Boston University School of Law

Scholarly Commons at Boston University School of Law

Faculty Scholarship

Fall 2020

Struggle for the Soul of Medicaid

Nicole Huberfeld

Boston University School of Public Health; Boston University School of Law

Sidney Watson

Alison Barkoff

Follow this and additional works at: https://scholarship.law.bu.edu/faculty_scholarship

Part of the Health Law and Policy Commons

Recommended Citation

Nicole Huberfeld, Sidney Watson & Alison Barkoff, *Struggle for the Soul of Medicaid* , *in* 48 Journal of Law, Medicine & Ethics 429 (2020).

Available at: https://doi.org/https://doi.org/10.1177/1073110520958865

This Article is brought to you for free and open access by Scholarly Commons at Boston University School of Law. It has been accepted for inclusion in Faculty Scholarship by an authorized administrator of Scholarly Commons at Boston University School of Law. For more information, please contact lawlessa@bu.edu.

Check for updates

Struggle for the Soul of Medicaid

Nicole Huberfeld, Sidney Watson, and Alison Barkoff

A struggle for the "soul" of Medicaid is underway as the Trump administration targets the Patient Protection and Affordable Care Act's (ACA) Medicaid eligibility expansion, and "traditional" Medicaid, with novel and often unlawful policies. Medicaid has core statutory features that shape the medical care offered through this safety net program, which covers more than 71 million Americans and is uniquely equipped to serve low-income, vulnerable populations. We begin by charting four key features that anchor Medicaid, then describe major ways the administration is testing them. Next, we explore challenges in accountability that have contributed to this struggle. We highlight that watchdogs are working to protect the soul of Medicaid and conclude with considerations for future health reform.

I. Medicaid's Core

Medicaid is a health insurance program created for low-income populations. Traditional Medicaid offers coverage to low-income children, parents, people with disabilities and the elderly. The ACA's Medicaid expansion adds coverage for other low-income adults. For both groups, Congress designed Medicaid to specifically address access barriers particular to medical care for the poor.

The soul of Medicaid resides in both what Medicaid is and how Medicaid is funded, a set of core benefits and protections meant to guarantee coverage and care. The Medicaid Act creates eligibility rules, a unique package of covered services, affordability requirements, and due process protections that support Medicaid's role as the nation's safety net.

To that end, federal law requires state Medicaid programs to implement four key protections that address the needs of low-income, often vulnerable and fragile, participants. First, unlike private insurance rules excluding people who miss annual enrollment periods, Medicaid has unique eligibility rules and processes that allow it to serve as a safety net insurer: anyone who is legally eligible can enroll at the moment of eligibility. This rolling, open enrollment makes it so coverage is available whenever people suffer a loss of income and need medical care. Medicaid's special eligibility rules also include policies such as three-month retroactive coverage, point-in-time income eligibility, and automatic enrollment of newborns.

Nicole Huberfeld, J.D., *is Professor of Health Law, Ethics & Human Rights and Professor of Law at Boston University;* **Sidney Watson, J.D.**, *is the Jane and Bruce Roberts Professor of Law at the Saint Louis University Center for Health Law Studies;* **Alison Barkoff, J.D.**, *is the Director of Advocacy at the Center for Public Representation.*

The Journal of Law, Medicine & Ethics, 48 (2020): 429-433. © 2020 The Author(s)
DOI: 10.1177/1073110520958865
https://doi.org/10.1177/1073110520958865 Published online by Cambridge University Press

Second, Medicaid covers benefits that other kinds of insurance such as Medicare and private insurance overlook. Unique benefits include long term services and supports (LTSS), non-emergency medical transportation (NEMT), Early and Periodic Screening, Diagnostic and Treatment (EPSDT) comprehensive services for children, and broad family planning services.

To highlight one unique benefit: Medicaid is vital to LTSS, covering a majority of people with disabilities and seniors who need long term care. LTSS provides assistance with daily activities like bathing, eating, chores, and participating in the community. Most other health insurance does not cover LTSS, and few individuals can afford to pay out of pocket. As a result, Medicaid has become the primary payor of LTSS, which comprises nearly a third of total Medicaid spending. LTSS can be provided in institutions like nursing homes or to individuals in their home or community, called Home and Community Based Services (HCBS). Despite a civil right to community living under the Americans with Disabilities Act,[1] institutional LTSS is a mandatory service but HCBS is optional. Because this is an optional benefit, states vary in covered services and asset and income limits, and the waitlist for HCBS is now around 600,000.

Third, the Medicaid Act contains strict limits on beneficiary out-of-pocket payments. The law protects those earning at or near the federal poverty level to ensure that costs are not a barrier to coverage or care. Premiums and deductibles are prohibited. Copays are barred for children. Adults cannot be charged more than $4 for most outpatient services, and copays are banned altogether for key services like emergency care, family planning, and pregnancy-related care. Patients cannot be refused care or lose coverage because of inability to pay. Out of pocket costs are capped at 5% of family income.[2]

Fourth, Medicaid has strong procedural due process and structural protections. Beneficiaries have a right to advance notice before services are reduced or discontinued. They also have a right to contest adverse actions in a fair hearing, including a right to representation and to continued services until a decision is issued (when a timely request for a fair hearing is made). Further, Medicaid's funding structure renders it an entitlement program for states and beneficiaries. States are guaranteed federal matching funds for the costs of Medicaid services and administration. Poorer states are entitled to a higher federal match and funds are not limited. This open-ended federal funding ensures that states have reliable financial support, especially important when events such as recessions, natural disasters, or public health emergencies occur. Open-ended federal funding means that everyone who is eligible actually gets enrolled and can obtain services they need.

II. Section 1115 Waivers as a Threat

Since 2018, the Department of Health and Human Services (HHS) has encouraged state applications for waivers that experiment with Medicaid in ways that unlawfully threaten the core of the program. Section 1115 of the Social Security Act gives the Secretary of HHS limited authority to waive certain provisions of the Medicaid Act to allow states to implement demonstration projects that are "likely to assist in promoting the objectives" of Medicaid. Over the decades, the Secretary has approved 1115 demonstrations to allow states to experiment by expanding eligibility, covering additional services, and creating innovative delivery system models, all of which further Medicaid's central objective: to furnish medical assistance.

Like prior administrations, the Trump administration is using 1115 waivers as a way to implement its policy preferences. Recent 1115 waivers are intended to roll back the ACA's Medicaid expansion by limiting coverage and transforming Medicaid from a safety

Medicaid is called a classic cooperative federalism program because the federal government invites states to implement federal policy with money and compliance with federal rules. Federalism often is claimed to serve democratic values such as sovereignty and accountability. States always have had flexibility to implement Medicaid with their own policy choices, and state sovereignty within the Medicaid program is robust, as demonstrated by successful state waiver negotiations with HHS to gain concessions reflecting state desires in Medicaid expansion and beyond.

The Journal of Law, Medicine & Ethics, 48 (2020): 429-433. © 2020 The Author(s)

https://doi.org/10.1177/1073110520958865 Published online by Cambridge University Press

net program to something that looks more like private insurance.[3] HHS has encouraged states to condition eligibility on novel, onerous "personal responsibility" rules and made eligibility more difficult in the hope that beneficiaries will find coverage elsewhere. Most recently, HHS invited waiver applications to restructure Medicaid financing from a guaranteed federal match to limited block grant funding.[4]

Sixteen states have pending or approved waivers that impose eligibility and enrollment restrictions including work requirements, premiums, waiting periods before coverage can begin, and locking people out of coverage. Fifteen states have pending or approved waivers that eliminate core benefits like coverage for NEMT and impose higher copayments.[5] These waivers will result in hundreds of thousands of beneficiaries losing coverage and care. In Arkansas, the only state to begin implementing a waiver with work requirements, over 18,000 people lost coverage within three months.

So far, federal courts have struck down work requirements and related provisions in four states' waivers finding that the administration's policy preferences do not "further the objectives" of the Medicaid Act.[6] These cases rely on the language of the Medicaid Act and prior case law in finding that the law's principal objective is providing health care coverage and holding that the Secretary acted unlawfully by failing to consider evidence of significant coverage losses due to these novel policies.

Yet, the Section 1115 waiver threat persists. First, the Trump administration is seeking Supreme Court review of lower court decisions blocking its waivers. Second, the administration has begun approving waivers for work requirements coupled with small eligibility expansions in an apparent effort to claim that such waivers expand rather than contract coverage. However, the threat remains: waivers that include work requirements and other eligibility restrictions, premiums, and higher co-pays will prevent otherwise eligible beneficiaries from access Medicaid coverage. Third, two states already have submitted waiver applications for capped spending in Medicaid, which will also result in limited enrollment, coverage, payments, and other features that strike at the core of Medicaid.

III. Federalism, Accountability, and Watchdogs

Medicaid is called a classic cooperative federalism program because the federal government invites states to implement federal policy with money and compliance with federal rules. Federalism often is claimed to serve democratic values such as sovereignty and accountability. States always have had flexibility to implement Medicaid with their own policy choices, and state sovereignty within the Medicaid program is robust, as demonstrated by successful state waiver negotiations with HHS to gain concessions reflecting state desires in Medicaid expansion and beyond.[7]

The Trump administration has issued new policies that target the core of Medicaid and weaken both federal and state accountability. Since 2017, HHS policies have diminished the ACA's strong federal statutory baselines in a variety of ways. For example, HHS reduced federal agency oversight of waivers while extending both initial and renewal approval periods.[8] Concurrently, novel policies extend HHS's administrative power through interpretations of the law of Medicaid in ways that no prior administration endorsed, such as inviting states to seek block grants for expansion populations to increase "state flexibility," a trade that purposefully decreases federal oversight of and accountability for state Medicaid programs.

Given the number of lives relying on Medicaid, strong federal policies promoting transparency, responsibility, and enforcement of national rules are key to ensuring that states, providers, and managed care organizations are not gaming or thwarting federal Medicaid rules. In fact, the ACA improved transparency in 1115 waiver negotiations through public notice and comment processes that must occur before HHS can approve. But, this new public process only works if the political branches protect Medicaid's core statutory provisions. CMS and states frustrate accountability in a number of ways, which risks the health of already vulnerable beneficiaries and the economic health of states.

States are testing the boundaries of their responsibility for the core of Medicaid. For example, South Carolina obtained approval for work requirements *without* expansion. Tennessee submitted an application for block granting Medicaid funding in exchange for significant state flexibility without federal oversight. Many states perennially underfund their Medicaid programs and choose to pay low reimbursement rates to providers, creating access challenges. The adequate payment problems go unchecked because HHS rolled back the Obama-era "equal access" regulations that were supposed to supplant court-based challenges. Further, state oversight of Medicaid managed care organizations (MCOs) is lax, allowing MCOs to hide reimbursement rates as trade secrets, so regulators cannot determine whether provider payment is sufficient to ensure access to care. Medicaid MCOs also bypass basic features of Medicaid, weakening the core by failing to deliver key services like EPSDT

The Journal of Law, Medicine & Ethics, 48 (2020): 429-433. © 2020 The Author(s)
https://doi.org/10.1177/1073110520958865 Published online by Cambridge University Press

for children, NEMT, and LTSS for those with chronic conditions.

Slack state oversight is exacerbated by Supreme Court decisions that have limited access to federal courts. Restrictions on Section 1983 private rights of action mean that providers no longer can challenge low reimbursement rates, and beneficiaries can enforce only specific sections of the Medicaid Act under Section 1983.[9] Medicaid beneficiaries and providers can pursue Administrative Procedure Act judicial review to challenge HHS actions on state plan amendments and waivers, but many of the problems with state accountability are beyond state plan amendments or waiver approvals. In other words, Medicaid's classic cooperative federalism is suffering from inadequate accountability.

IV. All Is Not Lost

Even though HHS — the agency responsible for Medicaid — seeks to unlawfully undercut its core, others have acted to protect it, including federal courts, legislative agencies, congressional committees, and advocacy groups. A federal district court has vacated HHS approvals of waivers implementing work requirements and other barriers to coverage in Kentucky, Arkansas, New Hampshire, and Michigan. Judge Boasberg found that the core purpose of Medicaid is to pay for coverage and provide care for low income people and that HHS acted arbitrarily and capriciously when it ignored both predicted and actual coverage losses.[10] The D.C. Circuit upheld the district court's decisions and came very close to declaring work requirements unlawful, because they are contrary to the statutory purpose of Medicaid to furnish medical assistance to eligible people and to pay for their medical care.[11] These decisions suggest that the administration's new block grant policy also will face headwinds, as federal funding is not a waivable feature of the Medicaid Act, and capped funding inevitably will lead to reductions in coverage and benefits, contravening the purpose of the program. Moreover, the Supreme Court's decision in *Department of Commerce v. New York* instructed federal agencies that they cannot engage in sham rulemaking, which the D.C. Circuit cited in vacating Arkansas's work requirements.[12]

The Medicaid and CHIP Payment and Access Commission (MACPAC) and the Government Accountability Office (GAO) have pressed HHS to protect Medicaid's core through letters and reports.[13] GAO has raised red flags repeatedly, for example in October 2018 calling for CMS action to ensure Medicaid MCOs provide reliable data; in April 2019 demanding overhaul of Medicaid managed care to be more formally constructed and to increase transparency; and in August 2019, demanding CMS account for children failing to receive screenings promised by EPSDT. Likewise, MACPAC pressed CMS to cease work requirement approvals because thousands of people were disenrolled. Further, members of Congress have demanded HHS change its policies; most recently, House leadership requested the Office of the Inspector General investigate the new block grant policy.[14] HHS has ignored such entreaties.

One example of grassroots organizations performing watchdog functions is the disability community's advocacy during 2017 repeal debates. Advocates publicly acted to protect the ACA, compelling Americans to watch disabled protesters pulled from their wheelchairs yelling that they would "rather go to jail than die without Medicaid."[15] People with disabilities, including children and their families, shared stories that provided a human face and showed how Medicaid keeps people in their homes, highlighting the importance of LTSS and HCBS. They educated members of Congress, other advocates, and the public. As a result, in 2019, universal health reform bills included mandatory HCBS benefits for the first time.[16]

***

The struggle for the soul of Medicaid offers lessons for health reform debates, hot again as a presidential election approaches. Attacking Medicaid's core invites and exacerbates health disparities. Polls indicate Medicaid is popular, evidenced by the key role it played in the grassroots movements that successfully defeated ACA repeal efforts. Medicaid uniquely protects low income people and provides fiscal security to states, especially in emergencies. Health reform proposals for Medicare-for-All and other universal health care plans cannot and should not replace Medicaid with health coverage that loses Medicaid's special sensitivity to the needs of low-income patients. Medicaid's core benefits and protections purposefully guarantee coverage and care for people who face special barriers to care. Health reform needs Medicaid, and Medicaid's soul.

Note

The authors have no conflicts to disclose.

References

1. 42 U.S.C. § 12132 (2020); *Olmstead v. L.C.*, 527 U.S. 581, 583 (1999).
2. 42 C.F.R. §§ 4476.50 – 447.56 (2020).
3. Centers for Medicare and Medicaid Services, "About Section 1115 Demonstrations," *available at* <https://www.medicaid.gov/medicaid/section-1115-demo/about-1115/index.html> (last visited July 12, 2020).
4. Letter from Calder Lynch, Deputy Administrator and Director Center for Medicaid & CHIP Services to State Medicaid Direc-

The Journal of Law, Medicine & Ethics, 48 (2020): 429-433. © 2020 The Author(s)

https://doi.org/10.1177/1073110520958865 Published online by Cambridge University Press

tors, "Healthy Adult Opportunity," January 30, 2020, *available at* <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd20001.pdf> (last visited July 12, 2020).

5. Kaiser Family Foundation, "Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State," March 10, 2020, *available at* <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/#Table3> (last visited July 12, 2020).
6. *Gresham v. Azar*, 950 F.3d 93, 99 (D.C. Cir. 2020); *Philbrick v. Azar*, 397 F. Supp. 3d 11 (D.D.C. 2019) (New Hampshire); *Stewart v. Azar* II, 366 F. Supp. 3d 125 (D.D.C. 2019) (second Kentucky decision); *Gresham v. Azar*, 363 F. Supp. 3d 165, 169 (D.D.C. 2019) (Arkansas); *Stewart v. Azar* I, 313 F. Supp. 3d 237, 243 (D.D.C. 2018) (first Kentucky decision).
7. A.R. Gluck and N. Huberfeld, "What Is Federalism in Healthcare For?" *Stanford Law Review* 70, no. 6 (2018): 1689-1803, at 1737, 1747.
8. CMCS Informational Bulletin, "Section 1115 Demonstration Process Improvements," November 6, 2017, *available at* <https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/cib110617.pdf> (last visited July 12, 2020).
9. *Armstrong v. Exceptional Child Center*, 575 U.S. 320, 347 (2015).
10. See *Gresham*, 950 F.3d 93 (Arkansas and Kentucky); See *Philbrick*, 397 F. Supp. 3d 11 (New Hampshire); *Young v. Azar*, Docket No. 1:19-cv-03526 (D.D.C. Mar. 4, 2020) (Minute Order granting summary judgment).
11. See *Gresham*, 950 F.3d at 103-104.
12. *Department of Commerce v. New York*, 139 S. Ct. 2551, 2575 (2019).
13. Letter from Penny Thompson, Chair of MACPAC to Alex Azar II, Secretary of the U.S. Department of Health and Human Services, November 8, 2018, *available at* <https://www.macpac.gov/wp-content/uploads/2018/11/MACPAC-letter-to-HHS-Secretary-Regarding-Work-Requirements-Implementation.pdf> (last visited July 12, 2020); Letter from Seema Verma, Administrator for Centers for Medicare and Medicaid Services to Penny Thompson, Chair of MACPAC, February 6, 2019, *available at* <https://ccf.georgetown.edu/wp-content/uploads/2019/02/2019_02_13_12_41_48.pdf> (last visited July 12, 2020); Government Accountability Office, "Medicaid Demonstrations: Approvals of Major Changes Need Increased Transparency," April 2019, *available at* <https://www.gao.gov/assets/700/698608.pdf> (last visited July 12, 2020).
14. Letter from Frank Pallone, Jr. and Ron Wyden to Christi A. Grimm, Principal Deputy Inspector General, January 14, 2020, *available at* <https://energycommerce.house.gov/sites/democrats.energycommerce.house.gov/files/documents/TN.pdf> (last visited July 12, 2020).
15. L. Plank, "People with disabilities are staging protests in senators' offices all over the country," *Vox*, July 6, 2017, *available at* <https://www.vox.com/health-care/2017/7/6/15927940/people-with-disabilities-staging-protests-senators-offices> (last visited July 12, 2020).
16. Medicare for All Act of 2019, H.R. 1384, 116th Cong. § 1129 (2019); Medicare for America Act of 2019, H.R. 2452, 116th Cong. (2019).

The Journal of Law, Medicine & Ethics, 48 (2020): 429-433. © 2020 The Author(s)

https://doi.org/10.1177/1073110520958865 Published online by Cambridge University Press