Holding on to Home:

The Lived Experience of Estate Recovery in Massachusetts

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INTRODUCTION

Serving nearly one in three Massachusetts residents, MassHealth (the name for Massachusetts' Medicaid program and Children's Health Insurance Program) provides access to health care services for low-income people of varying ages and life circumstances across the Commonwealth. These services improve enrollees' health and enable them to succeed in other aspects of their lives. For example, MassHealth is an essential, and often the only, source of coverage for long-term services and supports (LTSS) for seniors and people with disabilities, including services that can help them stay in their homes and communities and out of institutions. (For more information about LTSS, see the box to the right.)

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).

But for some members and their families, MassHealth may be both a vital lifeline and a source of financial distress. This is because state Medicaid programs are 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 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). While federal law sets minimum requirements for Medicaid estate recovery, states have the option to exceed those minimum standards and can choose to recover 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. State law requires MassHealth to seek recovery for all MassHealth services[1] provided to any member, aged 55 and over, regardless of whether they ever utilized MassHealth-covered LTSS.

In order to be able to pay off the outstanding MassHealth debt, surviving family members may be required to sell their loved one's home (in cases where the home is part of the deceased member's estate).[2] By preventing members from passing down modest homes and other assets to their heirs, Medicaid estate recovery has profound impacts on members and their families. On a personal level, it leaves families in emotional and financial turmoil while they may also be grieving the loss of a loved one. And on a systems level, it disrupts families' ability to break the cycle of intergenerational poverty.

With the goal of educating stakeholders, policymakers, and others about MassHealth's estate recovery program, the Massachusetts Medicaid Policy Institute (MMPI), a program of the Blue Cross Blue Shield of Massachusetts Foundation, produced two reports:

- A *policy brief* that describes Massachusetts' estate recovery policy and practices, including the reforms MassHealth introduced in 2021 to reduce the policy's impact on members and their families. The brief also describes how estate recovery requirements in Massachusetts compare to federal law and the practices and policies of other states, as well as what is known about how estate recovery impacts members and their families. Lastly, the brief outlines several policy and programmatic options that would build on the 2021 reforms, which may further reduce the burden of estate recovery on MassHealth members and their families.
- Qualitative profiles, appearing below, of Commonwealth residents whose lives have been impacted by MassHealth's estate recovery program. To develop these profiles, MMPI partnered with the Massachusetts Law Reform Institute (MLRI) to identify individuals who have been impacted by estate recovery. MLRI conducted in-depth personal interviews and photo shoots with four individuals from April to August 2023 to document the impact that

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

[2] 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*.

MassHealth estate recovery has had on their lives. It's important to note that the estate recovery claims described in these profiles were all submitted prior to MassHealth's 2021 reforms, which included the addition of two new hardship waivers; because of this timing, these individuals were not eligible for these additional hardship waiver options.

The policy brief provides an overview of MassHealth's estate recovery program, describes its overall impact on members and their families, and identifies options for reducing that impact. Behind these abstract policy options are real people – in diverse life circumstances – whose lives have been impacted by estate recovery. This report is devoted to telling a few of their stories.

Because estate recovery is a legal transaction, a glossary is included below to help the reader understand some of the key terms used in the profiles.

GLOSSARY OF KEY TERMS

Deed: A deed is a legal document used to transfer ownership of property. The deed describes the property and how the buyer(s) will hold the title to the property (e.g., solely or jointly with a spouse). After the death of a property owner, if the title was jointly held with the spouse, the property would not become an asset in the probate estate. Only probate assets are subject to estate recovery.

Deferral: A deferral is the process by which MassHealth will delay estate recovery in certain circumstances, including if the deceased member is survived by a spouse, a child who is under age 21, or a child of any age who is blind or permanently and totally disabled. Once the conditions allowing for a deferral are no longer met (e.g., the surviving family member dies), MassHealth will seek to recover its claim against the member's estate.

Hardship Waiver: Under federal law, state Medicaid agencies must establish a process for waiving estate recovery requirements when they would cause undue hardship on a member's surviving heirs. States are allowed to establish their own criteria for granting hardship waivers. Accordingly, states have enacted a range of criteria as part of their hardship waivers that are 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 or waiving recovery if heirs meet certain low-income thresholds.

Lien: A lien gives a creditor certain rights against a debtor's property if the debt is not repaid. Medicaid agencies can elect to place a lien on the house of a nursing home resident who is not expected to return home so long as certain relatives are not living in the house. If the nursing home resident does return home, the Medicaid agency must remove the lien.

Probate Estate: A probate estate includes any property or assets that were solely owned by a person at the time of their death. This may include real estate property (e.g., homes) and personal property (e.g., cars, funds in bank accounts, and other assets). Generally, IRAs, 401(k)s, and life insurance policies that designate a beneficiary payable on death are not part of the probate estate and are not subject to estate recovery.

Probate: Probate refers to the legal process of settling an estate after an individual dies, including transferring assets, distributing property to a person's heirs, and paying outstanding debts. Estate laws in many states (including Massachusetts) allow individuals to avoid the probate process by putting assets into a trust, owning property jointly, or for certain kinds of assets, naming transfer on death beneficiaries. Assets that do not become part of the probate estate are not subject to estate recovery in Massachusetts.

Title: A title encompasses the legal right to ownership of a property of value (e.g., homes, cars, boats, etc.), including the right to sell. When purchasing a house, the title to the home transfers to the buyer, along with the deed.

Sources: Blue Cross Blue Shield of Massachusetts Foundation. (2023). *Holding on to Home: A Primer on MassHealth Estate Recovery and Options for Reducing its Impact on Members and Families*; Gaudet, R. *What Is a Property Lien in Massachusetts?* The Law Offices of Richard Alan Gaudet, LLC. Available at https://gaudetlawoffice.com/what-is-a-property-lien-in-massachusetts/; MassHealth, Executive Office of Health and Human Services. *MassHealth Estate Recovery Fact Sheet for Members*. Available at https://www.mass.gov/doc/masshealth-estate-recovery-fact-sheet-for-members/download; Massachusetts State Records. *Massachusetts Liens Records*. Available at https://massachusetts.staterecords.org/liens; MassHealth. *MassHealth Estate Recovery FAQ*. Available at https://www.mass.gov/doc/estate-recovery-frequently-asked-questions-0/download.

SANDY LOGRANDE

Sandy LoGrande's father Salvatore – better known as Sam – came to Gloucester from Sicily when he was still a boy. Sam loved everything about America. Being very sociable, he easily made many lifelong friends. After graduation, Sam enlisted in the army. Soon after his discharge, he married his sweetheart Jeanne, took a job as a machinist, and started a family. In 1976, after saving for 11 years, he and Jeanne bought a house in Gloucester, to raise their growing family. It was one of his proudest moments, to have a home of his own. Life was good, but hard times were coming.

First, it was complications from Sam's cataract surgery and loss of vision in one eye. Then, after 35 years on the job, Sam injured his back and was forced to take an early retirement. His wife Jeanne fell sick soon after, with a devastating cancer diagnosis, and died at age 55. Sandy said it was as if the light went out of Sam's life. Tragedy struck again a few years later, when Sam's son died of cancer at 39. But the family still had joys, amidst their sorrows. Sandy's younger sister had a baby, and the new grandchild, Jeanne (named after Sam's wife Jeanne), brought back the light into Sam's life. However, a year after his grandchild was born, Sam was diagnosed with stage IV prostate cancer and began a course of hormone treatment.

Sandy, Sam's daughter, had worked in the restaurant industry for many years and had her own health problems. She was diagnosed with Crohn's disease and an intense form of arthritis; a year later, she was diagnosed with breast cancer. Her father worried about Sandy's health and asked her to move in with him so they could look out for one another.

After moving back into the family home, Sandy began searching for housekeeping assistance for her father while she recuperated from cancer treatment. As part of this search, she learned about Senior Care Options (SCO), a MassHealth program for seniors. She was told it was a program that would cover everything he needed.

Sam and Sandy had some misgivings about enrolling him in MassHealth: they had heard something about MassHealth putting liens on your property and asked the SCO plan representative about it. The representative reassured them that this would only happen if he went into a nursing home. Since Sam and Sandy didn't know about the estate recovery process that would lead MassHealth to seek reimbursement for the costs of his care after he dies regardless of whether he used nursing home care, this information put them at ease. Sandy knew that she and her sister planned to provide care for her father at home, rather than in a nursing home. With that assurance, Sam signed the application.

Sam responded well to the new hormone treatment for his cancer diagnosis and had four more good years. Then, abruptly, the pain intensified, and complications soon followed. He was hospitalized and then moved to rehab. Sandy was there every day, holding his hand. She arranged hospice services through the SCO plan, converted the living room into a bedroom, and eventually was able to bring him home, for what they were told would be his final days.

Back in a familiar setting, with Sandy as his full-time caregiver, he felt better. Every month that passed and every holiday he was able to celebrate felt like another miracle. Sam's younger daughter and granddaughter were living with them now as well. Sam was glad to have "all his chicks back in the nest." In 2016, after living comfortably for another nine months, Sam died in his own home, surrounded by his family, at the age of 76.

Sam had left the house to his two daughters, but there was still a mortgage to pay. They had fallen behind and Sandy had no choice but to go back to waitressing, working double shifts to catch up. A year later, she was hospitalized again, due to complications with her multiple health conditions.

She had only been out of the hospital for a few months, when she received a letter from MassHealth, requesting payment of $177,000 for her father's care. She was floored, and assumed it was a mistake, because her father had never been in a nursing home. She called the number on the letter and was informed that after a MassHealth member dies, the program seeks to recover from the member's estate everything it spent on their health care and coverage, after they turned age 55.

Sandy disputed the claim and asked for a hardship waiver, but it was denied. Even after all she had been through, she says this was one of the hardest things she ever had to face.

And then, another miracle: after exhaustively searching for legal representation and being turned down multiple times, Sandy saw an article about elder care, featuring an attorney from the Northeast Justice Center. She still remembers what the attorney said to her later when he agreed to take the case: "We can fight this." And they did. In 2019, the case was settled.

Sandy and her sister now own the home, free of the original claim against their father's estate. Financial constraints have forced them to make the painful decision to sell the family home. Knowing that so many others were not as privileged to even retain that option, they consider themselves extremely fortunate. Still, as Sandy is now over 55 and on MassHealth herself, she faces a looming new fear that estate recovery will seek out new reimbursement from her family.

MAN YING NG

Man Ying Ng arrived in the United States in 1990 shortly after marrying Fong Chou Ng. Her husband was already in his 50s when they married, and he owned a modest three-bedroom house in Springfield. Over the next 10 years, they filled the house with four children, the youngest born in 1999. Fong Chou worked at a restaurant and much later for a delivery service. Man Ying worked at restaurants and factories sewing clothes. From the day she came to the United States, she says, she never stopped working. The restaurant work and other jobs the couple held didn't offer health insurance, but because of their low income they qualified for MassHealth.

Fong Chou was still working in 2008 when he suffered a series of mini strokes. Man Ying now had to care for her husband and still keep working to pay the bills; all four of their children were under 18. While she worked at a part-time job in food preparation at the local airport, her sister volunteered to watch over Fong Chou.

In 2011, the mortgage was paid off, and Fong Chou worked with a lawyer to make out a will: he wanted everything he had to go to his wife. During that time, Fong Chou's condition was getting worse, and there were now many things he could no longer do for himself. Man Ying stopped working to care for her husband full time. They got by on Fong Chou's Social Security, including a dependents' allowance until the youngest child turned 18.

The care Fong Chou required eventually became too much for Man Ying, and he went into a nursing home. Man Ying went back to work at the airport. From the beginning, Man Ying worried about how they would pay for his nursing home care. The social workers at the nursing home assured her that MassHealth would cover everything.

Over time, Man Ying grew concerned about the care her husband was receiving at the nursing home. Because her older children could now help with the bills, and they could get by month to month without Man Ying working, she was able to bring her husband back home. She cared for him herself in the last year of his life. Fong Chou died in November 2016.

A few years later, Man Ying decided she had better get the deed to the home in her name and went back to the lawyer who had made out Fong Chou's will. He helped her file the papers in probate court in 2018. The papers estimated the value of the house at $121,500 and all other personal property at less than $10,000. Under state law, MassHealth is notified of all probate cases, and – after a MassHealth member dies – it can seek to recover the costs associated with covering that member after they turned 55. Fong Chou had been on MassHealth from age 55 until his death at age 80. In December 2018, MassHealth filed a claim for $332,000. Man Ying couldn't believe it. The lawyer who had made out Fong Chou's will told her there was nothing she could do.

Through an interpreter Man Ying said, "I worked so hard to help my husband and pay off the house. Every time I think about it, I cry. I become so emotional . . . when I hear MassHealth is going to take my house. Now I have nothing. No house. No husband."

Because of her low income and the number of years she has lived in the home, Man Ying may have been able to qualify for a hardship waiver that would have waived all or part of the MassHealth claim. However, the letter from MassHealth informing her about the hardship waiver was only in English. While Man Ying has been in the United States for 28 years, her first language is not English, and the letter was difficult for her to understand; as a result, she missed her chance to apply for a waiver.

Today, she is still living in the house with her youngest son. Under state and federal law, MassHealth will delay estate recovery and therefore cannot force the sale of a house if there is a surviving spouse. While they've been able to remain in the house, Man Ying can never forget that the $332,000 debt is hanging over them, and she knows she will not be able to pass down the house to her children. She is now working part-time at a Chinese restaurant while also collecting Social Security, and her son is taking classes online. Both have insurance from MassHealth. Man Ying has recently contacted Health Law Advocates, who are investigating her case.

VINCE GUNNING JR.

Vince Gunning Jr. comes from a large family that has lived in Lynn for many years. His grandparents bought a house in West Lynn on a street that ends at the Saugus River, and there they raised their 10 children. Vince grew up in the house next door, often visiting his grandmother and her daughter, Vince's Aunt Grace, who lived together for as long as he can remember. As a kid he brought them scrap wood from the riverbank to burn in their coal-fired furnace. The house passed to his Aunt Grace when her mother, Vince's grandmother, died.

In 1982, ten years after Vince returned from two tours of duty in the Navy during the Vietnam War, he moved in with Aunt Grace. They both worked: Grace in Boston, Vince in renovating bowling alleys and later at the post office.

In 2002, Vince's diabetes took its toll, and his leg was amputated at the thigh. After being fitted with a prosthetic leg and undergoing rehabilitation, he was able to return to work at the post office, but he couldn't get up on ladders anymore when the house needed repairs. Grace eventually retired on a small pension. She was mentally sharp until the end but getting physically weaker and falling more. Vince took her to doctor's appointments and helped look out for her at home, but he had to work, and Grace was getting too frail to be home alone.

Eventually, Grace entered a nursing home. Vince continued to live in the house, pay the bills, and visit his aunt. After several years in the nursing home, Aunt Grace died in 2008. The family was relieved to learn that she had passed the house to Vince in the will, which meant he would be able to stay in the house that he'd lived in for the last 26 years and in the neighborhood where he'd grown up.

Vince didn't see a compelling reason to go through probate to get the deed in his name and therefore there was no public record of Vince's ownership of the house. He continued paying the property taxes and carried on with his life; however, his amputation was giving him more trouble and often hurt him too badly to work. He couldn't do the maintenance the aging house needed, much less the renovations that would make it easier to manage, such as adding a bathroom to the first floor since the house's only bathroom was on the second floor. In 2012, at the age of 63, Vince retired from the post office and also obtained Social Security disability.

Grace had been covered by Medicare, but she had MassHealth too. Under state law MassHealth can recover for anything it spends on a person aged 55 or older if the person has assets in probate, like a house that isn't jointly owned. If no one else files for probate, MassHealth can ask a county's public administrator[3] to file on behalf of MassHealth as a creditor of the estate, which is what happened to Vince eight years after his aunt's death. Vince received some letters but didn't know what to make of them, so he put them aside. It all looked fishy to him, and he thought it was a scam. Then he received a notice that shocked him: it was an eviction notice. The public administrator had brought an eviction proceeding to remove Vince from the house so MassHealth could collect for the costs of having covered some of Grace's care.

During the eviction hearing, as the judge heard the details of the case and learned Vince was both disabled and a veteran, he referred him to the Northeast Justice Center. They took on the case beginning in 2016 and spent six years seeking a resolution that would keep Vince housed.

In the end, MassHealth agreed to reduce its claim so Habitat for Humanity (Habitat) could afford to buy the house and finance the needed repairs. A large group of veterans and other community volunteers took on the major renovations, including a first-floor bathroom and an outside ramp. Vince donated his car to Habitat, helped where he could, and cheered on the volunteers.

A ribbon cutting for the renovated house was held in the summer of 2022. By having Habitat buy the house and finance the repairs, Vince lost the title to the home but now has a place to live for the rest of his life. Then, Habitat will be able to sell the house to a first-time homebuyer and use the money from that sale to help someone else in need of housing, as the program had helped Vince.

TAWANDA RHODES

Tawanda Rhodes' father, Joseph, was a Korean War veteran and shipyard worker; her mother Edna worked as cook in the Boston Public Schools (BPS). Tawanda was the fourth of nine children and already a young adult living in New York by the time her parents bought a modest house in Dorchester in 1979. However, for her and the rest of the extended family, the house in Dorchester was what they called the Home House. It was the place where any of Edna and Joseph's children and grandchildren knew they would be welcome whenever they needed a home.

Life changed for the family in 1989 when Joseph died. His life insurance helped pay off the mortgage, but Edna later took out a second mortgage to pay for de-leading the house to make it safe for her grandchildren. Tawanda visited often from New York and sent money home to help pay the mortgage. When Edna developed breast cancer, Tawanda moved in to help care for her and take her to her radiation treatments. Afterwards, Tawanda returned to New York and one of her brothers moved in with Edna, though Tawanda continued to visit her mother frequently to help care for her.

[3] Public administrators are appointed officials in each county whom MassHealth can designate to file probate on an estate against which MassHealth has a claim if no one else has filed in the year following the death of a decedent. They can also act in other situations unrelated to MassHealth claims.

When Edna began showing signs of dementia, and Tawanda learned her brother had fallen behind in paying the bills, she arranged for a guardian from a local social service agency to help her brother manage Edna's finances and care.

After the brother died suddenly in 2004, the guardian moved Edna to a nursing home. In order to bring her home, Tawanda and her husband Oliver returned to Boston, and Tawanda became her mother's guardian. It was at this time that Tawanda learned that MassHealth had been paying for the nursing home, not her mother's insurance from BPS, and now had a lien on the family home.

After her mother left the nursing home, Tawanda reached out to cancel Edna's MassHealth since she had good primary insurance through her previous employer, BPS, and Tawanda would be taking care of her at home now. The person she spoke with told her to keep her mother on MassHealth; the lien was only for nursing home care, and now that Edna was home, MassHealth would remove it. No one told Tawanda anything about estate recovery.

Tawanda and Oliver cashed in their savings to repair the house, which had fallen into disrepair over the years. Four years later, in 2009, Edna died at home in Oliver's arms.

Tawanda had begun to see signs of Alzheimer's in her husband Oliver earlier, but after her mother's death, his condition deteriorated. He could no longer work, and she was needed at home more to care for him. Money was tight. She needed the deed to the house in her name to qualify for assistance with additional home repairs, so Tawanda filed probate.

She was stunned when she later opened a letter from MassHealth requiring repayment of almost $200,000. This had to be a mistake, she thought. When she called the name at the bottom of the letter, she was informed that this request for payment wasn't about the lien MassHealth had placed when Edna was in the nursing home. Instead, this was estate recovery – a separate process altogether.

The letter from MassHealth said there was something called a hardship waiver. She asked for one but did not receive it, possibly because she hadn't lived with her mother before she went into the nursing home. Her husband now needed her constant care, and her hair was falling out from anxiety. The worst part for her was the feeling that she'd let her parents down. The house was their legacy, and she was the one her mother trusted to take care of it.

Tawanda kept fighting by researching, writing to elected officials, and working with volunteer lawyers. MassHealth offered to reduce the claim, but she knew it would not be affordable given her limited income.

Oliver died in 2018. The following year, the Volunteer Lawyers Project called and asked if she wanted to talk to a reporter from a national magazine who was writing a story about Medicaid estate recovery. She agreed and the resulting story was called "Medicaid's Dark Secret." The article showed a picture of the house and Tawanda holding a photograph of her parents Edna and Joseph.

In 2022, a lawyer from the Massachusetts Law Reform Institute took a new look at her case along with a pro bono lawyer. They found some irregularities from back when Tawanda had asked for a hardship waiver. MassHealth agreed and waived their claim. But estate recovery had already taken a heavy toll on Tawanda's health and peace of mind. She still can't quite believe it's over. She hopes telling her story again might make a difference.

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