

2019

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Recommended Citation

Tracy Douglas *Medicaid Waivers and Consumer Protection: Evidence from the States*, 28 *Annals Health L.* 101 (2019).

Available at: <https://lawcommons.luc.edu/annals/vol28/iss2/3>

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Medicaid Waivers and Consumer Protection: Evidence from the States

*Tracy Douglas**

In Indiana, Sue Fredericks struggled to stay insured through the Healthy Indiana Plan (HIP), which is Indiana's version of the Affordable Care Act's (ACA) Medicaid Expansion.¹ She lacked her boss' signature on her verification of employment for the yearly determination, so the state cancelled her insurance because she did not prove her income.² She called the helpline and was told she needed to apply for the HIP again, which meant starting from the beginning.³ Thus, she gave up, even though she qualified for Medicaid based on her income.⁴ She was also confused by the letters she received from the managed care organization (MCO) in charge of her health plan and did not understand the fees she needed to pay for coverage.⁵ She was surprised when HIP did not cover bills she incurred for a broken ankle before receiving coverage.⁶ The restrictions put in place by Indiana through a section 1115 demonstration waiver – resubmitting proof of income every year, paying a monthly premium, and not having retroactive coverage –⁷ impeded Sue's access to Medicaid, but the harmful effects on people like Sue have not been highlighted in the political or academic discussion of Medicaid waivers.

Legal scholars have addressed some aspects of access with Medicaid waivers and Medicaid expansion. A few scholars discuss problems with the

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1. Tracie McMillan, *How One Company Is Making Millions Off Trump's War on the Poor*, MOTHER JONES (Jan. 2019), <https://www.motherjones.com/politics/2018/12/how-one-company-is-making-millions-off-trumps-war-on-the-poor/>.

2. *Id.*

3. *Id.*

4. *Id.*

5. *Id.*

6. *Id.*

7. MaryBeth Musumeci et al., *Approved Changes in Indiana's Section 1115 Medicaid Waiver Exception*, HENRY J. KAISER FAM. FOUND. (Feb. 9, 2018), <https://www.kff.org/medicaid/issue-brief/approved-changes-in-indianas-section-1115-medicicaid-waiver-extension/>.

waiver process and whether waivers are permitted under the law.⁸ Some defend waivers as allowing policy innovation and compromise.⁹ Others analyze the political rhetoric in expansion states, comments before administrative agencies, and advocacy by Medicaid beneficiaries.¹⁰ Scholars also look at problems of managed care and access to care.¹¹ They have not, however, looked at the evidence of how the policies sanctioned by these waivers are operating in practice and how they are affecting access to Medicaid. The empirical evidence from waiver states suggests that, instead of improving state Medicaid programs and expanding access to health insurance for low-income people, section 1115 and section 1915 waivers have, in practice, impeded access and made it more difficult for enrollees to participate in Medicaid.¹²

This article will examine empirical evidence from waiver states and demonstrate that these policies are destructive and antithetical to the objectives of Medicaid in contradiction to the purpose of waivers. The waivers, in effect, outsource administrative processes to private companies and leave Medicaid enrollees entangled in a web designed to impede access to healthcare and health insurance, at the mercy of a bureaucracy that they often do not understand.¹³ The outsourcing to private insurance companies is similar to how the Obama administration farmed out the Making Home

8. See generally Sidney D. Watson, *Out of the Black Box and Into the Light: Using Section 1115 Medicaid Waivers to Implement the Affordable Care Act's Medicaid Expansion*, 15 YALE J. HEALTH POL'Y, L., & ETHICS 213 (2015) [hereinafter Watson Black Box]; see also generally Laura D. Hermer, *On the Expansion of "Welfare" and "Health" Under Medicaid*, 9 ST. LOUIS UNIV. J. OF HEALTH L. AND POL'Y, 235 (2016); see also generally Sidney D. Watson, *Premiums and Section 1115 Waivers: What Cost Medicaid Expansion?*, 9 ST. LOUIS U. J. HEALTH L. & POL'Y 265 (2016) [hereinafter Watson Premiums].

9. See generally Barron & Rakoff, *supra* note 28, at 265; see also generally Gilliam E. Metzger, *Agencies, Polarization and the States*, 115 COLUM. L. REV. 1739 (2015); see also generally Jessica Bulman-Pozen, *Executive Federalism Comes to America*, 102 VA. L. REV. 953 (2016).

10. See generally Colleen M. Grogan, Phillip M. Singer, & David K. Jones, *Rhetoric and Reform in Waiver States*, 42 J. HEALTH POL., POL'Y, & L. 247 (2017); see also generally Marian Jarlenski, Philip Rocco, Renuka Tipimani, Amy Jo Kennedy, Nivedita Gunturi, & Julie Donohue, *Shaping Health Policy for Low-Income Populations: An Assessment of Public Comments in a New Medicaid Waiver Process*, 42 J. HEALTH POL., POL'Y, & L. 1039 (2017); see also generally Ashley Tallevi, *Out of Sight, Out of Mind? Measuring the Relationship between Privatization and Medicaid Self-Reporting*, 43 J. HEALTH POL., POL'Y, & L. 137 (2018).

11. See generally Jacobi, *infra* note 20; see also generally Brad Wright, Andrew J. Potter & Matthew C. Nattinger, *Iowa Wavering on Medicaid: From Expansion to Modernization*, 41 J. HEALTH POL., POL'Y, & L. 287 (2016); see also generally Crossley, *infra* note 21.

12. Grogan et al., *supra* note 10, at 247; Jarlenski et al., *supra* note 10, at 1043 (showing Medicaid Section 115 Waivers were approved in 5 states that limited benefits for nonfrail adults).

13. Jacobi, *infra* note 20.

Affordable loan modifications with little oversight to the very banks that caused the housing crisis in 2008 and left those homeowners vulnerable to a confusing process.¹⁴

Part I provides a background on section 1115 and 1915(b) waivers. Part II looks at the state of scholarship on waivers while Part III examines the available evidence from waiver states. Part IV concludes with a proposal for changing the conversation to include a discussion of consumer protection.

I. SECTION 1115 AND SECTION 1915 WAIVERS, A HISTORY

Section 1115 and section 1915(b) of the Social Security Act allow states to deviate from Medicaid program requirements in their state plans after receiving permission from the federal government.¹⁵ Section 1115 waivers, otherwise known as demonstration waivers, test new approaches to Medicaid,¹⁶ while section 1915 waivers allow states to use home and community-based services and managed care.¹⁷ The intended purpose of Medicaid waivers, especially section 1115 waivers, is to test ideas that are not consistent with program requirements.¹⁸ Waivers must also improve Medicaid and serve the objective of Medicaid, which is to improve access to health insurance and healthcare for low-income people.¹⁹

Managed care allows states to contract with commercial plans that manage healthcare claims and payments to providers instead of a state agency administering Medicaid.²⁰ At first, every use of managed care required a waiver, but Congress amended the law in 1997 to allow voluntary managed care enrollment without a waiver with the exception of children with special needs and dual eligibilities.²¹ This means states must have a waiver to require those recipients to be in managed care.²² Since the late 90s, managed care

14. Gretchen Morgenson, *A Slack Lifeline for Drowning Homeowners*, N.Y. TIMES (July 31, 2015), <https://www.nytimes.com/2015/08/02/business/pulling-down-underwater-borrowers.html>.

15. Social Security Act, 42 U.S.C. § 1315 (2014); *see also* Social Security Act, 42 U.S.C. § 1396 (2018).

16. Social Security Act, 42 U.S.C. § 1315 (2014).

17. Social Security Act, 42 U.S.C. § 1396n(b)(c) (2018).

18. Social Security Act, 42 U.S.C. § 1396n(b) (2018).

19. Social Security Act, 42 U.S.C. § 1396 (2018).

20. John V. Jacobi, *Medicaid, Managed Care, and the Mission for the Poor*, 9 ST. LOUIS U. J. HEALTH L. & POL'Y 187, 189 (2016).

21. Mary A. Crossley, *Giving Meaning to "Meaningful Access" in Medicaid Managed Care*, 102 KY. L. J. 1, 14 (2014).

22. Medicaid Program; Medicaid Managed Care, 66 Fed. Reg. 43613, 43615 (proposed Aug. 20, 2001) (to be codified at 42 C.F.R. pt. 438).

expanded across all of the states,²³ in 2010, thirty-five states and D.C. used managed care.²⁴

Section 1115 waivers predate Medicaid by three years with the original purpose of allowing experiments in state-administered public welfare programs authorized by the Social Security Act;²⁵ therefore, section 1115 demonstration waivers have existed since the 1965 creation of Medicaid as a program of health insurance for certain impoverished populations, such as pregnant women, children, and the disabled.²⁶ Indeed, the concept of a waiver from federal law has existed for some time, at least since the 1960s,²⁷ allowing Congress to frame the regulatory approach while giving the agency freedom in application and enforcement of the law.²⁸ However, the nature of section 1115 waivers changed in the wake of the Supreme Court's decision that Medicaid expansion through the ACA could not be mandatory.²⁹ To expand Medicaid in states hostile to the expansion, the federal government agreed to policy concessions otherwise not allowed by the Social Security Act, including premiums, lockout periods, disenrollment for untimely renewals, and co-payments.³⁰ President Trump's administration changed the character of these policy concessions by actively encouraging work requirement proposals and granting waiver applications to those that requested them.³¹

A. Section 1115 Waivers: Experimenting with Program Requirements

Section 1115 waivers allow states with federal approval to try novel approaches that differ from the requirements of Medicaid and conduct an

23. Marguerite E. Burns, *Medicaid Managed Care and Health Care Access for Adult Beneficiaries with Disabilities*, 44 HEALTH SERVICES RES. 1521, 1522 (2009).

24. Kyle J. Caswell & Sharon K. Long, *The Expanding Role of Managed Care in the Medicaid Program: Implications for Health Care Access, Use, and Expenditures for Nonelderly Adults*, INQUIRY 1, 1 (2015).

25. Sara Rosenbaum, *The Trump Administration Re-Imagines Section 1115 Medicaid Demonstrations – And Medicaid*, HEALTH AFFAIRS BLOG (Nov. 9, 2017), <https://www.healthaffairs.org/doi/10.1377/hblog20171109.297738/full/>.

26. Social Security Amendment of 1965, Pub. L. No. 89-97, 79 Stat. 286 (1965) (codified as amended at 42 U.S.C. § 1396 (1965)). Jarlenski et al., *supra* note 10, at 1040.

27. Edward H. Stiglitz, *Forces of Federalism, Safety Nets, and Waivers*, 18 THEORETICAL INQUIRIES L. 125, 131 (2017).

28. David J. Barron & Todd D. Rakoff, *In Defense of Big Waiver*, 113 COLUM. L. REV. 265, 265 (2013).

29. Anne McKenzie, *Section 1115 Waivers, The Future of Medicaid Expansion*, 27 HEALTH LAW. 12, 13-15 (2015).

30. Elizabeth Hinton, MaryBeth Musumeci, Robin Rudowitz, Larisa Antonisse, & Cornelia Hall, *Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers*, HENRY J. KAISER FAM. FOUND. (Feb. 12, 2019), <https://www.kff.org/medicaid/issue-brief/section-1115-medicare-demonstration-waivers-the-current-landscape-of-approved-and-pending-waivers/>.

31. *Id.*

empirical evaluation of the trial period.³² The trial period is typically a five-year period and can be extended, usually for three years.³³ Additionally, section 1115 waivers must further the objectives of Medicaid and cannot waive some requirements.³⁴ For example, the Secretary of Health and Human Services (HHS) cannot waive the federal matching payment system or the right to a fair hearing.³⁵

Waivers began as a Kennedy-era law intended to let states test new approaches to social welfare programs under the Social Security Act.³⁶ Indeed, they were described as a minor provision that would allow research.³⁷ Section 1115 waivers were used sparingly for Medicaid until the 1990s and 2000s.³⁸ During this time, waivers came into heavy use as both President Clinton and President George W. Bush's administrations wanted to expand health insurance to childless adults,³⁹ and with the Bush administration wanting to expand privatization of Medicaid.⁴⁰ One view, similar to those who argue that waivers promote compromise, is that the Clinton and Bush administrations viewed waivers as a way to respond to states' desires and not as a way to further policy learning.⁴¹ The ACA expanded Medicaid to cover childless adults aged nineteen to sixty-four with incomes up to 133 percent of poverty,⁴² but in 2012, the Supreme Court made Medicaid expansion optional.⁴³ As a result, power transferred to the states because the federal government could not mandate expansion; instead, states could negotiate for changes to the program through waivers in exchange for agreeing to expand Medicaid.

B. Section 1915 Waivers: Allowing Managed Care

States outsource the administration of Medicaid to private insurance companies through managed care, authorized either by statute for voluntary

32. Social Security Act, 42 U.S.C. § 1315 (2014); *see also* Hinton et al., *supra* note 30, at 1-2.

33. Social Security Act, 42 U.S.C. § 1315 (2014); *see also* Hinton et al., *supra* note 30, at 1-2.

34. Hinton et al., *supra* note 30, at 2.

35. Hinton et al., *supra* note 30, at 2.

36. Rosenbaum, *supra* note 25, at 3.

37. Wilbur J. Cohen & Robert M. Ball, *The Public Welfare Amendments of 1962 and Proposals for Health Insurance for the Aged*, SOC. SECURITY BULL. 3, 5 (1962).

38. Watson Black Box, *supra* note 8, at 219; *see also* Jarlenski et al., *supra* note 10, at 1041.

39. Watson Black Box, *supra* note 8, at 219; *see also* Jarlenski et al., *supra* note 10, at 1041.

40. Hermer *supra* note 8, at 238; *see also* Jarlenski et al., *supra* note 10.

41. Jarlenski et al., *supra* note 10, at 1042.

42. Social Security Act, Pub. L. No. 74-271, § 1902(a)(10)(A)(i)(VIII), 49 Stat. 620, 1982 (1935) (codified as amended at U.S.C. § 1396a (2012)).

43. Nat'l Fed'n of Indep. Bus. v. Sebelius, 567 U.S. 519, 588 (2012).

enrollment or by waiver for children with special needs and dual eligibilities.⁴⁴ Before the rise of managed care, states used the fee-for-service (FFS) model where an enrollee selected a provider who accepted Medicaid, and then that provider submitted claims for reimbursement to the state for each instance of service provided to the enrollee.⁴⁵ Medicaid managed care began in the 1980s, but by the 1990s, states turned to it to increase quality of care and improve access to providers.⁴⁶ States also justified Medicaid managed care as a cost-saving measure on the theory that commercial plans would cost less than the traditional FFS model because capitation payments would incentivize providers to offer efficient services to control costs.⁴⁷

Managed care organizations (MCO) function much like a managed health care plan in private health insurance by using a combination of primary care physicians, referrals to specialists, prior authorizations, and care coordination to control access to services.⁴⁸ The state pays a capitation payment per enrollee, which is a fixed monthly payment, and the MCO provides the necessary services to the enrollee.⁴⁹ Although the use of MCOs grew throughout the 1990s and 2000s, expansion to include enrollees with disabilities occurred largely as a result of the 2008 financial crisis and the adoption of the ACA.⁵⁰ States wanted to control Medicaid costs when they experienced a decline in state tax revenues after the financial crisis and an expected increase in the number of Medicaid enrollees from expansion in the ACA.⁵¹ By 2014, thirty-nine states used managed care to provide services, and in 2016, estimates projected that 76 percent of the Medicaid population would be enrolled in managed care.⁵²

Although the political discussion has focused on lowering costs and improving access to care, consideration of the effects of leaving enrollees at the mercy of MCOs that have their own bureaucracies separate from the state agency is missing from the discussion. Indeed, most of the legal scholarship on Medicaid waivers focuses on whether the waivers are an example of compromise between states and the federal government or not allowed by the

44. Crossley, *supra* note 21, at 14.

45. Kiyoshi Yamaki et al., *Impact of Medicaid Managed Care on Illinois's Acute Health Services Expenditures for Adults with Intellectual and Developmental Disabilities*, 56 *INTELL. & DEVELOPMENTAL DISABILITIES* 133, 133 (2018).

46. Jacobi, *supra* note 20, at 201.

47. Yamaki et al., *supra* note 45, at 134.

48. Yamaki et al., *supra* note 45, at 133.

49. Yamaki et al., *supra* note 45, at 133.

50. Yamaki et al., *supra* note 45, at 134.

51. Yamaki et al., *supra* note 45, at 134.

52. Wright et al., *supra* note 11, at 294.

Social Security Act.⁵³ The effects of these policies as demonstrated in empirical studies is absent from the discussion, which this article seeks to remedy.

II. STATE OF SCHOLARSHIP AND RESEARCH

Legal scholarship has addressed the concept of waivers from federal law as a policy.⁵⁴ The first wave of scholarship defended waivers as an example of federalism and flexibility in regulation.⁵⁵ In this view, Congress writes legislation as a first attempt at regulation and then the administrative state makes a workable scheme, using waivers if necessary.⁵⁶ Waivers are a means of controlling concerns because the application of waivers makes the regulatory scheme less rigid.⁵⁷ Congressional gridlock and partisan polarization prevent legislation from advancing in Congress, while agencies advance the agenda of the President, and in such a polarized atmosphere, waivers can give power to states in negotiations with agencies.⁵⁸ Legislative gridlock leads to executive power in policymaking through agencies, but states have power through waivers.⁵⁹ Seen through this lens, Medicaid waivers are an example of accommodation and compromise with the states.⁶⁰ Medicaid waivers also allowed expansion in so-called red states by enabling policymakers “to meet in the middle.”⁶¹ While the aforementioned scholarship generally approves of waivers, especially Medicaid waivers, as a tool of compromise and accommodation from the viewpoint of administrative law and federalism, later scholarship began to question whether some policies implemented through section 1115 waivers are allowed.⁶²

More recent critical scholarship makes the case that the Secretary does not have the power to waive portions of Medicaid requirements that some states seek to waive with their section 1115 applications.⁶³ Previous legal scholarship was lacking because it did not address inequality and viability of safety net programs.⁶⁴ In this more critical light, waivers should not be cheered but viewed with suspicion because they are a devolution in offering

53. *See, e.g.* Watson Premiums, *supra* note 8, at 268 (discussing the legal restrictions on states issuing Medicaid waivers).

54. *See, e.g.*, Watson Black Box, *supra* note 8.

55. *See, e.g.* Barron & Rakoff, *supra* note 28.

56. Barron & Rakoff, *supra* note 28, at 269, 336.

57. Barron & Rakoff, *supra* note 28, at 270.

58. Metzger, *supra* note 9, at 1748.

59. Bulman-Pozen, *supra* note 9, at 955.

60. Metzger, *supra* note 9, at 1782.

61. McKenzie, *supra* note 29, at 17.

62. Watson Premiums, *supra* note 8, at 269.

63. Watson Premiums, *supra* note 8, at 269.

64. Stiglitz, *supra* note 27, at 128.

stingy benefits and agencies not having enough information while scholars cheer policy innovation and compromise, not its effects.⁶⁵ Such a suspicious perspective points out that the ACA added notice and comment requirements to the section 1115 waiver process, but the Secretary does not have authority to waive parts of the law banning premiums and co-payments, nor does the Secretary have the power to authorize work requirements.⁶⁶ Instead of accepting it as a given, the Secretary needs to spell out how he has this authority.⁶⁷

Delving more specifically into waiver states, the HIP was justified as imposing personal responsibility on Medicaid expansion beneficiaries by requiring premiums, co-payments, disenrolling and lockouts,⁶⁸ while Oregon's program aimed to use a waiver to contain costs by emphasizing better outcomes, to provide better care and to improve health.⁶⁹ Before approving requests, the Secretary needs more data to support the idea behind the changes, i.e. that personal responsibility requirements support the objectives of Medicaid, which aim to increase coverage, increase access, improve health outcomes, and increase efficiency and quality of care.⁷⁰ Since the objective of Medicaid is not to teach personal responsibility, then the waiver proposals should be rejected.⁷¹

Recent waivers approved work requirements.⁷² It can be argued, though, that they not only reduce coverage but also do not promote Medicaid objectives or comply with legal requirements and are inconsistent with Congress specifically never approving work requirements for Medicaid.⁷³ Consistent with this analysis, courts should find them arbitrary and capricious.⁷⁴ The court in *Stewart v. Azar* concluded the same in rejecting Kentucky's work requirements.⁷⁵ While these articles discuss the specifics of waivers in Indiana and Oregon, for example, they do not look at what practical effects the waivers have had on the Medicaid population, largely because the data was not available yet. The data is, however, an important consideration in evaluating whether these waiver policies do, in fact, further the objectives of Medicaid or instead, create barriers to access to insurance and care.

65. Stiglitz, *supra* note 27, at 129-30.

66. Watson Black Box, *supra* note 8, at 213.

67. Watson Premiums, *supra* note 8, at 296.

68. Hermer, *supra* note 8, at 253.

69. Hermer, *supra* note 8, at 258-59.

70. Hermer, *supra* note 8, at 256.

71. Hermer, *supra* note 8, at 258.

72. David A. Super, *A Hiatus in Soft-Power Administrative Law: The Case of Medicaid Eligibility Waivers*, 65 UCLA L. REV. 1590, 1599 (2018).

73. *Id.*

74. *Id.*

75. *Stewart v. Azar*, 313 F. Supp. 3d 237, 243 (D.D.C. 2018).

However, there have been some empirical studies in the legal scholarship on Medicaid expansion and waivers requested to implement expansion.⁷⁶ One study showed that support for Medicaid expansion varied widely by race and that when the size of a state's African American population increases and white support for expansion is low, there is less likelihood that expansion will occur.⁷⁷ A study on comments submitted in the notice and comment period of the waiver process found that comments submitted by citizens tended to include personal stories and also mentioned specific provisions of the waiver while advocacy groups requested specific policy changes.⁷⁸ The study concluded that specific policy suggestions could affect waiver approval because CMS placed limitations on some waivers.⁷⁹ The authors, however, believe there is a role for increasing public engagement in the comment process as a way to build a constituency among low-income citizens; indeed, they found that sixty-four percent of comments were submitted by citizens.⁸⁰ However, that hopefulness of building a constituency is undermined by another study suggesting that an effect of states outsourcing administration to private insurance companies may be that beneficiaries do not realize they are on Medicaid and thus, do not advocate or participate when changes are proposed.⁸¹

Those proposed changes often used specific rhetoric to make the case for limiting the state Medicaid programs.⁸² One study on political rhetoric in red states that implemented the Medicaid expansion found that conservative politicians argued they were not expanding Medicaid or building on the program because they were using a private option to expand or were imposing personal responsibility requirements.⁸³ The effect was to push rhetoric to the right in political terms and question the deservingness of the Medicaid expansion population.⁸⁴ Legal scholarship has not, however, looked at the evidence from the states about the waivers' effects or checked to see if the political rhetoric and justifications are supported by the evidence. In other words, the question must be asked whether the waivers actually encourage personal responsibility or consumer behaviors. Such an examination shows that they do neither, which is discussed in detail below.

76. See, e.g., *Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State*, HENRY J. KAISER FAM. FOUND. (Mar. 01, 2019), <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/>.

77. Colleen M. Grogan & Sunggeun (Ethan) Park, *The Racial Divide in State Medicaid Expansions*, 42 J. HEALTH POL., POL'Y & L. 539, 539 (2017).

78. Jarlenski et al., *supra* note 10, at 1049.

79. Jarlenski et al., *supra* note 10, at 1057.

80. Jarlenski et al., *supra* note 10, at 1039, 1049.

81. Tallevi, *supra* note 10, at 164.

82. Jarlenski et al., *supra* note 10, at 1055.

83. Grogan et al., *supra* note 10, at 248.

84. Grogan et al., *supra* note 10, at 249.

III. EVIDENCE FROM THE STATES

A. Managed Care: Outsourcing to Private Insurance Companies

Medicaid managed care outsourced the administration of state Medicaid plans to private insurance companies.⁸⁵ Waivers were required for this process to occur, so many section 1115 applications were for managed care in the 1990s.⁸⁶ However, Congress specifically authorized voluntary enrollment without a waiver, but a waiver is still needed to include disabled children and elderly adults.⁸⁷ States often claimed that managed care would reduce costs and improve access by leaving the FFS model that many doctors rejected.⁸⁸ Instead, capitation rates are used whereby the state pays the company one fee for a beneficiary.⁸⁹ This shift from the FFS model has been shown to not be associated with dramatic changes in health care access, but it is associated with decreased access for providers.⁹⁰ It has been shown that increases in the use of Medicaid managed care is associated with an increase in the probability of an ER visit and difficulty in seeing a specialist.⁹¹

Managed care focuses on the payment of claims rather than the social determinants of health for low-income people,⁹² and research indicates that it does not save money or improve access to care, contrary to the official justifications.⁹³ Studies show that MCOs have not lowered costs in practice, especially for nonelderly enrollees overall or nonelderly adults with disabilities.⁹⁴ Additionally, the evidence showing that MCOs increase access to care is mixed.⁹⁵ Some studies show increased reliance on emergency departments as a usual source of care while others show a decrease in the use of the emergency department.⁹⁶ Other studies show that mandatory MCO enrollees did not have better access to care, while others found that MCOs had some improvements in access to care.⁹⁷

Demonstrating the rise in Medicaid managed care, plans serve fifty-four million enrollees, up from twenty million in 2000, and those plans received

85. Caswell & Long, *supra* note 24, at 1.

86. Hermer, *supra* note 8, at 238.

87. Caswell & Long, *supra* note 24, at 1.

88. Yamaki et al., *supra* note 45, at 133-134.

89. Yamaki et al., *supra* note 45, at 133.

90. Caswell & Long, *supra* note 24, at 2.

91. Caswell & Long, *supra* note 24, at 8-9.

92. *See* Jacobi, *supra* note 20, at 194 (demonstrating that although Medicaid serves the poor population, where social determinants of health play a major factor in their healthcare, the Medicaid program only provides coverage for “mainstream” healthcare services).

93. Jacobi, *supra* note 20, at 201.

94. Caswell & Long, *supra* note 24, at 1.

95. Caswell & Long, *supra* note 24, at 1-2.

96. Caswell & Long, *supra* note 24, at 1-2.

97. Caswell & Long, *supra* note 24, at 2.

nearly \$300 billion from state governments, up from \$60 billion a decade ago.⁹⁸ States with so-called personal responsibility requirements in their waivers have mixed histories with managed care.⁹⁹ Indiana and Michigan had managed care plans before waiver applications, while Iowa and Arkansas had virtually no Medicaid beneficiaries in managed care before the waivers.¹⁰⁰ The political conversation in these waiver states revolved around personal responsibility for Medicaid enrollees, but the actions of managed care organizations have generally not been questioned.¹⁰¹

Managed care plans receive billions in tax payments as more than two-thirds of Medicaid enrollees are served by those plans in thirty-eight states, but MCOs receive little oversight from state governments.¹⁰² Plans receive payments from states to pay for enrollees, but the MCOs can keep what they do not spend.¹⁰³ This means profits come from greater efficiency or, more cynically, from not paying for necessary care and reaping the rewards of excess government payments.¹⁰⁴ One company, Maximus, receives millions in contracts from states to manage Medicaid systems.¹⁰⁵ Maximus then communicates directly with Medicaid beneficiaries, which can lead beneficiaries to misunderstand that they are not Medicaid enrollees.¹⁰⁶ This misunderstanding could further lead to beneficiaries not advocating when changes are proposed.¹⁰⁷ With few exceptions, state governments have not questioned MCOs to determine if there is a return on their investment in managed care; studies by academics and newspaper investigations show there is no savings while the industry insists it saves money and improves care.¹⁰⁸ Similarly, individual case studies in Iowa, Texas, Illinois and Kentucky show that there are severe administrative issues with state MCOs, issues that leave beneficiaries and their families at the mercy of a system they do not understand and that is rigged against them.¹⁰⁹

98. Chad Terhune, *Private Medicaid Plans Receive Billions in Tax Dollars, with Little Oversight*, NPR (Oct. 18, 2018, 5:00 AM), https://www.npr.org/sections/health-shots/2018/10/18/657862337/private-medicaid-plans-receive-billions-in-tax-dollars-with-little-oversight?utm_source.

99. Jarlenski et al., *supra* note 10, at 1042.

100. Jarlenski et al., *supra* note 10, at 1042.

101. Terhune, *supra* note 98.

102. Terhune, *supra* note 98.

103. Terhune, *supra* note 98.

104. Terhune, *supra* note 98.

105. McMillan, *supra* note 1.

106. McMillan, *supra* note 1.

107. McMillan, *supra* note 1.

108. Terhune, *supra* note 98.

109. See Clayworth, *infra* note 114 (Iowa case study); see also *The Preventable Tragedy*, *infra* note 132 (Texas case study); see also Koetting, *infra* note 144 (Illinois case study); see also Marton, *infra* note 169 (Kentucky case study).

i. Iowa: Problematic Appeals Processes

Iowa provides an interesting case study in the managed care experience because it initially used a private option to expand Medicaid, which fell apart because of a lack of plans.¹¹⁰ Iowa had previously steadily expanded the use of managed care first in 1986 through waiver for one county, then gradually expanded through the 90s and 2000s to more counties.¹¹¹ However, before mandating managed care for most enrollees in 2015 through a section 1915(b) waiver, very few enrollees were in managed care.¹¹² Iowa contracted with four MCOs in 2015, and two of those MCOs, Amerigroup and AmeriHealth, faced legal problems in Illinois for not properly enrolling beneficiaries and in Kentucky for falsely reporting the provision of services.¹¹³ Unfortunately, these problems in other states were a prologue for issues in Iowa.

Severe problems with ensuring care for disabled children and elderly beneficiaries have emerged.¹¹⁴ In one case, after the elderly beneficiary won on appeal at the state hearing, the MCO again denied the care when the beneficiary requested pre-authorization for renewal of services, which will likely put the beneficiary in an endless cycle of appeals.¹¹⁵ In another case, AmeriHealth denied a converted van to transport a wheelchair to a 6-year-old with spinal muscular atrophy.¹¹⁶ The ALJ ruled in the family's favor, saying that without the modified van, transportation could endanger the child's life.¹¹⁷ The denials of medically necessary care seem to be systemic in the Iowa managed care program.

The state Ombudsman found the managed care companies to be "stubborn and absurd" when asked to correct issues with denying care even after beneficiaries had won state agency hearings to receive the care.¹¹⁸ The Ombudsman cited that companies do not send notices of reduction of services with appeal rights when denying care because the companies claim they are not technically reducing services but instead claim members did not need services, services were duplicate or members accepted the plan with less services.¹¹⁹ They denied services to beneficiaries despite the beneficiary

110. Wright et al., *supra* note 11, at 291-293.

111. Wright et al., *supra* note 11, at 294.

112. Wright et al., *supra* note 11, at 295; *see also* Jarlenski et al., *supra* note 10, at 1042, 1063.

113. Wright et al., *supra* note 11, at 295.

114. Jason Clayworth, *Care Denied: How Iowa's Medicaid Maze is Trapping Sick and Elderly Patients in Endless Appeals*, DES MOINES REG. & TRIB. CO. (2018), <https://features.desmoinesregister.com/news/medicaid-denials/>.

115. IOWA OFFICE OF OMBUDSMAN, ANNUAL REPORT (2017).

116. Clayworth, *supra* note 114.

117. Clayworth, *supra* note 114.

118. IOWA OFFICE OF OMBUDSMAN, *supra* note 115.

119. *Id.* at 1.

winning an appeal, and took a year and a half to resolve a payment dispute.¹²⁰ These findings were similar to the Des-Moines Register's deep dive into Iowa's managed care system.¹²¹

The Des-Moines Register examined 201 Medicaid appeals that went before administrative law judges (ALJs) and involved the MCOs that took over administering Medicaid in Iowa in 2016.¹²² The newspaper found that the ALJs ruled for the beneficiary twenty-five times and for the companies thirty-eight times and 138 appeals were withdrawn before the hearings were held.¹²³ The number of appeals making it to a state agency hearing in 2017 dropped between twenty-eight to forty-four percent from the previous five years, but that can be attributed to the MCOs having internal appeals processes before the beneficiary can go to the Agency.¹²⁴ In three of the previous five years, Iowa did not have mandatory managed care, suggesting that there were more appeals under the traditional program.¹²⁵ The decrease is not necessarily attributed to fewer denials of care; beneficiaries may not appeal because they are not aware that they can appeal.

As also noted by the Ombudsman, companies do a poor job of letting beneficiaries know that they can appeal to the state agency.¹²⁶ This is similar to banks not letting borrowers know they have appeal rights under the Consumer Financial Protection Bureau rules.¹²⁷ The Ombudsman review discovered that Medicaid beneficiaries are routinely denied care by managed care companies, who often ignore state agency and court orders to provide the care or make a new determination to deny care after the hearing, thus triggering a new appeals process and leaving the beneficiary in a cycle of appeals.¹²⁸ The managed care system leaves beneficiaries caught in a maze of corporate and state bureaucracy, fighting just to receive the medically necessary care that they need and are entitled to receive.¹²⁹ Unfortunately, Iowa is not unique in the failings of its managed care system.

120. *Id.* at 1-2.

121. Clayworth, *supra* note 114.

122. Clayworth, *supra* note 114.

123. Clayworth, *supra* note 114.

124. Clayworth, *supra* note 114.

125. Clayworth, *supra* note 114.

126. *See* IOWA OFFICE OF OMBUDSMAN, *supra* note 115.

127. *See* Press Release, Consumer Financial Protection Bureau, Consumer Financial Protection Bureau Takes Action Against Flagstar Bank for Violating New Mortgage Servicing Rules (Sept. 29, 2014) (available at https://www.ftc.gov/system/files/documents/public_events/597241/ehrllich_borrowers_beware.pdf).

128. IOWA OFFICE OF OMBUDSMAN, *supra* note 115.

129. *See* Clayworth, *supra* note 114.

ii. Texas: Lackluster State Oversight

Beginning in 2013, Texas expanded managed care to cover most enrollees.¹³⁰ Until 2016, Texas also had an 1115(b) waiver for part of its managed care program.¹³¹ The Dallas Morning News conducted a series examining Texas' managed care companies and the effects on access to care.¹³² In that state, politicians suggested that managed care would lower costs and provide budget predictability.¹³³ In fact, costs have not lowered because the companies requested more money for their contracts, money that instead of going to beneficiaries for care goes to lobbyists for the companies.¹³⁴ Similar to the findings in Iowa, the Morning News found that insurance companies routinely denied care and left beneficiaries at the mercy of corporate and state bureaucracy to attempt to get the care they are entitled to and need.¹³⁵ The newspaper also discovered in the case of a disabled child, the representative for the managed care company was able to take over the state agency appeal hearing and overwhelmed the mother of a disabled child who expected to have a fair hearing.¹³⁶ Just as Iowa's Ombudsman pointed out that the MCOs make a mockery of the hearing process, the Dallas Morning News' investigation shows similar problems plague the Texas Medicaid program.¹³⁷

Overall, the newspaper documented many failings of Texas' managed care system.¹³⁸ It found 8,000 Texans had unmet medical needs and appeals rose twenty-six percent for the elderly and disabled adults and thirty-one percent for foster children.¹³⁹ Texas often fails to challenge or even review the MCO policies that deny care to thousands and they fail to fine the companies for

130. *Expansion of Managed Care*, TEX. HEALTH & HUMAN SERVICES, <https://hhs.texas.gov/services/health/medicaid-chip/provider-information/expansion-managed-care> (last visited Feb. 28, 2019).

131. MaryBeth Musumeci, *Key Themes in Capitated Medicaid Managed Long-Term Services and Supports Waivers*, HENRY J. KAISER FAM. FOUND. (Nov. 14, 2014), <http://files.kff.org/attachment/key-themes-in-capitated-medicicaid-managed-long-term-services-and-supports-waivers-issue-brief>.

132. J. David McSwane & Andrew Chavez, *The Preventable Tragedy of D'ashon Morris: When a Giant Health Care Company Wanted to Save Money, a Foster Baby Paid the Price*, DALL. MORNING NEWS (June 3, 2018), <https://interactives.dallasnews.com/2018/pain-and-profit/part1.html> [hereinafter *The Preventable Tragedy*].

133. *Id.*

134. *Id.*

135. *Id.*

136. *Id.*

137. *Id.*

138. *See Id.*

139. J. David McSwane & Andrew Chavez, *As Patients Suffer, Companies Profit: Years of Poor State Oversight Have Allowed Companies to Skimp on Essential Care for Sick Kids and Disabled Adults*, DALL. MORNING NEWS (June 3, 2018), <https://interactives.dallasnews.com/2018/pain-and-profit/part2.html>.

their wrongful behavior,¹⁴⁰ not unlike the Trump Administration's Consumer Financial Protection Bureau giving State Farm Bank a \$0 fine for its wrongful behaviors.¹⁴¹ Government watchdogs are asleep at the switch and not conducting true oversight.

One promise of managed care was that it would expand access to doctors when they were unwilling to take Medicaid under the FFS model, but in Texas, the companies often overstate how many doctors are in their networks and have not hired enough care coordinators to connect people with treatment.¹⁴² Unfortunately, these problems are not unique to Texas as they are remarkably similar to what the Iowa Ombudsman and the Des Moines Register found in that state and to what Medicaid beneficiaries in Illinois faced when it moved to managed care.¹⁴³

iii. Illinois: Administrative Processes

Illinois experienced several problems with its managed care and outsourcing of redeterminations.¹⁴⁴ Similar to Texas, Illinois politicians embraced managed care because of expected savings from leaving the traditional FFS model and did so in the wake of the financial crisis after losing tax revenues.¹⁴⁵ However, one study showed Illinois has not saved because its FFS model was already one of the lowest reimbursing in the country.¹⁴⁶ Thus, switching to capitation rates did not save the state money.¹⁴⁷ A state audit of Illinois MCOs found that costs ballooned under managed care, from \$212.8 million in fiscal year 2008 to \$7.11 billion in fiscal year 2016, but this can be explained by the switch to mandating managed care enrollment after 2014.¹⁴⁸ The audit discovered the state agency in charge of monitoring the companies was not keeping the necessary records, such as denial data or the actual administrative costs, to effectively

140. *Id.*

141. Ryan Denham, *State Farm Bank Sanctioned Over Handling of Credit Reports*, WGLT (Dec. 14, 2018), <http://www.wglt.org/post/state-farm-bank-sanctioned-over-handling-credit-reports#stream/0>.

142. J. David McSwane & Andrew Chavez, *Texas Pays Companies Millions for 'Sham Networks' of Doctors: Managed-Care Companies Overstate the Number of Physicians Available to Treat the State's Sickest patients*, DALL. MORNING NEWS (June 4, 2018), <https://interactives.dallasnews.com/2018/pain-and-profit/part3.html>.

143. See IOWA OFFICE OF OMBUDSMAN, *supra* note 115; Clayworth, *supra* note 114.

144. Michael Koetting, *Medicaid Contradictions: Adding, Subtracting, and Redetermination in Illinois*, 41 J. HEALTH POL., POL'Y & L. 225, 229, 233 (2016); see also Yamaki et al., *supra* note 45, at 141.

145. Yamaki et al., *supra* note 45, at 134.

146. Yamaki et al., *supra* note 45, at 141.

147. Yamaki et al., *supra* note 45, at 141.

148. FRANK J. MAUTINO, STATE OF IL. OFFICE OF THE AUDITOR GEN., PERFORMANCE AUDIT OF MEDICAID MANAGED CARE ORGANIZATIONS (2018).

monitor the managed care contracts.¹⁴⁹ The audit also found that the agency made duplicate capitation payments for the same beneficiary, thus showing an example of waste rather than savings, as promised by the political rhetoric.¹⁵⁰ The state sanctioned Blue Cross and Blue Shield of Illinois for having an inadequate network of doctors and hospitals for Medicaid enrollees in its managed care and for not responding to grievances and appeals.¹⁵¹ Although sanctioning is a step in the right direction, the audit shows concerning elements in the lack of state oversight.¹⁵²

The state has also faced several difficulties with outsourcing redeterminations for Medicaid and implementing a new IT system for redeterminations, which shows that private companies are not set up to handle Medicaid administration.¹⁵³ The first problem revolved around the state's 2011 contract with Maximus to handle checking the State's Medicaid rolls and to recommend anyone not in compliance be taken off the state's Medicaid rolls.¹⁵⁴ Maximus' early work on the contract was so poor that the State delayed payments for the first four months.¹⁵⁵ The State's union challenged the contract with Maximus because state law required the redeterminations to be done by state employees, and the arbitrator ultimately sided with the union.¹⁵⁶ However, Maximus made recommendations for cancellations, but those recommendations were made because the beneficiary failed to return paperwork to Maximus after a rushed process.¹⁵⁷ There is no way to discover how many beneficiaries who were removed were in fact ineligible, and this shows that a state or company can kick people off Medicaid just by making the process onerous.¹⁵⁸

The second problem surfaced when the state tried to modernize its redetermination system.¹⁵⁹ In 2017, the state implemented a new IT system

149. *Id.* at i, v, ix.

150. *Id.* at i.

151. Lisa Schencker, *Illinois Sanctions Blue Cross for Medicaid Program Violations*, CHI. TRIB. (Apr. 17, 2018), <https://www.chicagotribune.com/business/ct-biz-medicaid-blue-cross-sanctions-0419-story.html>.

152. MAUTINO, *supra* note 148, at i-ii.

153. Koetting, *supra* note 144, at 232-33; *see also* Rae Hodge, *DHS Flounders: \$300M IT System Still Kicking Countless Illinoisans Off Medicaid and SNAP, Caseworkers Overloaded, Claims Delayed Up to 7 Months*, DAILY LINE (May 1, 2018), <http://thedailyline.net/chicago/05/01/2018/dhs-flounders-300m-it-system-still-kicking-countless-illinoisans-off-medicaid-and-snap-caseworkers-overloaded-claims-delayed-up-to-7-months>.

154. Koetting, *supra* note 144, at 228-29.

155. McMillan, *supra* note 1, at 14.

156. Koetting, *supra* note 144, at 230.

157. Koetting, *supra* note 144, at 229.

158. Koetting, *supra* note 144, at 233-34.

159. Hodge, *supra* note 153, at 2.

for redeterminations, designed by Deloitte.¹⁶⁰ Immediately, the system caused errors and backlogs in the annual process.¹⁶¹ The system also wrongfully kicked thousands off Medicaid and the Supplemental Nutrition Assistance Program (SNAP) and delayed claims up to seven months as caseworkers were overloaded.¹⁶² This again demonstrates that one way to discourage enrollees is to make the process overly burdensome and difficult.

Former deputy director of the Illinois Department of Healthcare and Family Services Michael Koetting draws on his experiences at the state agency in charge of Medicaid by proposing a better process for redeterminations through first using available information to detect ineligibility, such as no longer being a state resident or being over-income, and if none is available, the default should be to assume eligibility.¹⁶³ Koetting also recommends making enrollee communications with the state and companies easy and having actual audits of databases.¹⁶⁴ Making communications with the companies easy would be key because, as the experiences of Iowa, Texas and Illinois show, beneficiaries attempting to deal with the managed care maze often results in the loss of care.¹⁶⁵

iv. Kentucky: Successful Implementation

Kentucky began experimenting with managed care in the 1980s and gradually expanded through the 2000s.¹⁶⁶ The state did so through a combination of section 1915(b) and section 1115 waivers.¹⁶⁷ The expansion has not been without problems because the state had to sue one company for falsely reporting the provision of services.¹⁶⁸

Kentucky has shown some differences from the other states previously discussed. The final report from the Urban Institute on Kentucky's managed

160. Hodge, *supra* note 153, at 2-3.

161. Chris Coffey, *Glitch in Illinois Benefits System Bogs Down Process, Workers Say*, NBC CHI. (Apr. 10, 2018, 8:35 PM), <https://www.nbcchicago.com/investigations/Glitch-in-Illinois-Benefits-System-Bogs-Down-Process-Workers-Say-479341373.html>.

162. Hodge, *supra* note 153, at 2.

163. Koetting, *supra* note 144, at 235-36.

164. Koetting, *supra* note 144, at 236.

165. Clayworth, *supra* note 114; McSwane & Chavez, *supra* note 132; and Yamaki et al., *supra* note 45 (explaining the loss of care that resulted when beneficiaries were forced to attempt to navigate the managed care system on their own, in Iowa, Texas, and Illinois, respectively).

166. *Managed Care in Kentucky*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/managed-care/downloads/kentucky-mcp.pdf> (last visited Jan. 31, 2019).

167. *Id.* at 2.

168. Wright et al., *supra* note 11, at 295.

care implementation found that it did save the state money.¹⁶⁹ The report, though, did not address if these savings were the result of denials of care or reductions in care.¹⁷⁰ The Urban Institute found steady improvements over the course of implementation with the first year having trouble with the rollout but by the third year, many problems were resolved.¹⁷¹ The report concludes by recommending that the state create a monitor for managed care, one that could check the companies in real time.¹⁷²

The research and experiences from Iowa, Texas, Illinois and Kentucky point to significant problems in the administration of managed care and in beneficiaries' interactions with the private insurance company. Managed care allows the state to outsource the administration of its Medicaid program to insurance companies that then create their own processes for appealing decisions before the beneficiary can appeal to the state agency.¹⁷³ Iowa and Texas' systems make enrollees and their families fight the MCO for the medically necessary care they need, which is not unique in its managed care difficulties.¹⁷⁴ Much like Texas, Illinois implemented Medicaid managed care, but has not reaped the promised rewards of cost savings.¹⁷⁵ Furthermore, the evidence from Texas and Iowa shows that Medicaid MCOs often deny medically necessary equipment and care and force beneficiaries to navigate an appeals process maze they do not understand.¹⁷⁶

Legislators sold Medicaid managed care with promises to cut waste and provide cheaper care.¹⁷⁷ However, that is not the case in practice.¹⁷⁸ Enrollees in Medicaid managed care become caught up in a complex web of corporate bureaucracy that sets them up to fail and face inefficient systems that deny them the medically necessary care they need. This is similar to the experience of expansion beneficiaries in Iowa, Michigan, Indiana and Arkansas when those states implemented premiums, co-payments, lockout periods, disenrolling and work requirements under Section 1115 waivers.

169. James Marton et al., *Medicaid Managed Care in Kentucky*, URBAN INST., vii (Feb. 2017), https://www.urban.org/sites/default/files/publication/90196/2001253-kentucky_medicaid_managed_care.pdf.

170. *Id.*

171. *Id.* at 26-28.

172. *Id.* at 51.

173. Terhune, *supra* note 98, at 2-3.

174. IOWA OFFICE OF OMBUDSMAN, *supra* note 115, at 1; *see also* McSwane & Chavez, *supra* note 132.

175. Yamaki et al., *supra* note 45, at 140.

176. McSwane & Chavez, *supra* note 132, at 9; Consumer Financial Protection Bureau, *supra* note 127, at 2.

177. Robert Book, *Benefits and Challenges of Medicaid Managed Care*, FORBES (Oct. 18, 2012, 10:09 PM), <https://www.forbes.com/sites/aroy/2012/10/18/benefits-and-challenges-of-medicaid-managed-care/#4bb3d204720f>.

178. *Id.*

B. Section 1115 Waivers: Changing the Nature of Medicaid

When states' demonstration waiver applications are approved, the HHS must also approve the state's evaluation proposal, which explains how the state will conduct a study to measure the waiver policy's effectiveness and to test the underlying theory of the waiver.¹⁷⁹ Studies involving section 1115 waivers will ultimately evaluate whether personal responsibility requirements increase access.¹⁸⁰ Iowa, Michigan, Indiana, and Arkansas are all states with waivers that substantially change the nature of Medicaid.¹⁸¹ Unfortunately, because their demonstration waivers have not ended or recently ended, the final reports from the evaluation teams are not available.¹⁸² However, interim reports are available and even some independent studies in the case of Indiana, so the empirical evidence can be examined to see what the waivers' effects have been on the ground.¹⁸³

i. Iowa: Premiums and Co-payments

In Iowa, the legislature first expanded Medicaid with a private option, just as Arkansas did.¹⁸⁴ However, Iowa's private option failed because of the lack of available plans, so a traditional expansion was implemented instead with a waiver for premiums and co-payments.¹⁸⁵ Iowa's first section 1115 demonstration waiver for expansion ended in 2016,¹⁸⁶ but the Iowa Wellness Plan was extended to December 31, 2019.¹⁸⁷ Critically, while enrollees with income over the federal poverty line may be disenrolled for failing to pay the premium by the end of a ninety-day grace period, Iowa's waiver does not

179. *About Section 1115 Demonstrations*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/section-1115-demo/about-1115/index.html> (last visited Jan. 31, 2019).

180. *Id.*

181. Elizabeth Hinton et al., *Section 1115 Medicaid Demonstration Waivers: A Look at the Current Landscape of Approved and Pending Waivers Issue Brief*, HENRY J. KAISER FAM. FOUND. (Sep. 2017), <http://files.kff.org/attachment/Issue-Brief-Section-1115-Medicaid-Demonstration-Waivers-A-Look-at-the-Current-Landscape>.

182. *Id.* at Appendix C.

183. Musumeci, et al., *An Early Look at Medicaid Expansion Waiver Implementation in Michigan and Indiana*, Henry J. Kaiser Fam. Found. (Jan. 31, 2017), <http://files.kff.org/attachment/Issue-Brief-An-Early-Look-at-Medicaid-Expansion-Waiver-Implementation-in-Michigan-and-Indiana>.

184. Jane B. Wishner et al., *Medicaid Expansion, the Private Option, and Personal Responsibility Requirements: The Use of Section 1115 Waivers to Implement Medicaid Expansion Under the ACA* (May 2015), URBAN INST., <https://www.urban.org/sites/default/files/publication/53236/2000235-Medicaid-Expansion-The-Private-Option-and-Personal-Responsibility-Requirements.pdf>.

185. *Id.* at 10.

186. Watson Premiums, *supra* note 8, at 272.

187. *Iowa Wellness Plan*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/?entry=15143> (last visited Jan. 31, 2019).

include a lockout period for failing to pay because enrollees can re-enroll at any time after being disenrolled.¹⁸⁸ However, missed payments can become a collectible debt after ninety days.¹⁸⁹

The University of Iowa conducted two interim evaluations by surveying beneficiaries.¹⁹⁰ The first study found that less than a third of enrollees were aware of the premium payment and about a quarter of respondents reported it would worry them to pay a premium.¹⁹¹ This suggests that there are significant problems with communications with beneficiaries from the MCOs. One concern about personal responsibility requirements is that their effect will be to reduce access to care. This study found that respondents reported it would be very easy to obtain a physical exam.¹⁹² However, because Iowa does not lock out enrollees for failure to pay, measuring reduction in care is difficult in any study of respondents that does not ask if they have been denied medically necessary care by their insurance company.¹⁹³

The follow-up study found that very few of the respondents were aware that completing a wellness exam was part of a program to waive the contribution (premium) requirement.¹⁹⁴ The study found that because respondents did not know key details of the program, a majority of enrollees would have been subject to the premium requirement in 2015.¹⁹⁵ Again pointing to problems with understanding the program and communications from managed care organizations, enrollees reported confusion with the receipt of bills or premium notices.¹⁹⁶

Iowa disenrolled more than 14,000 for failure to pay a \$10 premium from January 2016 to September 2017.¹⁹⁷ The terms of the waiver, though, allow

188. Katharine Bradley et al., *Paying for Medicaid Coverage: An Overview of Monthly Payments in Section 1115 Demonstrations*, MEDICAID.GOV (Sept. 2019), <https://www.medicaid.gov/medicaid/section-1115-demo/downloads/evaluation-reports/paying-for-medicaid-coverage.pdf>.

189. *Id.* at 2.

190. Peter Damiano et al., *Iowa Health and Wellness Plan Evaluation Interim Report*, IOWA DEP'T HUMAN SERVICES (Dec. 2015), https://dhs.iowa.gov/sites/default/files/IHAWP_Interim_Report_2015.pdf?013120190345; see also Natoshia M. Askelson et al., *Health Behaviors Incentive Program Evaluation Interim Report* (Mar. 1, 2016), MEDICAID.GOV, <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ia/Wellness-Plan/ia-wellness-plan-bhvr-int-rpt-mar-2016.pdf>.

191. Damiano et al., *supra* note 190, at 67-68.

192. Damiano et al., *supra* note 190, at 68.

193. Bradley et al., *supra* note 188, at 2.

194. Askelson et al., *supra* note 190, at 32.

195. Askelson et al., *supra* note 190, at 19.

196. Askelson et al., *supra* note 190, at 33.

197. Phil Galewitz, *When Medicaid Charges Premiums, Thousands Fall Behind*, KAISER HEALTH NEWS (March 2, 2018, 9:55 AM), http://www.governing.com/templates/gov_print_article?id=475581313.

them to reapply for coverage at any time; there are no lock out periods in Iowa.¹⁹⁸ The public's awareness of this has not been tested, and the effect of disenrollment may be that it discourages the public from reapplying for coverage because they simply give up. This remains to be tested by further research.

ii. Michigan: Premiums

Michigan's first demonstration waiver for the Healthy Michigan Plan, which ended in 2018, let the state charge premiums of up to two percent of the beneficiaries' income, which can be between \$19-25 a month.¹⁹⁹ These premiums were sent to a health savings account, administered by Maximus.²⁰⁰ Michigan did not disenroll for nonpayment but "consistently" unpaid premiums may be garnished from lottery winnings and state income tax returns.²⁰¹ In 2018, Michigan had to mail letters to 13,550 beneficiaries to warn them about non-payment and also sent 68,000 enrollees notices that the state would begin garnishing state income tax refunds and lottery winnings.²⁰² About 7,000 beneficiaries paid as a result, and the state collected money from 19,400 tax refunds and fifty-nine from lottery winnings.²⁰³ The University of Michigan's study on the Healthy Michigan Plan found that eighty-eight percent of respondents thought the premium payments were fair, and seventy-two percent agreed that they would like to pay.²⁰⁴ However, from January through August 2017, fewer than half actually paid the premium despite some reporting that they want to pay the premium.²⁰⁵ Only nineteen percent reported doing the health risk assessment despite being able to receive a premium waiver if they did it.²⁰⁶

The study was part of the University of Michigan's Institute for Healthcare Policy and Innovation state waiver evaluation.²⁰⁷ In the interim report, survey respondents reported that 37.8 percent did not remember completing

198. *Id.*; See also Bradley et al, *supra* note 188, at 2.

199. Watson Premiums, *supra* note 8, at 272.

200. See generally McMillan, *supra* note 1.

201. MAXIMUS, HEALTHY MICHIGAN PLAN MI HEALTH ACCOUNT EXECUTIVE SUMMARY REPORT 18 (2017).

202. Galewitz, *supra* note 197.

203. Galewitz, *supra* note 197.

204. Galewitz, *supra* note 197.

205. Galewitz, *supra* note 197.

206. Galewitz, *supra* note 197.

207. Section 1115 Demonstration Waiver Amendment Evaluation Proposal, attached to Letter from Andrea J. Casart, Dir., Div. of Medicaid Expansion Demonstrations, to Chris Priest, Dir., Mich. Medical Servs. Admin. (Aug. 8, 2017) (available at www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/mi/Healthy-Michigan/mi-healthy-michigan-eval-dsgn-appvl-20170808.pdf).

the health risk assessment while 53.4 percent did it, but only three percent did it for the reward and only 0.2 percent did it to save money.²⁰⁸ Beneficiaries receive monthly statements for their accounts, and eighty-nine percent reported that they reviewed the statements with eighty-eight percent saying that it helped them be aware of healthcare spending.²⁰⁹ However, forty-eight percent did not know if premiums were charged regardless of health care use (they are not), and fifty-two percent did not know if they could be disenrolled.²¹⁰ This suggests that the enrollees are not understanding the terms of the waiver policy.

CMS approved an extension to Michigan's waiver through 2023 and also allowed changes to the project.²¹¹ The changes allow premiums of up to five percent of income for expansion enrollees, and added a requirement that the health risk assessment or healthy behavior be completed or the beneficiary will be disenrolled.²¹² The waiver approval says that the state should be able to continue studying whether health risk assessments and healthy behaviors have a positive effect on health and whether premiums encourage consumer behaviors.²¹³ The current research suggests these policies, in fact, do neither.

Just as in Iowa, one question for waiver states is whether the effect of personal responsibility requirements will be to reduce coverage and access to care, contrary to the objectives of Medicaid. Once getting coverage through the Healthy Michigan Plan, sixty-six percent used primary care while only 36.9 percent used the emergency room for care;²¹⁴ therefore, it appears that the Healthy Michigan Plan, when enrollees are not kicked off, expands coverage and access to care. However, it remains to be seen if premiums reduced coverage and access to care.

A related question is whether Medicaid and insurance coverage itself provides good effects. In Michigan, Medicaid itself seems to have relieved stress and reduced the damaging effects of medical debt.²¹⁵ Respondents said that they wanted health insurance before getting expansion coverage and that they had trouble with medical bills before getting coverage.²¹⁶ Research should follow-up on other potential good effects, such as lessening housing

208. SUSAN DORR GOOLD ET AL., U MICH. INST. FOR HEALTHCARE POL'Y & INNOVATION, HEALTHY MICHIGAN VOICES BENEFICIARY SURVEY INTERIM REPORT 11-12 (2016).

209. *Id.* at 27.

210. *Id.* at 33.

211. Healthy Michigan Plan, attached to Letter from Seema Verma, Ctrs. for Medicare & Medicaid Servs. To Rick Snyder, Governor (Dec. 21, 2018),

<https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/mi/mi-healthy-michigan-ca.pdf>.

212. *Id.*

213. *Id.*

214. GOOLD et al., *supra* note 208 at 16, 21.

215. *Id.* at 26-27.

216. *Id.* at 26.

instability as seen in one study on ACA marketplace subsidies where recipients were less likely to experience missed rent or mortgage payments.²¹⁷ Research is not complete in Michigan and Iowa, but there is a wealth of empirical evidence from Indiana's waiver experience.²¹⁸

iii. Indiana: Premiums, Co-payments and Lockout Periods

The HIP began in 2008 as an expansion waiver to give coverage to the population that would become the ACA expansion group.²¹⁹ In 2015, the state changed the plan to add personal responsibility requirements in the form of premiums, co-payments, disenrolling and lockouts, which were needed to get the expansion through the Indiana legislature and signed by then-Governor Mike Pence.²²⁰ All enrollees, even those below the poverty line, must make premium payments, which are not premiums in the usual sense but payments into a health savings account, known as POWER.²²¹ All enrollees are initially in HIP Plus, which has more benefits than HIP Basic, but if those below the federal poverty line fail to pay the premium, they are shifted to HIP Basic while expansion adults are disenrolled after sixty days of non-payment.²²² Expansion adults are then locked out of coverage for six months before they can reapply while there is no lockout for those below the poverty line.²²³ Therefore, Indiana's research data provides some of the strongest indicators of what happens when personal responsibility requirements are combined with harsh consequences for non-compliance with a complicated system.

First, the state's official evaluation interim report by the Lewin Group showed that more than half of those eligible to make premium payments did not do so, with those failing to make payments citing affordability and confusion as the reasons for not paying.²²⁴ As a result of failing to pay, the study found 2,677 people were disenrolled and 21,445 people were moved from HIP Plus to HIP Basic.²²⁵ However, another look at the data suggests fifty-seven percent of individuals with income at or below 100 percent of the federal poverty line were moved to HIP Basic, and fifty-one percent were

217. Emily A. Gallagher, Radhakrishnan Gopalan, & Michal Grinstein-Weiss, *The Effect of Health Insurance on Home Payment Delinquency: Evidence from ACA Marketplace Subsidies*, 172 J. PUB. ECON. 67, 77, 79, 82 (2019).

218. *See generally* LEWIN GROUP, *infra* note 224.

219. *See generally* Grogan et al., *supra* note 10.

220. Grogan et al., *supra* note 10, at 266.

221. Watson Premiums, *supra* note 8, at 279.

222. Watson Premiums, *supra* note 8, at 273.

223. Watson Premiums, *supra* note 8, at 273.

224. LEWIN GROUP, INDIANA HEALTHY INDIANA PLAN 2.0: INTERIM EVALUATION REPORT (2016).

225. *Id.* at 44.

disenrolled.²²⁶ Using the results from the Lewin Group study, the Kaiser Family Foundation concluded that administrative requirements create barriers to coverage.²²⁷

Second, other academic studies produced different results.²²⁸ One showed that Indiana's policies result in the state not having as many coverage gains as other traditional expansion states.²²⁹ Another study found that thirty-nine percent had not heard of POWER accounts, but twenty-nine percent had heard of the accounts but did not make payments while thirty-six percent had made payments.²³⁰ Of those who paid, fifty-seven percent said they thought about prices but forty percent said the accounts were hard to understand, which casts doubt on the justification that this encourages consumer behaviors.²³¹ Nine percent reported being locked out of their accounts.²³² These studies show that Indiana's policies have had the destructive effect of reducing coverage through confusion about the program and kicking people off Medicaid.

More recently, it was found that one in three were kicked off for failure to pay,²³³ and in a state that is the only one to impose lockouts, that is a significant barrier to coverage for the expansion population. These occurred in 2018 because until 2017, the federal government did not allow Indiana to enforce the lockout period, stating it was contrary to the objectives of Medicaid.²³⁴ However, the Trump administration allowed enforcement of the provision.²³⁵ In October 2018, the state announced that it would suspend the lockout policy, but did not discuss the details of the suspension.²³⁶

226. Robin Rudowitz, MaryBeth Musumeci, & Elizabeth Hinton, *Digging Into the Data: What Can We Learn from the State Evaluation of Health Indiana (HIP 2.0) Premiums*, HENRY J. KAISER FAM. FOUND. (Mar. 8, 2018), <http://files.kff.org/attachment/Issue-Brief-Digging-Into-the-Data-What-Can-We-Learn-from-the-State-Evaluation-of-Healthy-Indiana-HIP-20-Premiums>.

227. *Id.*

228. See Freedman et al., *infra* note 229; see also Sommers et al., *infra* note 230.

229. Seth Freedman et al., *Learning from Waiver States: Coverage Effects Under Indiana's HIP Medicaid Expansion*, 37 HEALTH AFFAIRS 936, 939 (2018).

230. Benjamin D. Sommers et al., *New Approaches in Medicaid: Work Requirements, Health Savings Accounts, and Health Care Access*, 37 HEALTH AFFAIRS 1099, 1099 (2018).

231. *Id.* at 1103.

232. *Id.*

233. Galewitz, *supra* note 197.

234. Jake Harper, *New Indiana Rules Could Lock HIP Enrollees Out of Coverage for Six Months*, SIDE EFFECTS (Feb. 6, 2018), www.sideeffectspublicmedia.org/post/new-indiana-rules-could-lock-hip-enrollees-out-coverage-six-months.

235. *Id.*

236. Lauren Bavis, *Indiana Halts Policy That Locks Some Medicaid Members Out of Coverage*, SIDE EFFECTS (Oct. 26, 2018), www.sideeffectspublicmedia.org/post/indiana-halts-policy-locks-some-medicaid-members-out-coverage.

In 2019, Indiana began enforcing a new waiver for the HIP, this time including work requirements.²³⁷ National Public Radio analyzed the state's waiver application and found they misrepresented the studies from the 2015 waiver, which supports the contention that HHS does not have enough information when evaluating the waivers.²³⁸ While Indiana starts enforcement of its work requirements, a hint at what will likely occur as a result comes from Arkansas' experience with its work requirements beginning in July 2018.

iv. Arkansas: Premiums and Work Requirements

Like Iowa, Arkansas initially expanded Medicaid with a private option, which allowed politicians to frame it as not Medicaid expansion or a government program.²³⁹ Unlike Iowa, Arkansas still has the private option instead of traditional expansion.²⁴⁰ Beginning in June 2018, Arkansas imposed work requirements on its expansion adults,²⁴¹ which made it the first state to do so since *Stewart v. Azar* halted Kentucky's work requirement pending reconsideration.²⁴² Arkansas also wanted to change eligibility to a different income threshold, but it was not allowed to change that.²⁴³

Beginning in 2016, the State started charging \$13 premiums, but only twenty percent paid, perhaps because enrollees do not lose coverage if they fail to pay.²⁴⁴ In 2019, the State plans to intercept tax refunds to make up for the failed payments.²⁴⁵ This seems to undercut the notion that the programs are creating consumerism and teaching personal responsibility, although

237. Phil Galewitz, *Indiana Adds Work Requirement To Medicaid, Will Block Coverage If Paperwork Is Late*, NPR (Feb. 2, 2018, 4:21 PM), www.npr.org/sections/health-shots/2018/02/02/582828039/indiana-adds-work-requirement-to-medicaid-will-block-coverage-if-paperwork-is-late.

238. Jake Harper, *Indiana's Claims About Its Medicaid Experiment Don't All Check Out*, NPR (Feb. 24, 2017, 5:01 AM), www.npr.org/sections/health-shots/2017/02/24/516704082/indiana-s-claims-about-its-medicaid-program-dont-all-check-out.

239. Robert B. Leflar, *Red-State Health Reform: Threading the Political Needle*, 24 ANNALS HEALTH L. 410, 416-417 (2015).

240. Dylan Scott, *Medicaid's Private Option is Nearly Gone*, VOX (Sep. 2, 2018, 9:40 AM), www.vox.com/policy-and-politics/2018/8/31/17806656/medicaid-private-insurance-states-work-requirements-voxcare.

241. Jennifer Wagner, *Commentary: As Predicted, Eligible Arkansas Medicaid Beneficiaries Struggling to Meet Rigid Work Requirements*, CTR. ON BUDGET & POL'Y PRIORITIES (Jul. 30, 2018), www.cbpp.org/health/commentary-as-predicted-eligible-arkansas-medicaid-beneficiaries-struggling-to-meet-rigid.

242. *Stewart*, 308 F.Supp. 3d at 272.

243. Phil Galewitz, *Feds Issue Split Decision on Arkansas Medicaid Waiver*, GOVERNING (Mar. 6, 2018, 10:28 AM), www.governing.com/topics/health-human-services/khn-arkansas-cms-trump-medicaid.html.

244. Galewitz, *supra* note 197.

245. Galewitz, *supra* note 197.

conservatives would say that enrollees do not pay because there is no punishment for failing to pay. However, studies from other waiver states do not support the idea that enrollees would pay if there was a penalty for non-payment;²⁴⁶ enrollees likely do not pay for a range of reasons including the financial burden.²⁴⁷

To implement work requirements, states need to modify eligibility systems, create compliance systems, inform beneficiaries of changes and hire additional staff.²⁴⁸ These changes all create additional costs and are potentially harmful to beneficiaries seeking to navigate reforms, as was the case in Arkansas where tens of thousands of individuals lost coverage due to system implementation challenges.²⁴⁹ From July to December, reports of enrollees losing coverage based on non-compliance increased every month.²⁵⁰ The Kaiser Family Foundation warned that more would lose coverage every month because, despite outreach efforts, enrollees did not know about the work requirement reporting.²⁵¹ By the end of 2018, almost 17,000 enrollees lost coverage for failing to report work hours, though they are allowed to reapply in 2019.²⁵² Arkansas Governor Hutchinson defended the program “as accomplishing its intent” because 4,100 enrollees secured jobs in line with the work requirements.²⁵³ One might more cynically say that the program accomplished its intent because 17,000 were kicked off of Arkansas’ Medicaid rolls;²⁵⁴ one intent behind work requirements and the

246. See Samantha Artiga, Petry Ubri, & Julia Zur, *The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings*, HENRY J. KAISER FAM. FOUND. (June 1, 2017), <http://files.kff.org/attachment/Issue-Brief-The-Effects-of-Premiums-and-Cost-Sharing-on-Low-Income-Populations> (reporting findings that individuals refrain from obtaining and maintaining Medicaid and CHIP in the face of premiums).

247. *Id.* (“Studies also show that those who become uninsured following premium increases face increased barriers to accessing care, have greater unmet health needs, and face increased financial burdens.”).

248. Jennifer Wagner & Judith Solomon, *States’ Complex Medicaid Waivers Will Create Costly Bureaucracy and Harm Eligible Beneficiaries*, CTR. ON BUDGET AND POL’Y PRIORITIES (May 23, 2018), www.cbpp.org/sites/default/files/atoms/files/5-23-18health2.pdf.

249. *Id.* at 1–2.

250. Wagner, *supra* note 241; see also Robin Rudowitz, MaryBeth Musumeci, & Cornelia Hall, *A Look at October State Data for Medicaid Work Requirements in Arkansas*, HENRY J. KAISER FAM. FOUND. (Nov. 19, 2018), <http://files.kff.org/attachment/Issue-Brief-A-Look-at-October-State-Data-for-Medicaid-Work-Requirements-in-Arkansas>.

251. Rudowitz et al., *supra* note 250.

252. Benjamin Hardy, *Update: Work Requirement Ends Medicaid Coverage for 4600 More Arkansans in December*, ARK. TIMES (Dec. 17, 2018, 1:08 PM), <https://www.arktimes.com/ArkansasBlog/archives/2018/12/17/work-rule-ends-medicaid-coverage-for-4600-more-arkansans-in-december>.

253. *Id.*

254. *Id.*

complicated structure of managed care is to make being on Medicaid so onerous that beneficiaries simply give up.

One way Arkansas made its work requirement program onerous and unnecessarily difficult is the manner through which enrollees were required to report their compliance.²⁵⁵ For example, enrollees had to report work through an online portal, which creates barriers for potential elderly, disabled and low-income enrollees.²⁵⁶ Arkansas has some of the worst Internet access in the country, and online reporting is particularly burdensome for the Medicaid population, which is poor and less likely than members of the general population to have reliable Internet access.²⁵⁷ It is similar to how Illinois made the only way to apply for Hardest Hit housing assistance online.²⁵⁸ A cynical reading is that states purposely design programs to make it too difficult to comply and thus, hard to be poor.

This also reflects a lack of thought to the hardships of poverty and the reality of lives for impoverished populations. Requiring Medicaid enrollees to get jobs harms low-income people when they live in towns where there are no jobs; it is not easy for impoverished people to travel to find work when they do not have money for relocation. One man had a job at a poultry plant, tried to comply with the work requirement reporting, but failed because he did not realize he had to report every month.²⁵⁹ Thus, he lost his Medicaid coverage.²⁶⁰ One woman believed she was exempt but received letters stating she needed to create an online account for reporting.²⁶¹ She cannot create an account because she does not have an email address and thus, she lost her coverage for not reporting.²⁶² In one Arkansas county, even the public library has a sign saying it does “not offer the Internet.”²⁶³ The court recently stayed Arkansas’ work requirement because HHS’ approval was

255. *Id.*; see also Anuj Gangopadhyaya et al., *Under Medicaid Work Requirements, Limited Internet Access in Arkansas May Put Coverage At Risk*, URBAN INST. (Oct. 29, 2018), <https://www.urban.org/urban-wire/under-medicaid-work-requirements-limited-internet-access-arkansas-may-put-coverage-risk> (pointing to barriers facing those individuals without regular internet access).

256. Gangopadhyaya et al., *supra* note 255.

257. *Internet Access in Arkansas*, BROADBANDNOW, <https://broadbandnow.com/Arkansas> (last updated Mar. 6, 2019) (revealing Arkansas to be the 50th most connected state in the Union); see also Gangopadhyaya et al., *supra* note 255 (finding that one in five adults between the ages of 19 and 49 with incomes below 138 percent of the Federal Poverty Level, the limit for Medicaid eligibility in Arkansas, reported having no internet access at home).

258. *Illinois Hardest Hit Program*, ILL. HARDEST HIT, <https://www.illinoishardesthit.org/> (last visited Mar. 27, 2019).

259. *Gresham v. Azar*, 363 F. Supp. 3d 165 (D.D.C. 2018).

260. *Id.*

261. Amy Goldstein, *A Job-scarce Town Struggles with Arkansas’ First-in-nation Medicaid Work Rules*, THE WASH. POST (March 27, 2019).

262. *Id.*

263. *Id.*

arbitrary and capricious, but the Governor indicated he would appeal the decision.²⁶⁴

Work requirements are just the beginning of changes that the Trump administration signaled it would approve; CMS would likely agree to let states impose drug testing and lifetime coverage limits as well.²⁶⁵ However, research shows that work requirements do not actually encourage more beneficiaries to get jobs because the vast majority of beneficiaries of public welfare programs are either already working, are elderly or are disabled, and are thus exempt from the work requirements, leaving a very small proportion of the welfare population who would benefit from getting a job.²⁶⁶ Indeed, one study showed that in Kansas only eleven percent of the combined Medicaid and uninsured population would be likely to look for a job, while forty-nine percent were already working and thirty-four percent had a disability.²⁶⁷ But from Arkansas' experience, it becomes clear that work requirements will, as some fear, simply make it more difficult to be in poverty, kick beneficiaries off the Medicaid rolls and impede access to insurance and health care. It will also impact people like Sue Fredericks in Indiana who find it difficult to keep a job and keep insurance through the HIP.²⁶⁸ What is missing from discussing the numbers of people kicked off or locked out of coverage are stories like Sue's and the impact on her and those like her; what is also missing when the conversation is about "personal responsibility" is also talking about core consumer protections that should exist for Medicaid beneficiaries in particular but also all health insurance customers.

III. CONSUMER PROTECTION: THE MISSING ELEMENT

The political rhetoric around expanding Medicaid focused on encouraging "personal responsibility" and promoting "consumerism" by teaching Medicaid beneficiaries about how insurance works through premiums and

264. Amy Goldstein, *Arkansas Governor Seeks Appeal of Decision Voiding Medicaid Work Rules*, THE WASH. POST (March 28, 2019).

265. Mattie Quinn, *Work Requirements May Be Just the Beginning of Medicaid Changes Under Trump*, GOVERNING (Jan. 12, 2018, 5:00 PM), <http://www.governing.com/topics/health-human-services/gov-medicaid-work-trump-drug-testing-kentucky.html>.

266. Heather Hahn et al., *Work Requirements in Social Safety Net Programs: A Status Report of Work Requirements in TANF, SNAP, Housing Assistance, and Medicaid*, URBAN INST., 15, (Dec. 2017), <https://www.urban.org/sites/default/files/publication/95566/work-requirements-in-social-safety-net-programs.pdf> (as an example, this study reported that in 2015, a housing assistance program benefitted a group of households of which 81 percent were elderly, disabled or with a member already working).

267. Sommers et al., *supra* note 230, at 1103–04.

268. McMillan, *supra* note 1.

co-payments.²⁶⁹ Key to this switch in rhetoric was the belief that individuals helped by the Medicaid expansion population should work to be good consumers of health care.²⁷⁰ Indiana said it encouraged “consumerism” by enrolling those who paid premiums in a superior plan with added benefits relative to those who did not pay, and by putting funds into a health savings account through which payers would pay their premiums.²⁷¹ Missing from the discussion of “consumerism” was consideration of core consumer protections, such as debt collection, grace periods, and limits on premium amounts.

Some waivers include consumer protections for debt collection, others do not. For example, Michigan’s plan treats unpaid premiums as debts to the state that allow for the state seizure of tax refunds and lottery winnings.²⁷² Iowa’s first demonstration waiver included that unpaid premiums were treated as a debt owed to the state, but the state allowed a hardship exemption as well as a ninety-day grace period for payment.²⁷³ However, unpaid premiums do become a debt owed to the state when the enrollee in question does not apply for renewal and had no claims for services delivered after the month of the last premium payment.²⁷⁴

Indiana’s 2015 plan did not allow payment of unpaid premiums to be a condition of re-enrollment, but did allow resulting debts to be collectible with the caveat that the debt not be reported to credit reporting agencies, not be used to file a lien against a home, not be used as the basis of a lawsuit nor wage garnishment, and not be sold as a debt to a third party.²⁷⁵ These policies effectively made the debt uncollectible. Indiana’s new demonstration waiver, approved by the Trump administration, included no such protections.²⁷⁶ Arkansas’ 2014 waiver included the creation of matching

269. Grogan et al., *supra* note 10, at 263–65 (discussing the nuances of the “personal responsibility” and “consumerism” rhetoric across the contexts of several states).

270. Grogan et al., *supra* note 10, at 265–66.

271. Grogan et al., *supra* note 10, at 266.

272. Watson Premiums, *supra* note 8, at 272.

273. Watson Premiums, *supra* note 8, at 272.

274. *See generally* Iowa Wellness Plan, attached to Letter from Brian Neale, Dir., Ctrs. for Medicare & Medicaid Servs., to Mikki Stier, Medicaid Dir., Iowa Dep’t of Human Servs. (Oct. 27, 2017), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ia/ia-wellness-plan-ca.pdf>.

275. *See generally* Healthy Indiana Plan 2.0 (2015), attached to Letter from Marilyn Tavenner, Adm’r, Ctrs. for Medicare & Medicaid Servs., to Joseph Moser, Medicaid Dir., Ind. Family & Soc. Servs. Admin. (Jan. 27, 2015), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-appv1-01272015.pdf>.

276. *See generally* Healthy Indiana Plan (2018), attached to Letter from Demetrios Kouzoukas, Principal Deputy Adm’r, Ctrs. for Medicare & Medicaid Servs., to Allison Taylor, Medicaid Dir., Ind. Family & Soc. Servs. Admin. (Feb. 1, 2018), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By->

health savings accounts for participants, which are funded both by the participant and the state, and result in participant debt to the state when a participant who doesn't claim hardship underpays an obligation.²⁷⁷ The state's newest waiver program provides that unpaid premium debt may be collected but not reported to credit reporting agencies, nor used as the basis for legal claims, liens or wage garnishments, nor can it be sold.²⁷⁸

As the above survey shows, treatment of debt collection varies in waiver states.²⁷⁹ Sometimes CMS imposes consumer protections, such as effective bans on debt collection, credit reporting or wage garnishments.²⁸⁰ In other waivers, CMS imposes no such consumer protections.²⁸¹ Instead of allowing states to experiment, CMS should use one uniform debt collection limitation in waivers; the lack of uniformity must frustrate the MCOs, which contract in multiple states.

Similarly, some waivers include grace periods for missed payments and limits on the amount of income that can go toward premiums; others do not.²⁸² For example, Indiana's first waiver included a sixty-day grace period and a limit of two percent of income going toward a premium.²⁸³ The State's newer waiver keeps the grace period but changes premium limitations from a two-percent-of-income cap to assessing premiums based on income bands.²⁸⁴ Iowa's first waiver included a ninety-day grace period and a requirement that the premium for expansion adults could only be \$10,²⁸⁵ while the new waiver keeps the grace period but changes the premium to a

Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-ca.pdf.

277. See Arkansas Health Care Independence Program, attached to Letter from Marilyn Tavenner, Ctrs. for Medicare & Medicaid Servs., to John Selig, Dir., Ark. Dep't of Human Servs. (Dec. 31, 2014), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ar/Health-Care-Independence-Program-Private-Option/ar-works-demo-appvl-12312014.pdf>.

278. See Arkansas Works, attached to Letter from Seema Verma, Ctrs. for Medicare & Medicaid Servs., to Asa Hutchison, Governor, 18 (Mar. 4, 2018), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ar/ar-works-ca.pdf>.

279. See generally Healthy Indiana Plan 2.0 (2015), *supra* note 275; see also Healthy Indiana Plan (2018), *supra* note 276; see also Arkansas Health Care Independence Program, *supra* note 277; see also Arkansas Works, *supra* note 278.

280. See generally Healthy Indiana 2.0 Plan (2015), *supra* note 275; see also Healthy Indiana Plan (2018), *supra* note 276; see also Arkansas Health Care Independence Program, *supra* note 277; see also Arkansas Works, *supra* note 278.

281. See Healthy Indiana Plan 2.0 (2015), *supra* note 275; see also Healthy Indiana Plan (2018), *supra* note 276.

282. See Healthy Indiana Plan 2.0 (2015), *supra* note 275.

283. Healthy Indiana Plan 2.0 (2015), *supra* note 275.

284. Healthy Indiana Plan (2018), *supra* note 276.

285. *Iowa Medicaid Expansion Waiver*, MACPAC (Aug. 2016), <https://www.macpac.gov/wp-content/uploads/2015/07/Iowa-Medicaid-Expansion-Waiver-.pdf>.

limit of five percent of family income not exceeding five dollars for those below the federal poverty line and ten dollars for those over the federal poverty level up to 138 percent of the federal poverty line.²⁸⁶ Arkansas' waiver includes a ninety-day grace period and two percent of income limit for premiums.²⁸⁷ Finally, Michigan's waivers had no grace period, though premiums could not be more than two percent of income (five percent for the renewal) and repayment of past premiums are required to renew.²⁸⁸ These grace periods are vulnerable to being not enforced evenly because it is not clearly defined if only one month must be paid or if the enrollee is two months behind by the sixtieth day, the whole two months of premiums need to be paid.²⁸⁹ The ACA included a ninety-day grace period on Marketplace plans.²⁹⁰ The Department of Housing and Urban Development requires housing to only be thirty-one percent of one's income in order to be considered affordable.²⁹¹ Similarly, controls on premium amounts help define healthcare affordability. This shows some consumer protection elements have been included, but the differences in waiver states shows more thought needs to be given to consumer protections in health insurance, especially for the vulnerable Medicaid population.

What is particularly worrisome is that enrollees likely do not understand the communications that are sent to them.²⁹² Persons with low literacy generate higher charges for healthcare and have poorer health status, are more apt to be hospitalized, and make more visits to the emergency room than literate counterparts.²⁹³ One study suggested that state Medicaid programs reduce the literacy level of their enrollment and renewal processes and establish literacy guidelines so that materials help applicants understand

286. Healthy Indiana Plan (2018), *supra* note 276.

287. *Arkansas Work Section 1115 Waiver Demonstration Fact Sheet*, MEDICAID.GOV (Mar. 5, 2018), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ar/ar-works-fs.pdf>.

288. Healthy Michigan Plan (2013), attached to Letter from Marilyn Tavenner, Ctrs. for Medicare & Medicaid Servs., to Stephon Fitton, Dir., Mich. Medical Servs. Admin., 14 (Dec. 30, 2013), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/mi/Healthy-Michigan/mi-healthy-michigan-cms-amend-appvl-12302013.pdf>; *see also* Healthy Michigan Plan (2018), *supra* note 211.

289. Healthy Michigan Plan (2018), *supra* note 288, at 14 (“No sooner than 60 days after the invoice date of the missed premium, beneficiaries who fail to pay the monthly contribution will be terminated from coverage after proper notice.”).

290. *Premium Payments, Grace Periods & Termination*, HEALTHCARE.GOV, <https://www.healthcare.gov/apply-and-enroll/health-insurance-grace-period/> (last visited Mar. 29, 2019).

291. FED. HOUSING ADMIN., *FHA SINGLE FAMILY HOUSING POLICY HANDBOOK* 413 (2016).

292. Barry D. Weiss & Raymond Palmer, *Relationship Between Health Care Costs and Very Low Literacy Skills in Medically Needy and Indigent Medicaid Population*, 17 J. AM. BOARD FAM. PRACTICE 44, 46 (Jan.–Feb. 2004).

293. *Id.* at 44.

the process.²⁹⁴ Another study showed the importance of communications that beneficiaries can understand by showing that women better understood the sterilization process when consent forms were written at a lower reading level.²⁹⁵ Another study recommended that managed care companies change their written communications from a tenth-grade reading level to a fourth- or sixth-grade reading level to ensure that beneficiaries understand the appeals process, but found resistance inside the organizations to the recommended change.²⁹⁶ Because healthcare consumers must understand the process within organizations, they need to be able to read and understand what they are being sent; a change to “if you have a problem, here’s what to do” would be an improvement over “if you have a grievance or appeal ...”²⁹⁷ Without these changes, Medicaid enrollees are more likely to experience problems when left to their own devices in a system difficult to navigate on one’s own.

At a time when the Trump administration and states are pulling back on the administrative state and enforcement of regulations, an analysis of how the policies accepted by Medicaid waivers shows the importance of legal aid and monitoring the actions of private companies to ensure that enrollees are not being wrongfully denied access. In the context of home foreclosure, the assistance of a lawyer has been shown to be vital in homeowners receiving loan modifications.²⁹⁸ It stands to reason that the assistance of a lawyer in navigating managed care and holding companies responsible would make a difference.

It is also important to change the conversation from personal responsibility to consumer protection and have more advocacy groups to do so. There are a few groups, such as Families USA and the National Health Law Program, which are doing important work.²⁹⁹ However, there needs to be more, and conversation must turn from imposing harsh requirements to ensuring consumers are treated fairly by the proposed changes and by MCOs.

The above analysis of waiver policies approved by CMS shows how consumer protections do not extend to healthcare and health insurance.

294. Susmita Pati et al., *Reading Level of Medicaid Renewal Applications*, 12 ACAD. PEDIATRICS 297, 299–300 (Jul. – Aug. 2012).

295. Nikki B. Zite & Lorraine S. Wallace, *Use of a Low-Literacy Informed Consent Form to Improve Women’s Understanding of Tubal Sterilization*, 117 OBSTETRICS & GYNECOLOGY 1160, 1164 (May 2011).

296. Jane Root & Sue Stableford, *Easy-to-Read Consumer Communications: A Missing Link in Medicaid Managed Care*, 24 J. HEALTH POL., POL’Y & L. 1, 13 (1999) (“resistance” stemmed from internal pressures on staff to roll-out Medicaid products, and lack of time).

297. *Id.* at 2, 4.

298. Amy Loftsgordon, *When Should I Hire a Foreclosure Attorney?*, LAWYERS.COM, <https://www.lawyers.com/legal-info/bankruptcy/foreclosures/when-to-hire-a-foreclosure-attorney.html> (last visited Mar. 29, 2019).

299. *Fighting for Health Rights for All*, NAT’L HEALTH L. PROGRAM, <https://healthlaw.org/> (last visited Mar. 29, 2019); see also *About Families USA*, FAMILIESUSA, <https://familiesusa.org/about> (last visited Mar. 29, 2019).

While the ACA enacted some consumer protections,³⁰⁰ insurance and healthcare do not implicate other consumer protection statutes. For the most part, policymakers do not see them as consumer protection issues.³⁰¹ They sold premiums as making enrollees have “skin in the game,” but this logic only applies to low-income people, who do not have lobbyists.³⁰² It is the Wild West in terms of oversight and regulation with healthcare consumers left unarmed.

Medicaid enrollees face a complicated system between managed care and waivers, a system that is rigged against them. Often, low-income clients, who are Medicaid and Medicaid expansion enrollees, do not understand the notices they are receiving or the enrollment process.³⁰³ It is a system that outsources state regulation to private companies and often states do not step in to enforce regulations. Medicaid waivers created this environment. Waivers that were meant to innovate and improve Medicaid have not done so based on the available evidence from the states. Instead, they impeded access to health insurance and healthcare for the impoverished and demonstrate the need for legal services and robust state oversight.

300. *What Consumer Protections Are Embedded in the Affordable Care Act?*, ROBERT WOOD JOHNSON FOUND. (Aug. 2011), https://www.rwjf.org/content/dam/farm/reports/issue_briefs/2011/rwjf71392.

301. Austin Frakt, *The Innovation vs Consumer Protection Tug-of-War in Health Policy*, NEWS@JAMA (Mar. 12, 2014), <https://newsatjama.jama.com/2014/03/12/jama-forum-the-innovation-vs-consumer-protection-tug-of-war-in-health-policy/>.

302. Yuval Rosenberg, *‘Skin in the Game’ Doesn’t Make Patients Better Health-Care Shoppers: Study*, FISCALTIMES (Mar. 5, 2019), <https://www.thefiscaltimes.com/2019/03/05/Skin-Game-Doesn-t-Make-Patients-Better-Health-Care-Shoppers-Study>.

303. Benjamin Geyerhahn, *Top 4 Things About Medicaid Enrollment That Confuse Clients*, BENEFITS PRO (Sep. 17, 2015 11:43 AM), <https://www.benefitspro.com/2015/09/17/top-4-things-about-medicaid-enrollment-that-confus/?slreturn=20190030105304>.

