Holding on to Home:

A Primer on MassHealth Estate Recovery and Options for Reducing its Impact on Members and Families

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I. INTRODUCTION

Like other state Medicaid programs, MassHealth—the name of Massachusetts' Medicaid program and Children's Health Insurance Program (CHIP)—is required under federal law to perform a practice known as estate recovery. Estate recovery is a process by which the state seeks reimbursement from the estates of Medicaid members after they die for the costs of providing long-term services and supports (LTSS) to: 1) members aged 55 or older, and 2) any member (regardless of age) permanently residing in a long-term care or other medical facility (i.e., nursing home). LTSS refers to services and supports commonly provided to older adults or individuals with disabilities to assist them with meeting personal and health care needs that may be offered at home, in community-based settings, or in long-term care facilities (see callout box for more information on LTSS). While federal law sets minimum requirements for Medicaid estate recovery, states have the option to exceed those minimum standards and can choose to seek reimbursement for the cost of *all* Medicaid-covered services provided, not just LTSS. In states that select this option, more members over the age of 55 are impacted by estate recovery, since it is not restricted to just those who use LTSS.

Massachusetts is among the states whose estate recovery policy exceeds the federally mandated minimum requirements. This is because state law requires that MassHealth seek reimbursement for *all* services[1] provided to any member, aged 55 and over, regardless of whether they ever utilized MassHealth-covered LTSS. Prior to reforms made in 2021 (see callout box below), MassHealth historically recovered more from member estates than any other state, even though it's only the 10th highest state in total Medicaid spending.[2] In fact, in fiscal year (FY) 2019, Massachusetts recovered 39 percent more in total gross[3] recoveries than the next highest state.[4]

Long-Term Services and Supports (LTSS) encompass a variety of health, health-related, and social services that assist individuals with functional limitations due to physical, cognitive, or mental conditions or disabilities. LTSS include both nursing facility stays and home- and community-based services (e.g., home health services, personal care, adult day health care).

In Massachusetts, MassHealth covers 69 percent of nursing home residents and is the primary payer for LTSS. In general, to receive MassHealth LTSS benefits, individuals must meet both income and asset limits but are allowed to retain certain assets while receiving services, such as their primary residence and vehicle, without it impacting their eligibility.

Sources: Blue Cross Blue Shield of Massachusetts Foundation. (2022). *MassHealth: The Basics Facts and Trends.* *https://www.bluecrossmafoundation.org/sites/g/files/csphws2101/files/2022-10/MassHealthBasics2022_FINAL_1.pdf*; Massachusetts Senate Working Group on Health Care Cost Containment. (2017). *https://malegislature.gov/assets/documents/ma-senate-healthcare-reform-report.pdf.*

In 2021, the Centers for Medicare & Medicaid Services (CMS) approved MassHealth's request to change certain estate recovery policies, including ceasing to pursue recoveries from estates valued at $25,000 or less, and offering new protections for low-income heirs (see callout box). As a result of these reforms, the state's gross estate recovery collections are projected to drop by at least half, from $47,175,541 prior to reforms in state fiscal year 2019, to an estimated $23,500,000 annually when all 2021 reforms are fully implemented (about half of which will be returned to the federal government).[5] Despite these reforms, Massachusetts' state law still requires the MassHealth estate recovery program to exceed federal minimum requirements by seeking reimbursement for the total cost of care for all MassHealth services (not just LTSS) provided to members aged 55 and older. Also, there are additional exemptions and waivers that Massachusetts could make available to MassHealth members to further lessen the impact of the policy. These exemptions and waivers would provide the opportunity for the state to go further in protecting members and their families from the burden of estate recovery, especially for individuals who are economically, racially, culturally, or socially marginalized (referred to in this brief as "marginalized populations"), since this practice often prevents the passing down of assets. Notably, while the home is typically the most valuable asset being passed down, surviving family members are often forced to sell the home in order to pay off the deceased member's MassHealth-related debt. Limiting the passing down of assets may perpetuate intergenerational poverty.

In 2021, MassHealth introduced a series of reforms to its estate recovery program in the following areas:

- Established a $25,000 cost-effectiveness threshold. This means the state will not pursue estate recovery for estates valued at $25,000 or less.
- Expanded hardship waiver criteria.
- Enhanced member noticing.

These reforms are described in more detail in Section III.

It is in this context that the Massachusetts Medicaid Policy Institute (MMPI)—a program of the Blue Cross Blue Shield of Massachusetts Foundation—contracted with Aurrera Health Group (Aurrera Health) to develop an issue brief that describes MassHealth's estate recovery policy and practices, including how they compare to federal law and other states' policies and practices. This brief also describes what we know about how estate recovery impacts MassHealth members with a particular focus on how it affects marginalized communities, and it identifies policy and programmatic options that the state could pursue to reduce the burden of estate recovery on members and their families.

To do this work, the Aurrera Health team conducted a literature review and environmental scan to compare MassHealth's estate recovery program to other states' programs. To gather insights on the evolution of different state estate recovery programs and the effects of estate recovery on members and their families, the team conducted interviews with MassHealth and Massachusetts-based advocates, as well as officials from two other states who recently reformed their estate recovery programs. See *Appendix A* for a list of the organizations interviewed. Because the focus of this report is tied to a legal construct, the language may be more technical than a typical MMPI publication. The goal of this report is to describe estate recovery in language that is accessible to a broad audience. For readers less interested in the technical aspects of this practice but who want to understand the implications for surviving family members, please see this *complementary report* that tells the stories of how estate recovery has impacted four individuals in Massachusetts after the loss of a loved one.

II. FEDERAL ESTATE RECOVERY POLICY

Medicaid is an essential, and often the only, source of LTSS coverage for seniors and nonelderly individuals with disabilities. Federally, the practice of estate recovery was initially developed as a mechanism to offset state and federal Medicaid spending by people who use LTSS.

While states have had the option to implement estate recovery since the establishment of the Medicaid program in 1965, the federal Omnibus Budget Reconciliation Act of 1993 made it a requirement for all state Medicaid programs. The federal estate recovery requirement applies to members who received Medicaid when they were age 55 or older and individuals of any age if they were expected to permanently reside in a long-term care setting. For such members, federal law requires states to pursue reimbursement for amounts at least equal to the total Medicaid benefits (state and federally funded) paid on their behalf for nursing facility services, home- and community-based services (HCBS),[6] and hospital and prescription drug services related to care provided in a nursing facility or through HCBS. In this way, a critique of estate recovery is that it provides coverage for certain Medicaid benefits (e.g., LTSS) as a loan that must be repaid after the member dies.[7]

Estate recovery requirements were created to promote personal responsibility for LTSS costs and help states offset these expenses. However, data shows that estate recovery recoups only a small fraction of all LTSS spending for states. In FY 2019 for example, Medicaid programs collected a total of $733.4 million from member estates, which is less than half a percent of total Medicaid spending that year.[8] From the state perspective, the value of estate recovery as a funding mechanism is restricted by the fact that a portion of what is recovered must be returned to the federal government as reimbursement for the share of the services it initially funded (typically at least 50 percent of a state's gross recovery).

An additional argument in support of estate recovery is that it partially mitigates inequities between homeowners and non-homeowners enrolling in Medicaid. In most states, including in Massachusetts, people aged 65 and older face restrictive asset limits and are required to spend down most of their assets to qualify for Medicaid. However, in Massachusetts, an individual's equity in their primary home typically does not count towards the asset limit.[9] In other words, homeowners aged 65 and over are not required to sell their home—often the most valuable asset—as part of the spend down to be determined eligible for MassHealth. In this way, the eligibility rules for MassHealth may leave homeowners better off at the end of the spend down process than those who don't own homes. Estate recovery potentially mitigates this inequity by recouping the cost of care from the estate of the deceased member, which often includes the equity in the home.

Federal law sets minimum standards for state estate recovery programs but also provides states with flexibility to exceed them, or recoup more from a deceased member's estate than those minimum standards required under federal law. Per state law, Massachusetts is among the states that opts to seek recovery for the total cost of care for *all* MassHealth services (not just LTSS) provided to members aged 55 and older. This aspect of the Massachusetts estate recovery policy and others are described in more detail in the next section.

III. COMPONENTS OF MASSACHUSETTS' ESTATE RECOVERY POLICY

Key Summary

MassHealth has made several reforms to its estate recovery policy in recent years. These reforms have resulted in enhanced member notification, increased hardship waiver applications, and reduced estate recovery collections. However, Massachusetts still exceeds the federally mandated minimum requirements for estate recovery because state law requires MassHealth to seek reimbursement for *all* MassHealth services provided to any member, aged 55 and over, regardless of if they ever utilized MassHealth-covered LTSS. As a result, more MassHealth members aged 55 and over are impacted by estate recovery, since it is not restricted to just those who use LTSS.

As noted earlier, prior to the estate recovery reforms implemented in 2021, Massachusetts collected more revenue from its estate recovery program than any other state. There are numerous factors that likely explain why Massachusetts collected more than others, including that Massachusetts' estate recovery program was more expansive, and exceeded minimum federal requirements, as explored in more detail below. Other factors influencing Massachusetts' larger estate recovery collections may be unrelated to estate recovery policy; for example, MassHealth has more expansive Medicaid eligibility criteria than many other state Medicaid programs, making it easier for older adults and individuals with disabilities to qualify. Massachusetts also upholds an individual mandate that requires anyone 18 or older to maintain affordable health insurance coverage, meaning individuals who qualify for MassHealth have an additional incentive to enroll, which can then put them at risk of recovery for the MassHealth-covered services they receive at or above age 55.[10]

Realizing that the MassHealth estate recovery program was more expansive than states with comparable Medicaid programs, in 2021 MassHealth requested approval from CMS to implement several reforms to reduce the policy's impact on low- and middle-income members and families. CMS approved these reforms, which reduced the amount the state recovers significantly. In an interview, a MassHealth official reported that the agency has eliminated approximately 41 percent of cases that were previously subject to estate recovery due to their new cost-effectiveness threshold (described below), and as a result, saw a decline in net revenue[11] from the estate recovery program.[12] Prior to reforms, net revenue to the state was about $24 million annually. Post-reforms, there has been a reduction by around 33 percent resulting in $16 million net revenue in FY 2022. MassHealth estimates this net revenue will go down even further to about $12 million recovered annually as estate recovery cases that were already underway prior to the 2021 changes are resolved. Based on FY 2019 data submitted to CMS, once the 2021 reforms are fully realized (i.e., once all open cases prior to 2021 are resolved), the state would drop significantly in terms of its total estate recovery collections relative to other states.[13]

Gross vs. Net Revenue

In this report we refer to both *gross* and *net* dollar amounts. The term "gross" refers to the total value of recoveries comprising both the federal and state share. Typically, about half of the total (gross) amount recovered in Massachusetts goes to the federal government. The term "net" refers to the amount retained by the state that goes back to the state's general fund.

But, even after the 2021 reforms, aspects of Massachusetts' estate recovery policy and practices still go beyond the federally required minimums—and beyond numerous other states' policies and practices.

Below, we describe Massachusetts' estate recovery program, including detail on the reforms implemented in 2021, and highlight how the Massachusetts policy compares to federal requirements and to other states' policies. This section is organized based on four key elements of estate recovery policy and practice in which states have flexibility:

- Scope of Medicaid services eligible for recovery
- Types of estates/assets subject to recovery
- Exemptions from estate recovery
- Member education and transparency

For additional information on how Massachusetts' policies compare to other states, see *Appendix B* for a table that details which states recover for services beyond the federal minimum requirements, as well as each state's use of expanded hardship waivers and cost-effectiveness thresholds.

Legislation that would further reform Massachusetts' estate recovery policy (S.726/H.1168, An Act Protecting the Homes of Seniors and Disabled People on MassHealth) has been introduced in the past two legislative sessions. See Box 1 on page 7 for more detail on the proposed legislation.

SCOPE OF MEDICAID SERVICES ELIGIBLE FOR RECOVERY

As of 2022, 27 states collected for only the mandatory LTSS benefits for individuals age 55 and over, as well as for individuals of any age if they are expected to permanently reside in a long-term care setting, in accordance with federal requirements.[14] However, states have the option to recover from the estates of certain individuals for any items and services covered under their state Medicaid plan, beyond the federally required minimum service categories.[15]

In Massachusetts, state law requires that MassHealth seek reimbursement for the total cost of care for *all* MassHealth-covered services[16] for any member aged 55 and older, or for members of any age who permanently reside in a long-term care or other medical facility. As of 2022, MassHealth was one of 24 states that recovered for all Medicaid-covered services—not just the federally required minimum services categories.[17] Services that MassHealth seeks to recoup the cost of that are *not federally required* to be recovered include, for example: preventive services such as mammograms or colonoscopies, acute care if a member was in a car accident, or treatment for a chronic condition, such as diabetes.

TABLE 1. MEDICAID SERVICES ELIGIBLE FOR ESTATE RECOVERY AMONG MEMBERS AGE 55+ AND INDIVIDUALS OF ANY AGE WHO ARE INSTITUTIONALIZED

	NURSING FACILITY SERVICES, HOME- AND COMMUNITY-BASED SERVICES, AND RELATED HOSPITAL AND PRESCRIPTION DRUG SERVICES	ALL OTHER MEDICAID SERVICES
FEDERAL REQUIREMENT	✓	X
REQUIRED UNDER MASSACHUSETTS' ESTATE RECOVERY PROGRAM	✓	✓

A reason some states may opt to collect for all services instead of just the federally required LTSS (i.e., "mandated benefits" or "mandated services") is because collecting for *all* Medicaid services is administratively easier. The challenge for a state that opts to collect for only the federally mandated benefits is that the state must review all the services a member received and determine which qualify as mandated services. This is complex because, for example, mandated services do not typically include hospital and prescription drug services—unless the hospital services and prescription drugs are related to care provided in a nursing facility or through HCBS. Another complexity exists for members enrolled in a managed care program, as a state recovering only mandated services would have to determine what portion of the capitated payment (a set payment per member per month to cover a set of defined services) paid to managed care plans was spent on mandated services. On the other hand, if a state chooses to pursue recovery for all Medicaid services, they simply make a claim for all services an individual received (or for the total capitation payment paid to the managed care plan).

TYPES OF ESTATES/ASSETS SUBJECT TO RECOVERY

States also have flexibility in how they define a member's estate and what assets may be subject to recovery. MassHealth only pursues assets that go through the probate process, which is in line with the minimum federal requirement, though some states elect to recover assets outside probate.

Probate refers to the legal process of settling an estate after an individual dies, including transferring assets and paying outstanding debts. Probate estates include assets that were solely owned by the individual at the time of death and may include real estate property (e.g., homes) and personal property (e.g., cars, funds in bank accounts, and other assets).

Estate planning laws allow individuals to avoid the probate process by putting assets into a trust or other arrangements, so assets are jointly owned and are therefore not part of the probate estate—and thus would not be subject to estate recovery in many states (including in Massachusetts). Ultimately, estate recovery disproportionately impacts those without the resources or awareness to avoid probate through estate planning.

One example of a state that recovers assets outside of probate is Minnesota, whose expanded definition of estate includes certain trusts and life insurance policies.[18] Florida is a unique example in their more limited treatment of assets; they only pursue assets that go through the probate process, but state law specifically protects the home from many estate claims.[19]

EXEMPTIONS FROM ESTATE RECOVERY

There are three primary types of exemptions that states can use to reduce the number of people subject to estate recovery: hardship waivers; cost-effectiveness thresholds (waiving estate recovery if the administrative cost of pursuing recovery outweighs the claim against the estate); and carving out specific groups based on their Medicaid eligibility category.[20] MassHealth's approach to each of these three types of exemptions is described below.

HARDSHIP WAIVERS

In addition to certain exceptions outlined in federal law, states must establish a process for waiving estate recovery requirements when they would cause undue hardship on a member's surviving heirs.[21] However, states are allowed to establish their own criteria for granting such waivers. Accordingly, states have enacted a range of hardship waiver criteria intended to limit the undue burden of estate recovery on members and their families. Common hardship exemptions include waiving estate recovery if a family member living in the home provided caregiving services to the deceased member and waiving recovery if heirs meet certain low-income thresholds.

Prior to its 2021 reforms, MassHealth only granted one type of hardship waiver: the "Residence and Financial Hardship Waiver." This type of waiver was available to heirs that had incomes below 133 percent of the federal poverty level (FPL) for two years while living in the member's home and that met other criteria.[22,23] This waiver was granted on a conditional basis, meaning that if at any time in the two years following the initial waiver determination the conditions were not met (e.g., if the property was sold or transferred, the heir's income increased above 133 percent FPL, or if an heir was not using the property as their primary residence), the claim against the estate could be recouped.

As part of the 2021 reforms, MassHealth removed the two-year conditional period so that Residence and Financial Hardship Waivers are permanently granted upon qualification. The state also enacted two new hardship waivers to reduce the number of people liable for estate recovery:

1. **Care Provided Hardship Waiver:** Waiving estate recovery in certain cases when an heir has lived in the home two years prior to a member's admission to an institution or death and provided care to the member. The underlying assumption of this waiver is that the care provided by an heir saved the member, state, and federal government money by avoiding the need for nursing home care.
2. **Income-Based Hardship Waiver:** If the heir(s) had a gross income below 400 percent FPL for two years prior to the estate claim, MassHealth will waive up to $50,000 per qualifying heir, or up to $100,000 total if there are multiple heirs.

MassHealth has seen a large increase in the number of hardship waiver applications, the number of waivers granted, and the amount of money waived since the implementation of its 2021 reforms (see Table 2). While there has been a significant increase in the *number* of hardship waiver applications submitted and granted since the 2021 reforms, there has only been a slight increase in the overall *percentage* of waivers granted compared to pre-2021 reforms, from 42 percent to 49 percent. According to MassHealth officials, the most common reason applications for the Residence and Financial Hardship Waiver and the Income-Based Hardship Waiver are denied is because the requestor did not meet the income requirement (i.e., their income was too high). For the Care Provided Hardship Waiver, the most common reason for denial is that the requestor did not provide the level of care required to keep the member from needing to be admitted to a nursing home.[24] MassHealth officials cited lack of sufficient documentation and untimely requests[25] as other common reasons for denials across all waiver types.

TABLE 2. MASSHEALTH HARDSHIP WAIVERS, PRE- AND POST-2021 REFORMS[26]

	PRE-2021 REFORM	POST-2021 REFORM
HARDSHIP WAIVERS	On average (per year): • 33 waiver applications • 14 waivers granted • $1.3 million (total, gross) waived	In 2022: • 323 waiver applications • 157 waivers granted • $14.1 million (total, gross) waived

MassHealth does not currently grant hardship waivers for the following two criteria used in other states: 1) for an asset that is the sole income-producing asset of a family (such as a family farm or other business), used by 36 of 48 states for which data were available in 2021, or 2) for a home of modest value–typically defined as 50 percent or less of the average price of homes in the county where the home is located, used by eight of 48 states for which data were available.[27]

TABLE 3. COMMON TYPES OF HARDSHIP WAIVERS USED BY STATES, 2021

COMMON TYPES OF HARDSHIP WAIVERS USED BY STATES	HARDSHIP WAIVERS AVAILABLE IN MASSACHUSETTS
RESIDENCE AND FINANCIAL	✓
INCOME-BASED	✓
CARE PROVIDED	✓
SOLE-INCOME PRODUCING ASSET	X
HOME OF MODEST VALUE	X

COST-EFFECTIVENESS THRESHOLDS

Federal requirements also allow states to waive estate recovery if it is not cost effective, meaning that the administrative cost of pursuing recovery outweighs the total claim against the estate. States establish this threshold individually. Some states have no minimum threshold and consider recovery cost effective if it would bring in even one dollar more than it would cost to pursue recovery. Since the cost of pursuing an estate is difficult to predict in advance, many states do not estimate the cost of pursuing recovery for any individual estate. Instead, they establish a threshold amount for the value of an estate worth pursuing, and only pursue recovery for estates equal to or greater than this threshold amount. For example, some states set the threshold amount at $5,000 and would therefore only consider estate recovery cost effective if the value of the estate amounts to at least $5,000.

A 2021 state performance audit demonstrated that between 2016 and 2018, MassHealth recovered over $96 million gross for Medicaid expenses paid by 3,440 estates.[28] Forty-six percent of the estate recoveries were for amounts of $25,000 or less. At that time, Massachusetts did not have a standard cost-effectiveness threshold, meaning that any estate, even those of minimal value, could be subject to recovery unless the member's surviving heirs could prove that recovery would cause undue hardship. As part of its 2021 reforms, MassHealth enacted a $25,000 cost-effectiveness threshold, meaning that recovery is waived for estates valued at $25,000 or less. This is among the highest cost-effectiveness thresholds across states, only exceeded by North Dakota and North Carolina, which each have a $50,000 threshold.[29,30] Other states with $25,000 probate estate thresholds include Illinois, Georgia, and South Carolina.[31]

ELIGIBILITY GROUP CARVE-OUTS

States also vary in their approach regarding the Medicaid-enrolled populations subject to estate recovery. For example, in 2014 the Affordable Care Act (ACA) expanded Medicaid eligibility to nearly all adults earning less than 133 percent FPL. In certain states, some newly eligible adults from this expanded adult group were hesitant to enroll in Medicaid coverage due to fear that the services they use when age 55 and older may be subject to estate recovery.[32] As a result, states like Minnesota and Colorado scaled back their estate recovery policies as more individuals enrolled in Medicaid, excluding their ACA expansion population from recovery for non-federally mandated services (i.e., non-LTSS).[33,34] Massachusetts has not excluded the ACA expansion population from estate recovery for these nonmandatory services.

Box 1. Pending Estate Recovery Legislation in Massachusetts

Legislation introduced in the Massachusetts Legislature in 2022 and 2023 (192nd and 193rd legislative sessions) seeks to codify and build upon the reforms implemented by MassHealth in 2021.

S.726/H.1168, An Act Protecting the Homes of Seniors and Disabled People on MassHealth, would:

- Limit estate recovery in Massachusetts to only the federally mandated minimums for nursing home care and home- and community-based services (HCBS).
- Codify recent MassHealth reforms related to the $25,000 cost-effectiveness threshold, Care Provided Hardship Waiver, and Income-Based Hardship Waiver.
- Add an additional hardship waiver to waive estate recovery for homes of "modest value."
- Limit recovery for managed care premiums that exceed the actual cost of Medicaid services received by the member.
- Require additional notice for individuals prior to enrollment on how spending subject to estate recovery will be determined if they enroll in a Medicaid delivery system that involves monthly premium payments.
- Exempt from estate recovery individuals enrolled in the CommonHealth program. The CommonHealth program is a buy-in option for children and working adults with disabilities who have a household income that exceeds the eligibility limits for standard MassHealth coverage.
- Exempt personal care attendant services from the types of HCBS that would be eligible for estate recovery.
- Alter the appeals process for denied hardship waivers to allow a personal representative of the estate to request an administrative hearing. Currently, state law requires a complex legal process through a court hearing to dispute the denial of a waiver.
- Require more information be made available when a claim is presented against a decedent's estate, such as how to obtain a detailed accounting of the claim or circumstances in which recovery may be waived.

Some of these provisions would merely codify into state law some components of existing MassHealth policy (such as the cost-effectiveness threshold and the two new hardship waivers). Other provisions represent significant limitations relative to MassHealth's current policy (such as limiting recovery to only the federally mandated services). This would significantly reduce the size of Massachusetts' estate recovery program and the amount of revenue collected. These provisions could require additional administrative work and therefore increase the administrative costs of running the program.

MEMBER EDUCATION AND TRANSPARENCY

States are required to provide notice to Medicaid applicants explaining Medicaid estate recovery policy. A common critique of estate recovery is that information about the policy is buried in applications or is otherwise unclear to members. In 2021, the state appellate court found that MassHealth had failed to provide adequate notice that the claim against an estate for a member enrolled in managed care would comprise the total capitation payment paid to plans on their behalf.[35] In response, MassHealth enhanced member notifications in an effort to ensure that current and prospective members, and their families, are more aware of the estate recovery program and the waivers available. For example, MassHealth now sends a standalone notice via USPS mail to every MassHealth member who could potentially be subject to estate recovery. There are also ongoing notices to all new members subject to estate recovery, as well as all existing members who newly become subject to recovery based on various changes in their circumstances. Also, the notices that heirs receive about a claim against deceased members' estates now include more information about available hardship waivers.

While there are no federal reporting requirements for states to publish estate recovery data, states have the option to publicly report data. Massachusetts does not require MassHealth to publicly report data on estate recovery, but at least one state (Illinois) has placed such transparency requirements on its Medicaid program. In 2022, the Illinois Department of Healthcare and Family Services was required to not only make information on hardship waivers easily accessible, but the state also must annually publish hardship waiver statistics on their website.[36] This data includes estate recovery cases pursued, hardship waiver applications received and granted, as well as hardship waiver demographic information.

IV. IMPACT OF ESTATE RECOVERY ON MEMBERS AND FAMILIES

Key Summary

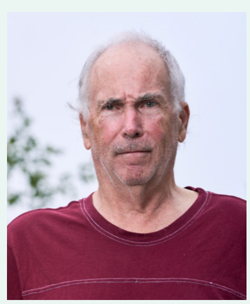
Despite recent reforms, estate recovery continues to negatively impact members and the families of deceased members, who are often already marginalized. Because this program limits the passing down of assets, including homes, it has the potential to perpetuate wealth disparities and intergenerational poverty.

Impact on low-income families: In Massachusetts, a large majority of MassHealth members have incomes far below the federal poverty level. In 2018, nearly 70 percent of MassHealth members over the age of 65 had income at or below 86 percent FPL, which was $17,871 for a family of three.[37] A home is often the only valuable asset for a Medicaid-eligible adult, and home equity[38] for Medicaid members is modest. The average net wealth among Medicaid decedents nationally is $46,692, with average home equity at $27,419.[39]

Profiles of Individuals in Massachusetts Impacted by Estate Recovery

While this section describes the impact of estate recovery on specific groups, the emotional and financial consequences for all individuals and their family members can be devastating. The Foundation, in partnership with the Massachusetts Law Reform Institute, developed a series of profiles that tell the stories of how estate recovery has impacted four individuals in Massachusetts after the loss of a loved one. Read more about their stories here.






Surviving family members and heirs who receive a notice of claim against their loved one's estate must often sell the home to pay the state's claim. Thus, estate recovery limits the ability for Medicaid members to pass down their homes to family members, despite these homes being a key source of intergenerational family wealth.[40] This perpetuates wealth disparities and limits economic advancement among marginalized populations, potentially keeping already low-income families in poverty. Exacerbating these disparities even more is that individuals who have economic resources have the means to protect themselves and their family members from this impact by paying for legal estate planning services (e.g., establishing trusts) to avoid probate and protect their assets from recovery.[41]

Impact on people with disabilities: Medicaid members who require LTSS are often people with physical or behavioral disabilities or older adults with limited financial resources who would otherwise not be able to afford care to meet their frequent, sometimes daily, LTSS needs. For example, given that the average annual cost of nursing care in Massachusetts is over $156,000 per year, many individuals who need LTSS cannot afford it without Medicaid coverage.[42] Commercial insurance, such as what people receive through their employers, typically does not cover LTSS. Many people with disabilities who require LTSS have no choice but to enroll in Medicaid for these services. Estate recovery inherently penalizes people with disabilities (and ultimately their family members) for seeking this coverage.

Impact on people of color: People of color are more likely than people who are White to get their coverage through MassHealth. Since estate recovery may serve as a barrier to homeownership for the families of MassHealth members, it has the potential to exacerbate well-documented racial gaps in homeownership and wealth caused by systemic racism and other institutional barriers.[43,44] National studies show that racial wealth divides are large and growing, despite income gaps narrowing slightly since the early 1990s. These trends are consistent with the limited local data available on wealth disparities in Massachusetts. One study by the Urban Institute estimated that White households in Boston have roughly 26 times the wealth of Hispanic households, and around 20 times the wealth of Black households.[45] Homeownership is also plagued by racial disparities; in the Greater Boston area, White households are almost twice as likely to own a home as Black and Latino households.[46]

To the extent estate recovery prevents the passing down of a home or home equity, it may play a role in exacerbating broader disparities. Additional data based on zip code, race, ethnicity, and language is needed to further evaluate the impacts of estate recovery on people of color and other marginalized populations (see Box 2).

A series of policy and programmatic options to further reduce the burden of estate recovery on members and their families in Massachusetts is discussed below.

Box 2. Need for Additional Data on Estate Recovery

Data on the impact of Medicaid estate recovery both nationally and in Massachusetts is limited, making it difficult to fully assess the impacts of this policy on Medicaid members and their heirs, including if the policy has a disproportionate impact on marginalized populations. Most states are not required to publicize data on estate recovery. None of the state interviewees had data on the effects of estate recovery on members or data to demonstrate the impact of estate recovery on marginalized communities.

V. POLICY AND PROGRAMMATIC OPTIONS FOR MASSHEALTH ESTATE RECOVERY

Key Summary

In 2021, MassHealth made several important changes to its estate recovery program to reduce its impact on members and their families. Building on these reforms, the state could consider several policies and practices implemented by other states that may further reduce the burden of estate recovery on MassHealth members and their families.

While the state's 2021 reforms have helped reduce the burden of estate recovery on members, Massachusetts could consider various policy and programmatic options to further reform its estate recovery program and protect more people, particularly people from marginalized populations, from the impacts of the policy. MassHealth has been a national leader in recent years in making an explicit goal to improve health equity and in developing innovative policies and programs to advance that goal;[47] the options outlined below are in line with MassHealth's broader health equity goals and initiatives. While some of the identified policy options require legislative approval, there are also programmatic changes that MassHealth can implement to increase awareness and better inform members and their family members of the state's estate recovery policy.

It is important to note that the proposed changes outlined below would have fiscal implications for the state, since many would reduce the revenue generated by estate recovery and in most cases would increase the administrative costs of running the program.

The policy and programmatic options are organized based on the same structural elements previously introduced in Section III. Specifically, these policy and programmatic options would:

1. Limit the scope of Medicaid services eligible for recovery
2. Expand exemptions from estate recovery
3. Increase member education, outreach, and transparency

The framework laid out in Section III also included "types of estates/assets subject to recovery." Because Massachusetts has already limited the types of estates/assets subject to recovery, this report does not have any policy and programmatic options in that category.

1. LIMIT THE SCOPE OF MEDICAID SERVICES ELIGIBLE FOR RECOVERY

The following policy option would reduce the scope of the estate recovery program such that the state would meet federal requirements while reducing the burden of recovery on members and their family members.

Prohibit estate recovery for nonmandatory services for individuals age 55 and over. Although MassHealth made several reforms to its estate recovery program in 2021, state law still requires MassHealth to pursue recovery for all services beyond just the minimum federally required LTSS that are used by members aged 55 and over and individuals who permanently reside in a long-term care setting. Limiting estate recovery to the federally mandated services for all impacted populations would mean that only those services related to a member's LTSS use would count against the member's estate. This would essentially limit the population subject to estate recovery to only members aged 55 and older who use LTSS.[48] MassHealth members aged 55 and older who do *not* use LTSS (which may include many individuals who qualify for Medicaid through the MassHealth expanded adult population) would no longer be subject to estate recovery. It would also be more equitable compared to other public programs such as Medicare, which provides benefits for some of the same (non-LTSS) services as Medicaid but does not pursue recovery from member estates for those services. This change would require legislative action.

Maine is an example of a state that in 2021 scaled back their estate recovery program to only collect for the federally required LTSS. Officials from Maine's Medicaid agency noted it had resulted in more relief from estate recovery for its members, which was a goal of the reforms. They also highlighted the loss of revenue that occurred but noted that the loss was not significant and easily absorbed within state budget allocations. Significant operational modifications were needed to implement the changes to their estate recovery program, as the state must now disaggregate costs spent on different types of services to isolate the costs of the federally mandated LTSS.[49]

As it did in Maine, limiting the total claim made against a beneficiary's estate to federally mandated LTSS would also create administrative challenges in Massachusetts. The state will need to disaggregate costs spent on different services to isolate the costs of the federally mandated LTSS. And when these services are part of a capitation payment, the state will need to develop a methodology to determine what portion of the capitation payment is attributable to these LTSS-related costs. Though these administrative and implementation challenges are real and significant, Maine's implementation of this policy demonstrates that they are surmountable and can help to limit the number of people subject to estate recovery.

2. EXPAND EXEMPTIONS FROM ESTATE RECOVERY

Establish additional hardship criteria that create more relief for caregivers and exempt from estate recovery any asset that is the sole income-producing asset of survivors and homes of modest value. Federal law requires that states establish programs to waive estate recovery if it would impose an undue hardship on heirs. As discussed earlier, states vary widely in how they define these hardships. CMS has provided certain examples to states but does not require that states use them. Two hardship exemptions raised as examples by CMS and that have been adopted by some states, but not Massachusetts, are: 1) assets that are the sole income-producing asset of survivors, and 2) homes of modest value, which can be defined as a home valued at less than the average home value in the county.[50] Massachusetts could consider adopting these exemptions. Allowing heirs to retain family businesses and/or family homes can present opportunities to grow intergenerational wealth and begin to counteract entrenched economic disparities.

In addition, Massachusetts could create more relief for caregivers in its hardship waiver program.[51] The state currently provides hardship protection in cases where a caregiver can prove they lived in the home for two years and provided care that delayed or prevented institutionalization. However, caregiving arrangements can be complex and shared across multiple family members, some of whom may have their own households as well. The state could make it easier for caregivers to qualify for relief. For example, Florida and Mississippi only require that caregivers have lived in the home for one year.[52] Washington state waives portions of estate claims for adult children equal to the financial assistance they provided for medical care or other necessities even if they did not reside in a member's home.[53] Establishing these added exemptions in Massachusetts would require approval by CMS.

Waive the first $25,000 in value of any estate subject to an estate recovery claim. MassHealth's 2021 estate recovery policy reforms included setting a $25,000 cost-effectiveness threshold for estate recovery. Under this policy, estates valued at $25,000 or less are exempt from estate recovery, but an estate valued at $26,000, for example, would still be subject to having the entirety of the estate recovered. Georgia and Illinois waive amounts at or below this $25,000 cost-effectiveness threshold, as well as $25,000 in recovery from *all* estates that exceed this threshold. MassHealth officials said they considered this policy but decided against it because it would provide relief to members with high-value estates. Indeed, this policy provides all recovered estates with some form of relief, and it continues to collect from larger estates.

3. INCREASE MEMBER EDUCATION, OUTREACH, AND TRANSPARENCY

According to various interviewees, awareness and understanding of estate recovery is limited among both MassHealth members and the public. While states are required to provide notice to Medicaid applicants explaining the Medicaid estate recovery policy, and MassHealth recently increased its notifications on the topic, these notices can often be confusing or get lost in the Medicaid application process. For members with limited English proficiency, the notices can be difficult to understand or may deter individuals from seeking Medicaid when needed. The policy and programmatic options below aim to better inform members about estate recovery and hardship waivers to ensure that they understand the policy and that members who might be eligible for hardship waivers understand how to apply.

Offer information on MassHealth's estate recovery program in multiple languages to enhance education and accessibility for different populations as well as promote cultural competency. A 2020 CMS report found that compared with other states, Massachusetts has the largest share of Medicaid members who speak a language other than English or Spanish as their primary language.[54] The MassHealth website currently has certain resources published only in English and Spanish.[55] To help members in the state make more informed health care decisions, MassHealth could include information on estate recovery, including mailed notices, factsheets or FAQs, hardship waiver information, and applications, in additional languages. For example, under state law, Illinois is required to maintain information on hardship waivers in English, Spanish, and the next four other most used languages in the state.[56] While translation services are currently provided upon request, proactively offering information in multiple languages could minimize barriers and ensure easy access to information for MassHealth members with limited English proficiency.

Educate trusted advisors and assisters who help individuals enroll in MassHealth to answer member questions on estate recovery and hardship waiver options. Assisters, including certified application counselors, hospital case managers, and nursing home staff may face challenging questions about estate recovery when enrolling individuals in

MassHealth. Providing these trusted advisors and assisters with additional education/training on estate recovery through tools including webinars and fact sheets may help to further support members navigating the enrollment process and increase overall access to accurate information on the estate recovery program.

Publish an annual report on the impacts of MassHealth's estate recovery program in the state, including data on hardship waivers. Data on the impact of Medicaid estate recovery both nationally and in Massachusetts is limited, making it difficult to fully assess the results of this policy on MassHealth members and their families. Increasing transparency around estate recovery and making data widely available will allow stakeholders to determine the impact of estate recovery more accurately. Annual reports could include data on the number of estates recovered and total recovery amounts, demographic and zip code data on estates recovered and the gross and net amounts recovered by the state, as well as the administrative costs of running the program.

In addition, this annual report could include the number of hardship waiver applications received, the number of hardship waivers granted, as well as the most common reasons waivers were denied. Demographic information should be included for individuals who submitted hardship waiver applications, as well as for those that have hardship waivers granted or denied. Collecting and publishing more data on hardship waivers is a fundamental step that can help improve understanding of why more hardship waivers are not submitted or approved.

Producing an annual report on the impacts of estate recovery and hardship waivers could help to analyze trends and establish an evidence base for future programmatic changes. This data would also help the public and stakeholders understand the impact of estate recovery on MassHealth members and members' families and would allow for a regular assessment to better understand the impact of the estate recovery program on marginalized populations, including populations of color.

VI. CONCLUSION

Medicaid estate recovery is a requirement under federal law. However, like many aspects of the Medicaid program, states do have some flexibility in how they implement these requirements. MassHealth began taking important steps in 2021 to reform its estate recovery policy and reduce its burden on impacted members and families, coming more in line with the minimum federal requirements.

Opportunities remain to reduce the burden of estate recovery, particularly on marginalized populations, and there are many other state examples from which Massachusetts can learn to shape its policies. States that have reformed estate recovery recently have tended to do so in ways that further limit the scope of services subject to recovery or expand hardship exemptions. In addition, there are a variety of options that could increase member education and outreach, and improve program transparency, many of which only require executive, and not legislative, action. Through these potential reforms Massachusetts can fulfill the federal mandate of estate recovery while relieving members and their families of some of its burdens. This may be a particularly important tool as part of MassHealth's overarching strategy to advance health equity given the adverse impacts estate recovery can have on allowing the transfer of intergenerational wealth and potentially discouraging MassHealth enrollment among those with care needs.

APPENDIX A: INTERVIEWEES

The Massachusetts Medicaid Policy Institute would like to thank representatives from the following organizations for participating in interviews to inform this work:

- Disability Policy Consortium
- ForHealth Consulting at UMass Chan Medical School
- Illinois Department of Healthcare and Family Services
- Maine Department of Health and Human Services
- Massachusetts Law Reform Institute
- MassHealth, Massachusetts Executive Office of Health and Human Services

APPENDIX B: STATE COMPARISON TABLE*

STATE	RECOVERS FOR NON-MANDATORY SERVICES FOR INDIVIDUALS AGE 55+	HARDSHIP CRITERIA: INCOME PRODUCING ASSET	HARDSHIP CRITERIA: HOME OF MODEST VALUE	COST-EFFECTIVENESS THRESHOLD
ALABAMA	Yes	Yes	No	No threshold; amount recovered must exceed cost of recovery, determined on case by case basis
ALASKA	No	Yes	Yes	Other; the potential recovery amount must result in twice the administrative cost, with a minimum pursuable net amount of $10,000
ARIZONA	No	Yes	No	No threshold; there is a $5,700 threshold for litigation
ARKANSAS	No	Yes	No	No threshold; amount recovered must exceed cost of recovery
CALIFORNIA	No	Yes	Yes	$5,000
COLORADO	No	Yes	No	$500
CONNECTICUT	No	No	No	$100
DELAWARE	No	Yes	No	$5,000
DISTRICT OF COLUMBIA	Yes	Yes	No	$100
FLORIDA	No	Yes	Yes	Other; Liquid assets: $100; Non-liquid assets: $1,000; Non-homestead real estate: $50,000
GEORGIA	No	Yes	No	$25,000
HAWAII	No	Yes	No	No threshold; recovery amount must exceed contingency payment for contractors or administrative fees for the state
IDAHO	Yes	Yes	No	$500
ILLINOIS	Yes	No	No	$25,000
INDIANA	Yes	Yes	No	No threshold; recovery amount must exceed state's administrative and related costs
IOWA	Yes	No	No	No threshold
KANSAS	Yes	Yes	No	No threshold; recovery amount must exceed state's administrative and related costs
KENTUCKY	No	No	No	$10,000
LOUISIANA	No	Yes	No	Other; amount expected to be recovered must exceed costs by $1,000
MAINE	No	Yes	No	No threshold, evaluated on a case by case basis
MARYLAND	Yes	Unknown	Unknown	Unknown
MASSACHUSETTS	Yes	No	No	$25,000
MICHIGAN	No	Yes	Yes	$1,000
MINNESOTA	No	Yes	No	No threshold; recovery amount must exceed state's administrative and related costs
MISSISSIPPI	No	Yes	Yes	$2,000 or if the value of the estate is less than 25 percent of the recovery amount
MISSOURI	Yes	No	No	No threshold; recovery amount must exceed state's administrative and related costs

*KFF Survey of Medicaid Financial Eligibility & Enrollment Policies for Seniors & People with Disabilities, 2022; MACPAC, 2021; Information from state officials; Aurrera Health Group analysis of CMS State Plan Amendments, 2023.

STATE	RECOVERS FOR NON-MANDATORY SERVICES FOR INDIVIDUALS AGE 55+	HARDSHIP CRITERIA: INCOME PRODUCING ASSET	HARDSHIP CRITERIA: HOME OF MODEST VALUE	COST-EFFECTIVENESS THRESHOLD
MONTANA	Yes	Yes	No	No threshold; recovery amount must exceed contingency payment for contractors or administrative fees for the state
NEBRASKA	Yes	No	No	No threshold; recovery amount must exceed state's administrative and related costs
NEVADA	Yes	Yes	No	No threshold; recovery amount must exceed state's administrative and related costs
NEW HAMPSHIRE	Yes	Yes	No	$200
NEW JERSEY	Yes	Yes	Yes	$500 and the gross estate is in excess of $3,000
NEW MEXICO	Yes	Yes	Yes	No threshold; recovery amount must exceed state's administrative and related costs
NEW YORK	Yes	Yes	No	No threshold, case by case decision
NORTH CAROLINA	No	Yes	No	Gross assets: $50,000; Medicaid payments subject to recovery: $10,000; actual recovery expected at least $5,000
NORTH DAKOTA	Yes	No	No	$50,000
OHIO	Yes	Yes	No	No threshold
OKLAHOMA	No	No	No	Unknown
OREGON	No	No	No	No threshold
PENNSYLVANIA	Yes	Yes	No	$2,400
RHODE ISLAND	Yes	Yes	No	$3,000
SOUTH CAROLINA	No	No	Yes	$25,000
SOUTH DAKOTA	No	No	No	$100, and if recovery amount exceeds costs
TENNESSEE	No	Yes	No	No threshold
TEXAS	No	Yes	No	$10,000
UTAH	Yes	Yes	No	$500
VERMONT	No	Yes	No	No threshold for liquid resources; there is a $2,000 threshold for personal property
VIRGINIA	Yes	Unknown	Yes	Unknown
WASHINGTON	No	Yes	No	$100 for medical assistance payments, other cases are evaluated individually
WEST VIRGINIA	No	Yes	No	$5,000
WISCONSIN	No	Yes	No	$100
WYOMING	Yes	Yes	No	No threshold; recovery amount must exceed state's administrative and related costs

ENDNOTES

1 This excludes Medicaid payments for Medicare cost sharing provided to individuals dually enrolled in Medicare and Medicaid.

2 Kaiser Family Foundation. (2023). *FY 2021 Total Medicaid Spending.* *https://www.kff.org/medicaid/state-indicator/total-medicaid-spending/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Total%20Medicaid%20Spending%22,%22sort%22:%22desc%22%7D*.

3 States must return a portion of what they recover to the federal government. This varies by state but is about 50 percent for Massachusetts. In this report we use the term "gross" to refer to the total value of recoveries comprising both the federal and state share and "net" to refer to what is retained by the state.

4 Medicaid and CHIP Payment and Access Commission (MACPAC). (2021). *Report to Congress on Medicaid and CHIP – Chapter 3: Medicaid Estate Recovery: Improving Policy and Promoting Equity.* *https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf*. Note: Two states, Delaware and Vermont, reported no collections for FY 2016–2019.

5 This is the projected total gross amount once all open cases prior to the 2021 reforms are resolved. About half of the total amount recovered in Massachusetts goes to the federal government. Data provided by MassHealth officials, December 2023.

6 HCBS offer opportunities for Medicaid members to receive LTSS in their homes or communities, rather than institutions and other restricted settings.

7 Mullins, L., & Jolicoeur, L. (2022). *Did Your Loved One Die? MassHealth May Bill Their Estate.* *https://www.wbur.org/news/2022/07/27/massachusetts-masshealth-medicaid-estate-recovery*.

8 MACPAC, 2021; Centers for Medicare & Medicaid Services (CMS). (2021). *Medicaid Long Term Services and Supports Annual Expenditures Report Federal Fiscal Year 2019.* *https://www.medicaid.gov/media/133646*.

9 There are qualifiers to this exemption and limits to the allowable amount of home equity exempt from countable assets. Effective January 1, 2024, the maximum home equity limit is $1,071,000. For more information, see: *https://www.mass.gov/info-details/program-financial-guidelines-for-certain-masshealth-applicants-and-members*.

10 As well as for individuals of any age if they are expected to permanently reside in a long-term care setting.

11 Net revenue refers to the amount that goes back to the state's general fund, since about half of the total amount recovered in Massachusetts goes to the federal government.

12 Data provided during an interview with MassHealth officials, March 2023.

13 MACPAC, 2021.

14 Kaiser Family Foundation (KFF). (2022). *Medicaid Public Health Emergency Unwinding Policies Affecting Seniors & People with Disabilities: Findings from a 50-State Survey.* *https://www.kff.org/report-section/medicaid-public-health-emergency-unwinding-policies-affecting-seniors-people-with-disabilities-findings-from-a-50-state-survey-appendix/*.

15 A Medicaid state plan is a document approved by CMS describing how the state administers its Medicaid program.

16 This excludes Medicaid payments for Medicare cost sharing provided to individuals dually enrolled in Medicare and Medicaid.

17 KFF, 2022.

18 Minnesota Department of Human Services. (2023). *Understanding Medical Assistance Claims.* *https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=SRU-020103*.

19 Florida state law exempts homestead property from creditors in certain circumstances. FL Const. art. X §4.

20 Though less frequent, the following are two other types of exceptions states can use to reduce the number of people subject to estate recovery: 1) the member had certain long-term care insurance that meets minimum coverage requirements, and 2) the estate includes certain resources, assets, or income belonging to American Indians or Alaska Natives.

21 There are some exceptions disallowing MassHealth from seizing a home occupied by a spouse or a dependent child of the late Medicaid member until they die or move. A list of exceptions, deferrals, and waivers can be found in the *MassHealth Estate Recovery FAQ*. *https://www.mass.gov/doc/estate-recovery-frequently-asked-questions-0/download*.

22 MassHealth. (2021). *Updates to the MassHealth Estate Recovery Policy.* *https://www.mass.gov/doc/eom-21-08-updates-to-the- masshealth-estate-recovery-policy-0/download#:~:text=Revisions%20to%20estate%20recovery%20requirements,and%20provided%20care%2C%20along%20with*.

23 Federal poverty levels are updated each year and are tied to many state and federal benefits. In 2023, the annual income for an individual and family of four at 133% FPL is $14,580 and $30,000, respectively.

24 The application for this waiver requires a signed letter from a physician who treated the member during the time the requesting heir provided care to the member attesting that the member would have required admission to a facility if it weren't for the care provided by the requesting heir. MassHealth reserves the right to request the deceased member's medical records from the attesting physician for the two years of treatment prior to the member's admission to a facility or the member's death and may ultimately disagree with the attestation from the physician.

25 MassHealth requires completed forms and all required documentation for hardship waivers no more than 60 days after the MassHealth notice of claim is filed in the probate court.

26 Data provided during an interview with MassHealth officials, March 2023.

27 MACPAC, 2021.

28 Office of the State Auditor. (2021). *Audit of the Office of Medicaid (MassHealth): Review of Estate Recovery.* *https://www.mass.gov/audit/audit-of-the-office-of-medicaid-masshealth-review-of-estate-recovery*.

29 MACPAC, 2021; Aurrera Health Group analysis of CMS (2023). State Plan Amendments. *https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html*.

30 North Carolina uses a three-part cost-effectiveness evaluation to assess the following conditions: 1) the gross estate assets prior to any disbursements, distributions, or any other payments are at least $50,000, 2) the Medicaid claim is at least $10,000, and 3) the actual recovery from the estate on the Medicaid claim (regardless of the actual claim amount) is expected to be at least $5,000.

31 Ibid.

32 MACPAC. (2015). *Medicaid's New Adult Group and Estate Recovery*. *https://www.macpac.gov/wp-content/uploads/2015/11/Medicaid%E2%80%99s-New-Adult-Group-and-Estate-Recovery.pdf*.

33 Ibid.

34 MACPAC, 2021.

35 EOHHS v. Trocki Medicaid Estate Recovery Decision, reported at 100 Mass. App. Ct. 117 (2021).

36 Illinois Public Act 102-1037 (2022). *https://www.ilga.gov/legislation/publicacts/102/102-1037.htm*.

37 Blue Cross Blue Shield of Massachusetts Foundation. (2019). *Faces of MassHealth: Portrait of a Diverse Population*. *https://www.bluecrossmafoundation.org/sites/g/files/csphws2101/files/2020-09/BCBSF_FacesofMassHealth_ChartPack_Final.pdf*.

38 Home equity refers to the equity a member has in their home, or the value of the home minus any outstanding debt against it.

39 MACPAC, 2021.

40 Justice in Aging. (2021). *Issue Brief: How Medicaid Estate Recovery Perpetuates Poverty*. *https://justiceinaging.org/issue-brief-how-medicaid-estate-recovery-perpetuates-poverty/*.

41 MACPAC, 2021.

42 Genworth Financial. (2022). *Cost of Care Survey.* *https://www.genworth.com/aging-and-you/finances/cost-of-care.html*.

43 Systemic racism refers to the structures, policies, practices, and norms resulting in differential access to the goods, services, and opportunities of society by "race" (e.g., how major systems – the economy, politics, education, criminal justice, health, etc. – perpetuate unfair advantage). Centers for Disease Control and Prevention. (2020). *Health Equity Style Guide for the COVID-19 Response: Principles and Preferred Terms for Non-Stigmatizing, Bias-Free Language.*

44 State Health and Value Strategies. (2022). *Making Medicaid Estate Recovery Policies More Equitable: State Toolkit.* *https://www.shvs.org/wp-content/uploads/2022/04/Medicaid-Estate-Recovery-State-Toolkit.pdf*.

45 Urban Institute. (2022). *Financial Health and Wealth Dashboard.* *https://apps.urban.org/features/financial-health-wealth-dashboard/*.

46 Ibid.

47 Blue Cross Blue Shield of Massachusetts Foundation. (2023). *The MassHealth Demonstration Extension 2022-2027: Building on Success, Focusing on Equity.* *https://www.bluecrossmafoundation.org/publication/masshealth-demonstration-extension-2022-2027-building-success-focusing-equity*.

48 Assuming the estate's total value exceeds $25,000 and the individual does not meet the criteria for any of the other available exemptions.

49 Short-term operational changes in Maine included the process of revising state policy and spending significant time answering phone calls from estate representatives regarding how the policy change impacted estate recovery.

50 MACPAC, 2021.

51 Many waivers for caregivers are limited to family members.

52 Triage Cancer. (2023). *Medicaid State Laws: Estate Recovery.* *https://triagecancer.org/state-laws/medicaid-estate-recovery*.

53 Ibid.

54 CMS. (2020). *Primary Language Spoken by the Medicaid and CHIP Population in 2020.* *https://www.medicaid.gov/medicaid/data-and-systems/downloads/macbis/prmary-lang-data-brf.pdf*.

55 MassHealth. (2023). *Massachusetts Medicaid Estate Recovery*. *https://www.mass.gov/info-details/massachusetts-medicaid-estate-recovery*.

56 Illinois, 2022.

MASSACHUSETTS

FOUNDATION