

The Ongoing Racial Paradox of the Medicaid Program

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ABSTRACT: Medicaid, the largest public health insurance program for low-income people, has since 1965 extended health coverage to millions of people, including people of color. At the same time, it has perpetuated disparities based on race. Central in the paradox of Medicaid is that racism is “baked into the program,” yet it has transformed opportunities for health care and decreased racial disparities in coverage and access. It includes features that, with attention and creativity, can make significant contributions to reducing inequities in the health care system.

In this article, we review Medicaid’s history, from its birth during the civil rights era to the present day, including the significant changes wrought by the Affordable Care Act. Most notably, this includes the Medicaid expansion that has brought coverage for the first time to millions of adults, many of those people of color. We discuss the racism woven through its history and the ways in which the program has perpetuated racial inequity. We conclude by describing Medicaid’s potential to address systemic racism in health care, including innovations in care delivery and management, and full implementation of the expansion.

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ARTICLE CONTENTS

Introduction	98
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Medicaid's Paradoxical History	98
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Medicaid's Potential to Address Systemic Racism	102
Medicaid Expansion	103
Medicaid Managed Care	106
Race and Ethnicity Data	108

Conclusion	111
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INTRODUCTION

Medicaid is the single most important publicly funded health program for low-income and underserved people. Providing insurance coverage to over 75 million people, Medicaid coverage largely removes affordability from the access to care equation.¹

Medicaid's role flew under the radar for many years. When added as Title XIX to the Social Security Act in 1965, Medicaid went largely unnoticed by the public, overshadowed by the much more visible Medicare program for older adults. Inserted into the Act quietly (there is little discussion of the law in the Congressional Record accompanying its enactment), Title XIX borrowed both the programmatic structure and the stigma associated with “welfare” in the United States. It was a common assumption among those in the know that Medicare would expand to provide universal coverage, while Medicaid “was just another substandard state program for the poor that would fade away.”² But rather than go away, Medicaid evolved. Over the years, Medicaid has extended significant health coverage and benefits to millions of people, including people of color. Yet, it has often perpetuated disparities and exclusions based on race.

This is the central paradox of Medicaid. It has “racism baked into the program”³ and yet, it has transformed opportunities for health care, decreased racial disparities in coverage and access, and includes features that—with attention and creativity—can make significant contributions to addressing inequities in the health care system.

MEDICAID'S PARADOXICAL HISTORY

Medicaid was born during an era of great civil rights struggle and advancement in the United States. Enacted on July 30, 1965, Medicaid followed passage of the Voting Rights Act by a month and preceded enactment of the Civil Rights Act by less than 11 months.⁴ Not surprisingly, Medicaid was the product of compromise. On the one hand, the Medicaid Act brought life-saving health coverage to millions of people of all races. On the other hand, its basic structure perpetuated racial inequities in the health care system. Three features defined Medicaid in 1965, and they continue to do so today.

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- 1 Aside from limited cost sharing, Medicaid beneficiaries cannot be charged for the services they receive. Medicaid-participating providers must accept, as payment in full, the amounts paid by the state Medicaid agency, plus any deductible or copayment authorized by the state to be paid by the individual. 42 C.F.R. § 447.15 (2022). The Medicaid Act establishes the limits on deductibles and copayments that states can impose on individual enrollees. 42 U.S.C. §§ 1396o, 1396o-1 (2021).
 - 2 DAVID BARTON SMITH, *THE POWER TO HEAL: CIVIL RIGHTS, MEDICARE, AND THE STRUGGLE TO TRANSFORM AMERICA'S HEALTH CARE SYSTEM* 193 (2016).
 - 3 Cindy Pearson, Nat'l Women's Health Network, *Protecting and Expanding Medicaid Means Confronting Racism Baked into the Program* (Apr. 3, 2019), <https://nwhn.org/protecting-and-expanding-medicaid-means-confronting-racism-baked-into-the-program/>.
 - 4 DAVID BARTON SMITH, *HEALTH CARE DIVIDED: RACE AND HEALING A NATION* at 116–17 (1999).

First, unlike Medicare which is administered by the federal government, Medicaid was established as an optional program for states. As a result, state uptake and administration were uneven from the start. States in the South lagged. Thirty-two states had adopted Medicaid before even the first former Confederate state had adopted it.⁵

Second, Medicaid's structure was borrowed from preexisting welfare programs. Medicaid grew out of the Kerr-Mills Act of 1960, an inadequately funded and voluntary health coverage program for states. Not all states participated. This was particularly true for states in the South with large populations of Black Americans, such that "the 10 states comprising the Deep South and neighboring states (Texas, Arkansas, Louisiana, Tennessee, Mississippi, Alabama, Florida, Georgia, South Carolina, and North Carolina), an area often referred to as the 'Black Belt,' accounted for 3.3 percent of [Kerr-Mills] participants."⁶ Building from Kerr-Mills, Medicaid eligibility was tied to the receipt of public cash assistance, such as Aid to Families with Dependent Children (AFDC), as well as Old Age Assistance, Aid to the Blind, and Aid to the Totally and Permanently Disabled, which eventually became Supplemental Security Income (SSI) for the aged, blind, and disabled.⁷ Thus, "medical assistance was burdened with the social stigma and political disadvantages associated with a welfare program."⁸ To qualify, a person had to be poor and fit within a population group deemed worthy of coverage.

Third, the Medicaid Act conditioned state participation on covering five services, skewed somewhat to addressing acute care needs (i.e., inpatient and outpatient hospital, laboratory and x-ray, physician, and skilled nursing facility services).⁹ Moreover, when monitoring state activities with respect to Medicaid coverage, the federal administrative agency aligned itself as a partner with participating states, shying away from its duties as an enforcement agency. This left states to exercise, often unchecked and at times illegal, their own discretion as they

5 See Cindy Pearson, *Protecting and Expanding Medicaid Means Confronting Racism Built into the Program*, NAT'L WOMEN'S HEALTH NETWORK (Apr. 3, 2019), <https://nwhn.org/protecting-and-expanding-medicaid-means-confronting-racism-baked-into-the-program/>.

6 LaShyra T. Nolen et al., *How Foundational Moments in Medicaid's History Reinforced Rather than Eliminated Racial Health Disparities*, HEALTH AFFS. FOREFRONT (Sept. 1, 2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200828.661111/full/#:~:text=Multiple%20studies%20have%20demonstrated%20the,conditions%2C%20and%20improved%20mental%20health.>

7 See 42 U.S.C. § 1396a(a)(10)(A)(i) (2021).

8 Judith D. Moore & David G. Smith, *Legislating Medicaid: Considering Medicaid and Its Origins*, 27 HEALTH CARE FIN. REV. 45, 46 (2005), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194918/> (discussing the predecessor Kerr-Mills Act).

9 See Social Security Act Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 286, 343-52 (1965) (adding Title XIX, codifying services at 42 U.S.C. § 1396d). Medicaid does not fund care for individuals between age 21 and 65 who are patients in institutions for mental diseases (residential facilities with more than 16 beds primarily providing mental health/substance use services). *Id.* § 1396d(a)(31)(B); see also *id.* § 1396d(a)(xvi). As a result, health care expenditures for these individuals remain the responsibility of the states in full. Congress has recently relaxed this long-standing exclusion. As part of the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities (SUPPORT) Act, Congress amended the Medicaid Act to provide an option for states to cover substance use services in IMD settings for limited periods of time. *Id.* § 1396n(l) (added by SUPPORT Act, Pub. L. No. 115-271, Title V, § 5052, 132 Stat. 3894, 3971) (Oct 24, 2018).

operated their programs.¹⁰ For example, health care providers that received Medicaid funding were subject to Title VI of the Civil Rights Act, which prohibits entities that receive federal funding from discriminating on the basis of race, color, or national origin. Yet, nursing facilities that received significant Medicaid funding were and remain segregated by race. Government enforcement of Title VI in nursing facilities has bordered on being non-existent.¹¹ Racial disparities in facilities extend, for example, to pain management, flu vaccinations, pressure ulcer treatment, and use of physical restraints.¹² Most recently, the proportion of Black residents in a nursing home was associated with an increased probability of a COVID-19 outbreak, from 45% to 300%.¹³

Despite the lack of federal intervention to enforce federal requirements, Medicaid—with its structure in place—did not fade away but rather, evolved and expanded. Between 1984 and 1990, Congress established a national floor of coverage for children, pregnant women, and the aged, blind, and disabled. Through incremental and permanent expansions, Congress began to uncouple Medicaid eligibility from the receipt of public cash assistance—such as AFDC for families and children and SSI for the aged, blind, and disabled—and determined eligibility by looking instead to whether the person’s income fell below a percentage of the federal poverty level.¹⁴ In another action, Congress established and expanded a gold standard for children’s health coverage—early and periodic screening, diagnostic, and treatment services specifically tailored to meet the needs of low-income children and youth (including, for example, lead and sickle cell testing, developmental screening, case management, and transportation services).¹⁵ Despite these expansions, the federal government did not always move in a uniform direction. In 1996, for example, Congress imposed a five-year bar to Medicaid coverage for immigrants.¹⁶

10 Sara Rosenbaum, *Medicaid and the Role of the Courts*, COMMONWEALTH FUND (2018), https://www.commonwealthfund.org/sites/default/files/2018-06/Rosenbaum_Medicaid_and_the_Courts_v2.pdf.

11 See DAVID BARTON SMITH, *HEALTH CARE DIVIDED* 159-61 (1999); *id.* at 160 (noting that “[t]he nursing home industry concluded that so long as discriminatory practices were not flaunted, there would be no interventions by federal officials”).

12 Philip D. Sloane et al., *Addressing Systemic Racism in Nursing Homes: A Time for Action*, 22 J. POST-ACUTE & LONG-TERM CARE MED. P886 (2021) (citing recent research).

13 *Id.*

14 See, e.g., Deficit Reduction Act (DRA) of 1984, Pub. L. No. 98-369, § 2361, 98 Stat. 494, 1104 (codified at 42 U.S.C. §§ 1396d(n), 1396a(a)(10)(A)(i)(III)); Omnibus Budget Reconciliation Act of 1986, Pub. L. No. 99-509, § 9401, 100 Stat. 1874, 2050 (codified at 42 U.S.C. §§ 1396a(l), 1396a(a)(10)(A)(ii)); Medicare Catastrophic Coverage Act of 1988 (MCCA), Pub. L. No. 100-360, § 302, 102 Stat. 683, 750 (codified at 42 U.S.C. §§ 1396a(a)(10)(A)(i)(IV), 1396a(l)(2)(A)(iii)); Omnibus Budget Reconciliation Act (OBRA) of 1990, Pub. L. No. 101-508, § 4601(a)(1), 104 Stat. 1388, 1388-166.

15 See Social Security Act Amendments of 1967, Pub. L. No. 90-248, §§ 224, 302, 81 Stat. 821, 902, 929 (then codified at 42 U.S.C. § 1396a(a)(13)). For in-depth discussion, see Jane Perkins & Sarah Somers, *Medicaid’s Gold Standard Coverage for Children and Youth: Past, Present, and Future*, 30 ANNALS HEALTH L. & LIFE SCI. 153 (2021), <https://lawcommons.luc.edu/cgi/viewcontent.cgi?article=1499&context=annals>.

16 8 U.S.C. §§ 1613(a), 1613(c)(2)(A) (indicating that individuals subject to the five-year bar are eligible for emergency Medicaid). For in-depth discussion, see Sarah Grusin & Catherine McKee, *Medicaid Coverage for Immigrants*, NAT’L HEALTH L. PROGRAM (May 17, 2021), <https://healthlaw.org/resource/medicaid-coverage-for-immigrants/>.

Most recently, Medicaid was addressed as part of the sweeping health care expansion and reforms wrought by the Affordable Care Act (ACA). Among the ACA's many provisions, Medicaid was expanded to all non-elderly adults who did not already qualify and whose incomes fall below 133% of the federal poverty level.¹⁷ As noted by Chief Justice John Roberts, the expansion was an "element of a comprehensive national plan to provide universal health insurance coverage."¹⁸ Nevertheless, the Chief Justice wrote the majority decision in *National Federation of Independent Business v. Sebelius* (NFIB), holding that Medicaid expansion was unduly coercive on the states and thus unconstitutional.¹⁹ As a result of this opinion, the federal government cannot deny federal funding to a state that refuses to take up Medicaid expansion.²⁰

Complicating the ACA's attempt to expand coverage even more, President Trump entered office vowing to "explode" the ACA and its Medicaid expansion.²¹ Following that direction, Centers for Medicare & Medicaid Services (CMS) Administrator Seema Verma declared that Medicaid expansion did not "make sense" and announced that CMS would resist that change by allowing states to condition coverage of the Medicaid expansion population on stringent work requirements.²² Work requirements ignored the fact that the vast majority of people eligible for expansion coverage were already working or cannot work due to chronic health conditions or caregiving responsibilities.²³ The work requirements also carried racial overtones. Michigan legislators, for instance, introduced a mandatory work requirement bill that was predicted to terminate coverage for more than 100,000 people and would have exempted those living in counties with high unemployment rates, but not Medicaid beneficiaries living in mostly African American cities like Flint and Detroit.²⁴

President Biden and the 117th Congress have attempted to mitigate the damage wrought by the Supreme Court and the Trump administration. The Biden administration acted quickly to revoke the work requirement policies.²⁵ Congress is considering legislation that would extend coverage to the expansion populations in states that have refused to expand as a result

17 See 42 U.S.C. § 1396a(a)(10)(A)(i)(VIII) (added by Patient Protection and Affordable Care Act).

18 *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 583 (2012).

19 *Id.* at 575-87.

20 *Id.*

21 See Amy Goldstein & Juliet Eilperin, *Affordable Care Act Remains "Law of the Land," but Trump Vows to Explode It*, WASH. POST, Mar. 24, 2017.

22 Speech: Remarks by Administrator Seema Verma at the National Association of Medicaid Directors (NAMD) 2017 Fall Conference (Nov. 7, 2017), <https://www.cms.gov/newsroom/fact-sheets/speech-remarks-administrator-seema-verma-national-association-medicaid-directors-namd-2017-fall>.

23 Rachel Garfield et al., *Work Among Medicaid Adults: Implications of Economic Downturn and Work Requirements*, KAISER FAM. FOUND. (Feb. 11, 2021), <https://www.kff.org/report-section/work-among-medicaid-adults-implications-of-economic-downturn-and-work-requirements-issue-brief/>.

24 Jamila Michener, *The Politics and Policy of Racism in American Health Care*, VOX (May 24, 2018, 1:10 PM), <https://www.vox.com/polyarchy/2018/5/24/17389742/american-health-care-racism>.

25 See Joan Alker, *Biden Administration Withdraws Medicaid Work Requirements Guidance and More*, CTR. FOR CHILD. & FAMS. GEORGETOWN UNIV. HEALTH POL'Y INST. (Feb. 17, 2021), <https://ccf.georgetown.edu/2021/02/17/biden-administration-withdraws-medicaid-work-requirements-guidance-and-more/>.

of NFIB.²⁶ Yet, threats remain. A subsequent administration or Congress could revive work requirements or other restrictive measures. Moreover, as of this writing, it is not clear whether the Medicaid coverage gap legislation will pass.²⁷

Meanwhile, the failure to expand hurts millions of low-income people, a large proportion of whom are Black, Latino, or other people of color. Today, echoing the original holdouts from adopting Medicaid, 12 states still refuse to expand their Medicaid programs.²⁸ The percentage of the population that is Black in these states are Mississippi 38%, Georgia 31%, Alabama 27%, South Carolina 26%, North Carolina 21%, Tennessee 16%, Florida 15%, Texas 12%, Kansas 6%, Wisconsin 6 %, South Dakota 2 %, and Wyoming 1%.²⁹ Seven of these states have populations of Black people higher than the national rate of 13%.³⁰ Texas also has the highest proportion of Hispanic residents of any state (40%), while South Dakota has the third highest proportion of Native Americans (8%).³¹

Research has confirmed what these numbers suggest. The likelihood of state adoption of Medicaid expansion significantly decreases as the percentage of the Black population increases.³² Not surprisingly, states with lower racial sympathy and higher racial resentment on average show a strong resistance to Medicaid expansion.³³ In addition, when Whites are less supportive of expansion, the state is less likely to adopt the expansion regardless of non-White levels of support.³⁴ Racial resentment persists and continues to influence attitudes toward Medicaid and health policy in general.³⁵

MEDICAID'S POTENTIAL TO ADDRESS SYSTEMIC RACISM

Despite the racism that is woven throughout its history, Medicaid has been the single most important health insurance program and thus guarantor of access to care for low-income

26 See, e.g., Build Back Better Act, H.R. 5376, 117th Cong., 1st Sess. § 1948 (2021), <https://www.govinfo.gov/content/pkg/BILLS-117hr5376rh/pdf/BILLS-117hr5376rh.pdf> (establishing federal Medicaid program to close coverage gap in nonexpansion states).

27 Sahil Kapur & Benjy Sarlin, *Manchin Says Build Back Better is 'Dead': Here's What He Might Resurrect*, NBC News (Feb. 2, 2022), <https://www.nbcnews.com/politics/congress/manchin-says-build-back-better-dead-here-s-what-he-n1288492>.

28 See *Status of State Medicaid Expansion Decisions: Interactive Map*, KAISER FAM. FOUND. (Feb. 24, 2022), <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.

29 Zamir Brown, *States by Medicaid Expansion, Household Income, and Racial Demographics (Poverty Rate, Population Distribution, and Medicaid Participation)* (Aug. 27, 2021) (unpublished research) (on file with author).

30 *Quick Facts*, U.S. CENSUS BUREAU, <https://www.census.gov/quickfacts/fact/table/US/PST045221> (last visited Apr. 9, 2022).

31 *Id.*

32 Colleen M. Grogan & Sunggeun Ethan Park, *The Racial Divide in State Medicaid Expansions*, 42 J. HEALTH POL., POL'Y L. 539, 541 (2017).

33 Daniel Lanford & Jill Quadagno, *Implementing ObamaCare: The Politics of Medicaid Expansion under the Affordable Care Act of 2010*, 59 SOCIO. PERSPS. 619, 630-31 (2015).

34 Colleen M. Grogan & Sunggeun Ethan Park, *The Racial Divide in State Medicaid Expansions*, 42 J. HEALTH POL., POL'Y L. 539, 558 (2017).

35 *Id.* at 543.

people, millions of whom are people of color.³⁶ As noted above, it covers more than 75 million people, more than a fifth of the U.S population.³⁷ Thus, Medicaid holds immense potential to further address the country's profound disparities in coverage, access to services, and health outcomes. Below, we discuss several ways that the Medicaid program can address health disparities and the impact of systemic racism, thus advancing health equity between races.

Medicaid Expansion

The Medicaid expansion authorized by the ACA has proven to be one of the most significant advances in health equity in generations. If all low-income people can benefit from the expansion, including those who live in the 12 states that have not yet expanded, the advances will be that much more significant.

If Medicaid coverage were expanded in the non-expansion states, at least 4 million uninsured adults would be newly eligible for Medicaid coverage, nearly 60% of whom are people of color.³⁸ Approximately 957,000 non-Latino Black adults would become eligible for Medicaid if the remaining holdout states expanded Medicaid.³⁹ In the non-expansion states of Texas, Mississippi, Georgia, Florida, and South Dakota, more than half of those who would gain coverage through expansion are people of color.⁴⁰

Medicaid expansion has produced numerous health and community benefits. Expansion is linked to gains in coverage and consequently, to improvements in access to care, financial security, and health outcomes.

Health Coverage: Overwhelming evidence shows that expansion has improved access to care and narrowed racial and ethnic health disparities.⁴¹ In particular, the disparities in health

36 *Introduction to Medicaid*, CTR. ON BUDGET AND POLICY PRIORITIES, <https://www.cbpp.org/sites/default/files/atoms/files/policybasics-medicaid.pdf> (last updated Aug. 16, 2016); see also Medicaid 101, MACPAC, <https://www.macpac.gov/medicaid-101/> (last visited Apr. 9, 2022).

37 *May 2021 Medicaid and CHIP Enrollment Trends Snapshot*, CTR. FOR MEDICAID & CHIP SERVS., <https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/downloads/may-2021-medicaid-chip-enrollment-trend-snapshot.pdf>.

38 Jesse Cross-Call, *Medicaid Expansion Has Helped Narrow Racial Disparities in Health Coverage and Access to Care*, CTR. ON BUDGET & POL'Y PRIORITIES (Oct. 21, 2020), <https://www.cbpp.org/research/health/medicaid-expansion-has-helped-narrow-racial-disparities-in-health-coverage-and>. Hispanic people account for 29% of this gain, and Black people 23%.

39 *Issue Brief: Health Insurance Coverage and Access to Care Among Black Americans: Recent Trends and Key Challenges*, Off. Assistant Sec'y for Plan. & Evaluation, U.S. Dep't of Health & Hum. Servs., at 5 (2022), <https://aspe.hhs.gov/reports/health-insurance-coverage-access-care-among-black-americans> (hhs.gov).

40 Jesse Cross-Call, *Medicaid Expansion Has Helped Narrow Racial Disparities in Health Coverage and Access to Care*, CTR. ON BUDGET & POL'Y PRIORITIES, at 3 (Oct. 21, 2020), <https://www.cbpp.org/research/health/medicaid-expansion-has-helped-narrow-racial-disparities-in-health-coverage-and>.

41 Madeline Guth et al., *Effects of the ACA Medicaid Expansion on Racial Disparities in Health and Health Care*, KAISER FAMILY FOUND. (Sept. 30, 2020), <https://www.kff.org/medicaid/issue-brief/effects-of-the-aca-medic-aid-expansion-on-racial-disparities-in-health-and-health-care/>; see also Samantha Artiga et al., *Health Coverage by Race and Ethnicity, 2010-2019*, KAISER FAMILY FOUND. (July 16, 2021), <https://www.kff.org/racial-equity-and-health-policy/issue-brief/health-coverage-by-race-and-ethnicity/>.

insurance coverage and cost related access problems narrowed between Black and White and Hispanic and White beneficiaries in expansion states more significantly than they did in non-expansion states.⁴² The gap in uninsured rates between White and Black adults shrunk by 51% in expansion states after passage of the ACA, compared with a 33% decrease in non-expansion states.⁴³ The gap between White and Hispanic adults shrunk by 45% in expansion states, but only 27% in non-expansion states.⁴⁴

Access to Care: Medicaid expansion significantly improved “access to primary care and medications, affordability of care, preventive visits, screening tests, and self-reported health.”⁴⁵ After the expansion, Black adults in expansion states were more likely to report a usual source of care than White adults in non-expansion states, and they were about as likely to have a usual source of health care as Whites in expansion states.⁴⁶ Medicaid expansion also reduced disparities in coverage for Black and Hispanic patients newly diagnosed with cancer.⁴⁷ Expansion has narrowed racial disparities in outpatient and emergent settings. This includes reducing disparities in rates of perforated appendicitis, which is a proxy for delayed care.⁴⁸ Similarly, Medicaid expansion led to greater parity in timely initiation of treatment of Black and White patients with advanced cancer⁴⁹ and reduced disparities between Black and

42 Jesse C. Baumgartner et al., *How the Affordable Care Act Has Narrowed Racial and Ethnic Disparities in Access to Health Care*, COMMONWEALTH FUND, at 6-7 (Jan. 2020), https://www.commonwealthfund.org/sites/default/files/2020-01/Baumgartner_ACA_racial_ethnic_disparities_db.pdf.

43 Jesse Cross-Call, *Medicaid Expansion Has Helped Narrow Racial Disparities in Health Coverage and Access to Care*, CTR. ON BUDGET & POL’Y PRIORITIES, at 1 (Oct. 21, 2020), <https://www.cbpp.org/research/health/medicaid-expansion-has-helped-narrow-racial-disparities-in-health-coverage-and>.

44 *Id.* at 1-2.

45 Benjamin D. Sommers et al., *Three-Year Impacts of the Affordable Care Act: Improved Medical Care and Health Among Low-Income Adults*, 36 HEALTH AFFS. 1119, 1124 (2017), <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2017.0293>.

46 Jesse C. Baumgartner et al., *How the Affordable Care Act Has Narrowed Racial and Ethnic Disparities in Access to Health Care*, COMMONWEALTH FUND, at 6-7 (Jan. 2020), https://www.commonwealthfund.org/sites/default/files/2020-01/Baumgartner_ACA_racial_ethnic_disparities_db.pdf.

47 Madeline Guth et al., *Effects of the ACA Medicaid Expansion on Racial Disparities in Health and Health Care*, KAISER FAMILY FOUND. (Sept. 30, 2020) (citing Ankit Agarwal et al., *The Impact of the Affordable Care Act on Disparities in Private and Medicaid Insurance Coverage Among Patients Under 65 with Newly Diagnosed Cancer*, 105 INT’L J. RADIATION ONCOLOGY, BIOLOGY, PHYSICS 25, 26 (May 2019), [https://www.redjournal.org/article/S0360-3016\(19\)30783-7/pdf](https://www.redjournal.org/article/S0360-3016(19)30783-7/pdf)), Xuesong Hang, et al., *Comparison of Insurance Status and Diagnosis Stage Among Patients with Newly Diagnosed Cancer Before vs After Implementation of the Patient Protection and Affordable Care Act*, 12 JAMA ONCOLOGY 1713, 1714 (2018).

48 Cheryl K. Zogg et al., *Impact of Affordable Care Act Insurance Expansion on Pre-Hospital Access to Care: Changes in Adult Perforated Appendix Admission Rates after Medicaid Expansion and the Dependent Coverage Provision*, 228 J. AM. COLL. SURGEONS 29 (2019).

49 Blythe Adamson et al., *ACA Medicaid Expansion Association with Racial Disparity Reductions in Timely Cancer Treatment*, 27 AM. J. MANAGED CARE 274 (July 2021) (defining timely treatment as first-line systemic therapy starting within 30 days after diagnosis of advanced or metastatic disease).

White patients in listings for heart transplants for African Americans.⁵⁰ Studies have also shown reduction in disparity in hypertension treatment for Mexican-heritage Latinos.⁵¹

Outcomes: There is evidence that expansion improves health outcomes. Near-elderly adults in expansion states have experienced a substantial drop in mortality compared to those in non-expansion states, with research estimating that in the four years following Medicaid expansion, approximately 15,600 deaths could have been averted if the Medicaid expansions were adopted nationwide as intended by Congress.⁵² Medicaid expansion has also led to improved maternal health outcomes with the effect “concentrated among non-Hispanic Black mothers, indicating that Medicaid expansion could be contributing to a reduction in the large racial disparity in maternal mortality faced by Black mothers.”⁵³ One study found large improvements in mortality from end-stage renal disease (ESRD) in expansion states compared to non-expansion states.⁵⁴ Patients with ESRD who lived in an expansion state saw significant reduction in mortality. Those mortality reductions were greatest for Black patients.⁵⁵

An analysis of coverage in two Southern states illustrates the power of Medicaid expansion to reduce disparities. Louisiana expanded Medicaid in 2016. Subsequently, the uninsured rates for Black and White adults dropped from more than 18% to 16%.⁵⁶ The overall uninsured rate for Black adults dropped to 11.3% by 2018, which was lower than the rate for Black adults in non-expansion Georgia (19.2%) and White adults in Georgia (14.9%).⁵⁷

Expanding Medicaid is a critical tool for reducing racial disparities in coverage and access to care. It is having a positive impact on outcomes and, if expanded to include the non-expansion states, could do even more.

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- 50 Khadijah Breathett et al., *The Affordable Care Act Medicaid Expansion Correlated with Increased Heart Transplant Listings in African-Americans but not Hispanics or Caucasians*, 5 J. AM. COLL. CARDIOLOGY HEART 148 (2017), <https://doi.org/10.1016/j.jchf.2016.10.013>.
- 51 Ryan McKenna et al., *The Affordable Care Act Reduces Hypertension Treatment Disparities for Mexican-heritage Latinos*, 55 MED. CARE 654 (2017), <https://doi.org/10.1097/MLR.0000000000000726>.
- 52 See Sarah Miller et al., *Medicaid and Mortality: New Evidence from Linked Survey and Administrative Data* 3, 23 (NBER Working Paper Series No. 26081, 2019), https://www.nber.org/system/files/working_papers/w26081/w26081.pdf, estimating that the probability of mortality in expansion states was reduced by 6.4%.
- 53 Erica L. Eliason, *Adoption of Medicaid Expansion Is Associated with Lower Maternal Mortality*, 30 WOMEN'S HEALTH ISSUES 147, 150 (2020), <https://doi.org/10.1016/j.whi.2020.01.005>; see also, e.g., Clare C. Brown et al., *Association of State Medicaid Expansion Status with Low Birth Weight and Preterm Birth*, 321 JAMA 1598 (2019), <https://jamanetwork.com/journals/jama/fullarticle/2731179> (finding expansion to be associated with improvements in relative health disparities for Black infants compared with White infants); Chintan B. Bhatt & Consuelo M. Beck-Sague, *Medicaid Expansion and Infant Mortality in the United States*, 108 AM. J. PUB. HEALTH 565 (2018), <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2017.304218> (suggesting that expansion may have contributed to a decline in infant mortality rates, especially among African American infants).
- 54 Shailender Swaminathan et al., *Association of Medicaid Expansion With 1-Year Mortality Among Patients With End-Stage Renal Disease*, 320 JAMA 2242, 2248 (2018), <https://jamanetwork.com/journals/jama/fullarticle/2710505>.
- 55 *Id.* at 2248-49.
- 56 Jesse C. Baumgartner et al., *How the Affordable Care Act Has Narrowed Racial and Ethnic Disparities in Access to Health Care*, COMMONWEALTH FUND, at 9 (Jan. 2020), https://www.commonwealthfund.org/sites/default/files/2020-01/Baumgartner_ACA_racial_ethnic_disparities_db.pdf.
- 57 *Id.*

Medicaid Managed Care

Federal law gives states the option to require Medicaid beneficiaries to enroll in managed care plans with a limited slate of participating providers. Nearly all states have taken this option. Over the last four decades, managed care has become by far the predominant delivery system in the Medicaid program. More than 90% of beneficiaries are enrolled in some type of Medicaid managed care, and 69% are enrolled in plans that receive a capitated payment in exchange for providing a defined set of services.⁵⁸

Managed care was originally conceived as a means to control and predict costs in the Medicaid program, a use that persists today.⁵⁹ The primary mechanism for cost control was the use of capitated payment systems⁶⁰ in which plans receive a set payment per person regardless of how many services a beneficiary received. This structure provides an incentive to limit care, potentially harming patients.⁶¹ Over the years, researchers and patient advocates have criticized managed care for attempting to meet its obligations by limiting necessary services to save money or creating barriers that prevent access to services.⁶² They have also found significant access and quality problems.⁶³ At the same time, managed care has the potential to benefit patients by using case management to coordinate health care services and connect people to necessary health and social services.

58 *Managed Care*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, <https://www.macpac.gov/topics/managed-care/> (last visited Apr. 10, 2022); *Total Medicaid MCO Enrollment*, KAISER FAMILY FOUND., <https://tinyurl.com/2p9adr8p> (last visited Apr. 10, 2022).

59 See, e.g., Deborah A. Freund & Robert E. Hurley, *Managed Care in Medicaid: Selected Issues in Program Origins, Design, and Research*, 8 ANN. REV. PUB. HEALTH 137, 141 (1987), <https://www.annualreviews.org/doi/pdf/10.1146/annurev.pu.08.050187.001033s.org>.

60 Notably, researchers have questioned whether managed care actually succeeds in controlling costs. See, e.g., Mark Duggan & Tamara Hayford, *Has the Shift to Managed Care Reduced Medicaid Expenditures? Evidence from State and Local-Level Mandates* 4, 16, 18 (2013), http://web.stanford.edu/~mgduggan/Research/MD_Hayford_2013.pdf (finding increase in managed care enrollment led to increased Medicaid spending).

61 *Managed Care's Effect on Outcomes*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, <https://www.macpac.gov/subtopic/managed-cares-effect-on-outcomes/> (last visited Apr. 10, 2022) (collecting studies).

62 See Mark Duggan & Tamara Hayford, *Has the Shift to Managed Care Reduced Medicaid Expenditures? Evidence from State and Local-Level Mandates* 11 (2013), http://web.stanford.edu/~mgduggan/Research/MD_Hayford_2013.pdf (finding need for referrals and restricted networks of providers may provide barriers to care); *Issue Brief: Transitioning Beneficiaries with Complex Care Needs to Medicaid Managed Care: Insights from California*, Kaiser Comm'n on Medicaid & the Uninsured (2013), <https://www.kff.org/wp-content/uploads/2013/06/8453-transitioning-beneficiaries-with-complex-care-needs2.pdf> (describing beneficiary problems obtaining treatment); Mike Shields, *Work in Progress: KanCare Problems Persist for Providers*, KAN. HEALTH INST. (Sept. 23, 2013); <http://www.khi.org/news/article/kancare-problems-persist-providers/> (describing problems for providers and beneficiaries in Medicaid managed care rollout); Jason Clayworth, *Serious Service Errors Plague Medicaid Companies*, DES MOINES REG. (Sept. 19, 2015), <http://www.desmoinesregister.com/story/news/investigations/2015/09/19/serious-service-errors-plague-medicaid-companies/71903372/> (describing delay and wrongful denial of services by managed care plans).

63 See *Medicaid Long-Term Services and Supports: Access and Quality Problems in Managed Care Demand Improved Oversight* (Nov. 16, 2020), <https://www.gao.gov/products/gao-21-49>.

Over the years, states have employed managed care models to address the unique needs of certain at-risk populations, including, for example, children with special needs.⁶⁴ The thinking behind such models is they will improve care by providing care coordination, enhancing continuity of care, and ensuring networks have specialty providers.⁶⁵ It is not clear, however, whether these models have been successful.

More recently, some states have started employing features of managed care to address racial health disparities and other problems arising from systemic racism.⁶⁶ CMS provides some tools that have contributed to this trend. The long-standing requirements related to quality assurance in managed care are one such tool.⁶⁷ Medicaid law requires that states have a written quality strategy for their managed care programs, as well as managed care plans to implement their own quality assessment and Performance Improvement Programs (PIP).⁶⁸ Regulations direct plans to design these PIPs to improve health outcomes and enrollee satisfaction, detect under- and over-utilization, and assess quality of care for beneficiaries with special needs.⁶⁹

When CMS revised the Medicaid managed care regulations in 2016, it added a requirement that states include a plan to improve health equity as part of the written quality strategy. The final rule requires states to “identify, evaluate, and reduce, to the extent practicable, health disparities based on age, race, ethnicity, sex, primary language, and disability status.”⁷⁰ In June 2021, CMS issued a Medicaid Managed Care Quality Strategy Toolkit to help states formulate their quality strategies, which includes guidance on implementing this regulation.⁷¹ It emphasizes the importance of data collection and provides “considerations” for inclusion in the disparities plan, such as coordinating with public health, and links to resources on data collection and health disparities.⁷² A few states had implemented these plans as of mid-2021. Hopefully, the guidance in the toolkit will spur more states to follow suit.⁷³

64 *How Six States Use Medicaid Managed Care to Serve Children with Special Health Care Needs*, NAT'L ACAD. FOR STATE HEALTH POL'Y (May 7, 2018), <https://www.nashp.org/how-six-states-use-medicaid-managed-care-to-serve-the-unique-needs-of-children-with-special-health-care-needs/>.

65 *Id.*

66 *Reducing Racial and Ethnic Disparities: A Quality Improvement Initiative in Medicaid Managed Care*, CTR. FOR HEALTH CARE STRATEGIES (2007), https://www.chcs.org/media/Racial__Ethnic_Health_Disparities.pdf.

67 42 C.F.R. pt. 438, subpt. E (2022).

68 *Id.*

69 *Id.* § 438.330(b); *Quality requirements under Medicaid managed care*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, <https://www.macpac.gov/subtopic/quality-requirements-under-medicaid-managed-care/> (last visited Apr. 10, 2022).

70 42 C.F.R. § 438.340(b); *see also id.* § 438.340(b)(6), <https://healthlaw.org/resource/addressing-health-equity-in-medicaid-managed-care/>. This guidance, of course, predates the regulatory revision.

71 *Medicaid and Children's Health Insurance Program (CHIP) Managed Care Quality Strategy Toolkit*, CTRS. FOR MEDICARE & MEDICAID SERVS. (2021), <https://www.medicaid.gov/medicaid/downloads/managed-care-quality-strategy-toolkit.pdf>.

72 *Id.* at 23.

73 *See* David Machledt, *Addressing Health Equity in Medicaid Managed Care*, NAT'L HEALTH L. PROGRAM, at 4 (2021), <https://healthlaw.org/resource/addressing-health-equity-in-medicaid-managed-care/> (describing health equity plans in Colorado, Delaware, and Nebraska).

In addition to efforts by federal authorities, non-profit organizations and states have launched projects designed to advance health equity through Medicaid managed care. The non-profit Institute for Medicaid Innovation has partnered with the University of Chicago and Center for Health Care Strategies in an initiative to identify best practices and policy innovations to advance equity and eliminate health and health care disparities.⁷⁴ Seven states are participating in this initiative: Delaware, Illinois, Maine, New Jersey, Pennsylvania, Tennessee, and Washington. Each project includes a state agency, a Medicaid managed care plan, and a health care provider.⁷⁵ Projects are ongoing and are focusing on, among other things, disparities in access to care for Black children in Delaware, diagnosis of mood disorders postpartum for Black women in New Jersey, and sexually transmitted infection rates for adolescents in Pennsylvania.⁷⁶

States have also focused on ways Medicaid managed care can address disparities. For example, North Carolina's Health Equity Payment Incentive provided time-limited, enhanced payments to health care providers participating in the state's Primary Care Case Management System, Carolina Access.⁷⁷ The state explains that "[t]his initiative ultimately aims to improve access to primary care and preventive services for Medicaid and NC Health Choice [the Children's Health Insurance Program] beneficiaries in North Carolina at a time when historically marginalized populations are facing challenges highlighted by the COVID-19 public health emergency."⁷⁸ Participating providers are eligible for enhanced per-member-per-month payments depending on a score based on the level of poverty in a member's service area. The payments come in two tiers and are to be used to cover services that will address health equity such as (1) training on implicit bias, trauma informed care, and health equity; (2) recruitment of staff aimed at reducing health inequity, e.g., dietitians, community health workers, coaches, and doulas; (3) telehealth; and (4) improvements to practice structures to "address non-medical drivers of health." The project concluded in June 2021.⁷⁹ Approximately 1,250 practices participated.⁸⁰ A report is anticipated later this year.⁸¹

Race and Ethnicity Data

Collecting comprehensive data on race, ethnicity, language, and disability status is crucial in promoting health equity. Such data enables health care providers, payers, policy makers, and

74 *Disparities & Equity*, INST. FOR MEDICAID INNOVATION, <https://www.medicaidinnovation.org/current-initiatives/disparities-equity> (last visited Apr. 10, 2022).

75 *Id.*

76 *Id.*

77 *Health Equity Payment Initiative*, NC MEDICAID DIV. OF HEALTH BENEFITS (Mar. 19, 2021), <https://medicaid.ncdhhs.gov/blog/2021/03/19/health-equity-payment-initiative>.

78 *Id.*

79 *Id.*

80 E-mail from Emma Sandoe, PhD, Associate Director of Strategy and Planning, Division of Health Benefits, N.C. Dep't of Health and Human Servs., to author (Dec. 2, 2021, 11:30 EST) (on file with author).

81 *Id.*

advocates to identify disparities in quality of care and more importantly, target interventions to improve utilization and quality of care.⁸² Detailed data that is broken down by demographic categories is essential to monitor problems and develop prevention and treatment programs, ensuring that care is culturally and linguistically appropriate and capable of tracking across populations.⁸³ In the words of Dr. Marcella Nunez-Smith, Chair of the Biden Administration's COVID-19 Health Equity Task Force, collection of good data on health inequities is crucial "because we can't fix what we cannot see."⁸⁴

Data has enabled researchers to uncover profound disparities in health status. For decades, research has shown that Black people have higher rates of death, disease, and other health problems, including infant mortality, homicide, suicide, cancer, hypertension, and communicable diseases.⁸⁵ Though these statistics are grim and the problems they reveal are stubbornly persistent,⁸⁶ making the problems known has led to improvements in health status.⁸⁷

Conversely, failure to collect adequate data impedes progress towards addressing health disparities. When data results from incomplete or erroneous reporting, it is impossible to detect the true extent of disparities. For example, gaps in data on patient race and ethnicity delayed health care providers and policy makers from detecting the disproportionate impact of COVID-19 on Black, Hispanic, Latino, Asian, and Native American communities. This slowed the public health and policy response, leading to more illness and death among these populations.⁸⁸

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- 82 See, e.g., *Inventory of Resources for Standardized Demographic and Language Data Collection*, CTCS FOR MEDICARE & MEDICAID SERVICES. (2022), <https://www.cms.gov/about-cms/agency-information/omh/downloads/data-collection-resources.pdf>.
- 83 David Moskowitz et al., *The Role of Data in Health Care Disparities in Medicaid Managed Care*, 2 MEDICARE & MEDICAID RSCH. REV. E1 (2012), https://www.cms.gov/mmrr/Downloads/MMRR2012_002_04_A02.pdf.
- 84 Jessica Kim Cohen, *5 Highlights from ONC's 2021 Annual Meeting*, MODERN HEALTHCARE (Mar. 31, 2021, 11:27 AM), <https://www.modernhealthcare.com/information-technology/5-highlights-oncs-2021-annual-meeting>.
- 85 See, e.g., Jane Perkins, *Race Discrimination in America's Health Care System*, 27 CLEARINGHOUSE REV. 371 (1993) (providing statistics on health disparities).
- 86 See, e.g., *2019 National Healthcare Quality and Disparities Report: Executive Summary*, AGENCY FOR HEALTHCARE RSCH. & QUALITY, at ES1 (2020), <https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2019qdr-final-es-cs061721.pdf>; Nambi Ndugga & Samantha Artiga, *Disparities in Health and Health Care: 5 Key Questions and Answers*, KAISER FAMILY FOUND. (May 11, 2021), <https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/>.
- 87 See, e.g., *2019 National Healthcare Quality and Disparities Report: Executive Summary*, AGENCY FOR HEALTHCARE RSCH. & QUALITY, at ES1 (2020), <https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2019qdr-final-es-cs061721.pdf>; see generally Jesse C. Baumgartner et al., *How the Affordable Care Act Has Narrowed Racial and Ethnic Disparities in Access to Health Care*, COMMONWEALTH FUND, at 6-7 (Jan. 2020), https://www.commonwealthfund.org/sites/default/files/2020-01/Baumgartner_ACA_racial_ethnic_disparities_db.pdf; Ch. 2: *The State of Health Disparities in the United States*, in COMMUNITIES IN ACTION: PATHWAYS TO HEALTH EQUITY, at 59 (NAT'L ACAD. SCIS. 2017), <https://www.ncbi.nlm.nih.gov/books/NBK425844/> (stating "[a]lthough significant progress has been made in narrowing the gap in health outcomes . . . the elimination of disparities in health has yet to be achieved.").
- 88 Kevin Casey McAvey & Alisha Reginal, *Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action*, MANATT HEALTH, at 4 (2021).

Congress and CMS have taken initial steps toward improving the quality of health data. The ACA mandated that all national federal data collection efforts gather information on race, ethnicity, sex, primary language, and disability status.⁸⁹ The U.S. Department of Health and Human Services (HHS) has centered data as essential to reducing health disparities. In its 2011 Action Plan to Reduce Racial and Ethnic Disparities, HHS identified accurate data collection as key to reducing health disparities and named increasing the availability, quality, and use of data to improve the health of minority populations as an overarching priority.⁹⁰ In its 2016 quality strategy for Medicaid and other programs it oversees, CMS identified elimination of racial and ethnic disparities as a primary goal.⁹¹ One of the activities it identified as necessary to meet this goal was the stratification of data by race, ethnicity, disability, and primary language to identify disparities.⁹² The Medicaid Managed Care Quality Strategy Toolkit, mentioned above, heavily emphasizes the importance of stratified data collection, referring states to technical assistance tools on data stratification.⁹³

Lack of funding impedes efforts to improve, expand, and standardize data collection. Researchers and advocates can, however, fill some of the gaps left by federal and state agencies. To this end, the National Health Law Program, funded by the Robert Wood Johnson Foundation, has launched a two-year project to identify and analyze demographic data collection and reporting in Medicaid and other federally funded programs. The project will assess the progress that has been made in these programs and recommend improvements to the policies and practices governing demographic data collection and reporting policies and practices.⁹⁴ Results of this effort are expected in 2024.

89 The ACA mandated that all national federal data collection efforts gather information on race, ethnicity, sex, primary language, and disability status. Section 4302(b)(1) specifically requires the collection of data on these five demographic characteristics in Medicaid and CHIP and imposes standards for that collection. The ACA data collection mandate is a powerful tool, but the federal government has failed to deploy it or even take it out of the tool box. The provision needs dedicated funding to go into effect, which Congress never appropriated. See David Machledt, *Addressing Health Equity in Medicaid Managed Care*, NAT'L HEALTH L. PROGRAM, at 1 (May 25, 2021), <https://healthlaw.org/resource/addressing-health-equity-in-medicaid-managed-care/>.

90 *HHS Action Plan to Reduce Racial and Ethnic Health Disparities: A Nation Free of Disparities in Health and Health Care*, U.S. DEP'T OF HEALTH AND HUMAN SERVS., at 5, 12, 29, https://www.minorityhealth.hhs.gov/assets/pdf/hhs/HHS_Plan_complete.pdf (last visited Apr. 10, 2022).

91 *CMS Quality Strategy 2016*, <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf> (last visited Apr. 10, 2022).

92 *Id.* at 30, see generally David Machledt, *Addressing Health Equity in Medicaid Managed Care*, NAT'L HEALTH L. PROGRAM, at 3 (2021), <https://healthlaw.org/resource/addressing-health-equity-in-medicaid-managed-care/>.

93 *Medicaid and Children's Health Insurance Program (CHIP) Managed Care Quality Strategy Toolkit*, CTRS. FOR MEDICARE & MEDICAID SERVS., at 23 (2021), <https://www.medicaid.gov/medicaid/downloads/managed-care-quality-strategy-toolkit.pdf>; Webinar, <https://www.medicaid.gov/medicaid/quality-of-care/downloads/performance-measurement/core-set-stratification-webinar.pdf>.

94 *Improving Demographic Data Collection: Proposal*, NAT'L HEALTH L. PROGRAM (Apr. 16, 2021) (on file with author).

CONCLUSION

Racism shaped the Medicaid program. Yet, over its 55-year history, it has chipped away at disparities, particularly for African Americans. It has not only increased coverage but also expanded access to services and improved health outcomes. It also has significant but untapped potential to diminish these disparities and create progress toward greater health equity. The Medicaid expansion offers perhaps the most significant opportunity to make progress as abundant evidence has already shown its potential to improve health equity. The federal government has made improving data quality and standardizing data collection a high priority, which is essential to identifying disparities and targeting interventions to specific subsets of the population. Finally, while much study remains to be done, managed care has the potential to address disparities and may also prove to advance equity. Medicaid provides the tools and structure. With funding, creativity, and increased effort, it may realize its promise as a true tool to fight the impact of systemic racism.

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