

ARTICLES

Hidden Until the End: The Need to Inform Medicaid Enrollees of Estate Recovery Costs Before Their Death

Ashley Bassel Griffith*

ABSTRACT

Medicaid provides health care coverage to approximately one in every five individuals living in the United States. The program insures some of the country's most economically disadvantaged populations, including low-income seniors and low-income individuals living with disabilities. Yet, Medicaid is the only federal public assistance program in the United States that requires certain recipients to pay back the amounts spent on their behalf. Under the Medicaid estate recovery program, states are required to pursue recovery of payments made for long-term care services from the estates of individuals who received such services at age fifty-five or older or who were determined permanently institutionalized. The estate recovery program essentially transformed what was once an entitlement into a loan that must be repaid from Medicaid enrollees' estates.

Currently, Medicaid applicants and enrollees are often unaware of the financial consequences of estate recovery loans, as federal law does not require states to provide notice of estate recovery costs to applicants and enrollees. Likewise, a review of all states' estate recovery laws, Medicaid applications, and publicly available estate recovery brochures indicates that no state proactively provides notice to enrollees of their accrued estate recovery costs. Instead, states typically send the first notice of estate recovery costs after the enrollee dies at the time of collection. This delayed notice leads to devastating emotional and financial distress for affected families and deprives enrollees of the ability to make informed health care decisions. To solve this problem, this Article proposes a federal requirement that states provide the costs of estate recovery to Medicaid applicants and enrollees. As the number of individuals needing long-term care is expected to rapidly grow during the next three decades, the detrimental impact of the program's lack of transparency will become more

* Assistant Professor of Law, Belmont University College of Law. I would like to thank my research assistants, Sander Fess, Mason Bixenman, Jonah Riojas, Smith Kaiser, and Shelby McGuire, for their contributions to this Article. I am deeply grateful to my husband, Brian, for his unwavering support and encouragement, and to my parents, John and Barbara Bassel, whose lifelong dedication to helping the underserved has inspired my work. Finally, I would like to thank the dedicated public servants at Tennessee's state Medicaid agency, TennCare, for giving me the opportunity to see firsthand the importance and impact of innovation in Medicaid. © 2024, Ashley Bassel Griffith.

widespread. To safeguard the ability of older and disabled individuals to make informed decisions regarding their health care, estate recovery costs should be brought to light when such individuals are better able to make health care decisions rather than after their death.

- I. INTRODUCTION. 3
- II. THE MEDICAID PROGRAM 7
 - A. *Medicaid Long-Term Services & Supports*. 8
 - B. *Medicaid Service Delivery Models* 10
- III. THE ESTATE RECOVERY PROGRAM 12
 - A. *Federal Estate Recovery Framework* 13
 - B. *Estate Recovery Exemptions and Hardship Waivers*. 15
 - C. *Calculation of Estate Recovery Claims* 16
- IV. CURRENT LAW DOES NOT REQUIRE ADEQUATE NOTICE OF THE FINANCIAL IMPACT OF ESTATE RECOVERY 19
 - A. *Federal Estate Recovery Notice Requirements* 19
 - B. *State Estate Recovery Notice Requirements* 20
 - C. *State Estate Recovery Notice Practices* 23
 - D. *Medicaid Enrollees and Their Families’ Surprise and Confusion Regarding Estate Recovery* 25
- V. MEDICAID ENROLLEES SHOULD RECEIVE NOTICE OF ESTATE RECOVERY COSTS DURING THEIR LIFETIME. 27
 - A. *Medicaid Enrollees’ Ability to Weigh Options for Medical Care and Assess the Value of Medicaid Services* 28
 - B. *Medicaid Enrollees’ Ability to Document Eligibility for Exemptions and Waivers.* 31
 - C. *Medicaid Enrollees’ Medical and Health Literacy Limitations.* 34
 - D. *The Public Policy of Protecting Loan Recipients Through Required Disclosures* 36
- VI. A FEDERAL NOTICE REQUIREMENT IS NEEDED TO ENSURE MEANINGFUL NOTICE OF ESTATE RECOVERY 38
 - A. *Potential Objections to the Proposed Notice Requirement and Responses* 40
 - 1. *The Proposed Notice Requirement is Feasible for Medicaid Agencies* 41
 - 2. *As a Matter of Law, an Estate Recovery Claim Arises Upon the Receipt of Services* 43
 - 3. *Federal Law Broadly Regulates Medicaid Notice Requirements* . . . 44

4. Retrospective Capitation Rate Adjustments Do Not Prevent Implementation of the Proposed Notice Requirement	46
5. California’s Approach Unfairly Shifts the Burden of Notice to Medicaid Enrollees	47
VII. CONCLUSION	48
APPENDIX A	50
APPENDIX B	55

I. INTRODUCTION

Salvatore LoGrande enrolled in Medicaid in Massachusetts to receive needed medical care during his battle with cancer.¹ During his Medicaid enrollment, Mr. LoGrande received long-term care at home, briefly entered the hospital due to pain from cancer, and later received hospice care.² Mr. LoGrande passed away in 2016.³ One year after he died, his daughter, Sandy LoGrande, received a letter from Massachusetts’ Medicaid agency stating that Mr. LoGrande’s estate owed the agency \$177,000 for his Medicaid expenses.⁴ Ms. LoGrande thought that the letter was a mistake, as this was the first time that either Mr. LoGrande or his family had received a bill for his care.⁵

The letter to Mr. LoGrande’s estate was not a mistake, but instead is part of the federally mandated Medicaid estate recovery program.⁶ Under this program, state Medicaid agencies must pursue recovery of the payments made for long-term care services from the estates of individuals who received these services at age fifty-five or older or who were determined permanently institutionalized (the “aged and institutionalized”).⁷ In other words, in exchange for providing medical care, Medicaid provides the aged and institutionalized with a loan.⁸ State Medicaid agencies are then required to try to collect on this loan after the Medicaid enrollee’s death.⁹ While comprehensive data regarding the total number of estates pursued and average recoveries is not available, aggregate estate

1. Amanda Seitz, *States Try to Seize Medicaid Patients’ Homes After They Die to Recoup Healthcare Costs*, L.A. TIMES (Mar. 18, 2024), <https://www.latimes.com/world-nation/story/2024-03-18/state-medicaid-offices-target-dead-peoples-homes-to-recoup-their-health-care-costs>.

2. *Id.*

3. *Id.*

4. *Id.*

5. *Id.*

6. 42 U.S.C.A. § 1396p(b) (West, Westlaw through Pub. L. No. 118-66).

7. *Id.*; States must try to recover the costs of long-term care services as well as related hospital and prescription services. *Id.* At their option, states can also pursue recovery of the costs of any items or services under the Medicaid State Plan. *Id.* § 1396p(b)(1)(B)(ii).

8. *See* *In re Est. of Burns*, 928 P.2d 1094, 1101 (Wash. 1997) (finding that Medicaid estate recovery transformed the recipient’s property right in Medicaid payments into a loan to be repaid from estate assets); *Est. of Wood v. Ark. Dep’t of Hum. Servs.*, 894 S.W.2d 573, 576 (Ark. 1995) (describing estate recovery as “a loan from DHS to be repaid from the assets of her estate”).

9. *See* 42 U.S.C.A. § 1396p(b).

recovery collections are substantial and are increasing over time.¹⁰ In Fiscal Year 2019, state Medicaid agencies collected approximately \$733.4 million from the estates of aged and institutionalized Medicaid beneficiaries through estate recovery.¹¹

For Mr. LoGrande's estate, Massachusetts' estate recovery claim threatened the asset that meant the most to him: his home.¹² This is common for those subject to Medicaid estate recovery.¹³ Although Medicaid applicants must meet income and asset thresholds to become eligible to receive long-term care, the applicant's primary residence generally is not counted as an asset for purposes of qualifying for Medicaid.¹⁴ As a result, the home is often the only valuable asset remaining in an aged and institutionalized individual's estate upon death.¹⁵ Such estates are, therefore, often required to sell or incur a mortgage on the family home to satisfy an estate recovery claim.¹⁶

With these significant financial consequences at stake, Medicaid enrollees should fully understand the terms of an estate recovery loan. Yet, as in the case of Mr. LoGrande, Medicaid enrollees typically do not receive notice of the costs of estate recovery.¹⁷ Federal law does not require that Medicaid agencies notify Medicaid applicants or enrollees of their anticipated or accrued estate recovery costs.¹⁸ Rather, federal guidance instructs Medicaid agencies to provide notice of estate recovery costs only when Medicaid seeks to collect these amounts from the enrollee's estate, *after the Medicaid enrollee dies*.¹⁹ This is precisely what

10. MACPAC, Report to Congress on Medicaid and CHIP ("MACPAC") 89–90, 118 (Mar. 2021), <https://www.macpac.gov/wp-content/uploads/2021/03/March-2021-Report-to-Congress-on-Medicaid-and-CHIP.pdf> [hereinafter MACPAC Report].

11. *Id.* While working in state government, I was one of many interviewed by MACPAC as part of its research for the March 2021 Report to Congress. *See id.* at 73, 96 n. 1.

12. Seitz, *supra* note 1.

13. MACPAC REPORT, *supra* note 10, at 92; OFF. OF THE ASSISTANT SEC'Y FOR PLAN. & EVALUATION, DEP'T OF HEALTH & HUM. SERV., MEDICAID LIENS 1–2, 4 (Apr. 2005), <https://aspe.hhs.gov/sites/default/files/private/pdf/74096/liens.pdf> [hereinafter MEDICAID LIENS].

14. U.S. GOV'T ACCOUNTABILITY OFF., FINANCIAL CHARACTERISTICS OF APPROVED APPLICANTS AND METHODS USED TO REDUCE ASSETS TO QUALIFY FOR NURSING HOME COVERAGE 2, 6–8 (2014), <https://www.gao.gov/assets/gao-14-473.pdf>; MACPAC REPORT, *supra* note 10, at 77.

15. MEDICAID LIENS, *supra* note 13, at 2; Janel C. Frank, *How Far is Too Far? Tracing Assets in Medicaid Estate Recovery*, 79 N.D. L. REV. 111, 139 (2003).

16. JUSTICE IN AGING ET AL., MEDICAID ESTATE CLAIMS: PERPETUATING POVERTY & INEQUALITY FOR A MINIMAL RETURN 3–4 (2021), <https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf>.

17. *See* MACPAC REPORT, *supra* note 10, at 86; Jon M. Zieger, *The State Giveth and the State Taketh Away: In Pursuit of a Practical Approach to Medicaid Estate Recovery*, 5 ELDER L. J. 359, 392 (1997); ERICA F. WOOD & ELLEN M. KLEM, PROTECTIONS IN MEDICAID ESTATE RECOVERY: FINDINGS, PROMISING PRACTICES, AND MODEL NOTICES vi–vii, 9–10 (2007), https://assets.aarp.org/rgcenter/il/2007_07_medicaid.pdf; *see, e.g.*, sources cited *infra* note 216; *see also* discussion *infra* Section IV.

18. *See* 42 U.S.C.A. § 1396p(b) (Westlaw through Pub. L. No. 118-66); CTRS. FOR MEDICARE & MEDICAID SERVS. ("CMS"), STATE MEDICAID MANUAL § 3810, <https://www.cms.gov/regulations-and-guidance/guidance/manuals/paper-based-manuals-items/cms021927> (last visited Jul. 31, 2024) [hereinafter CMS MANUAL].

19. CMS MANUAL, *supra* note 18, § 3810(G) (instructing that state Medicaid agencies "should give a specific notice to individuals affected by the proposed recovery *whenever you seek adjustment or recovery*") (emphasis added).

happened in the case of Mr. LoGrande, whose family received the first “bill” for \$177,000 only after his death.²⁰ Referring to the timing of the notice, Ms. LoGrande stated, “[t]hat’s what ripped my guts out” because “[i]t was dishonest.”²¹

This Article proposes that federal law be amended to ensure that Medicaid applicants and enrollees receive clear, meaningful notice of the estimated and accrued costs of estate recovery loans while they are *alive*. Disclosure of estate recovery costs is necessary to allow individuals to make fully informed decisions regarding their health care options. When considering whether to enroll in Medicaid, individuals may have other options for medical care, such as family members or the ability to privately pay for certain services.²² To make an informed decision about Medicaid enrollment, families must understand the costs of Medicaid and determine whether the costs outweigh the benefits. After enrollment, enrollees and their families need to be able to continually assess the value of Medicaid services considering changes in the enrollee’s condition, in the availability of familial supports, and in the quality and reliability of services.²³ Without meaningful notice of estate recovery costs, individuals are unable to make well-informed decisions that impact their health and finances. Moreover, the advanced age, medical needs, and limited health literacy of Medicaid enrollees subject to estate recovery increases the likelihood that they may not understand estate recovery absent clear and periodic disclosures.²⁴ As recognized by consumer protection laws such as the Truth in Lending Act, individuals who receive open-ended loans should receive notice of loan terms before and during their usage. The rules for estate recovery loans should be no different.²⁵

Medicaid recipients should not assume a loan without clear financial disclosures regarding its terms. As background, Section II of this Article begins by describing Medicaid’s structure and eligibility, with a specific focus on individuals who receive long-term services and supports (LTSS). LTSS is one of the most expensive types of coverage that Medicaid provides, and payments for this coverage are required to be pursued through estate recovery.²⁶ This section then

20. Seitz, *supra* note 1.

21. *Id.*

22. BIPARTISAN POL’Y CTR., ADDRESSING THE DIRECT CARE WORKFORCE SHORTAGE: A BIPARTISAN CALL TO ACTION 16 (2023), <https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2023/11/BPC-Direct-Care-Workforce-Report-Final.pdf> (providing that half of people age sixty-five or older who receive LTSS rely on unpaid caregivers only).

23. See Medicaid Program; Ensuring Access to Medicaid Services, 88 Fed. Reg. 27960, 27964 (May 3, 2023) (to be codified at 42 C.F.R. pts. 431, 438, 441, 447); see also BIPARTISAN POL’Y CTR., *supra* note 22, at 20.

24. WOOD & KLEM, *supra* note 17, at vii, 11; see CMS, MEDICAID LONG TERM SERVICES AND SUPPORTS ANNUAL EXPENDITURES REPORT 1 (2023), <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2020.pdf>; Zieger, *supra* note 17, at 392.

25. 15 U.S.C.A. §§ 1601–67f (Westlaw through Pub. L. No. 118-70); 12 C.F.R. §§ 226.5, 226.7 (Westlaw 2024).

26. See 42 U.S.C.A. § 1396p(b) (Westlaw through Pub. L. No. 118-66); Priya Chidambaram & Alice Burns, *How Many People Use Medicaid Long-Term Services and Supports and How Much Does*

describes the two primary service delivery models used in Medicaid, the fee-for-service and managed care models.

Providing Medicaid enrollees with notice of estate recovery costs is especially vital in states that use a managed care model to deliver long-term care or other recoverable services.²⁷ In these states, state Medicaid agencies pay a flat monthly rate for each Medicaid member (a “capitation rate”) to a managed care organization (MCO).²⁸ The MCO then pays providers for the health care services for that member.²⁹ The flat per-member, per-month capitation rate can exceed the costs of the services provided to an individual member.³⁰ Yet, CMS requires states employing this model to calculate estate recovery claims based on *the capitation rate*, not on the MCO’s payments to providers.³¹ The Medicaid enrollee’s estate will be charged the capitation rate every month that the beneficiary is enrolled in Medicaid recoverable services.³² Despite this fact, Medicaid enrollees typically do not see the capitation rate during their lifetime.³³ Whether in a managed care or fee-for-service model, Medicaid recipients need clear, ongoing notice alerting them to the amount of debt their estate has incurred to date.³⁴

Section III of this Article provides an overview of Medicaid estate recovery, including Medicaid enrollees who are subject to estate recovery, estate recovery exemptions and hardship waivers, and how an estate recovery claim is calculated. Section IV then summarizes current federal and state requirements for providing notice to enrollees regarding estate recovery. A review of all fifty states’ estate recovery laws, Medicaid applications, and publicly available estate recovery brochures indicates that no state proactively notifies Medicaid enrollees of accrued estate recovery costs.³⁵ Under states’ current requirements and practices, the

Medicaid Spend on Those People?, KFF (Aug. 14, 2023), <https://www.kff.org/medicaid/issue-brief/how-many-people-use-medicaid-long-term-services-and-supports-and-how-much-does-medicaid-spend-on-those-people/>.

27. See MACPAC REPORT, *supra* note 10, at 86, 94, 97 n.13.

28. HARVEY L. MCCORMICK, 2 MEDICARE AND MEDICAID CLAIMS AND PROCEDURES § 25:1 (4th ed. 2023).

29. *Id.*

30. MACPAC REPORT, *supra* note 10, at 86, 94, 97 n.13.

31. CMS MANUAL, *supra* note 18, § 3810(A)(6). In its March 2021 report, MACPAC proposed to Congress that it should amend Section 1917 of Title XIX of the Social Security Act to allow states providing LTSS under managed care arrangements to pursue estate recovery based on the costs of care when the costs of services used by a beneficiary was less than the capitation payment made to a managed care plan. MACPAC REPORT, *supra* note 10, at 94–95. Congress has not acted on this proposal. If MACPAC’s proposal is adopted, states would be allowed, but not required, to pursue recovery of the costs of care. Moreover, even in states that opted to pursue recovery of the costs of care, individuals need to receive regular notice of the actual costs to their estate during their lifetime to ensure they are making fully informed decisions regarding their care.

32. CMS MANUAL, *supra* note 18, § 3810(A)(6). If a state has opted to recover for all Medicaid services, it must seek to recover the total capitation payments paid on behalf of the beneficiary to the MCO. *Id.* If a state instead seeks to recover only the costs of long-term care services, the state must seek recovery of the portion of the capitation payment attributable to the recoverable services. *Id.*

33. MACPAC REPORT, *supra* note 10, at 94; see discussion *infra* Sections III.C, IV.

34. See MACPAC REPORT, *supra* note 10, at 94.

35. See discussion *infra* Section IV.

families of Medicaid enrollees are often shocked to learn of substantial estate recovery claims after the enrollee passes away, as documented by several examples in Section IV.

Section V of this Article explains why it is essential for Medicaid enrollees to receive meaningful notice of the loan they are assuming when they enroll in Medicaid. Finally, Section VI of the Article proposes a federal notice requirement requiring Medicaid agencies to provide notice of the anticipated costs of estate recovery to Medicaid applicants as well as periodic notice of the accrued costs of estate recovery to Medicaid enrollees subject to recovery. Section VI also addresses potential arguments against this proposal, ultimately concluding that a federal notice requirement is feasible, supported by applicable case law, and consistent with Congress' broad regulation of Medicaid notices.³⁶ Given the profound financial impact of estate recovery collections on families, including the potential loss of their home, it is essential that individuals understand estate recovery costs while they are still alive and thus in a better position to make decisions regarding their care.

II. THE MEDICAID PROGRAM

In 1965, Congress established the Medicaid Program to provide medical care for individuals who lacked the income and assets needed to meet their medical needs.³⁷ Since that time, Medicaid has become the largest source of health coverage in the United States.³⁸ As of February 2024, approximately 22% of the United States' population, or 76 million individuals, were enrolled in Medicaid.³⁹

Medicaid is a cooperative federal-state program, under which the federal government reimburses states for a portion of the costs associated with providing care to enrollees.⁴⁰ At the federal level, the Centers for Medicare & Medicaid

36. While eliminating the estate recovery program altogether would address the problems identified in this Article, Congress has repeatedly rejected proposals to do so. *See* H.R. 6698, 117th Cong. (2022); H.R. 7573, 118th Cong. (2024). Additionally, calculating estate recovery claims based on the costs of care rather than capitation rates could create better transparency in this area, but Congress has not acted on a similar proposal made by MACPAC in 2021. MACPAC REPORT, *supra* note 10, at 94–95. Moreover, even if MACPAC's proposal were adopted, periodic estate recovery notices are needed to ensure that individuals are aware during their lifetime of the debt their estate is accruing. Finally, even with the solution proposed by this Article, additional systemic changes to the long-term care system are needed to ensure that Medicaid enrollees' family members do not feel compelled to either accept the financial consequences of estate recovery or provide the care themselves.

37. *See* 42 U.S.C.A. §§ 1396–1396w-8 (Westlaw through Pub. L. 118-70); MEDICAID LIENS, *supra* note 13, at 1; *see also* S. REP. NO. 89-404, at 1943–45 (1965), *reprinted in* 1965 U.S.C.C.A.N. 1943, 1965 WL 4458.

38. CMS, *Medicaid Eligibility*, <https://www.medicaid.gov/medicaid/eligibility/index.html> (last visited Jul. 20, 2024).

39. CTRS. FOR MEDICAID & CHIP SERVS., FEBRUARY 2024 MEDICAID AND CHIP ENROLLMENT TRENDS SNAPSHOT (2024), <https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/downloads/february-2024-medicaid-chip-enrollment-trend-snapshot.pdf>; U.S. CENSUS BUREAU, *Population*, <https://www.census.gov/topics/population.html> (last visited Jul. 23, 2024).

40. MACPAC, REPORT TO CONGRESS ON MEDICAID AND CHIP 3 (June 2024), https://www.macpac.gov/wp-content/uploads/2024/06/MACPAC_June-2024-WEB-508.pdf.

Services (CMS), a division of the Department of Health and Human Services, administers Medicaid.⁴¹ States must meet all federal requirements to participate in Medicaid and receive federal matching funds.⁴² Within this federal framework, states have considerable flexibility to design their Medicaid programs.⁴³ States set forth the nature and scope of their Medicaid programs in a Medicaid State Plan approved by CMS.⁴⁴

Medicaid provides coverage to economically disadvantaged populations, including low-income children and their families, low-income seniors, and low-income individuals living with disabilities.⁴⁵ To become eligible for Medicaid coverage, individuals must meet the requirements of a specific eligibility pathway offered by the state.⁴⁶ Each eligibility pathway sets forth the group of individuals covered by the pathway (i.e. categorical criteria) and the financial criteria applicable to that group.⁴⁷ Certain eligibility pathways are mandatory for states, such as the ones for low-income pregnant women and children; aged, blind, and disabled individuals who receive Supplemental Security Income (SSI); and low income parents of dependent children.⁴⁸ Federal law also allows states to cover optional categories of individuals.⁴⁹ For example, states have the option to expand Medicaid coverage to nonelderly adults with income up to 133% of the federal poverty level.⁵⁰ States may also seek waivers and demonstration authority to operate their Medicaid programs outside of federal requirements.⁵¹ Due to these flexibilities afforded to states, there is significant variation in Medicaid eligibility, covered benefits, and program administration across the states.⁵² The following sub-sections discuss two components of Medicaid that are pertinent to Medicaid's estate recovery program: (A) coverage of long-term services and supports, and (B) the two primary delivery models used to provide Medicaid services.

A. Medicaid Long-Term Services & Supports

State Medicaid agencies must try to recover, at a minimum, the costs of long-term services and supports (LTSS).⁵³ LTSS includes institutional care, such as

41. CONG. RSCH. SERV., RL43357 MEDICAID: AN OVERVIEW, 1 (Feb. 8, 2023), <https://crsreports.congress.gov/product/pdf/R/R43357>.

42. *Id.*

43. *Id.*

44. *Id.*

45. MACPAC, REPORT TO CONGRESS ON MEDICAID AND CHIP 4–6 (June 2017), <https://www.macpac.gov/wp-content/uploads/2017/06/June-2017-Report-to-Congress-on-Medicaid-and-CHIP.pdf>.

46. *Id.* at 4; Nat'l Conf. of State Legislatures, *Medicaid Eligibility and Enrollment* (July 27, 2023), <https://www.ncsl.org/health/medicaid-eligibility-and-enrollment>.

47. CONG. RSCH. SERV., *supra* note 41, at 4.

48. MACPAC, *supra* note 45, at 4–6.

49. *Id.*

50. CONG. RSCH. SERV., *supra* note 41, at Summary.

51. *Id.*

52. *Id.*

53. *Id.* at 8.

care provided in nursing facilities, intermediate care facilities for individuals with intellectual or developmental disabilities, mental health facilities, and home and community-based services (HCBS).⁵⁴ Medicaid enrollees who receive LTSS have various types of physical and cognitive disabilities and range in age.⁵⁵ For example, individuals receiving Medicaid LTSS may include an elderly nursing home resident with Alzheimer's disease, a child with cerebral palsy in an intermediate care facility, or a middle-aged adult with epilepsy who receives care at home.⁵⁶ Medicaid LTSS can include a combination of medical and non-medical care.⁵⁷ Non-medical LTSS services include assistance with activities of daily living such as eating, dressing, bathing, toileting, and instrumental activities of daily living such as preparing meals, housekeeping, and managing medication.⁵⁸

Compared with other categories of Medicaid eligibility, Medicaid LTSS recipients often have complex medical needs and are thus among the most expensive Medicaid members.⁵⁹ In 2020, Medicaid spending on Medicaid LTSS recipients was nearly nine times higher than those who did not receive LTSS.⁶⁰ Additionally, while Medicaid enrollees receiving LTSS make up a small sector of the total Medicaid population, they account for a significant percentage of Medicaid spending.⁶¹ In 2020, Medicaid LTSS recipients comprised 6% of Medicaid enrollment but 37% of Medicaid expenditures.⁶²

For an individual to become eligible for Medicaid LTSS, they must be determined to meet certain medical criteria showing a need for long term care and an income and asset limit established by the State.⁶³ States have implemented various pathways to attain Medicaid LTSS financial eligibility, and the eligibility criteria are complex.⁶⁴ For many of these pathways, to become eligible for Medicaid LTSS, an applicant must have no more than \$2,000 in assets for an individual, and \$3,000 for a couple.⁶⁵ Certain assets, however, are not counted for purposes

54. *Id.*

55. MACPAC, *Long Term Services and Supports*, <https://www.macpac.gov/topics/long-term-services-and-supports/> (last visited Jul. 20, 2024).

56. See CMS, *Home & Community-Based Services 1915(c)*, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html> (last visited Jul. 20, 2024).

57. RICHARD W. JOHNSON & JUDITH DEY, LONG-TERM SERVICES AND SUPPORTS FOR OLDER AMERICANS: RISKS AND FINANCING 1 (2022), <https://aspe.hhs.gov/sites/default/files/documents/08b8b7825f7bc12d2c79261fd7641c88/ltss-risks-financing-2022.pdf>; Chidambaram & Burns, *supra* note 26.

58. JOHNSON & DEY, *supra* note 57, at 1.

59. MACPAC, *supra* note 55.

60. Chidambaram & Burns, *supra* note 26 (noting that Medicaid agencies spent an average of \$4,480 per enrollee who did not use Medicaid LTSS and \$38,769 per enrollee who used LTSS in 2020).

61. *Id.*

62. *Id.*; see also MACPAC, *supra* note 55.

63. MACPAC REPORT, *supra* note 10, at 74; CONG. RSCH. SERV. RL43357, *supra* note 41, at 8.

64. MACPAC REPORT, *supra* note 10, at 74–75; Chidambaram & Burns, *supra* note 26.

65. MACPAC REPORT, *supra* note 10, at 76–77. Under spousal impoverishment rules, states set income and asset amounts that a spouse living in the community may keep without preventing their spouse from becoming eligible for Medicaid LTSS. *Id.* at 79.

of establishing Medicaid LTSS eligibility, including an applicant's primary residence and one automobile.⁶⁶ States may set a maximum home equity limit for the primary home to be excluded as an asset.⁶⁷ In 2024, most states have set the home equity limit at \$713,000.⁶⁸ This means that if an individual's home equity is less than \$713,000, the home is not counted towards the applicable asset limit to receive Medicaid LTSS.⁶⁹ Often, the home is the only significant asset that remains in a Medicaid enrollee's estate after the enrollee's death.⁷⁰

In the United States, Medicaid is the primary payer of LTSS, and the number of individuals needing Medicaid LTSS is expected to increase rapidly in upcoming years.⁷¹ Private insurance and Medicare provide only limited LTSS coverage, so many individuals must deplete their resources to become eligible for Medicaid LTSS.⁷² The number of individuals needing Medicaid LTSS is also expected to grow as the number of elderly Americans is rapidly rising.⁷³ From 2012 to 2050, the population age sixty-five and older is predicted to more than double, far outpacing the growth rate for other age ranges during that same period.⁷⁴ As the largest payer of long-term care, Medicaid will likely experience significant increases in LTSS enrollment as more individuals deplete their resources to become eligible in the next three decades.⁷⁵

B. Medicaid Service Delivery Models

To understand the way state Medicaid agencies calculate estate recovery claims requires an understanding of the two primary types of Medicaid service

66. *Id.* at 77.

67. *Id.*; U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 14, at 8–9.

68. See MACPAC REPORT, *supra* note 10, at 77; DANIEL TSAI, CTR. FOR MEDICAID & CHIP SERVS., UPDATED 2024 SSI AND SPOUSAL IMPOVERISHMENT STANDARDS 2, <https://www.medicaid.gov/federal-policy-guidance/downloads/cib05222024.pdf>.

69. MACPAC REPORT, *supra* note 10, at 77; TSAI, *supra* note 68, at 2.

70. Frank, *supra* note 15, at 139; WOOD & KLEM, *supra* note 17, at 11.

71. CMS, *supra* note 24, at 1; Zoe Caplan, *U.S. Older Population Grew from 2010 to 2020 at Fastest Rate Since 1880 to 1890*, U.S. CENSUS BUREAU (May 25, 2023), <https://www.census.gov/library/stories/2023/05/2020-census-united-states-older-population-grew.html>; JOHNSON & DEY, *supra* note 57, at 2. In Fiscal Year 2020, Medicaid LTSS expenditures totaled \$199.4 billion, accounting for 57% of all LTSS spending nationally. CMS, *supra* note 24, at 1, 6.

72. CMS, *supra* note 24, at 1. Medicare generally covers short-stay residents in a nursing facility for up to 100 days. MACPAC, ESTIMATES OF MEDICAID NURSING FACILITY PAYMENTS RELATIVE TO COSTS 2 (2023), <https://www.macpac.gov/wp-content/uploads/2023/01/Estimates-of-Medicaid-Nursing-Facility-Payments-Relative-to-Costs-1-6-23.pdf>. Most Medicaid enrollees residing in nursing facilities are dually eligible for Medicare and Medicaid, with Medicare covering the first part of their stay. *Id.*

73. Caplan, *supra* note 71; JOHNSON & DEY, *supra* note 57, at 2.

74. AARP, ACROSS THE STATES: PROFILES OF LONG-TERM SERVICES AND SUPPORTS 7 (9th ed. 2012), https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf. Approximately 70% of individuals age sixty-five and older are predicted to use LTSS services. Erica L. Reaves & MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer*, KFF (Dec. 15, 2015), https://www.kff.org/report-section/medicaid-and-long-term-services-and-supports-a-primer-report-dec-2015/#endnote_link_172646-7.

75. Neda Jasemi, *Top Five Medicaid Budget Pressures for Fiscal Year 2025*, NAT'L ASS'N OF MEDICAID DIRECTORS (Apr. 23, 2024), <https://medicaiddirectors.org/resource/top-five-medicaid-budget-pressures-for-fiscal-year-2025>.

delivery systems.⁷⁶ Under a traditional “fee-for-service” model, the state pays health care providers directly for each service provided to the Medicaid enrollee.⁷⁷ In contrast, under a “managed care” model, the state pays an insurance company (i.e. “managed care organization”) a flat monthly fee for each Medicaid member enrolled in that MCO’s plan.⁷⁸ In exchange for the flat monthly fee, referred to as a “capitation payment,” the MCO agrees to pay for each member’s medical care.⁷⁹ Thus, in the managed care model, it is the MCO rather than the state that pays providers for services.⁸⁰

Under the managed care model, states work with actuaries to develop capitation rates for eligibility categories for the prospective twelve-month period.⁸¹ The capitation rates are calculated based on the estimated amounts needed to cover the health care costs of each category of coverage.⁸² The state’s capitation payment does not change based on the amount or type of services received by a specific enrollee.⁸³ The capitation rate is intended to cover the needs of the member; however, the MCO bears the financial risk of this arrangement.⁸⁴ If the MCO’s costs for an enrollee are more than the monthly capitation rate, then the MCO may lose money with respect to that enrollee.⁸⁵ If the MCO’s costs for an enrollee are less than the monthly capitation rate, the MCO stands to profit with respect to that enrollee.⁸⁶ Importantly for purposes of estate recovery, the state’s monthly capitation payment to the MCO for an enrollee may be greater than or less than the amounts the MCO pays providers for that enrollee’s services.⁸⁷ Moreover, even if the enrollee receives no services in a given month, the state still makes the monthly capitation payment to the MCO for that month.⁸⁸

76. Hannah Maniates, *Why Did They Do It That Way? Understanding Managed Care*, NAT’L ASS’N OF MEDICAID DIRECTORS (Jan. 22, 2024), <https://medicaiddirectors.org/resource/understanding-managed-care/#:~:text=The%20two%20main%20delivery%20system,pays%20providers%20for%20covered%20services>. While this article focuses on the two primary Medicaid service delivery systems, the need for notice of estate recovery costs applies to these as well as other such systems.

77. MCCORMICK, *supra* note 28, § 25:1.

78. *Id.*

79. *Id.*; CMS, *Capitation and Pre-payment*, <https://www.cms.gov/priorities/innovation/key-concepts/capitation-and-pre-payment> (last visited Jul. 20, 2024). The MCO must also handle other functions, including developing a provider network. Maniates, *supra* note 76.

80. CONG. RSCH. SERV. RL43357, *supra* note 41, at 16; Elizabeth Hinton & MaryBeth Musumeci, *Medicaid Managed Care Rates and Flexibilities: State Options to Respond to COVID-19 Pandemic*, KFF (Sept. 9, 2020), <https://www.kff.org/medicaid/issue-brief/medicaid-managed-care-rates-and-flexibilities-state-options-to-respond-to-covid-19-pandemic>.

81. MACPAC, *MEDICAID MANAGED CARE CAPITATION RATE SETTING 1* (2022), <https://www.macpac.gov/wp-content/uploads/2022/03/Managed-care-capitation-issue-brief.pdf>.

82. *Id.*

83. MACPAC REPORT, *supra* note 10, at 86, 94, 97 n.13.

84. Maniates, *supra* note 76.

85. *Id.*

86. *Id.*

87. MACPAC REPORT, *supra* note 10, at 86, 94, 97 n.13.

88. *Id.*

The managed care model is the predominant delivery system for Medicaid.⁸⁹ While some states have carved out specific services such as LTSS from their managed care plans, states are increasingly incorporating these services into MCO contracts.⁹⁰ As of 2021, twenty-five states had implemented managed care LTSS programs that covered some or all of the LTSS benefits for their members.⁹¹ As discussed in greater detail below, in these states, Medicaid enrollees may be charged for estate recovery amounts greater than the actual costs of the services they receive, thus underscoring the need for Medicaid enrollees to receive clear notice of estate recovery costs.⁹²

III. THE ESTATE RECOVERY PROGRAM

When the Medicaid program was established in 1965, estate recovery was made optional for states.⁹³ The estate recovery program was aimed at providing states with a means to replenish Medicaid funds and provide for future services.⁹⁴ Additionally, estate recovery was intended to ensure that Medicaid members contributed to the cost of their care when they had assets available.⁹⁵ Under the optional estate recovery program, states could elect to pursue recovery of Medicaid costs from the estates of enrollees who were sixty-five years of age or older, with certain exceptions.⁹⁶ When estate recovery was optional, twenty-eight states implemented the program.⁹⁷ This changed in 1993, when estate recovery became mandated for states participating in Medicaid.⁹⁸ The following sub-sections describe the federal estate recovery program, the exemptions and potential waivers from estate recovery, and the way that estate recovery claims are calculated.

89. Elizabeth Hinton & Jada Raphael, *10 Things to Know About Medicaid Managed Care*, KFF (May 1, 2024), <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-managed-care/#footnote-619805-1> (providing that, as of July 2023, forty states and the District of Columbia used managed care plans to provide care to at least some of their Medicaid beneficiaries).

90. *Id.*

91. MACPAC REPORT, *supra* note 10, at 85. The Kaiser Family Foundation has concluded that, as of July 2023, the number of states using exclusively managed care for their Medicaid populations has increased to thirty-three. Hinton & Raphael, *supra* note 89.

92. MACPAC REPORT, *supra* note 10, at 86, 94, 97 n. 13.

93. *West Virginia v. U.S. Dep't of Health & Hum. Servs.*, 289 F.3d 281, 284 (4th Cir. 2002).

94. *Belshe v. Hope*, 38 Cal. Rptr. 2d 161, 173 (Cal. Ct. App. 1995).

95. *Id.*; MACPAC REPORT, *supra* note 10, at 83.

96. *West Virginia*, 289 F.3d at 284; MACPAC REPORT, *supra* note 10, at 81.

97. NAOMI KARP ET AL., ABA COMM'N ON LAW AND AGING, MEDICAID ESTATE RECOVERY: A 2004 SURVEY OF STATE PROGRAMS AND PRACTICES 9 (June 2005), https://digirepo.nlm.nih.gov/master/borndig/101256282/2005_06_recovery.pdf.

98. Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-66 § 13612, 107 Stat. 312, 627 (1993), amending 42 U.S.C. § 1396p(b).

A. Federal Estate Recovery Framework

In 1993, Congress passed the Omnibus Budget Reconciliation Act of 1993 (OBRA '93), which made sweeping changes to the estate recovery program.⁹⁹ The most notable of these changes was to *require* states to pursue estate recovery.¹⁰⁰ This legislation was passed as an effort to curb rapidly escalating Medicaid costs, without depriving eligible recipients of necessary care.¹⁰¹ A report by the Office of Inspector General laid the groundwork for the estate recovery mandate, concluding that “it is not unreasonable to believe that much of the long-term care funding crisis could be resolved by harnessing the home equity of the elderly.”¹⁰² The report indicated that, by making estate recovery mandatory, families wishing to protect their estates would be incentivized to purchase private long-term care insurance.¹⁰³ Some states such as West Virginia objected to this mandate, describing it as a “betrayal of the New Deal” that most heavily burdens the poorest elderly individuals.¹⁰⁴ The Fourth Circuit Court of Appeals ultimately rejected this challenge, finding that the mandate was constitutional.¹⁰⁵ Other states delayed implementation of estate recovery.¹⁰⁶ For example, Michigan established an estate recovery program in 2007, only after the federal government threatened the state with the loss of Medicaid funding.¹⁰⁷

Under OBRA '93, states are required to “seek adjustment or recovery of any medical assistance correctly paid on behalf of an individual . . . who was 55 years of age or older when the individual received such medical assistance.”¹⁰⁸ OBRA '93 also requires states to pursue recovery from the estates of Medicaid recipients who are determined to be permanently institutionalized¹⁰⁹ and those with long-term care insurance policies under certain circumstances.¹¹⁰ Finally, the Act expanded the definition of “estate” to allow states to pursue not only the probate

99. *Id.*; Ian S. Oppenheim & Alex L. Moschella, *National Perspective on Expanded Estate Recovery: Case Law Analysis, Emerging Legislative Trends and Responsive Strategies for the Elder Law Attorney*, NAT'L ACAD. ELDER L. ATT'YS J., 1, 7–8 (2005).

100. *See* 42 U.S.C.A. § 1396p(b)(1) (West, Westlaw through Pub. L. No. 118-66); *see also* 42 U.S.C.A. § 1396a(a)(18) (West, Westlaw through Pub. L. 118-70).

101. *See* West Virginia, 289 F.3d at 284; OFF. OF INSPECTOR GEN., MEDICAID ESTATE RECOVERIES: NATIONAL PROGRAM INSPECTION 52 (1988), <https://oig.hhs.gov/documents/evaluation/1398/OAI-09-86-00078-Complete%20Report.pdf>.

102. OFF. OF INSPECTOR GEN., *supra* note 101, at 49.

103. *Id.* at v, vi; Sarah True, *Debt After Death: The Painful Blow of Medicaid Estate Recovery*, U.S. NEWS & WORLD REP. (Oct. 14, 2021), <https://www.usnews.com/news/health-news/articles/2021-10-14/debt-after-death-the-painful-blow-of-medicaid-estate-recovery>.

104. West Virginia, 289 F.3d at 285.

105. *Id.* at 291.

106. *See, e.g.*, GA. COMP. R. & REGS. 111-3-8-.04(17) (West, Westlaw through June 27, 2024) (providing the effective date of Georgia's estate recovery program as May 3, 2006).

107. Alexandria Smith, Note, *Widening the Gap Between Rich and Poor: Issues and Recommendations for the Implementation of Michigan's Medicaid Estate Recovery Law*, 90 U. DET. MERCY L. REV. 141, 141 (Fall 2012).

108. 42 U.S.C.A. § 1396p(b) (West, Westlaw through Pub. L. No. 118-66).

109. *Id.*

110. MACPAC REPORT, *supra* note 10, at 82.

estate as defined by state law, but also property that passes outside of the probate estate such as assets conveyed to a survivor through joint tenancy.¹¹¹ With respect to Medicaid enrollees over age fifty-five, states may pursue recovery only after the enrollee has passed away.¹¹² For those determined permanently institutionalized, the state may place a lien upon the enrollee's property while the recipient is living.¹¹³

While national estate recovery collections are substantial, comprehensive data regarding the number of estate recovery claims pursued, average claim amounts, and the average recovery amounts per estate in each state are not available. In the aggregate, states collected approximately \$733.4 million through the estate recovery program in Fiscal Year (FY) 2019.¹¹⁴ The five states with the highest recoveries that year were Massachusetts (\$83.1 million), New York (\$59.8 million), Pennsylvania (\$54.1 million), Ohio (\$43.8 million), and Wisconsin (\$41.4 million).¹¹⁵ These five states accounted for 38.5% of all reported estate recoveries in FY 2019.¹¹⁶ CMS does not appear to require detailed estate recovery reporting from states, aside from total recoveries reported in each state's CMS-64 expenditure reports.¹¹⁷

As part of its March 2021 Report to Congress, the Medicaid and CHIP Payment and Access Commission (MACPAC) received self-reported estate recovery information from ten states which indicated wide variation in the number of estates pursued and average recoveries per estate.¹¹⁸ Importantly, MACPAC noted that the results are "not completely comparable" due to variation in states' recordkeeping and reporting methods.¹¹⁹ For states responding to that survey, in

111. Oppenheim & Moschella, *supra* note 99, at 11.

112. 42 U.S.C.A. § 1396p(b)(1)(B) (West, Westlaw 2024).

113. *Id.* § 1396(a), (b)(1)(A). Authorized by the Tax Equity Fiscal Responsibility Act of 1982 (TEFRA), a state may collect on a TEFRA lien while the enrollee is alive if the enrollee chooses to transfer or sell their property. *Id.* § 1396(b)(1)(A); Zeiger, *supra* note 17, at 370–71. In this scenario, the TEFRA lien requires the enrollee to use the equity value in the property to repay his or her institutional costs. MEDICAID LIENS, *supra* note 13, at 4. Before a state Medicaid agency imposes a TEFRA lien, the agency must provide notice of its intention to make a medical determination that the enrollee cannot reasonably be expected to return home and provide an opportunity for a hearing. 42 U.S.C.A. § 1396(a)(1)(B)(ii); 42 C.F.R. § 433.36 (West, Westlaw 2024). The notice must also include an explanation of liens and the effect of the lien on the enrollee's ownership of property. 42 C.F.R. § 433.36 (West, Westlaw 2024). Because those subject to TEFRA liens are afforded notice protections during their lifetime, this Article focuses primarily on states' post-death estate recovery efforts, for which such notices are not required. To the extent that individuals subject to TEFRA liens do not receive notice of Medicaid lien amounts, the notice requirement proposed in this Article should apply to those individuals.

114. MACPAC REPORT, *supra* note 10, at 73.

115. *Id.* at 118–20.

116. *Id.* at 88, 118–20.

117. *See id.* at 88–89. The HHS Office of Inspector General has recently stated that it is auditing estate recovery programs and has completed one such audit of Kansas. DEP'T OF HEALTH & HUMAN SERVS., OFF. OF INSPECTOR GEN., A-07-22-03254, KANSAS' MEDICAID RECOVERY PROGRAM WAS COST EFFECTIVE, BUT KANSAS DID NOT FOLLOW ITS PROCS., WHICH COULD HAVE RESULTED IN REDUCED RECOVERIES 1 (Mar. 2024), <https://oig.hhs.gov/documents/audit/9818/A-07-22-03254.pdf>.

118. MACPAC REPORT, *supra* note 10, at 89.

119. *Id.*

FY 2019, states pursued an average of 7,873 estates and recovered from an average of 2,188 estates.¹²⁰ That same year, the average recovery amount per estate ranged from \$3,479 in Missouri to \$36,759.39 in Georgia.¹²¹ As an example of the wide variation among states' collections from the previous fiscal year, FY 2018, Alaska recovered from only twelve estates but had an average recovery of \$71,556 per estate.¹²² Research suggests that states could recover more through estate recovery than they are currently recovering.¹²³

B. Estate Recovery Exemptions and Hardship Waivers

OBRA '93 maintained certain protections regarding when estate recovery can be pursued.¹²⁴ For aged and institutionalized individuals, states may recover only after the death of the enrollee's surviving spouse, and only when there is no child of the enrollee living in the home who is under age twenty-one, blind, or disabled.¹²⁵ Additionally, for permanently institutionalized individuals, a lien may not be enforced against a property when a sibling or child of the Medicaid enrollee (1) continuously resided in the home for a specified period leading to enrollee's institutionalization, (2) continuously resided in the home since the institutionalization, and (3) with respect to a child, provided care to the enrollee that allowed him or her to reside at home rather than at an institution.¹²⁶

In addition to these exemptions, Congress also required states to establish procedures under which the state will waive estate recovery due to undue hardship or cost effectiveness.¹²⁷ CMS provides examples of potential hardships, but it does not require states to use them.¹²⁸ These examples include when an estate is the sole income-producing asset of the survivors (e.g. a family farm), when recovery is sought against a "home of modest value" (defined as roughly half the average home value in the county), or "other compelling circumstances."¹²⁹ The

120. *Id.* at 90–91. These averages excluded states that did not provide the respective data point. Additionally, states may have interpreted "pursued recovery" differently.

121. *Id.* In general, states that recovered from a smaller number of estates had higher recovery amounts per estate, whereas states that recovered from a larger number of estates had a smaller average recovery amount per estate. *Id.* at 89–90.

122. *Id.* at 90.

123. *Id.* at 89 (citing one study that estimated that states could have collected 5.5 times more from 2002 to 2011 if those states matched the efforts of those that were most effective at estate recovery, but recognizing the limitations of this study).

124. 42 U.S.C.A. § 1396p(b) (Westlaw through Pub. L. No. 118–66).

125. *Id.* § 1396p(b)(2)(A).

126. *Id.* § 1396p(b)(2)(B).

127. *Id.* § 1396p(b)(3). States may waive estate recovery in cases in which recovery is not cost effective to pursue. CMS MANUAL, *supra* note 18, § 3810(E). States must specify the methodology for determining cost-effectiveness in their State Plan. *Id.*

128. CMS MANUAL, *supra* note 18, § 3810(C)(1).

129. *Id.* CMS does not require that states use a specific methodology to define a home of modest value. *Id.* As guidance, CMS has instructed that states can define this as 50% or less of the average price of homes in the county where the home is located, as of the date of the Medicaid recipient's death. *Id.* States are not allowed to set the threshold so high as to negate the intent of the estate recovery program. *Id.*

limited data available suggests that hardship waivers are very seldom sought by applicants or granted by states.¹³⁰

C. Calculation of Estate Recovery Claims

Federal law requires states to seek recovery of the amounts spent on certain services, at a minimum, but states have the option of recovering the costs of additional services.¹³¹ With respect to Medicaid enrollees age fifty-five or older, states must seek to recover the amounts paid by Medicaid for nursing facility services, HCBS, and related hospital and prescription drug services.¹³² At the state's option, the state may recover "any items or services under the State plan" except for Medicare cost-sharing.¹³³ With respect to permanently institutionalized individuals, states must seek to recover the amounts the state spent on all of the services provided in the institution, regardless of whether they were furnished before or after the individual was determined to be permanently institutionalized.¹³⁴ The state may also elect to recover for all medical assistance provided.¹³⁵ In this Article, the services for which a state seeks to recover the costs are referred to as "recoverable services."

How states calculate the costs of recoverable services for purposes of estate recovery claims depends on the model they use to deliver services. In states using a fee-for-service model to deliver recoverable services, the state Medicaid agency must calculate the estate recovery claim by totaling the amounts that the state Medicaid agency paid providers for the recoverable services.¹³⁶ As stated above, this must include the payments to providers for nursing facility, HCBS, and related hospital and prescription drug services, and this can also include the payments made for any items or services under the state plan at the state's option.¹³⁷

In states using a managed care model to deliver recoverable services, the calculation is more complex. If a state has opted to recover for all Medicaid services, it must seek to recover the total capitation payments paid on behalf of the beneficiary to the MCO.¹³⁸ If a state instead seeks to recover the costs of nursing facility, HCBS, and related hospital and prescription drug services, the state must seek to recoup the portion of the capitation payment attributable to the recoverable services.¹³⁹ Thus, the estate recovery claim in a managed care state will be comprised

130. *Id.* at 91, 121–22.

131. 42 U.S.C.A. § 1396p(b).

132. *Id.* § 1396p(b)(1)(B)(i).

133. *Id.* § 1396p(b)(1)(B)(ii).

134. CMS MANUAL, *supra* note 18, § 3810(A)(1).

135. *Id.*

136. MACPAC REPORT, *supra* note 10, at 85.

137. 42 U.S.C.A. § 1396p(b)(1)(B).

138. CMS MANUAL, *supra* note 18, § 3810(A)(6).

139. *Id.*

of capitation payments, in whole or in part, rather than payments made directly to providers.¹⁴⁰

In states using managed care, Medicaid enrollees generally do not receive a notice identifying the capitation rates that the state pays on their behalf.¹⁴¹ When capitation rates are made available online, they are frequently contained in long, dense actuarial reports, in which the rate applicable to a specific person or group is difficult to find.¹⁴² Moreover, comprehensive data comparing states’ capitation rates for Medicaid LTSS or other services is not publicly available. The following table provides examples of monthly capitation payment ranges in select states for LTSS categories, including individuals enrolled in both Medicare and Medicaid (Dual members) and individuals enrolled only in Medicaid (Non-Dual members):

State	Dual member	Non-Dual member
Arizona ¹⁴³	\$3,812–\$5,070	\$7,778–\$10,513
California ¹⁴⁴	\$8,496–\$8,757	\$10,428–\$10,913
South Carolina ¹⁴⁵	\$1,842–\$7,438	Not available
Tennessee ¹⁴⁶	\$1,779–\$5,301	\$4,167–\$7,159

140. *Id.* If a state has opted to recover for all Medicaid services, it must seek to recover the total capitation payments paid on behalf of the beneficiary to the MCO. *Id.* If a state instead seeks to recover only the costs of long-term care services, the state must seek recovery of the portion of the capitation payment attributable to the recoverable services. *Id.*

141. MACPAC REPORT, *supra* note 10, at 94 (“Beneficiaries are likely unaware of the amount of capitation paid on their behalf.”); see discussion *infra* Section IV.

142. See, e.g., Mercer Gov’t Hum. Servs. Consulting, Fiscal Year 2024 Cardinal Care Managed Care MLTSS Rate Rep. (Dec. 21, 2023), <https://www.dmas.virginia.gov/media/5p0p0zlf/fy2024-cmcmltss-rate-report-effective-january-1-2024.pdf>; Letter from Rudd & Wisdom, Inc. to Michael Joyner (Jan. 15, 2024), <https://pfd.lhs.texas.gov/sites/default/files/documents/managed-care/2024/2024-ffy-revised-star-plus-rates.pdf>.

143. ARIZ. HEALTH CARE COST CONTAINMENT SYS., CONTRACT YEAR ENDING 2024 ARIZ. LONG TERM CARE SYS. – ELDERLY AND PHYSICAL DISABILITY (ALTCS-EPD) PROGRAM 1 (Aug. 11, 2023), https://www.azahcccs.gov/PlansProviders/Downloads/CapitationRates/ALTCS/ALTCS-EPD_RatesEffectiveOct12023.pdf (reflecting long-term care capitation rates effective Oct. 1, 2023 through Sept. 30, 2024).

144. CAL. HEALTH & HUMAN SERVS., CY 2023 REGIONAL MODEL RATES (Feb. 20, 2024), <https://data.chhs.ca.gov/dataset/medi-cal-managed-care-capitation-rates-regional-model-rural-expansion/resource/6f2f6cd2-7cfb-4da8-98d9-e11c39430fdc> (type “LTC/Full-Dual - SIS” and then “LTC - SIS” in Search field) (reflecting long-term care capitation rates for Medicaid enrollees with satisfactory immigration status effective during 2023).

145. S.C. DEP’T OF HEALTH & HUMAN SERVS., S.C. HEALTHY CONNECTIONS PRIME CY 2024 MEDICARE AND MEDICAID RATE REPORT § II (Apr. 26, 2024), <https://www.scdhhs.gov/sites/default/files/managedcare/SC%20CY24%20Rate%20Report%20Medicare%20and%20Medicaid%20Com.pdf> (reflecting capitation rates for HCBS Waiver and Nursing Facility services effective during 2024).

146. STERLING FELSTED ET AL, ACTUARIAL REV. OF TENNCARE PROGRAM 18, <https://www.tn.gov/content/dam/tn/tenncare/documents2/actuarial22.pdf> (reflecting capitation rates for nursing facility (CHOICES 1), HCBS (CHOICES 2), and HCBS for those at-risk of needing institutionalization (CHOICES 3) for State Fiscal Year 2022).

In states using a fee-for-service model, the extent to which Medicaid enrollees receive documentation of Medicaid payments made on their behalf varies across states.¹⁴⁷ Medicaid agencies are not required to send Explanation of Benefits letters (EOBs) explaining Medicaid payments to enrollees, and the limited information available on states' use of EOBs suggests that they are not broadly disseminated to enrollees.¹⁴⁸ Some states send EOBs to selected Medicaid enrollees as a program integrity measure to verify that these enrollees received the services billed by providers.¹⁴⁹ At least one state, Alaska, makes EOBs available to Medicaid enrollees through a portal; however, the state's last annual report indicates that only 1,611 individuals, approximately 1% of the state's Medicaid enrollees, use the portal.¹⁵⁰ Even when an EOB is sent, the EOB may not identify the specific costs subject to estate recovery.¹⁵¹ In states where the state Medicaid agency does not send EOBs to Medicaid enrollees, Medicaid enrollees may have difficulty finding fee-for-service rates and determining how these rates apply to them.¹⁵² While many state Medicaid agencies provide fee-for-service schedules on their websites, these sites are often intended for use by health care providers and are difficult to interpret.¹⁵³ For this reason, even if an

147. See sources cited *infra* notes 148–50.

148. CTR. FOR HEALTH L. & POL'Y INNOVATION, HARVARD L. SCH., CONFIDENTIALITY & EXPLANATION OF BENEFITS: PROTECTING PATIENT INFO. IN THIRD PARTY BILLING 3 (Aug. 2016), https://chlpj.org/wp-content/uploads/2013/12/Confidentiality-and-Explanation-of-Benefits_issue-brief_August-2016.pdf; see sources cited *infra* note 149.

149. 42 C.F.R. § 455.20(a) (Westlaw 2024); CMS, REV. OF STATE MEDICAID PROGRAM INTEGRITY PROCS. NAT'L REP. 11 (Fiscal Year 2002), <https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/FraudAbuseforProfs/Downloads/pirpt02.pdf>; see, e.g., Tex. Health & Hum. Servs., R-2500, *Explanation of Benefits*, <https://www.hhs.texas.gov/handbooks/medicaid-elderly-people-disabilities-handbook/r-2500-explanation-benefits>; N.Y. Off. of Medicaid Inspector Gen., *Explanation of Medical Benefits (EOMB)*, <https://omig.ny.gov/information-resources/explanation-medical-benefits-eomb> (last visited Jul. 27, 2024).

150. ALASKA STAT. ANN. § 47.05.270(a) (Westlaw through 2024 2d. Reg. Sess.); ALASKA DEP'T OF HEALTH, ALASKA DEP'T OF HEALTH ANN. MEDICAID REFORM REP. FY 2022 6 (Nov. 15, 2022), <https://health.alaska.gov/HealthyAlaska/Documents/redesign/FY-2022-Annual-Medicaid-Reform-Report.pdf>; CTR. ON HEALTH INS. REFORMS, GEORGETOWN UNIV. MCCOURT SCH. OF PUB. POL'Y, *Alaska* 1, <https://healthjournalism.org/wp-content/uploads/2023/12/Alaska-Insurance-Media-Guide.pdf> (last visited Jul. 28, 2024).

151. See ALASKA STAT. ANN. § 47.05.270(a); ALASKA STAT. ANN. § 47.05.055(e); ALASKA DEP'T OF HEALTH, *supra* note 150, at 6.

152. See MACPAC, THE MEDICAID FEE-FOR-SERVICE PROVIDER PAYMENT PROCESS 6 (July 2018), <https://www.macpac.gov/wp-content/uploads/2018/07/Medicaid-Fee-For-Service-Provider-Payment-Process.pdf>; see sources cited *infra* note 153.

153. See, e.g., GA. DEP'T OF CMTY. HEALTH, FEE SCHEDULES, <https://www.mmis.georgia.gov/portal/Default.aspx?tabid=20&BMLUsed=20160127> (last visited Jul. 27, 2024); ME. DEP'T OF HEALTH & HUM. SERVS., CODES & RATES, <https://www.maine.gov/dhhs/oms/providers/code-rates> (last visited Jul. 28, 2024); MO. DEP'T OF SOC. SERVS., MHD FEE SCHEDULE, <https://apps.dss.mo.gov/fmsFeeSchedules/DLFiles.aspx> (last visited Jul. 28, 2024); OKLA. HEALTHCARE AUTH., *SoonerCare Fee Schedules*, <https://oklahoma.gov/ohca/providers/claim-tools/fee-schedule.html> (last visited Jul. 27, 2024). CMS recently passed a payment transparency rule, however, requiring states to post their Medicaid fee-for-service payment rates on a website by July 1, 2026. 42 C.F.R. § 447.203(b)(1) (Westlaw 2024). These websites provide a useful resource for states to use in complying with the notice requirement proposed in this Article, as discussed below in Section VI.

individual can find an applicable fee schedule on the state Medicaid agency's website, using and applying the fee schedule may be challenging.¹⁵⁴

IV. CURRENT LAW DOES NOT REQUIRE ADEQUATE NOTICE OF THE FINANCIAL IMPACT OF ESTATE RECOVERY

Current law does not require state Medicaid agencies to proactively provide enrollees with a notice of estate recovery costs during their lifetime.¹⁵⁵ CMS's sub-regulatory guidance requires only that applicants receive a general explanation of estate recovery and, when applicable, a separate notice that premium payments made to MCOs are included in the estate recovery claim.¹⁵⁶ CMS guidance does not require a description of what "premium payments" are, the approximate amounts of these premium payments, or that premium payments may exceed the costs of care.¹⁵⁷ Likewise, states have failed to fill this gap. A review of all fifty states' estate recovery laws, Medicaid applications, and publicly available estate recovery brochures indicates that no state proactively provides accrued estate recovery costs to Medicaid enrollees.¹⁵⁸ Only one state, California, provides a statutorily required process for individuals to inquire about their estate recovery costs.¹⁵⁹ Further, only one state, Arizona, provides any numerical figure estimating an estate recovery charge in its estate recovery brochure.¹⁶⁰ With these limited exceptions, states are not required to provide, and states do not appear to provide in practice, notice of estimated or accrued estate recovery costs to Medicaid enrollees.

A. Federal Estate Recovery Notice Requirements

For individuals age fifty-five or older, federal law is devoid of specific requirements regarding notice of estate recovery during the enrollee's lifetime.¹⁶¹ Instead, CMS has provided limited guidance in its State Medicaid Manual (SMM).¹⁶² The SMM describes its instructions as "official interpretations of the law and regulations" that are "binding on Medicaid State agencies"; however, these do not have the force of law.¹⁶³

154. See sources cited *infra* Appendix A and Appendix B.

155. See 42 U.S.C.A. § 1396p(b) (Westlaw through Pub. L. No. 118-66); 42 C.F.R. § 433.36 (Westlaw 2024); CMS MANUAL, *supra* note 18, § 3810.

156. CMS MANUAL, *supra* note 18, § 3810(A)(6), (G)(1).

157. *Id.* § 3810(A)(6), (G)(1).

158. See sources cited *infra* Appendix A and Appendix B.

159. CAL. WELF. & INST. CODE § 14009.5 (West, Westlaw through Ch. 156 of 2024 Reg. Sess.).

160. ARIZ. HEALTH CARE COST CONTAINMENT SYS., STATE OF ARIZ. MEDICAID ESTATE RECOVERY PROGRAM 3 (Jan. 1, 2024), https://www.azahcccs.gov/Members/Downloads/Publications/DE-810_english.pdf.

161. See 42 U.S.C.A. § 1396p(b) (West, Westlaw through Pub. L. No. 118-66); 42 C.F.R. § 433.36 (Westlaw 2024).

162. CMS MANUAL, *supra* note 18, § 3810(A)(6), (G)(1).

163. *Id.* at ch. 1; see Sai Kwan Wong v. Doar, 571 F.3d 247, 260 (2d Cir. 2009) (characterizing the SMM "as precisely the kind of informal interpretation that warrants some significant measure of

The SMM provides that states “should provide notice to individuals at the time of application for Medicaid that explains the estate recovery program in your State.”¹⁶⁴ The SMM does not provide any guidance as to what components of the estate recovery program must be explained, instead only that the program should generally be explained.¹⁶⁵ Additionally, the SMM provides that when an individual enrolls in an MCO, “[the State Medicaid agency] must provide a separate notice to the beneficiary that explains that the premium payments made to the managed care organization are included either in whole or in part in the claim against the estate.”¹⁶⁶ Again, this guidance indicates that a statement that references “premium payments” as part of the estate recovery claim, without any further description or explanation, is sufficient.

Rather than requiring notice of estate recovery costs during an enrollee’s lifetime, CMS requires such notice only after the enrollee has died. The SMM instructs that states “should give a specific notice to individuals affected by the proposed recovery *whenever [the State Medicaid agency] seek[s] adjustment or recovery.*”¹⁶⁷ The SMM instructs that the notice should be served on the executor or legally authorized representative of the individual’s estate or, if these are not known to the State, “other survivors or heirs.”¹⁶⁸ The SMM further provides that the notice should include the action the State intends to take, the reason for the action, the individual’s right to a hearing, the method by which the individual may obtain a hearing, procedures for applying for a hardship waiver, and the amount to be recovered.¹⁶⁹ Under this federal guidance, states may send the first accounting of estate recovery expenses only after the enrollee dies, to someone other than the enrollee.

B. State Estate Recovery Notice Requirements

Most states have not enacted legislation or promulgated rules requiring notice of estate recovery to Medicaid enrollees.¹⁷⁰ Of all fifty states reviewed, fifteen states have laws requiring that notice of estate recovery be provided to living enrollees.¹⁷¹ Most of these states require that the state Medicaid agency provide a

deference”) (quoting with alteration *Morenz v. Wilson-Coker*, 415 F.3d 230, 235 (2d Cir. 2005); *Exec. Off. of Health & Hum. Servs. v. Trocki*, 174 N.E.3d 322, 327 (Mass. App. Ct. 2021) (explaining that the SMM does not carry the force of regulations, but the court will consider it “carefully for its persuasive power”) (quoting *Daley v. Sec’y of Exec. Off. of Health & Hum. Servs.*, 74 N.E.3d 1269, 1279 (Mass. 2017))).

164. CMS MANUAL, *supra* note 18, § 3810(G)(1).

165. *Id.*

166. *Id.* § 3810(A)(6) (“you” refers to the state Medicaid agency).

167. *Id.* § 3810(G)(2) (emphasis added).

168. *Id.*

169. *Id.*

170. See sources cited *infra* Appendix A.

171. ALASKA ADMIN. CODE tit. 7, § 160.210(a) (West, Westlaw through Supp. Jan. 2024); 016.20 ARK. CODE R. § 1-H-620) (West, Westlaw through May 15, 2024); CAL. WELF. & INST. CODE § 14009.5 (e) (West, Westlaw through Ch. 156 of 2024 Reg. Sess.); 10 COLO. CODE REGS. § 2505-10:8.100.5.D (West, Westlaw through Vol. 47, No. 6, Mar. 25, 2024); 16 DEL. ADMIN. CODE § 5100-20500.2 (West, Westlaw through Vol. 27, Issue 12, June 1, 2024); GA. CODE ANN. § 49-4-147.1(a) (West, Westlaw through 2024 Reg. Sess.); GA. COMP. R. & REGS. 111-3-8-.04(3) (West, Westlaw through June 17, 2024); 907 KY. ADMIN. REGS. 1:585 (West, Westlaw through Vol. 51, No. 1, July 1, 2024); LA. ADMIN. CODE tit.

notice generally explaining estate recovery at the time of application, without specifying in detail what aspects of estate recovery must be explained in the notice.¹⁷² For example, Kentucky requires only that the state Medicaid agency provide “a *general written notice* regarding estate recovery” to applicants for long-term care or their authorized representatives.¹⁷³ New Mexico vaguely requires that “information explaining estate recovery” be provided to applicants or eligible recipients during the application or recertification process.¹⁷⁴ Maine’s estate recovery statute requires only that “reasonable efforts to give notice of [e] state [r]ecovery requirements” be made at the time of application.¹⁷⁵ Some of these states have added additional procedural guidelines, such as requiring that the estate recovery notice be separate from the application,¹⁷⁶ that the applicant sign an acknowledgment that they received the notice,¹⁷⁷ or that a caseworker discuss estate recovery information with individuals during the Medicaid application process.¹⁷⁸

While these fifteen states have gone further than most in codifying notice requirements, the common problem among most of these provisions is that they focus generally on “notice of the estate recovery program,” or “notice that medical assistance costs could be recovered,” without any notice of the actual financial impact of estate recovery.¹⁷⁹ In other words, under these authorities, Medicaid applicants may receive notice generally referencing an estate recovery program and recovery of payments, but they are not provided with an idea of what these payment amounts are. While Washington’s statute goes further than other states in requiring that the state “fully disclose in advance verbally and in writing, in easy to understand language, the terms and conditions of estate recovery,” the statute does not specify what is considered a “term and condition.”¹⁸⁰ In the one state statute—in Virginia—that references capitation payments in its notice

50, pt. I, § 8103(A) (West, Westlaw through Vol. 50, No. 6, June 20, 2024); 10-144 ME. CODE R. ch. 101, ch. VII, § 5.05 (West, Westlaw through Sept. 27, 2023); MICH. COMP. LAWS ANN. § 400.112g(3) (e), g(7) (West, Westlaw through P.A. 2024, No. 80, 2024 Reg. Sess.); 32 MISS. CODE R. § pt. 1, subpt. 2, R. 6.10 (West, Westlaw through May 2024); N.M. ADMIN. CODE 8.200.430.19(E). (West, Westlaw through Volume XXXV, Issue 10, May 21, 2024); 1 TEX. ADMIN. CODE § 373.305 (West, Westlaw through 49 Tex. Reg. No. 3854, May 24, 2024); 12 VA. ADMIN. CODE § 30-20-141(C)(4) (West, Westlaw through 40:23 VA.R. July 1, 2024); WASH. REV. CODE ANN. § 74.39A.170(3) (West, Westlaw through 2024 Reg. Sess.). This figure does not include state notice requirements for pre-death TEFRA liens.

172. See, e.g., ALASKA ADMIN. CODE tit. 7, § 160.210(a); 10 COLO. CODE REGS. § 2505-10:8.100.5.D; 16 DEL. ADMIN. CODE 5100-20500.2; 907 KY. ADMIN. REGS. 1:585; LA. ADMIN. CODE tit. 50, pt. I, § 8103(A); N.M. ADMIN. CODE 8.200.430.19(E).

173. 907 KY. ADMIN. REGS. 1:585 (emphasis added).

174. N.M. ADMIN. CODE 8.200.430.19(E).

175. 10-144 ME. CODE R. ch. 101, ch. VII, § 5.05.

176. See, e.g., 16 DEL. ADMIN. CODE 5100-20500.2; 12 VA. ADMIN. CODE § 30-20-141(C)(4).

177. GA. CODE ANN. § 49-4-147.1(a); GA. COMP. R. & REGS. 111-3-8-.04(3).

178. See, e.g., 016.20 ARK. CODE R. § 1-H-620.

179. See, e.g., 10 COLO. CODE REGS. § 2505-10:8.100.5.D (“The eligibility site shall provide written information . . . explaining the provisions of the Medical Assistance Program and how those provisions may pertain to the applicant); LA. ADMIN. CODE tit. 50, pt. I, § 8103(A) (“The applicant/recipient shall be informed . . . that federal law and regulations mandate estate recovery action by the states and that medical assistance claims paid by the department may be subject to estate recovery.”).

180. WASH. REV. CODE ANN. § 74.39A.170(3).

requirement, the statute fails to require any description of what a capitation rate is or the estimated capitation rate amount.¹⁸¹ Additionally, most of the states with codified estate recovery notice requirements to enrollees require notice only at the time of application, redetermination, or when an enrollee turns fifty-five, without any notice related to estate recovery periodically throughout enrollment.¹⁸²

Texas is the only state that has codified detailed, substantive estate recovery notice requirements to living enrollees; however, Texas does not require any disclosure of estimated or accrued estate recovery costs.¹⁸³ In Texas, the state Medicaid agency must provide a written notice containing (1) a description of the estate recovery program; (2) information regarding covered long-term care services subject to estate recovery; (3) estate recovery claim procedures; (4) the penalties for transferring property for less than fair market value while enrolled in Medicaid; (5) a description of undue hardship waiver requests and related procedures for requesting a waiver; and (6) information concerning the state's notice of intent to file a claim upon the recipient's death.¹⁸⁴ Yet, Texas does not require notice of estate recovery costs. This notice requirement is missing even though nearly all of Texas' Medicaid population is enrolled in managed care, such that the state Medicaid agency should be able to readily provide the monthly capitation rates that will be charged in estate recovery.¹⁸⁵

Standing out from other states, California provides current or former aged and institutionalized enrollees with a statutory right to inquire about their estate recovery costs once per calendar year for a \$5 fee.¹⁸⁶ California's Medicaid agency is required to include on its website and other estate recovery notices the procedures for making this request, which must include the ability to submit a request by phone, mail, or electronically.¹⁸⁷ The agency must provide a copy of the amount of recoverable Medicaid expenses to the requestor within ninety days of receiving the request.¹⁸⁸ Individuals must submit photo identification such as driver's license, DMV identification card, birth certificate, or submit a form that

181. 12 VA. ADMIN. CODE § 30-20-141(C)(4). Instead, Virginia's estate recovery statute requires that applicants enrolled in an MCO receive a separate notice "that explains that the capitation payments made to the managed care organization are included in whole in the claim against the estate." *Id.*

182. *See, e.g.*, ALASKA ADMIN. CODE tit. 7, § 160.210(a); 016.20 ARK. CODE. R. § 1-H-620; GA. CODE ANN. § 49-4-147.1(a); GA. COMP. R. & REGS. 111-3-8-.04(3); 907 KY. ADMIN. REGS. 1:585; LA. ADMIN. CODE tit. 50, pt. I, § 8103(A); 10-144 ME. CODE R. ch. 101, ch. VII, § 5.05; N.M. CODE R. § 8.200.430.19(E); 12 VA. ADMIN. CODE § 30-20-141(C)(4).

183. 1 TEX. ADMIN. CODE § 373.305.

184. *Id.*; *see also* §§ 373.301, 373.303.

185. *See Share of Medicaid Population Covered under Different Delivery Systems*, KFF, <https://www.kff.org/medicaid/state-indicator/share-of-medicaid-population-covered-under-different-delivery-systems> (July 1, 2022) (showing 97% of Texas' Medicaid population is enrolled in managed care); *see also* MACPAC REPORT, *supra* note 10, at 104.

186. CAL. WELF. & INST. CODE § 14009.5(e).

187. *Id.*

188. *Id.*

is notarized.¹⁸⁹ If the requestor is someone other than the Medicaid member, he or she must submit proof of authorization to act on behalf of the member.¹⁹⁰ If the request includes an address different than on the face of the photo identification, then a utility bill or other proof of address must be provided.¹⁹¹ While California has surpassed other states in its efforts towards transparency in estate recovery, its policy shifts the administrative and financial burden of ascertaining estate recovery amounts owed onto Medicaid enrollees.

C. State Estate Recovery Notice Practices

In practice, most states include a short disclaimer regarding estate recovery in their general Medicaid application or in an application specific to long-term care, but the content of these disclaimers varies widely.¹⁹² Appendix A to this Article provides a list of each state's Medicaid application containing estate recovery language, the page number on which the estate recovery language is located, and the website for each application.¹⁹³ Of the forty-two states with publicly-available Medicaid applications containing estate recovery provisions, none include a numerical figure of estimated costs of estate recovery.¹⁹⁴ Additionally, none of the Medicaid applications provide the applicant with a description of where they can find the actual costs of estate recovery or capitation rates.¹⁹⁵

Estate recovery language in Medicaid applications varies in its specificity, and many disclaimers appear to indicate that estate recovery is permissive rather than mandatory. For example, several applications indicate that the state "may" seek recovery or that the state "can" file a claim against an estate.¹⁹⁶ Texas' application states that, for long-term care enrollees, "the state of Texas has the right to ask for money back from your estate after you die," but "in some cases, the state might not ask for anything back."¹⁹⁷ Additionally, while many of these provisions describe which services are recoverable through estate recovery, several applications do not provide this information.¹⁹⁸ For instance, Connecticut's application explains that the State "recovers money from my estate" if the applicant is aged

189. CAL. DEP'T OF HEALTH CARE SERVS., REQUEST FOR MEDI-CAL EXPENSES SUBJECT TO ESTATE RECOVERY (2020), <https://www.dhcs.ca.gov/services/Documents/DHCS-4017-0619.pdf>.

190. *Id.*

191. *Id.*

192. See sources cited *infra* Appendix A. Forty-two states include estate recovery language in either their general Medicaid application or an application or form specific to long-term care. The following states did not have fully accessible Medicaid applications or the accessible applications did not include estate recovery language: Arizona, California, Georgia, Kentucky, Mississippi, New Hampshire, Oklahoma, and Virginia.

193. See sources cited *infra* Appendix A.

194. See *id.*

195. See *id.*

196. See *id.* at Alabama, Alaska, Minnesota, Missouri, New Jersey, New Mexico, Nevada, New York, Ohio, Tennessee, Texas, Washington.

197. See *id.* at Texas.

198. See *id.* at Alabama, Connecticut, Missouri, North Dakota.

or institutionalized and does not meet an exception.¹⁹⁹ Several states' applications reference the state's authority or right to pursue recovery, rather than explaining that estate recovery is required.²⁰⁰ Arkansas strangely describes estate recovery as one of the applicant's responsibilities, stating that "you have the responsibility to have the amount of health care benefits that DHS paid on your behalf to be recovered from your estate or grantee of a beneficiary deed after your death."²⁰¹

In at least one state, a court upheld placing notice language generally describing estate recovery in the fine print of a Medicaid application as in compliance with applicable law. In the *Matter of the Estate of Rasmer*, the estate of Olive Rasmer challenged Michigan's estate recovery claim on the grounds of insufficient notice.²⁰² Ms. Rasmer's estate claimed that Michigan's state Medicaid agency failed to give her enough information to put her on notice of the particular actions that it could take against her estate, because the state's notice lacked any specificity as to the nature and scope of the estate recovery program and did not make her aware of the potential financial consequences to her estate after her death.²⁰³ Michigan's estate recovery statute requires the Medicaid agency to provide to those seeking long-term care services "written materials explaining the process for applying for a waiver from estate recovery due to hardship" and written information "describing the provisions of the Michigan medicaid estate recovery program, including, but not limited to, a statement that some or all of their estate may be recovered."²⁰⁴ Michigan sought to comply with this requirement by including the following statement in its eligibility application:

12. Estate Recovery. I understand that upon my death [DHHS] has the legal right to seek recovery from my estate for services paid by Medicaid. [DHHS] will not make a claim against the estate while there is a legal surviving spouse or a legal surviving child who is under the age of 21, blind, or disabled living in the home. An estate consists of real and personal property. Estate Recovery only applies to certain Medicaid recipients who received Medicaid services after the implementation date of the program. [DHHS] may agree not to pursue recovery if an undue hardship exists. For further information regarding Estate Recovery, call 1-877-791-0435.²⁰⁵

The Supreme Court of Michigan held that this notice met the requirements of Michigan's statute and rejected the estate's claim of insufficient notice.²⁰⁶ The Court reasoned that the notice apprised the enrollee of the possibility of estate recovery after

199. *See id.* at Connecticut.

200. *See id.* at Florida, New Jersey, South Dakota.

201. *Id.* at Arkansas.

202. *In re Est. of Rasmer*, 903 N.W.2d 800, 804 (Mich. 2017).

203. *Id.* at 809.

204. *Id.* at 806 (citing MICH. COMP. LAWS ANN. §§ 400.112g(3)(e), 400.112g(7)).

205. *Id.* at 809.

206. *Id.*

enrollment and signaled that the agency may make a claim against the estate.²⁰⁷ According to the Court, by mentioning “recovery” five times, the notice conveyed that the “nature” of the program was to seek reimbursement from the individual’s estate.²⁰⁸ At the same time, the Court recognized that the agency’s statement “could have provided greater detail” about estate recovery, “and perhaps, as a matter of best practices, it should have done so.”²⁰⁹ Even though the notice was “open-ended and not particularly exacting,” the Court held that the statement was sufficient to meet the applicable statutory requirements.²¹⁰

In addition to estate recovery notice language contained in Medicaid applications, at least thirty-four states have developed estate recovery brochures, hand-outs, frequently asked questions, or other similar documents to give to Medicaid applicants.²¹¹ Appendix B provides a list of these documents that are publicly accessible on state government websites.²¹² While many states’ publicly available estate recovery brochures include a description of recoverable services, only one state includes an *actual monetary figure* of estimated estate recovery costs. Arizona’s brochure extensively describes the types of expenses that an agency can recover through estate recovery, including capitation payments, reinsurance payments, and fee-for-service payments.²¹³ The brochure further explains that “the monthly capitation payment to program contractors can exceed \$7,800 per month” but varies based on the health plan, county of residence, and year.²¹⁴ The notice then states in bold font that “it is important to be aware that capitation payments can exceed the actual costs of services provided during the month.”²¹⁵

In summary, state Medicaid agencies’ publicly available documents indicate that states are not providing Medicaid enrollees with written notice of their accrued costs of estate recovery. Additionally, other than Arizona, which only provides a minimum capitation rate, states’ publicly available information also indicates that they do not provide the estimated costs of estate recovery to Medicaid applicants.

D. Medicaid Enrollees and Their Families’ Surprise and Confusion Regarding Estate Recovery

Under current state practices, many Medicaid enrollees and their families are unaware of the nature of estate recovery and of the extent of the program’s potential

207. *Id.*

208. *Id.* at 809–10.

209. *Id.* at 809.

210. *Id.* at 809–10.

211. See sources cited *infra* Appendix B.

212. Appendix B is intended to be illustrative only, as state Medicaid agencies and/or their contractors may distribute documents related to estate recovery that are not publicly accessible.

213. ARIZ. HEALTH CARE COST CONTAINMENT SYS., *supra* note 160, at 3–4.

214. *Id.* at 3.

215. *Id.*

financial impact.²¹⁶ Many family members of Medicaid enrollees have described the surprise, confusion, and disbelief they felt upon receiving these notices. The Public Policy Institute of the AARP has noted that, “[a]lthough no one should be taken by surprise by Medicaid estate recovery, all too often, that is exactly what happens.”²¹⁷

For example, Jen Coghlan, the daughter of a Medicaid enrollee in Iowa, described her shock when she received a notice of an estate recovery claim for \$226,611 against her mother’s estate.²¹⁸ Her response was, “What is this letter for? What is this?”²¹⁹ Ms. Coghlan said that her family did not realize that her mother was enrolled in Medicaid, having filled out a form for “Title 19 or Medicaid.”²²⁰ The paperwork she saved did not clearly explain that the government might seek reimbursement for these services.²²¹ She said that she likely would have declined to accept the money if she had known the government would try to recoup it after her mother died.²²² In commenting on this story, Iowa State Representative Jan Schakowsky stated that surviving family members are often caught unaware by estate recovery notices, leading to devastating outcomes for their families.²²³

Similarly, in Massachusetts, the family of Elmer Bartels was shocked to receive a claim from the Medicaid agency for \$413,000 two months after Mr. Bartels passed away.²²⁴ Mr. Bartels had been the commissioner of the Massachusetts Rehabilitation Commission for over thirty years.²²⁵ He was enrolled in CommonHealth, a program for disabled individuals aimed at offsetting the cost of employing personal care attendants.²²⁶ Unbeknownst to Mr. Bartels and his family, this program ultimately merged with Massachusetts’ Medicaid

216. See, e.g., Mary Kielar, *I-Team: Medicaid’s Claim on Homes Leaves Thousands in Limbo, Sparking Legislative Action*, CNY CENTRAL (June 18, 2024), <https://cnycentral.com/news/local/medicaid-home-seizure-lien-new-york-state-jan-schakowsky-collection-property-estate-recovery-bills-legislative-action-stop-unfair-medicaid-recoveries-act>; Paula Span, *When Medicaid Comes After the Family Home*, N.Y. TIMES (Mar. 16, 2024), <https://www.nytimes.com/2024/03/16/health/medicaid-estate-recovery-seniors.html>; Nick Blizzard, *I’m Going to Be Homeless: Ohio Medicaid Collects \$87.5M From Families After Loved Ones’ Death*, DAYTON DAILY NEWS (July 29, 2023); Tony Leys, *They Could Lose the House – to Medicaid*, NAT’L PUB. RADIO (Mar. 2, 2023), <https://www.npr.org/sections/health-shots/2023/03/01/1159490515/they-could-lose-the-house-to-medicaid>; True, *supra* note 103; Colin A. Young, *Some Families Blindsided by MassHealth Estate Recovery*, WWLP (Sept. 28, 2021), <https://www.wwlp.com/news/state-politics/some-families-blindsided-by-masshealth-estate-recovery>; Shannon Mullen, *Medicaid’s Death Bill Leaves Homes, Assets at Risk*, USA TODAY (Feb. 16, 2014), <https://www.usatoday.com/story/news/nation/2014/02/16/medicaid-death-bill-homes-assets-at-risk/5534575>.

217. WOOD & KLEM, *supra* note 17, at Foreword.

218. Leys, *supra* note 216.

219. *Id.*

220. *Id.*

221. *Id.*

222. *Id.*

223. *Id.*

224. Young, *supra* note 216.

225. *Id.*

226. *Id.*

program and became subject to estate recovery requirements.²²⁷ The family believed that Mr. Bartels had other health insurance, not Medicaid, and that the claim had to be in error.²²⁸ In response to this situation, Massachusetts State Senator Jo Comerford commented that, despite Medicaid's mission to provide services to those who cannot afford them, it is providing the services "in the form of a loan that must be repaid upon death."²²⁹ She continued, "At least when people take out a loan they know they're taking out a loan. But far too many grieving families . . . are caught by surprise when an exorbitant bill arrives in the mail unexpectedly and they're grieving for a loved one."²³⁰

In another account recently published in the *New York Times*, a Medicaid enrollee's daughter explained that she was stunned to receive a letter from the state Medicaid agency—stating that her mother had incurred a Medicaid debt of more than \$77,000—after her mother passed away.²³¹ She thought the letter might be some sort of scam.²³² Her mother was well-insured, having been covered by Medicare, a private supplemental "Medigap" policy, and long-term care insurance.²³³ She enrolled in Medicaid only because it allowed her daughter to receive modest payments for caregiving.²³⁴ She did not know that this would also trigger monthly estate recovery charges that the agency would seek through estate recovery.²³⁵

These accounts are among many highlighting the way that Medicaid enrollees and their families have not understood the financial consequences of estate recovery until after the enrollee's death.²³⁶ To avoid putting families through this unnecessary confusion and strife, and for the reasons discussed below, state Medicaid agencies should be required to provide meaningful notice of estimated estate recovery costs at the time of application and throughout enrollment.

V. MEDICAID ENROLLEES SHOULD RECEIVE NOTICE OF ESTATE RECOVERY COSTS DURING THEIR LIFETIME

Medicaid enrollees should receive clear notice of estate recovery costs during their lifetime. At the time of application, Medicaid agencies should provide applicants an initial notice describing how an estate recovery claim is calculated and

227. *Id.*

228. *Id.*

229. *Id.*

230. *Id.*

231. Span, *supra* note 216.

232. *Id.*

233. *Id.*

234. *Id.* States have the option to allow enrollees to self-direct their Medicaid services, which gives the enrollee decision-making authority and responsibility to manage service delivery. CMS, *Self-Directed Services*, <https://medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html> (last visited Jul. 25, 2024). Medicaid enrollees approved for self-directed care may have the option to hire the individuals who furnish services to them and, in some states, this can result in a family member being paid to provide Medicaid services. *See id.*

235. Span, *supra* note 216.

236. *See generally* sources cited *supra* note 216.

the best available estimate of what those costs are likely to be upon enrollment. After enrollment, individuals who are fifty-five years or older or who are receiving care in an institution should receive a periodic notice of the itemized estate recovery charges accrued to date.

Initial and periodic notice of estate recovery costs is necessary for many reasons. Medicaid applicants and enrollees need this notice to weigh their options and make a fully informed decision regarding their medical care. Once enrolled, Medicaid recipients also need to be able to assess whether the medical services they are receiving are worth the costs of estate recovery. This is especially important because an enrollee's estate recovery costs may exceed the costs of services provided to the enrollee. Each of these reasons becomes even more pronounced when considering the physical and financial limitations of those subject to recovery. Additionally, Medicaid enrollees should be entitled to regular notice of estate recovery costs, as well as the ways to seek an exemption or hardship waiver, so that they have adequate time and ability to support a request for exemption or waiver. Finally, the public policy underlying consumer protection laws such as the Truth in Lending Act supports the need for clear loan disclosures in the estate recovery context to ensure that individuals can make fully informed health care decisions.

A. Medicaid Enrollees' Ability to Weigh Options for Medical Care and Assess the Value of Medicaid Services

Clear notice of estate recovery costs is necessary to allow individuals to make informed decisions regarding their medical care. When an individual is considering applying for Medicaid, they may have other options to receive the care they need. For individuals who need LTSS, family members or close friends may be able to provide personal care assistance in the home.²³⁷ Alternatively, some families may be able to privately pay for a limited amount of in-home assistance. Families need to be able to compare the actual costs of Medicaid LTSS with these other options. For example, an individual may need four hours of in-home personal assistance services, four days per week, which could be privately paid for approximately \$432 per week, or \$1,872 per month.²³⁸ Medicaid LTSS would likely provide a wider array of benefits, but the costs accrued for purposes of estate recovery could be substantially higher in states employing a capitated rate model to deliver LTSS. In the above scenario, the state of Arizona would charge between \$3,812 and \$5,069 per month in estate recovery for a member who also

237. BIPARTISAN POL'Y CTR., *supra* note 22, at 16. To be clear, family members should not be compelled to provide care for their loved ones, and systemic improvements beyond the scope of this Article are needed to address this problem. At a minimum, families should receive clear notice regarding estate recovery so that they can make a fully informed decision regarding the delivery of long-term care services.

238. AARP, *Home Care Cost* (2021), <https://ltsschoices.aarp.org/scorecard-report/2023/dimensions-and-indicators/home-care-cost> (indicating an average hourly rate of \$27/hour for privately paid in-home care in 2021).

has Medicare, and between \$7,778 and \$10,513 for an enrollee without Medicare.²³⁹ The only way for families to make an informed decision in these circumstances is to have access to the estimated costs of Medicaid as compared to the estimated costs of privately funded options.

Information about estate recovery costs is not only needed to consider health care options at the outset of enrollment, but also throughout an individual's enrollment in Medicaid. An individual's condition may change over time, leading to an increased or decreased need for Medicaid services. Other circumstances may also change, such as the availability of other familial supports. For example, once a Medicaid enrollee begins receiving HCBS services at home, family members may observe the services being provided. These family members may decide that they are able to perform these services, especially if this will prevent the enrollee's estate from losing thousands of dollars per month or their family home. When an enrollee does not understand the financial implications of estate recovery, and possibly even believes that the program is free of charge, he or she lacks any motivation to engage in this decision-making process and does not have the tools to do so in a meaningful way.

Notice of accrued estate recovery costs during an individual's Medicaid enrollment is also necessary so that enrollees can continually weigh the value of the services being performed against the cost of estate recovery. For example, an HCBS recipient may be approved to receive services at home such as personal care services and home-delivered meals.²⁴⁰ After receiving these services for a few months, the enrollee is in a better position to decide whether these services are worth the cost of estate recovery per month. There is no way to do this calculus when the cost of estate recovery each month is unknown.

The need to weigh the estate recovery costs against the benefits of Medicaid enrollment is heightened in states using a managed care model because, in these states, the estate recovery costs can exceed the actual costs of services and can accrue even when no services are provided.²⁴¹ As discussed in Section III.C above, regardless of how much or what type of services are actually delivered to the Medicaid enrollee, these states pay a pre-determined, flat monthly amount to the MCO for that enrollee.²⁴² The state is then required to try to recover that flat monthly amount through estate recovery.²⁴³ In these states, individuals may therefore be charged an amount that bears no direct relation with the amount or type of services they received.²⁴⁴ In some cases, the capitation rate may be less than the costs of services.²⁴⁵ For example, when care is received in a nursing facility or

239. ARIZ. HEALTH CARE COST CONTAINMENT SYS., CONTRACT YEAR ENDING 2024 ARIZONA LONG TERM CARE SYSTEM – ELDERLY AND PHYSICAL DISABILITY (ALTCS-EPD) PROGRAM 1 (Aug. 11, 2023), https://www.azahcccs.gov/PlansProviders/Downloads/CapitationRates/ALTCS/ALTCS-EPD_RatesEffectiveOct12023.pdf.

240. See CMS, *supra* note 56.

241. MACPAC REPORT, *supra* note 10, at 86, 94, 97 n.13.

242. *Id.*; CMS MANUAL, *supra* note 18, § 3810(A)(6).

243. CMS MANUAL, *supra* note 18, § 3810(A)(6).

244. MACPAC REPORT, *supra* note 10, at 86, 94, 97 n.13.

245. *Id.* at 86.

other institution, the state's monthly rate may be less than the facility's monthly costs for an enrollee.²⁴⁶ In other cases, the capitation rate may be more than the costs of services.²⁴⁷ This is especially likely when a member receives HCBS but does not need many services each month.²⁴⁸

The disconnect between the costs of services to a Medicaid enrollee and that enrollee's estate recovery costs can be illustrated through an example, which occurred in Ohio.²⁴⁹ After being diagnosed with Parkinson's disease, David Miller enrolled in Medicaid in Ohio.²⁵⁰ He received Medicaid HCBS services at home for approximately two years before his death in 2018.²⁵¹ During this period, his daughter, Rebecca Miller, lived in the home and provided care for him.²⁵² Approximately one month after his death, Ms. Miller received a letter from the Ohio Attorney General's Office stating that her father's estate owed \$56,000 to Medicaid estate recovery.²⁵³ Ms. Miller's immediate response was to call Medicaid "to find out why – what kind of services are you saying [he owes] \$56,000 for?"²⁵⁴ She explained that he was never in a nursing home, he never had a nurse, and she provided some of his care at home, so she did not understand how the Attorney General's Office arrived at the total claim amount.²⁵⁵

Most of Ohio's Medicaid enrollees are enrolled in managed care, which means that the \$56,000 total was likely the total of capitation payments made to Mr. Miller's MCO for his care.²⁵⁶ This means that the care Ms. Miller provided him did not offset or reduce the amount of the pre-determined flat monthly rate that Ohio's Medicaid agency paid to his MCO.²⁵⁷ Instead, this monthly rate was based on factors such as his eligibility group and his geographic location.²⁵⁸ Lacking estate recovery notice, Ms. Miller did not realize that the rates her father's estate was charged were not directly related to the services he was individually provided.²⁵⁹ Her first notice of an estate recovery claim came upon Mr. Miller's death, and the claim may result in the loss of the family's home.²⁶⁰

Additionally, when recoverable services are delivered through managed care, estate recovery costs can continue to accrue even when the enrollee is receiving

246. See MACPAC, *supra* note 71, at 1.

247. MACPAC REPORT, *supra* note 10, at 86.

248. See ARIZ. HEALTH CARE COST CONTAINMENT SYS., *supra* note 160, at 4.

249. Blizzard, *supra* note 216.

250. *Id.*

251. *Id.*

252. See *id.*

253. *Id.*

254. *Id.*

255. *Id.*

256. See Samantha Wildow, *Medicaid Estate Recovery Can Charge Ohioans More Than Medical Care Provided*, DAYTON DAILY NEWS (Oct. 25, 2023), <https://www.daytondailynews.com/ohio/medicaid-estate-recovery-can-charge-ohioans-more-than-medical-care-provided/X72RGEEB2FCHNOUL23NSN2GRPE/>.

257. *Id.*; Blizzard, *supra* note 216.

258. Wildow, *supra* note 256.

259. Blizzard, *supra* note 216.

260. *Id.*

no Medicaid benefits.²⁶¹ Medicaid enrollees receiving LTSS may experience gaps in services due to staffing shortages.²⁶² For the last two decades, the United States has experienced a shortage of direct care workers, including personal care aides, home health aides, certified nurse aides, and psychiatric aides.²⁶³ This staffing shortage extends to both nursing facilities and in-home care.²⁶⁴ In discussions with CMS, state Medicaid agencies and provider groups have routinely cited a shortage of direct care workers as among their greatest challenges in providing high quality and cost effective HCBS.²⁶⁵ Due to this shortage of direct care workers, as well as other reasons, Medicaid beneficiaries enrolled in HCBS may experience days or weeks where their approved hours are not staffed.²⁶⁶ If enrollees believe they are receiving HCBS services for free, they may believe that there is no further action that should be taken for these temporary breaks in service.²⁶⁷ On the other hand, if a Medicaid enrollee is aware of significant charges to their estate, he or she may decide that the benefit is not worth the costs.

Enrollees receiving services through fee-for-service programs also need to receive notice of the accrued costs of estate recovery to weigh the costs and benefits of those services. In a fee-for-service arrangement, an enrollee's estate recovery costs will be calculated based on the amount and type of services that are being provided specifically to the enrollee.²⁶⁸ An enrollee can therefore choose to use fewer or less expensive services to avoid having their estates charged for greater amounts.²⁶⁹ Without periodic notice of the accrued costs of estate recovery, enrollees in fee-for-service programs do not have the information necessary to decide whether they should voluntarily reduce their services to lower their costs.²⁷⁰ In either delivery system, individuals need to be informed of the costs of estate recovery so that they can weigh their options for medical care and assess the relative value of services throughout enrollment.

B. Medicaid Enrollees' Ability to Document Eligibility for Exemptions and Waivers

In addition to being able to make informed decisions regarding their medical care, Medicaid enrollees need to receive notice of estate recovery charges so that

261. MACPAC REPORT, *supra* note 10, at 94.

262. Medicaid Program; Ensuring Access to Medicaid Services, 88 Fed. Reg. 27960-01, 27965 (May 3, 2023) (to be codified at 42 C.F.R. pts. 431, 438, 441, 447); *see also* BIPARTISAN POL'Y CTR., *supra* note 22, at 20.

263. BIPARTISAN POL'Y CTR., *supra* note 22, at 13.

264. *Id.* at 20.

265. 88 Fed. Reg. § 27960-01, 27965.

266. Gaps in the provision of Medicaid services can occur due to staffing shortages, provider management issues, third-party insurance coverage, and other reasons. *See* MACPAC REPORT, *supra* note 10, at 86.

267. *See* sources cited *supra* note 216.

268. *See* MACPAC REPORT, *supra* note 10, at 82–83.

269. *See id.* at 94.

270. *See* discussion *supra* Section IV.

they can consider and begin documenting proof of eligibility for a hardship waiver or exemption.²⁷¹ Under states' current practices, many Medicaid enrollees are not aware of the option to apply for a hardship waiver.²⁷² The first detailed notice of this option is required by CMS guidance only after the enrollee has passed away, when the state sends a notice of claim.²⁷³ The low number of hardship waiver applications submitted to state Medicaid agencies indicates enrollees' lack of awareness of those waivers. For example, in 2019, Maryland received only five applications for hardship waivers, while recovering from 498 estates that year.²⁷⁴ Also in 2019, New York received 14 hardship applications while recovering from 4,222 estates.²⁷⁵ Many Medicaid enrollees are not aware of states' waiver policies, and applications for waivers are often difficult to complete without assistance.²⁷⁶

If families received notice of estate recovery costs along with an explanation of exemptions and hardship waivers, they could begin planning to substantiate eligibility for an exemption or waiver. For example, to qualify for the exemption based on a son or daughter residing in the home, a family may need to show that the son or daughter provided care that permitted the enrollee to stay out of the institution.²⁷⁷ To qualify for this exemption, a family would need to understand the amount and kind of evidence needed to support the exemption, such as a doctor's attestation from a treating physician or other health care provider, a statement from a witness, or other evidence. Under applicable CMS guidance, Medicaid agencies are not required to provide notice of the procedures for applying for these potential exemptions until the Medicaid enrollee has passed away.²⁷⁸

Moreover, documentation supporting an application for hardship waiver or exemption may become harder to gather as time passes after the date of enrollment. Some individuals are enrolled in Medicaid LTSS for years.²⁷⁹ As time goes on, applicants may find it more difficult to obtain an attestation from a doctor describing the care that a family member provided to an individual leading to his or her receipt of Medicaid LTSS.²⁸⁰ Likewise, they may face challenges providing documentation proving continuous residence for a period of one to two years

271. See 42 U.S.C.A. § 1396p(b)(2)–(3) (Westlaw through Pub. L. No. 118-66).

272. MACPAC REPORT, *supra* note 10, at 87.

273. CMS MANUAL, *supra* note 18, § 3810(D).

274. MACPAC REPORT, *supra* note 10, at 90–91, 121–22.

275. *Id.*

276. *Id.* at 91; True, *supra* note 103.

277. 42 U.S.C.A. § 1396p(b)(2)(B) (Westlaw through Pub. L. No. 118-66).

278. See CMS MANUAL, *supra* note 18, § 3810(D).

279. OFF. OF THE ASSISTANT SEC'Y FOR PLAN. & EVALUATION, DEP'T OF HEALTH & HUM. SERV., EXTENDED LTSS UTILIZATION MAKES OLDER ADULTS MORE RELIANT ON MEDICAID ISSUE BRIEF (JAN. 2021), https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/198996/ExtLTSSIB.pdf.

280. See 42 U.S.C.A. § 1396p(b)(2)(B); see, e.g., 471 NEB. ADMIN. CODE ch. 38 § 004.03(B) (Westlaw through May 1, 2024) (defining undue hardship as including when an heir “resided in the recipient’s home for two years prior to the recipient’s receipt of recoverable medical services and during that time provided the type and quantity of unreimbursed care that delayed the recipient’s receipt of

leading to institutionalization as times passes.²⁸¹ These issues extend to hardship waivers, for instance, where a family needs to provide documentation that their home is the sole income producing asset. To support eligibility for this waiver, a family may need to produce tax records or other income and wage documentation for all members of the family.²⁸² Families need time to identify what they need, locate supporting documentation, and complete an application for hardship waiver, and they are often in the best position to do this at the outset of enrollment.

After a Medicaid enrollee passes away, states may give families a short window to prove their entitlement to an exemption or waiver.²⁸³ For example, under New Jersey law, an individual must file an application for a hardship waiver within twenty days of receiving notice of an estate recovery claim.²⁸⁴ If applicants do not meet this deadline, “the Division shall not grant a waiver or compromise based upon undue hardship.”²⁸⁵ In Michigan, an applicant must file an application for a hardship waiver within sixty days from the date the Medicaid agency sends the notice of intent to file a claim to the estate’s contact.²⁸⁶ The notice of claim may take time to reach an heir or other personal representative of the enrollee’s estate, creating an even tighter window to provide documentation of hardship.²⁸⁷ This was alleged to have occurred in the case of David Miller, the deceased Ohio Medicaid recipient described in Section V.A above.²⁸⁸ Mr. Miller’s daughter stated that she learned of the hardship exemption only after the deadline to apply for the exemption had passed.²⁸⁹ Courts have also found that, even when an estate meets the criteria for a hardship waiver (such as a home of modest value), the state is entitled to reject the request if the estate fails to follow the state’s procedural rules to request the waiver.²⁹⁰ Receiving clear, ongoing notice of the costs of estate recovery during the Medicaid enrollee’s lifetime, together with information

those services” (emphasis added)); see also N.H. CODE ADMIN. R. He-W 895.04–.05 (Westlaw through Feb. 1, 2024).

281. See 42 U.S.C.A. § 1396p(b)(2)(B).

282. See, e.g., CAL. DEP’T HEALTH & HUMAN SERVS., *Application for Hardship Waiver* 6 § D (2023), <https://www.dhcs.ca.gov/services/Documents/DHCS-6195-Hardship-Waiver.pdf> (requiring tax statements and pay stubs for each adult member of the household).

283. See sources cited *infra* notes 284–87.

284. N.J. ADMIN. CODE § 10:49-14.1(h)(3) (Westlaw through Volume 56, Issue 13, July 2024).

285. *Id.*

286. MICH. DEP’T OF HEALTH & HUM. SERV., YOUR GUIDE TO ESTATE RECOVERY 2 (July 6, 2017), https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder2/Folder39/Folder1/Folder139/dch_3895.pdf?rev=bef9a6b6df4847749568a2324c8b752e.

287. THERESA RICH, MICHIGAN PROBATE: A PRACTICE SYSTEMS LIBRARY MANUAL § 8:30 (Sept. 2023) (“[A]n undetermined group of beneficiaries have 60 days to respond to a notice that they may or may not receive. By the deadline, the beneficiaries, who are by definition in poverty themselves, must compile a well-documented case for hardship based on information they may or may not have to meet mysterious criteria that they must research.”)

288. Blizzard, *supra* note 216.

289. *Id.*

290. See *In re Est. of Klein*, 891 N.W.2d 544, 548 (Mich. Ct. App. 2016); *In re Est. of Clark*, No. 320720, 2015 WL 3448767, at *4–5 (Mich. Ct. App. May 28, 2015).

regarding available exemptions and hardship waivers, would allow families to take action, seek more information, and prepare documentation to support a hardship or exemption.

C. Medicaid Enrollees' Medical and Health Literacy Limitations

The need for clear notice of estate recovery costs at the time of application and throughout Medicaid enrollment is especially critical due to the advanced age, medical needs, and limited health literacy of Medicaid enrollees subject to estate recovery. Individuals receiving Medicaid LTSS often are older, have complex conditions and substantial medical needs (including physical, intellectual, mental, or other disabilities and conditions), and reside in institutional settings.²⁹¹ These circumstances increase the likelihood that they will not understand estate recovery absent clear and periodic disclosures.²⁹²

According to a 2003 national study, Medicaid enrollees generally have health literacy levels that are approximately 80% of the level of those with employer-sponsored health insurance.²⁹³ Health literacy is an individual's capacity to "obtain, process, and understand basic health information and services needed to make appropriate health-related decisions."²⁹⁴ Approximately 30% of Medicaid recipients had "below basic" health literacy, which ranged from being nonliterate in English to having no more than the most simple and concrete literacy skills.²⁹⁵ An additional 30% of Medicaid recipients had "basic" health literacy.²⁹⁶ For these combined 60% of Medicaid recipients, reading and understanding moderately dense prose texts or locating information in complex documents was not within their abilities.²⁹⁷ While these statistics reflect the health literacy of the Medicaid population generally, the advanced age and complex medical needs of those receiving Medicaid LTSS make them even more likely to have difficulty understanding health care information.²⁹⁸ These individuals also may be under severe

291. CMS, *supra* note 24, at 1; see sources cited *supra* notes 55–57.

292. See sources cited *supra* notes 55–57.

293. Jessica Greene & Ellen Peters, *Medicaid Consumers and Informed Decisionmaking*, 30 HEALTH CARE FIN. REV. 25, 26 (Spring 2009), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4195072/pdf/hcfr-30-03-025.pdf>. While this is an older study, disparities in education across socioeconomic classes are unlikely to have changed, as lower educational outcomes still correlate with lower rates of employment and pay. Nat'l Ctr. for Educ. Stat., NCES 2024-144, Report on the Condition of Education, 40 (2024), <https://nces.ed.gov/pubs2024/2024144.pdf>.

294. MARK KUTNER ET AL., U.S. DEP'T OF EDUC., THE HEALTH LITERACY OF AMERICA'S ADULTS 17–18 (2006), <https://files.eric.ed.gov/fulltext/ED493284.pdf>.

295. *Id.* at v, 5, 17. Individuals in this category were able to locate easily identifiable information in short, commonplace prose texts and in simple documents and able to locate numbers and use them to perform simple quantitative operations when the mathematical information is very concrete and familiar. *Id.*

296. *Id.* at 5, 17–18. Individuals in this category were able to read and understand information in short, commonplace prose texts or simple documents, locate easily identifiable quantitative information, and use it to solve simple, one step problems. *Id.*

297. *Id.*

298. See WOOD & KLEM, *supra* note 17, at 6.

stress and lack legal representation, further affecting their ability to comprehend this information.²⁹⁹

With these limitations, individuals subject to estate recovery are unlikely to clearly understand the financial obligations of estate recovery when they receive a one-time, general description of the program in a long Medicaid application and possibly an estate recovery brochure. An aged or disabled individual applying for Medicaid LTSS is likely to have difficulty absorbing all of the information received during the eligibility process, especially for those who are actively experiencing a health event or crisis.³⁰⁰ A short, general description of estate recovery listed in a lengthy Medicaid application form does not adequately or conspicuously convey the monetary impact of estate recovery.³⁰¹ Nor does a general description of estate recovery in a brochure provide the information needed to understand the financial agreement that is being undertaken. Instead, to be meaningful, Medicaid applications or brochures need to provide the key terms of estate recovery—that is, the financial costs of the loans—to the aged and institutionalized so these vulnerable applicants fully understand their anticipated impact. This must necessarily include numerical figures that clearly convey a dollar amount.

Medicaid estate recovery can also have a devastating financial impact on families, thus underscoring the importance of clear notice in this area. A substantial portion of older adults enrolled in Medicaid have little to no wealth.³⁰² Estate recovery primarily impacts those with limited means, for which the family home is their most significant asset.³⁰³ The home is also an asset that Medicaid enrollees and their loved ones value for intrinsic reasons unrelated to fair market value.³⁰⁴ For many Medicaid recipients, the home represents the one asset that can protect future generations from poverty or housing insecurity.³⁰⁵ In opposing OBRA 93's estate recovery mandate, West Virginia pointed to the program's disproportionate impact on the poorest Medicaid recipients.³⁰⁶ West Virginia argued that estate recovery generally affected the poorest segment of the elderly population, those who cannot afford to buy long-term insurance, and those who cannot afford legal advice necessary to engage in estate planning to protect their assets.³⁰⁷ West Virginia also argued that the program creates non-financial problems, including widespread clinical depression in aged and disabled nursing home residents.³⁰⁸ Given the significant financial and intergenerational costs of

299. *Id.*

300. MACPAC REPORT, *supra* note 10, at 92.

301. *See* WOOD & KLEM, *supra* note 17, at vii.

302. MACPAC REPORT, *supra* note 10, at 81. During survey periods from 2012 through 2016, approximately 50% of Medicaid recipients age sixty-five or older had an average net wealth of \$304 or less. *Id.* The average home equity of the total sample of Medicaid recipients was \$27,364. *Id.* Approximately 50% of these recipients had an average of \$8 of home equity or less. *Id.*

303. *Id.* at 92.

304. *See* WOOD & KLEM, *supra* note 17, at 11.

305. JUSTICE IN AGING ET AL., *supra* note 16, at 4; Frank, *supra* note 15, at 143.

306. *West Virginia v. U.S. Dep't of Health & Hum. Servs.*, 289 F.3d 281, 285 (4th Cir. 2002).

307. *Id.*

308. *Id.*

estate recovery to those with limited means, it is all the more critical that Medicaid recipients understand what they are agreeing to with respect to estate recovery.

D. The Public Policy of Protecting Loan Recipients Through Required Disclosures

For decades, federal consumer protection laws have recognized the importance of loan disclosures to promote informed financial decision-making, and this policy should extend to an individual's decision to assume an estate recovery loan. For example, the Truth in Lending Act (TILA) requires creditors to disclose credit terms to protect consumers against inaccurate and unfair billing practices and to enable consumers to make informed choices among available payment methods.³⁰⁹ TILA defines "credit" as "the right granted by a creditor to a debtor to defer payment of debt or to incur debt and defer its payment."³¹⁰ The Act defines a "creditor" who comes within its scope as (1) a person who regularly extends consumer credit, which is payable by agreement in more than four installments or for which the payment of a finance charge is or may be required; and (2) the person to whom the debt arising from the consumer credit transaction is initially payable.³¹¹ Under this provision, TILA extends to banks, retail stores, credit card issuers, car dealers, credit unions, mortgage bankers, and other individuals or entities who regularly extend credit to consumers.³¹² The Act applies to consumer credit transactions, where credit is extended to a natural person primarily for personal, family, or household purposes.³¹³

TILA applies to both open-end and closed-end credit transactions.³¹⁴ TILA defines an "open-end" credit plan as one under which the creditor contemplates repeated transactions, prescribes the terms of such transactions, and provides for a finance charge that may be computed from time to time on the outstanding unpaid balance.³¹⁵ For such transactions, TILA requires that creditors provide the consumer with (1) an initial disclosure statement describing the terms of the plan before consumer makes the first transaction and (2) periodic billing statements

309. See 15 U.S.C.A. §§ 1601–67f (Westlaw through Pub. L. No. 118-70); U.S. FED. RESRV. BD., REG. Z 4–5 (2010), <https://www.federalreserve.gov/boarddocs/caletters/2010/1010/10-10-attachment.pdf>.

310. 15 U.S.C.A. § 1602(f) (Westlaw through Pub. L. No. 118-70).

311. *Id.* § 1602(g).

312. 73 AM. JUR. PROOF OF FACTS 3D 275, *Violation of the Truth-in-Lending Act and Regulation Z* § 8 (2024).

313. 15 U.S.C.A. § 1602(h). TILA does not apply to extensions of credit primarily for business or commercial purposes or to certain credit transactions over a specified dollar threshold that is adjusted annually. *Id.* § 1603(i); Truth in Lending (Regulation Z), 88 Fed. Reg. 83322, 83323–83329 (Nov. 29, 2023) (to be codified at 12 C.F.R. pts. 226, 1026).

314. 73 AM. JUR. PROOF OF FACTS 3D 275, *supra* note 312, § 30, 36.

315. 15 U.S.C.A. § 1602(j); 12 C.F.R. § 1026.2(20) (Westlaw 2024). A closed-end credit transaction is any consumer credit other than "open-end" credit, such as a home mortgage or car loan that occurs in a single transaction. See 12 C.F.R. § 1026.2(10).

for each billing cycle at the end of which there is an outstanding balance.³¹⁶ The periodic statement must include, among other requirements, each credit transaction, the account balance outstanding on the closing date of the billing cycle, and the due date.³¹⁷ These requirements are intended to ensure that credit terms are disclosed such that consumers can compare credit terms more readily and knowledgeably.³¹⁸

The policy behind TILA is equally applicable in the Medicaid estate recovery context. When an individual is considering whether to enroll in Medicaid recoverable services, they must decide whether to take on a substantial amount of debt in exchange for the care they receive. In this transaction, the state Medicaid agency provides the Medicaid applicant with credit, i.e., the right to incur debt and defer its payment.³¹⁹ The state Medicaid agency acts as a creditor by regularly extending credit for personal use that is payable by the consumer.³²⁰ Moreover, just like in an “open-end” credit plan under TILA, Medicaid repeats transactions as services are provided to the individual throughout enrollment.³²¹ Medicaid also prescribes the “terms” of those transactions, including not only the due date for the outstanding balance *but also the underlying costs of services*.³²² While Medicaid does not assess finance charges on its loans during the enrollee’s lifetime, the absence of a finance charge does not detract from the need for notice of the loan’s terms.³²³ Just like hidden “finance charges,” the costs of Medicaid services provided are otherwise hidden from, or at least difficult to discern by, the Medicaid consumer.³²⁴ The absence of this cost information coming from any other source creates even more compelling justification for the disclosure of estate recovery costs to Medicaid recipients.

Courts have also recognized that state Medicaid agencies are providing loans to Medicaid enrollees through the estate recovery program.³²⁵ In *Estate of Wood v. Arkansas Department of Human Services*, the issue presented was whether the state’s estate recovery statute could be applied retroactively to services provided to Ms. Wood prior to its enactment.³²⁶ The court found that, prior to the statute’s enactment, Ms. Wood had no reason to believe that the Medicaid payments were anything other than an entitlement.³²⁷ After the statute’s enactment, according to

316. 12 C.F.R. §§ 1026.6, 1026.7.

317. 12 C.F.R. § 1026.7.

318. U.S. FED. RSRV., *supra* note 309, at 4.

319. *Id.* at 4–5.

320. Arguably, states meet TILA’s requirement that the debt be payable by agreement in more than four installments, as the SMM allows states to establish a payment schedule subject to reasonable interest to collect amounts recovered from estates. CMS MANUAL, *supra* note 18, § 3810(D).

321. *See* 12 C.F.R. § 1026.2(20).

322. *See id.*

323. Instead, Medicaid may begin to charge interest only when the estate recovery debt becomes due after death. CMS MANUAL, *supra* note 18, § 3810(D).

324. *See* discussion *supra* Sections III.C and IV.

325. *Est. of Wood v. Ark. Dep’t of Hum. Servs.*, 894 S.W.2d 573, 576 (Ark. 1995).

326. *Id.* at 575.

327. *Id.* at 576.

the court, “it was as if she had a loan from DHS to be repaid from the assets of her estate.”³²⁸ Because the estate recovery statute created a new legal right and affected Ms. Wood’s vested property interest, the court held that the statute could not be applied retroactively.³²⁹ The Supreme Court of Washington later followed this precedent, finding that estate recovery statutes “transformed the recipient’s property right in the Medicaid payments already received into a loan to be repaid from estate assets.”³³⁰

Because the estate recovery program changes what was once an entitlement into a loan, Medicaid applicants and beneficiaries should receive the same protections as individuals receiving loans in any other context. This protection should include an initial disclosure describing the terms of the loan and periodic statements identifying each credit transaction and the total outstanding balance accrued to date. Periodic notices are needed to ensure that individuals fully understand their financial obligations throughout the life of the estate recovery loan. A one-time general statement of the existence of a debt at the time of application without any description of the exact amount of debt does not provide meaningful notice that allows individuals to understand the financial consequences of Medicaid enrollment.

VI. A FEDERAL NOTICE REQUIREMENT IS NEEDED TO ENSURE MEANINGFUL NOTICE OF ESTATE RECOVERY

CMS should amend federal law to require that individuals receive clear notice regarding the costs of estate recovery loans during their lifetime.³³¹ Federal law should specifically require an initial notice of the estimated costs of estate recovery at the time of application (“Initial Notice”) and periodic notices of the accrued costs of estate recovery to date throughout enrollment (“Periodic Notice”). These are the *key terms* of the loan to which aged and institutionalized individuals agree when they enroll in Medicaid. Yet, under current federal and state authorities, these terms are not required to be disclosed to the enrollee. Applicants are therefore blindly enrolling in Medicaid without a clear understanding of the anticipated costs to their estate, and they are blindly continuing enrollment without any notice of the accrued costs to their estate. Even the most progressive of states’ policies in this area places the burden on the Medicaid enrollee to seek out and pay to obtain their accrued estate recovery costs.³³²

Federal law should require that, at the time of application, the state provide an Initial Notice that contains the following elements: (1) a clear statement that aged and institutionalized individuals are taking on a debt that the state is required

328. *Id.*

329. *Id.*

330. *In re Est. of Burns*, 928 P.2d 1094, 1101 (Wash. 1997).

331. Specifically, CMS should promulgate rules to implement this notice requirement at 42 CFR § 433.36, which currently implements the estate recovery provisions of the Social Security Act. CMS should further incorporate these requirements into its State Medicaid Manual at § 3810.

332. *See* CAL. WELF. & INST. CODE § 14009.5(e) (Westlaw through Ch. 156 of 2024 Reg. Sess.).

to recover upon death; (2) a description of how an estate recovery claim will be calculated; (3) the best available estimate of estate recovery costs to Medicaid applicants; and (4) in states delivering recoverable services through a managed care model, a statement that the amounts recovered through estate recovery can exceed the actual costs of services. Medicaid agencies should provide the Initial Notice to any applicant seeking to obtain a recoverable service. Additionally, for individuals who begin receiving recoverable services at some point after enrollment, such as those who turn fifty-five years old while receiving LTSS, Medicaid agencies should also give an Initial Notice in advance of their qualifying event.

Regardless of the delivery model used to provide recoverable services, the state should provide the best available estimate of anticipated estate recovery costs in the Initial Notice. Where recoverable services are provided through a managed care model, the Initial Notice should include the monthly capitation rates for each eligibility group receiving recoverable services. In states where there are numerous applicable capitation rates, the state could provide a range of rates. A capitation disclosure that only includes a minimum amount, such as Arizona's brochure language, would not be sufficient because the upper limit is unknown.³³³ Even though Arizona's brochure indicates that "the monthly capitation payment to program contractors can exceed \$7,800 per month," Arizona's capitation rate information indicates that capitation rates for LTSS may be as high as \$10,513 per month, which is 35% more than the disclosed amount.³³⁴ States should be responsible for updating this disclosure to reflect current capitation ranges across time. For this reason, states may likely choose to provide the Initial Notice in a document separate from the application.

In states that provide recoverable services through a fee-for-service model, states should provide applicants with notice of the best available estimate of estate recovery costs. This could include a list of examples of fee-for-service rates for common LTSS services (e.g., the average incremental rates for nursing care, personal care, and skilled nursing care in the home and the average per diem rates for nursing facility services), together with information on how to learn other fee-for-service charges.³³⁵ This approach is consistent with CMS's recently passed rule regarding Medicaid payment rate transparency.³³⁶ This rule requires states to post their Medicaid fee-for-service payment rates on a website, in a way that a member of the public can readily determine the amount that Medicaid would pay for the service, by July 1, 2026.³³⁷ While an Initial Notice would not be able to

333. ARIZ. HEALTH CARE COST CONTAINMENT SYS., *supra* note 160, at 3.

334. ARIZ. HEALTH CARE COST CONTAINMENT SYS., *supra* note 143, at 1.

335. For example, Arizona's Medicaid agency has provided a user-friendly list of its current Medicaid fee-for-service rates, which includes separate schedules for HCBS and nursing facility care. Ariz. Health Care Cost Containment Sys., *Fee-for-Service Fee Schedules*, <https://www.azahcccs.gov/PlansProviders/RatesAndBilling/FFS/> (last visited Jul. 26, 2024). Sample or average rates for selected services from these schedules could be used to provide an estimate of anticipated estate recovery charges in the Initial Notice. *See id.*

336. 42 C.F.R. § 447.203(b)(1) (Westlaw 2024).

337. *Id.*

list every fee-for-service payment rate used by the Medicaid agency, the agency should be able to provide estimated payment ranges for common LTSS and other recoverable services.

In addition to the Initial Notice, federal law should require that individuals who are age fifty-five or older or are institutionalized³³⁸ receive a periodic statement of estate recovery charges accrued to date (Periodic Notice). The Periodic Notice should be sent to the enrollee every three months following enrollment. Each Periodic Notice should include (1) an itemization of accrued estate recovery costs for the period covered by the notice; (2) the total charges accrued to date; (3) a description of estate recovery exemptions and available hardship waivers in the state; (4) information regarding how an individual can learn more about estate recovery; and (5) notice that the enrollee can withdraw from Medicaid at any time.

The recommended timing of the Periodic Notice is intended to strike a balance between enrollees' need for information and the administrative burden on state Medicaid agencies. When recoverable services are delivered through a fee-for-service model, the itemization should provide a description of and the payment made for each service or benefit provided to the enrollee. When recoverable services are delivered through a managed care model, the itemization should show each capitation rate payment made on behalf of the enrollee and the period of time covered by the payment.³³⁹

A. Potential Objections to the Proposed Notice Requirement and Responses

Opponents of this proposal may point to legal or logistical barriers to implementation, but these arguments are unavailing.³⁴⁰ First, some may argue that this federal requirement is too burdensome or not feasible for state Medicaid agencies. Second, some may argue that, as a matter of law, an estate recovery claim does not exist until after the enrollee's death, thus necessitating notice only at this time. Third, opponents may contend that this proposal would lead to federal overreaching. Fourth, some may point out that capitation rates may be adjusted retrospectively, rendering periodic notices to be inaccurate. Finally, some may argue that California's approach of allowing individuals to inquire as to their estate recovery costs is more reasonable than the proposed requirement. None of these arguments effectively obstruct the implementation of the proposed notice requirement.

338. In states that impose TEFRA liens, the Periodic Notice should be sent to all individuals receiving Medicaid services in an institution. This is needed because these states must seek to recover the payments made for all institutional services provided to the permanently institutionalized, including those provided before the determination of permanent institutionalization was made. CMS MANUAL, *supra* note 18, § 3810(A)(1).

339. In a Medicaid program that delivers recoverable services through both models, both capitation payments and fee-for-service payments should be included in the Periodic Notice.

340. The most obvious solution to the lack of transparency identified in this Article is elimination of the estate recovery program altogether. Legislation has been proposed to eliminate the program, but Congress has repeatedly chosen not to pass it. *See* H.R. 6698, 117th Cong. (2022); H.R. 7573, 118th Cong. (2024).

1. The Proposed Notice Requirement is Feasible for Medicaid Agencies

While the proposed notice requirement may be perceived as overly burdensome for state Medicaid agencies, agencies currently have the information and systems needed to implement the requirement. Practically, the cost information contained in the notices is already available to the agency. Regarding the estimated costs required in the Initial Notice, both capitation rates and fee-for-service rates are known by the state Medicaid agency. State Medicaid agencies generally determine capitation rates for a prospective twelve-month period, and the rates must be submitted to CMS ninety days prior to their effective date.³⁴¹ States that deliver recoverable services through managed care do not have to estimate the projected charges because they have the exact charges readily available at the time the person enrolls in Medicaid.³⁴² These states would only need to provide the monthly capitation rates for recoverable services in the Initial Notice.

While providing estimated fee-for-service charges in an Initial Notice is more challenging than providing capitated rates, states can provide a sample of estimated charges. Fee-for-service payment rates are known by and available to the State, but payments will vary based on the type and number of services provided to each Medicaid enrollee.³⁴³ To account for this variation, states could provide a list of commonly recoverable services and an average range of costs for those services. As discussed above, the state Medicaid agency could disclose an average range of nursing facility payment rates, personal attendant payment rates, or other commonly recoverable charges, together with information on how to learn additional fee-for-service rates. Again, states would be expected to provide the best available estimate in the Initial Notice, based on the information known to the agency, with the goal of providing individuals with the anticipated costs of the estate recovery loan.

With respect to accrued estate recovery costs in Periodic Notices, these are also known by the Medicaid agency when the Medicaid agency pays the provider (in a fee-for-service model) or the MCO (in a capitated rate model). In a fee-for-service delivery model, providers generally submit claims through the state Medicaid agency's Medicaid Management Information System (MMIS) which processes the claim, and the provider is typically paid as claims are received and adjudicated.³⁴⁴ In a managed care delivery model, the MMIS keeps record of the capitation rates paid to each MCO.³⁴⁵ In either delivery model, upon a Medicaid enrollee's death, the state typically uses its MMIS to generate an itemized list of

341. MACPAC, *supra* note 81, at 1, 3.

342. *Id.* at 1.

343. *Id.*

344. CMS, *The Medicaid Management Information System Snapshot 1–2* (Aug. 2016), <https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/ebulletins-medicicaidmanage-infosystem.pdf>.

345. See, e.g., Wis. Dep't of Health Servs., *ForwardHealth Reimbursement and Capitation*, https://www.forwardhealth.wi.gov/WIPortal/content/Managed%20Care%20Organization/Reimbursement_and_Capitation/Home.htm.spage#scprcd (last visited Jul. 26, 2024); see generally CMS, *supra* note 344.

expenditures and total estate recovery claim amount.³⁴⁶ The payment information does not come into existence after the enrollee has died; instead, it is available in the MMIS when the payments are made to providers and MCOs.³⁴⁷ To implement this proposal, the state Medicaid agency will need to generate the itemized list of payments earlier in time and on a periodic schedule. Because the payment information used to calculate estate recovery claims is available when the payments are made, the availability of cost information does not pose a barrier to providing accrued estate recovery costs to enrollees in Periodic Notices.

Additionally, state Medicaid agencies already have systems in place to distribute the proposed notices. The Initial Notice can be included together with any Medicaid application for recoverable services. This would involve adding a disclosure to the online or paper application and requiring that the disclosure be read aloud to anyone applying via telephone.³⁴⁸ To distribute Periodic Notices, the agency would be able to use the same processes that it currently uses to send other notices to enrollees. The agency could allow individuals to receive both the Initial and Periodic Notices through an electronic portal, which is currently used by many agencies to communicate with enrollees.³⁴⁹ Although the proposed notice requirement would necessarily involve additional resources to generate and mail the notices, the underlying systems needed to implement this notice are largely already in place.

The proposed timeline for distribution of Periodic Notices is also feasible for Medicaid agencies. The timeline of sending a similar notice once every quarter has been used in Medicare successfully. Medicare sends a Medicare Summary Notice (MSN) every three months to individuals enrolled in Medicare Parts A and B who received services during the preceding three months.³⁵⁰ The MSN provides an itemization showing the services or other benefits that were billed to Medicare, the amounts that Medicare paid, and the maximum amounts that the enrollee may owe to the provider.³⁵¹ Acknowledging the administrative differences between Medicare and Medicaid, the MSN model generally supports providing enrollees with a quarterly notice detailing services received and related charges. Furthermore, Medicaid agencies are already sending periodic mailings

346. WOOD & KLEM, *supra* note 17, at xiii-ix, 19; *see, e.g.*, 016.20 ARK. CODE. R. § 1-H-630 (Westlaw through May 15, 2024).

347. *See supra* notes 344–46.

348. State Medicaid agencies must accept applications submitted via an online portal, by telephone, by mail, in person, and through other commonly available electronic means. 42 C.F.R. § 435.907(a) (Westlaw 2024).

349. Tricia Brooks et al., *A Look at Medicaid and CHIP Eligibility, Enrollment, & Renewal Policies During the Unwinding Continuous Enrollment & Beyond*, KFF (June 20, 2024), <https://www.kff.org/medicaid/report/a-look-at-medicare-and-chip-eligibility-enrollment-and-renewal-policies-during-the-unwinding-of-continuous-enrollment-and-beyond/> (stating that 49 states allow Medicaid applicants to create online accounts with a range of features including viewing notices).

350. CMS, *Medicare Summary Notice*, <https://www.medicare.gov/basics/forms-publications-mailings/mailings/costs-and-coverage/medicare-summary-notice> (last visited Jul. 19, 2024).

351. *Id.*

of other types to enrollees, such as renewal reminders.³⁵² In summary, while increased funding and staff will be necessary to implement the proposed notice requirement, state Medicaid agencies are well positioned to implement the proposal because they already possess the required information and systems to do so. Moreover, because state Medicaid agencies have effectively entered the business of issuing loans, they must develop the systems and processes needed to adequately apprise loan recipients of the terms of those loans.

2. As a Matter of Law, an Estate Recovery Claim Arises Upon the Receipt of Services

Opponents of this proposal may further argue that an estate recovery claim can be pursued only after the Medicaid enrollee's death; therefore, it is premature to send a claim itemization prior to that date. In contrast, most courts that have addressed this issue have concluded that a Medicaid estate recovery claim arises when Medicaid services are provided, not when the claim becomes enforceable.³⁵³ Furthermore, even though a total estate recovery claim amount is not able to be calculated until after the enrollee's death, this does not prevent states from calculating the costs of estate recovery accrued as of a certain date while the enrollee is living.³⁵⁴

In the *Matter of Estate of Abad*, the Supreme Court of Alaska held that an estate recovery claim arises before death.³⁵⁵ This case presented the issue of whether a Medicaid estate recovery claim arises before or after death, for purposes of determining the deadline for the state to provide notice of its claim to the estate.³⁵⁶ The state argued that a Medicaid estate recovery claim arises when the services are provided to the beneficiary, even if it is not enforceable until the beneficiary's death.³⁵⁷ The Court agreed with the state and held that an estate recovery claim arises before death.³⁵⁸ The Court found that Black's Law Dictionary's first definition of "arise" supports the conclusion that the estate recovery claim "came into being" with the provision of Medicaid services.³⁵⁹ The court further found that this type of claim is "akin to a contract claim" because "in exchange for receiving services, the beneficiary incurs a contingent obligation to repay after death, with funds from the beneficiary's estate." The court reasoned

352. See Bradley Corallo, et al., *Unwinding of Medicaid Continuous Enrollment: Key Themes from the Field*, KFF (Jan. 10, 2024), <https://www.kff.org/medicaid/issue-brief/unwinding-of-medicaid-continuous-enrollment-key-themes-from-the-field/>.

353. In re Est. of Abad, 540 P.3d 244, 251 (Alaska 2023).

354. Of thirty-five states that responded to a 2006 survey, more than half of the responding states indicated that, when recovery is sought from an estate, they make an itemized list of Medicaid expenditures for which recovery is sought, available upon request. WOOD & KLEM, *supra* note 17, at 19.

355. In re Est. of Abad, 540 P.3d at 248.

356. *Id.* at 247.

357. *Id.*

358. *Id.* at 248.

359. *Id.*

that this type of claim is far less similar to funeral expenses and expenses at administration, which are statutory examples of claims arising at or after death.³⁶⁰

Other courts have reached the same conclusion, holding that Medicaid estate recovery claims arise when services are provided to a Medicaid recipient. For example, in the *Matter of the Estate of Melby v. Lohman*, the Iowa Supreme Court held that an estate recovery claim “establishes a debt owed by the recipient of medical services when the services are provided,” even though the state may not collect that debt until the death of the recipient.³⁶¹ In the *Matter of the Estate of Reimers v. Nebraska Department of Health and Human Services*, the Nebraska Court of Appeals likewise held that Medicaid estate recovery creates a debt that accrues during the recipient’s lifetime which is held in abeyance for payment until the recipient’s death.³⁶² Because most courts that have addressed the issue have concluded that Medicaid estate recovery claims arise when services are provided to the Medicaid recipient, there is no legal basis to wait until an enrollee has died to provide notice of accrued estate recovery costs.³⁶³

3. Federal Law Broadly Regulates Medicaid Notice Requirements

Some may characterize the proposed notice requirement as federal overreaching, instead supporting states’ discretion to design their own estate recovery programs and determine the content of estate recovery notices. In contrast, the area of Medicaid notices is otherwise heavily regulated by CMS. For example, federal regulations require that Medicaid agencies provide applicants and beneficiaries with advance written notice of any decision affecting their Medicaid eligibility, including an approval, denial, or termination of eligibility, or a denial or change in benefits or services.³⁶⁴ Federal regulations set forth the required content of these notices as well as accessibility requirements.³⁶⁵ Furthermore, federal regulations provide detailed notice requirements for Medicaid administrative hearings.³⁶⁶

Congress not only broadly regulates Medicaid notices, but also specifically requires advance notice of other changes impacting Medicaid enrollees’ financial obligations to contribute to their costs of care. Specifically, Medicaid agencies are required to provide advance written notice of any changes to a Medicaid enrollee’s cost-sharing obligations, including copayments ranging from \$4.00 to \$75.00.³⁶⁷ When Medicaid enrollees are entitled to advance written notice of a change in a fee as small as \$4.00, enrollees unquestionably should receive notice

360. *Id.* at 248–49.

361. *In re Est. of Melby v. Lohman*, 841 N.W.2d 867, 877 (Iowa 2014).

362. *In re Est. of Reimers v. Neb. Dep’t of Health & Hum. Servs.*, 746 N.W.2d 724, 728 (Neb. Ct. App. 2008).

363. *In re Est. of Abad*, 540 P.3d at 252; *In re Est. of Burns*, 928 P.2d 1094, 1099 (Wash. 1997).

364. 42 C.F.R. §§ 431.211, 435.917 (Westlaw 2024).

365. *Id.* §§ 431.210, 435.917 (Westlaw 2024); *see also id.* § 435.918 (Westlaw 2024).

366. *Id.* § 431.206 (Westlaw 2024).

367. *Id.* § 435.917; CMS, *CMCS Informational Bulletin 4* (Mar. 15, 2024), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib03152024.pdf>; MACPAC, *Cost Sharing and Premiums* (Apr. 30, 2018), <https://www.macpac.gov/subtopic/cost-sharing-and-premiums/>.

of much larger estate recovery costs. Whether in the form of a cost-sharing obligation or an estate recovery cost, the enrollee agrees to pay an amount in exchange for medical care. The only difference is the timing of the payment, which in the estate recovery context is delayed until after death.

Federal regulation of Medicaid notices also ensures that state Medicaid agencies consistently prioritize and implement these protections for their members. State Medicaid agencies' ability to make systemic changes is limited by budget constraints, staffing needs, and other required programs and priorities. For example, as a condition of receiving an enhanced federal matching rate during the COVID-19 pandemic, states were required to maintain enrollment for nearly all Medicaid enrollees.³⁶⁸ States were then given a short, twelve-month window to "unwind" from the public health emergency, which involves working through a three-year backlog of eligibility renewals for millions of Medicaid members.³⁶⁹ Medicaid leaders and staff have been working tirelessly to ensure that this process takes place in accordance with federal requirements and such that eligible individuals retain their Medicaid coverage.³⁷⁰ State Medicaid agencies are also faced with other budget pressures, including a growing population of older adults requiring LTSS and national healthcare workforce shortages.³⁷¹

In this context, Medicaid leaders are required to make strategic and careful choices about the allocation of resources. New projects and initiatives require buy-in from those leading the agency, considering financial resources, human resources, technological resources, and other factors. In this setting, federal requirements often lead to the prioritization of a program change. For instance, recent changes in federal eligibility rules are requiring state Medicaid agencies to make significant investments into their IT systems and to hire staff and contractors to operate these systems.³⁷²

These challenges are heightened in estate recovery, which involves multiple divisions of a Medicaid agency. Because notice of estate recovery is currently provided when individuals apply for Medicaid, the agency's eligibility division typically creates and distributes these notices.³⁷³ The eligibility division may operate separately from the agency's estate recovery unit, which begins to take action in a case only after the enrollee dies.³⁷⁴ A survey by the American Bar Association's Commission on Law and Aging documented that certain states' estate recovery units did not know when or how their states' estate recovery brochure was distributed because it was the responsibility of the eligibility office.³⁷⁵

368. CMS, *Unwinding and Returning to Regular Operations after COVID-19*, <https://www.medicaid.gov/resources-for-states/coronavirus-disease-2019-covid-19/unwinding-and-returning-regular-operations-after-covid-19/index.html> (last visited Jul. 19, 2024).

369. Jasemi, *supra* note 75.

370. *Id.*

371. *Id.*

372. *Id.*

373. See WOOD & KLEM, *supra* note 17, at vi, 7.

374. See *id.* at 6.

375. *Id.*

Other divisions, such as the information technology and fiscal divisions, may be involved in the development of itemizations of estate recovery costs. Because a change in estate recovery procedures would potentially require agreement and resources from numerous agency divisions, which are already facing competing priorities and budget pressures, CMS should address the insufficiency of current estate recovery notice requirements by amending federal law.³⁷⁶

4. Retrospective Capitation Rate Adjustments Do Not Prevent Implementation of the Proposed Notice Requirement

Opponents of this proposal may further argue that it is not possible to provide accurate estate recovery costs to enrollees in states that use a managed care model because capitation rates can change retrospectively. While retrospective adjustments occur, these do not pose an obstacle to the proposed notice requirement. As discussed above, Medicaid agencies generally develop capitation payment rates and apply them prospectively for a twelve-month period.³⁷⁷ While the capitation rate typically remains in effect regardless of changes in health care costs or the utilization of services, a state and its actuary may determine that a retrospective adjustment to the capitation rates is necessary.³⁷⁸ Agencies may make these retrospective adjustments when significant and unanticipated events occur, such as large changes in enrollment or utilization of services.³⁷⁹ For example, in response to the COVID-19 pandemic, CMS allowed states to make capitation rate adjustments, prospectively or retrospectively, of less than 1.5% without a revised actuarial certification.³⁸⁰

Retrospective adjustments to capitation rates do not pose a barrier to the proposed notice requirement. First, each Periodic Notice could easily include language that notifies the recipient of the potential for retroactive adjustments. California has provided exemplary language in its “Request for Medi-Cal Expenses Subject to Estate Recovery” form.³⁸¹ The second sentence of this form instructs the requester to “Please note payment information may change due to

376. A federal amendment is needed to ensure the consistent prioritization, implementation, and funding of the proposed notice requirement. Based on my experience working at a state Medicaid agency for nearly a decade, I believe that those working at state Medicaid agencies support the implementation of solutions such as this proposal that help applicants and enrollees understand the program. *See also id.* at 7 (noting that several states expressed interest in conducting estate recovery training for eligibility staff but indicated insufficient state funds to do so); Leys, *supra* note 216 (quoting Iowa Medicaid Director Elizabeth Matney as stating that, “We do not like families or members being caught off guard.”).

377. MACPAC, *supra* note 81, at 1.

378. 42 C.F.R. § 438.7(c)(2) (Westlaw 2024); CMS, 2022-2023 MEDICAID MANAGED CARE RATE DEVELOPMENT GUIDE 6 (Apr. 2022), <https://www.medicaid.gov/medicaid/managed-care/downloads/2022-2023-medicaid-rate-guide-03282022.pdf>.

379. AM. ACAD. OF ACTUARIES, CONSIDERATIONS FOR REFLECTING THE IMPACT OF COVID-19 IN MEDICAID MANAGED CARE PLAN RATE SETTING 19-20 (Nov. 2021), <https://www.actuary.org/sites/default/files/2021-11/COVID19.ImpactMedicaid11.21.pdf>.

380. Hinton & Musumeci, *supra* note 80.

381. CAL. DEP’T OF HEALTH CARE SERVS., *supra* note 189, at 1.

adjustment in rates, pending claims from providers, or additional services rendered.”³⁸² Second, by providing a quarterly notice of estate recovery amounts accrued throughout enrollment, any changes in accrued estate recovery costs caused by retrospective capitation rate adjustments would become apparent to the enrollee close in time to when the adjustment is made.

5. California’s Approach Unfairly Shifts the Burden of Notice to Medicaid Enrollees

While California has improved the transparency of its estate recovery program compared with other states, its estate recovery statute does not go far enough. First, California’s estate recovery statute shifts the burden to enrollees to seek out the amounts that they owe.³⁸³ This practice is inconsistent with the public policy behind consumer protection laws, such as TILA, which recognize that the entity that provides an open-ended loan for personal use is responsible for periodically providing notice of its terms to the loan recipient.³⁸⁴ In contrast, in California, the estate recovery loan recipient’s understanding of the loan is wholly dependent upon an action that he or she may not be able to take due to medical, cognitive, or other limitations. Aged and institutionalized enrollees are often older, have physical and intellectual disabilities, and are dependent upon other caregivers for assistance with personal needs.³⁸⁵ Actions such as photocopying identification, completing paperwork, scanning, emailing, or mailing can be monumental (if not impossible) tasks for the aged and institutionalized.

Second, California’s \$5 charge to receive estate recovery costs poses an additional, unnecessary burden on Medicaid enrollees who have spent down their income and resources to become eligible for Medicaid.³⁸⁶ This fee serves as a financial deterrent from receiving estate recovery cost information. Minimal copay amounts as little as \$1 to \$5 are associated with a reduction in Medicaid recipients’ use of health services such as preventative care, primary care, and mental health visits.³⁸⁷ When minimal fees deter individuals from using medically necessary services, such fees are likely to deter individuals from seeking out estate recovery information.

Finally, California’s limitation of providing estate recovery costs upon request only once per calendar year is insufficient to adequately apprise Medicaid enrollees of their debt. For the reasons discussed in Section V above, Medicaid enrollees need periodic notice to be able to assess the value of Medicaid

382. *Id.*

383. CAL. WELF. & INST. CODE § 14009.5(e) (Westlaw through ch. 156 of 2024 Reg. Sess.).

384. *See* 12 C.F.R. §§ 1026.6, 1026.7 (Westlaw 2024).

385. MACPAC, *supra* note 55; *see* JOHNSON & DEY, *supra* note 57, at 1.

386. *See* CAL. DEP’T OF HEALTH CARE SERVS., *supra* note 189, at 1.

387. Samantha Artiga et al., *The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings*, KFF (Jun. 1, 2017), <https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/>.

services throughout enrollment. Also, once an individual submits an inquiry to California's Medicaid agency, that individual would be unable to see the estate recovery charges associated with changes in their care for the next eleven months. For example, if an individual submits an inquiry in January and then decides to transition from a nursing facility to HCBS in February, the estate recovery costs associated with this change would not be available until the next calendar year. Thus, the charges associated with additions, reductions, or changes in services would be hidden for almost an entire year.

Rather than requiring aged and institutionalized Medicaid enrollees to bear the burden of submitting paperwork and paying a fee to learn about the loan they have received, states should be responsible for regularly and consistently providing this notice. This approach will ensure that individuals do not encounter barriers to their receipt of estate recovery costs, whether based on their physical or cognitive abilities, location in an institution, access to printers or scanners, ability to pay a fee, or awareness of the need to request this information in the first place.

VII. CONCLUSION

The costs of Medicaid estate recovery should be provided to Medicaid enrollees during their life and not only to their families during their afterlife. Through the Medicaid estate recovery program, Medicaid enrollees who receive recoverable services implicitly agree to take out a loan from the government for Medicaid payments made on their behalf and to repay that loan upon their death. The amounts charged in estate recovery can be thousands of dollars per month of enrollment, and the resulting estate recovery claim can result in devastating financial loss for Medicaid enrollees' families, who are simultaneously experiencing the loss of a loved one.

Current law does not provide adequate protections to ensure that Medicaid enrollees understand the financial consequences of estate recovery. Federal law is devoid of any estate recovery notice requirement applicable to living Medicaid enrollees. Under CMS's sub-regulatory guidance, state Medicaid agencies must only provide a notice to Medicaid applicants that explains the estate recovery program and, when applicable, explains that premium payments will be included in an estate recovery claim. Similarly, of the small number of states that have codified estate recovery notice requirements applicable to Medicaid enrollees, most require only a general explanation of estate recovery rather than notice of its financial impact. States' Medicaid applications and estate recovery brochures further indicate that states are not providing the key term of estate recovery loans to enrollees – *the costs*. In this context, after Medicaid enrollees pass away, their families are often shocked to receive a notice of a substantial estate recovery claim, which must often be satisfied by selling or mortgaging the family home.

As recognized by consumer protection laws applicable to open-end credit transactions, individuals should be informed of the terms and conditions of loans before and during their usage. When taking out a loan for medical care, individuals

must have a clear understanding of their financial obligations so that they can weigh their options and make a fully informed decision. Once enrolled, Medicaid recipients need to regularly see the accrued costs of estate recovery so that they can weigh the costs and benefits of Medicaid services based on their current medical needs and the availability of other supports. In states that use the managed care delivery model, an enrollee's accrued estate recovery costs may be more than the amounts paid to providers for their services, thus underscoring the need for cost transparency. Each of these reasons becomes even more pronounced when considering the medical and health literacy limitations of the groups subject to estate recovery.

Federal law should be amended to require that Medicaid enrollees do not blindly agree to receive recoverable Medicaid services without understanding the terms of estate recovery loans. At the time of application, federal law should require an Initial Notice that includes: (1) a statement that aged and institutionalized individuals are taking on a debt that the State is required to recover upon death; (2) a description of how an estate recovery claim will be calculated; (3) the best available estimate of estate recovery costs to Medicaid applicants; and (4) in states delivering recoverable services through a managed care model, a statement that the amounts recovered through estate recovery can exceed the actual costs of services. Throughout Medicaid enrollment, federal law should require that individuals who are age fifty-five or older or are institutionalized receive a Periodic Notice at least every three months that includes (1) an itemization of accrued estate recovery costs for the period covered by the notice; (2) the total charges accrued to date; (3) a description of estate recovery exemptions and available hardship waivers in the state; (4) information regarding how an individual can learn more about estate recovery; and (5) notice that the enrollee can withdraw from Medicaid at any time. This proposed federal notice requirement is necessary to ensure transparency in the costs of estate recovery, so that individuals considering Medicaid enrollment can make fully informed decisions regarding their medical care. As the number of individuals needing Medicaid LTSS is expected to increase substantially in the next three decades, so too does the importance of cost transparency increase in Medicaid estate recovery.

* * *

APPENDIX A

Estate Recovery Notice Provisions in Medicaid Applications³⁸⁸

Alabama: ALA. MEDICAID AGENCY, APPLICATION/REDETERMINATION FOR ELDERLY AND DISABLED PROGRAMS 12 (2023), https://medicaid.alabama.gov/documents/9.0_Resources/9.4_Forms_Library/9.4.1_Applicant-Recipient_Forms/9.4.1_Form_204-205_ED_App_Paper_5-9-24.pdf.

Alaska: ALASKA DEP'T OF HEALTH, APPLICATION FOR SERVS. 4 (2024), <http://dpaweb.hss.state.ak.us/e-forms/pdf/GEN-50C.pdf>.

Arkansas: ARK. DEP'T OF HUM. SERVS., APPLICATION FOR SNAP, HEALTH CARE, AND TEA/RCA BENEFITS 24–25 (2020), <https://humanservices.arkansas.gov/wp-content/uploads/DCO-0004.pdf>.

Colorado: CONNECT FOR HEALTH COLO. & COLO. DEP'T OF HEALTH CARE POL'Y & FIN., APPLICATION FOR HEALTH INSURANCE AND HELP PAYING COSTS 13 (2023), <https://hcpf.colorado.gov/sites/hcpf/files/Health%20First%20Colorado%20-%20Child%20Health%20Plan%20Plus%20Application%20-%20English.pdf>.

Connecticut: CONN. DEP'T OF SOC. SERVS., W-1LTSS APPLICATION FOR LONG-TERM SERVICES AND SUPPORTS W-0016RR 3 (2023), <https://portal.ct.gov/-/media/departments-and-agencies/dss/long-term-care/w1ltss-packet-rev-123.pdf>.

Delaware: DEL. DEP'T OF HEALTH & SOC. SERVS. (DHSS), APPLICATION FOR FOOD BENEFITS, CASH, MEDICAL, AND CHILD CARE ASSISTANCE 14 (2016), https://www.dhss.delaware.gov/dhss/dss/files/Form100_Application_42016ENGLISH.pdf.

Florida: FLA. DEP'T OF CHILD. & FAMS., ACCESS FLA. APPLICATION 13 (2016) <https://www.myflfamilies.com/services/public-assistance/additional-resources-and-services/ess-forms> (follow “this application” hyperlink under subheading “ACCESS Florida Application”).

388. This Appendix includes publicly accessible long-term care applications and/or supplemental forms containing estate recovery language. If a state did not have a separate long-term care application or such application was not accessible, this Appendix includes the general Medicaid application if it contains estate recovery language. The following states are excluded from this Appendix because their applications could not be accessed or, if accessible, did not include estate recovery language: Arizona, California, Georgia, Kentucky, Mississippi, New Hampshire, Oklahoma, and Virginia.

Hawaii: HAW. DEP'T OF HUM. SERVS., EVALUATION FOR THE PLACEMENT OF LIENS 1 (2020), https://medquest.hawaii.gov/content/dam/formsanddocuments/client-forms/1169-evaluation-for-the-placement-of-liens/DHS_1169_Form_Rev_11_2020_11_16_20.pdf/jcr:content?type=pdf&process=.

Idaho: IDAHO DEP'T OF HEALTH & WELFARE, APPLICATION FOR MEDICAID 9 (2022), <https://publicdocuments.dhw.idaho.gov/WebLink/DocView.aspx?id=3174&dbid=0&repo=PUBLIC-DOCUMENTS&cr=1>.

Illinois: ILL. DEP'T OF HUM. SERVS., REQUEST FOR CASH ASSISTANCE – MEDICAL ASSISTANCE – SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP) 17, <https://hfs.illinois.gov/content/dam/soi/en/web/hfs/sitecollectiondocuments/il444-2378b.pdf> (last visited Oct. 7, 2024).

Indiana: DIV. OF FAM. RES., NOTICE REGARDING RIGHTS & RESPONSIBILITIES FOR HEALTH COVERAGE 2, <https://d2l2jhoszs7d12.cloudfront.net/state/Indiana/Indiana%20Family%20and%20Social%20Services%20Administration/Indiana%20Family%20and%20Social%20Services%20Administration/httpswww.in.govfssaforms.htm/Forms/55367.pdf> (last visited Oct. 7, 2024).

Iowa: IOWA HEALTH & HUM. SERVS., APPLICATION FOR HEALTH COVERAGE AND HELP PAYING COSTS 16 (Apr. 2024), <https://hhs.iowa.gov/media/5825/download?inline=>.

Kansas: KAN. DEP'T FOR AGING & DISABILITY SERVS., ELDERLY AND PERSONS WITH DISABILITIES MEDICAL ASSISTANCE APPLICATION 28 (Jan. 2023), https://www.kancare.ks.gov/docs/default-source/consumers/apply/elderly-and-disabled/kc-1500-elderly-and-persons-with-disabilities-medical-assistance-application_1-23.pdf?sfvrsn=8b5c531b_2

Louisiana: LA. DEP'T OF HEALTH, APPLICATION FOR LONG-TERM CARE SERVS. 12 (Jan. 2021), <https://ldh.la.gov/assets/medicaid/MedicaidEligibilityForms/LongTermCare.pdf>

Maine: OFF. FOR FAM. INDEP., APPLICATION FOR LONG TERM CARE MAINECARE 8, <https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/LTC%20Application.pdf> (last visited Oct. 7, 2024).

Maryland: MD. DEP'T OF HUM. RES., LONG-TERM CARE/WAIVER MED. ASSISTANCE APPLICATION 15 (Jul. 1, 2011), [https://health.maryland.gov/mmcp/Medicaid%20Applications/LTC%20Application%20FINAL%207-1-11%20-2_508v5%20\(1\).pdf](https://health.maryland.gov/mmcp/Medicaid%20Applications/LTC%20Application%20FINAL%207-1-11%20-2_508v5%20(1).pdf).

Massachusetts: EXEC. OFF. OF HEALTH AND HUM. SERVS., APPLICATION FOR HEALTH COVERAGE FOR SENIORS AND PEOPLE NEEDING LONG-TERM-CARE SERVS. 19, <https://www.mass.gov/doc/application-for-health-coverage-for-seniors-and-people-needing-long-term-care-services/download> (last visited Oct. 7, 2024).

Michigan: MICH. DEP'T OF HEALTH AND HUM. SERVS., ASSISTANCE APPLICATION 9 (Oct. 2023), https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Folder2/Folder79/Folder1/Folder179/MDHHS-1171_Assistance_Application_and_Program_Supplements.pdf?rev=d621397c500d409287a3446bbfd06523&hash=B4FA68B5AA2DD826DA5141428926CC4A.

Minnesota: MINN. DEP'T OF HUM. SERVS., APPLICATION FOR HEALTH COVERAGE AND HELP PAYING COSTS 22 (Nov. 2023), <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6696-ENG>.

Missouri: MO. DEP'T OF SOC. SERVS., APPLICATION FOR HEALTH COVERAGE & HELP PAYING COSTS 8 (2023), <https://dssmanuals.mo.gov/wp-content/uploads/2020/09/IM-1SSL-Fillable-Secured-6-24-21.pdf>.

Montana: MONT. DEP'T OF PUB. HEALTH & HUM. SERVS., APPLICATION FOR LONG-TERM CARE OR RELATED MED. ASSISTANCE 4 (2014), https://forms.benefitscheckup.org/mt_mdcd_nursing_home_hcbs_eng_app.pdf.

Nebraska: NEB. DEP'T OF HEALTH & HUM. SERVS., APPLICATION FOR NEBRASKA MEDICAID FOR AGED AND DISABLED 7 (2020), <https://public-dhhs.ne.gov/Forms/DisplayPDF.aspx?item=3114>.

Nevada: NEV. DEP'T OF HEALTH & HUM. SERVS., APPLICATION FOR ASSISTANCE 6 (2024), https://dwss.nv.gov/uploadedFiles/dwssnv.gov/content/Home/Features/Forms/2920-EM_Application%20for%20Assistance%20Medicaid-MAABD-SNAP.pdf.

New Jersey: N.J. DEP'T OF HUM. SERVS., NJ FAMILYCARE AGED, BLIND, DISABLED PROGRAMS APPLICATION 14 (2022), https://www.nj.gov/humanservices/dmahs/clients/medicaid/abd/ABD_Application.pdf.

New Mexico: N.M. HUM. SERVS. DEP'T, MEDICAID APPLICATION 14 (2020), https://www.hsd.state.nm.us/wp-content/uploads/2020/12/HSD-100-revised-2_24_20-2.pdf.

New York: N.Y. STATE DEP'T OF HEALTH, SUPPLEMENT A 8 (2015),

<https://www.nyc.gov/assets/hra/downloads/pdf/services/micsa/DOH-4495A%20Supplement%20A.PDF>.

North Carolina: N.C. DEP'T OF HEALTH & HUM. SERVS., APPLICATION FOR HEALTH COVERAGE & HELP PAYING COSTS 20, <https://policies.ncdhhs.gov/wp-content/uploads/dhb-5200-ia-9-2020.pdf> (last visited Oct. 7, 2024).

North Dakota: N.D. DEP'T OF HEALTH & HUM. SERVS., MEDICAID APPLICATION FOR THE ELDERLY AND DISABLED 12 (2024), <https://apps.nd.gov/itd/recmgmt/rm/stFrm/efrms/Doc/sfn00958.pdf>.

Ohio: OHIO DEP'T OF JOB & FAM. SERVS., SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (SNAP), CASH, MED., AND/OR CHILD CARE ASSISTANCE APPLICATION 16 (2024), <https://www.odjfs.state.oh.us/forms/num/JFS07200/pdf>.

Oregon: OR. HEALTH AUTH., APPLICATION FOR OR. HEALTH PLAN BENEFITS 38, 40, (2020), <https://shredsystems.dhsoha.state.or.us/DHSforms/Served/he7210.pdf>.

Pennsylvania: PA. DEP'T OF HUM. SERVS., MED. ASSISTANCE (MEDICAID) FIN. ELIGIBILITY APPLICATION FOR LONG TERM CARE, SUPPORTS AND SERVS. 8, <https://www.pa.gov/content/dam/copapwp-pagov/en/dhs/documents/services/assistance/documents/benefits-applications/PA-600-L-AS-5-20-Final.pdf> (last visited Oct. 7, 2024).

Rhode Island: R.I. DEP'T OF HUM. SERVS., R.I. DEP'T OF HUM. SERVS. APPLICATION FOR ASSISTANCE 31 (2016), https://eohhs.ri.gov/Portals/0/Uploads/Documents/Applications/DHS-2_English_Rev09-16.pdf; R.I. DEP'T OF HUM. SERVS., LIEN AND RECOVERY NOTICE 1 (1998), https://eohhs.ri.gov/sites/g/files/xkgbur226/files/Portals/0/Uploads/Documents/MA_89_LR.pdf (last visited Oct. 7, 2024).

South Carolina: S.C. DEP'T OF HEALTH & HUM. SERVS., APPLICATION FOR MEDICAID AND AFFORDABLE HEALTH COVERAGE 14 (2024), <https://www.scdhhs.gov/sites/default/files/documents/FM%203400-compressed.pdf>.

South Dakota: S.D. DEP'T OF SOC. SERVS., APPLICATION FOR RES. ASSESSMENT, LONG-TERM CARE, OR OTHER RELATED MED. ASSISTANCE 15 (2023), <https://dss.sd.gov/formsandpubs/docs/MEDELGBLTY/EA240.pdf>.

Tennessee: TENN. DEP'T OF FIN. & ADMIN., DIV. OF TENNCARE, APPLICATION FOR HEALTH COVERAGE & HELP PAYING COSTS 15 (2024), <https://www.tn.gov/content/dam/tn/tenncare/documents/TEDSPaperApp.pdf>.

Texas: TEX. HEALTH & HUM. SERVS., MEDICAID APPLICATION FOR THE ELDERLY AND PEOPLE WITH DISABILITIES 20 (2022), https://www.yourtexasbenefits.com/GeneratePDF/StaticPdfs/en_US/H1200_Jan2022.pdf; TEX. HEALTH & HUM. SERVS., MEDICAID EST. RECOVERY PROGRAM RECEIPT ACKNOWLEDGEMENT 1-2 (2020), <https://www.hhs.texas.gov/sites/default/files/documents/laws-regulations/forms/8001/8001.pdf>.

Utah: UTAH DEP'T OF HEALTH & HUM. SERVS., MEDICAID APPLICATION 9 (2023), [https://medicaid.utah.gov/Documents/pdfs/61MED%20\(10.23\)%20eDOCs_D2232390074_.pdf](https://medicaid.utah.gov/Documents/pdfs/61MED%20(10.23)%20eDOCs_D2232390074_.pdf).

Vermont: DEP'T OF VT. HEALTH ACCESS, APPLICATION FOR LONG-TERM CARE MEDICAID 13 (2018), <https://dvha.vermont.gov/sites/dvha/files/documents/Members/202LTC%2002%2018-1.pdf>; DEP'T OF VT. HEALTH ACCESS, LONG-TERM CARE RECOVERY FROM EST. 1 (2012), https://dvha.vermont.gov/sites/dvha/files/doc_library/204REC%20fillable.pdf.

Washington: WASH. STATE HEALTH CARE AUTH., WASH. APPLE HEALTH APPLICATION FOR AGED, BLIND, DISABLED/LONG-TERM SERVS. AND SUPPORTS 17 (2023), <https://www.hca.wa.gov/assets/free-or-low-cost/18-005.pdf>.

West Virginia: W. VA. HEALTH & HUM. RES., APPLICATION FOR LONG TERM CARE MEDICAID AND CHILD. WITH DISABILITIES CMTY. SERV. PROGRAM 7 (2022), <https://dhhr.wv.gov/bfa/programs/Documents/DFA-MA-1%20Application%20for%20Long%20Term%20Care%20Medicaid%20Rev%2010-22.pdf>.

Wisconsin: WIS. DEP'T OF HEALTH SERVS., WISCONSIN MEDICAID FOR THE ELDERLY, BLIND OR DISABLED APPLICATION PACKET 4 (2024), <https://www.dhs.wisconsin.gov/forms/fl/f10101.pdf>.

Wyoming: WYO. DEP'T OF HEALTH, APPLICATION FOR HEALTH COVERAGE & HELP PAYING COSTS APP. D (2023), <https://health.wyo.gov/wp-content/uploads/2023/01/Application-for-Health-Coverage-Help-Paying-Costs-January-2023-10-1.pdf>.

APPENDIX B

Estate Recovery Brochures or Similar Documents³⁸⁹

Alabama: ALA. MEDICAID AGENCY, ALABAMA ESTATE RECOVERY PROGRAM Q AND A (2023), https://medicaid.alabama.gov/documents/7.0_Providers/7.1_Benefit_Coordination_3rd_Party/7.1.1_Estate_Recovery/7.1.1_Estate_Recovery_FAQs_12-22-23.pdf.

Alaska: ALASKA DEP'T OF HEALTH & SOC. SERVS., ALASKA MEDICAID RECIPIENT HANDBOOK (2020), <https://health.alaska.gov/dhcs/Documents/PDF/Recipient-Handbook.pdf>.

Arizona: ARIZ. HEALTH CARE COST CONTAINMENT SYS., STATE OF ARIZONA MEDICAID ESTATE RECOVERY PROGRAM (2024), https://www.azahcccs.gov/Members/Downloads/Publications/DE-810_english.pdf.

Arkansas: ARK. DEP'T OF HUM. SERVS., YOUR GUIDE TO MEDICAID ESTATE RECOVERY IN ARKANSAS (2010,) https://humanservices.arkansas.gov/wp-content/uploads/Your_Guide_to_Medicaid_Estate_Recovery_in_Arkansas.pdf.

California: CAL. DEP'T OF HEALTH CARE SERVS., MEDI-CAL ESTATE RECOVERY (2017), https://www.dhcs.ca.gov/services/Documents/ER_Brochure_Eng_0619.pdf.

Georgia: GA. DEP'T OF CMTY. HEALTH, MEDICAID AND ESTATE RECOVERY (2017), <https://medicaid.georgia.gov/organization/about-georgia-medicaid/medicaid-fact-sheets> (follow “Medicaid and Estate Recovery” hyperlink).

Idaho: IDAHO DEP'T OF HEALTH & WELFARE, IDAHO MEDICAID ESTATE RECOVERY PROGRAM (2023), <https://publicdocuments.dhw.idaho.gov/WebLink/DocView.aspx?id=29213&dbid=0&repo=PUBLIC-DOCUMENTS>; IDAHO DEP'T OF HEALTH & WELFARE, IDAHO MEDICAID HEALTH PLAN BOOKLET (2024), <https://publicdocuments.dhw.idaho.gov/WebLink/DocView.aspx?id=2080&dbid=0&repo=PUBLIC-DOCUMENTS&cr=1>.

Illinois: ILL. DEP'T OF HEALTHCARE & FAM. SERVS., HFS 3191 LONG TERM SERVICES & INFORMATION FOR COUPLES (Feb. 2015), <https://hfs.illinois.gov/info/brochures-and-forms/brochures/hfs3191.html>.

389. This Appendix includes brochures and other similar documents regarding estate recovery that appear to be intended for public distribution and that were found on state government websites. This list is meant to be illustrative only, as state Medicaid agencies and/or their contractors may distribute documents related to estate recovery that are not publicly accessible.

Iowa: HEALTH AND HUM. SERVS., IMPORTANT INFORMATION FOR YOU AND YOUR FAMILY MEMBERS ABOUT THE ESTATE RECOVERY PROGRAM (Mar. 2024), <https://hhs.iowa.gov/media/6458/download?inline=>.

Kansas: KAN. DEP'T OF HEALTH & ENV'T, KANSAS MEDICAL ASSISTANCE FACT SHEET: ESTATE RECOVERY (Sept. 2021), https://kancare.ks.gov/docs/default-source/consumers/benefits-and-services/fact-sheets/fs-5-estate-recovery-fact-sheet.pdf?sfvrsn=eae7501b_2.

Kentucky: KY. CABINET FOR HEALTH & HUM. SERVS., DEP'T FOR MEDICAID SERVS., MEDICAID ESTATE RECOVERY FACT SHEET, <https://www.chfs.ky.gov/agencies/dms/MAPForms/MAP708.pdf> (last visited Oct. 7, 2024).

Maine: ME. DEP'T OF HEALTH & HUMAN SERVS., ESTATE RECOVERY OVERVIEW (May 1, 2023), <https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Estate%20Recovery%20Overview%20.pdf>.

Maryland: DEP'T OF HEALTH AND MENTAL HYGIENE, MEDICAL ASSISTANCE (MEDICAID) PROPERTY LIENS & ESTATE RECOVERY FACT SHEET (Nov. 2006), https://health.maryland.gov/mmcp/docs/estatefactsheet_1106final.pdf.

Massachusetts: EXEC. OFF. OF HEALTH & HUM. SERVS., MASSHEALTH ESTATE RECOVERY FACT SHEET FOR MEMBERS, <https://www.mass.gov/doc/masshealth-estate-recovery-fact-sheet-for-members/download> (last visited Oct. 7, 2024).

Michigan: MICH. DEP'T OF HEALTH & HUM. SERVS., YOUR GUIDE TO ESTATE RECOVERY IN MICHIGAN (Jul. 6, 2017), https://www.michigan.gov/mdhhs/-/media/Project/Webistes/mdhhs/Folder2/Folder39/Folder1/Folder139/dch_3895.pdf; MICH. DEP'T OF HEALTH & HUM. SERVS., MICHIGAN ESTATE RECOVERY FREQUENTLY ASKED QUESTIONS (Dec. 23, 2015), https://www.michigan.gov/mdhhs/-/media/Project/Webistes/mdhhs/Folder1/Folder11/ER_FAQ.doc.

Minnesota: MINN. DEP'T OF HUM. SERVS., MINNESOTA HEALTH CARE PROGRAMS ESTATE RECOVERY AND LIENS (Oct. 2022), <https://edocs.dhs.state.mn.us/lfsrver/Public/DHS-7273-ENG>.

Mississippi: MISS. DIV. OF MEDICAID, MEDICAID FACT SHEET ESTATE RECOVERY, https://www.medicaid.ms.gov/wp-content/uploads/2015/05/Fact-Sheet_Estate-Recovery.pdf (last visited Oct. 7, 2024).

Missouri: MO. DEP'T OF SOC. SERVS., ESTATE RECOVERY (2011), https://dssmanuals.mo.gov/wp-content/themes/mogovwp_dssmanuals/public/memos/memos_13/im42_13att-estate-wp.pdf.

Montana: MONT. DEP'T OF PUB. HEALTH & HUM. SERVS., MONTANA MEDICAID LIEN & ESTATE RECOVERY PROGRAMS (2020), <https://medicaidprovider.mt.gov/docs/nursingfacility/SLTC-011MTMedicaidLienEstateRecoveryProg.pdf>.

Nebraska: NEB. DEP'T OF HEALTH & HUM. SERVS., NEBRASKA MEDICAID ESTATE RECOVERY (2021), <https://public-dhhs.ne.gov/Forms/DisplayPDF.aspx?item=3710>.

Nevada: NEV. DEP'T OF HEALTH & HUM. SERVS., MEDICAID ESTATE RECOVERY NOTIFICATION OF PROGRAM OPERATION (2019), <https://dhcfp.nv.gov/uploadedFiles/dhcfpnvgov/content/Providers/PI/MER%20NOTIFICATION%20OF%20PROGRAM%20OPERATION%20-%20English%20and%20Spanish.pdf>.

New Jersey: N.J. DEP'T OF HUM. SERVS., THE NEW JERSEY MEDICAID PROGRAM AND ESTATE RECOVERY WHAT YOU SHOULD KNOW (2017), <https://www.nj.gov/humanservices/dmahs/clients/>