs. California’s Department of Health Care Services offers a centralized webpage providing plain language information on the state’s estate recovery program, links to hardship waiver applications, a collection of online forms, an estate recovery brochure in English and Spanish, and links to other related resources.³⁹

Finally, in Illinois, there is a dearth of public information about how estate recovery functions. Medicaid estate recovery has been called “Medicaid’s Dark Secret.”⁴⁰ To advance equity and justice in the estate recovery process, the state must publicly report on its estate

³⁴ Erica F. Wood & Ellen M. Klem, *Protections in Medicaid Estate Recovery: Findings, Promising Practices, and Model Notices*, ABA Commission on Law and Aging, AARP Public Policy Institute, 6 (2007) (http://www.canhr.org/reports/2007/2007_07_medicaidprotections.pdf).

³⁵ Ill. Admin. Code tit. 89, § 102.210.

³⁶ See Illinois Department of Healthcare and Family Services, *HFS 3419B Property Liens & Estate Claims*, available at <https://www2.illinois.gov/hfs/info/Brochures%20and%20Forms/Brochures/Pages/HFS3419b.aspx>.

³⁷ Wood & Klem, *supra* note 34 at vi.

³⁸ Massachusetts Medicaid Estate Recovery, <https://www.mass.gov/info-details/massachusetts-medicaid-estate-recovery>.

³⁹ Estate Recovery Program, https://www.dhcs.ca.gov/services/Pages/TPLRD_ER_cont.aspx.

⁴⁰ Rachel Corbett, *Medicaid’s Dark Secret*, The Atlantic (Oct. 2019), <https://www.theatlantic.com/magazine/archive/2019/10/when-medicaid-takes-everything-you-own/596671/>.

recovery activities so the public can serve as a check on how the program is operating. Further, the state must provide more consumer-friendly, comprehensive information to beneficiaries and their heirs about how estate recovery operates and hardship exemptions. Not only should the state provide multilingual plain language explanations of the program and the process for applying for exemption, but the state should also provide accessible contact information for state agents to assist individuals impacted by the estate recovery program and an online portal for submitting applications and questions. The state must provide clear, accessible resources, and information about its estate recovery activities, for the amendments to the estate recovery program urged here to achieve their aim.

Conclusion:

Medicaid stands alone among federal benefit programs in requiring that states recoup program funds from beneficiaries' estates. Data suggests that state Medicaid estate recovery programs primarily collect from beneficiaries of modest means, disrupting the opportunity to build intergenerational wealth through home ownership. Meanwhile, beneficiaries with the knowledge and resources to secure legal estate planning services are often able to avoid estate recovery. The impact of estate recovery on individual beneficiary's families can be significant, but the aggregate effect of these collections for the state is minimal. In Fiscal Year 2019, for example, Illinois recouped no more than 0.83% of its fee for service LTSS Medicaid spending through estate recovery.⁴¹

Federal law gives states significant discretion in granting estate recovery exemptions. Expanding the available exemptions in Illinois will help to alleviate the heavy burden borne by Medicaid beneficiaries and their families, and will help to narrow the race wealth gap in the state by allowing more beneficiaries to pass on their homes and other probate assets. Adopting these exemptions would also bring Illinois in line with guidance from MACPAC and CMS regarding Medicaid estate recovery, which recognize the need to protect beneficiaries of limited means and preserve opportunities to secure intergenerational stability.

Illinois should exercise its discretion to expand the recognized exemptions to estate recovery for Medicaid services. By expanding the current economic hardship exemption, implementing undue hardship exemptions for homes of modest values and income-producing assets, and establishing a minimum cost-effectiveness threshold, the state can minimize the burden of Medicaid estate recovery on low-income people and communities of color. Additionally, by improving clarity of information and resources provided to heirs subject to estate recovery proceedings, the state can ensure that beneficiaries deserving of and qualified for recovery exemptions will be able to secure them.

⁴¹ *Medicaid Estate Recovery: Improving Policy and Promoting Equity, Chapter 3 Medicaid Estate Recovery: Improving Policy and Promoting Equity*, MACPAC, (2021), <https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf>, at table 3E-1.