



An **Advocate's Guide** to Reproductive and Sexual Health in the Medicaid Program



Chapter III.

Section 1115 Demonstration Waivers

Section 1115 of the Social Security Act allows states to request waivers of certain, but not all, Medicaid requirements in order to test experimental projects that further the longstanding objectives of the Medicaid program. Those objectives are to enable states 1) to furnish medical assistance, as far as practicable, to individuals who lack the income and resources to meet the costs of necessary medical care, and 2) to furnish such assistance and services to help these individuals attain or retain the capacity for independence and self-care.¹

States have used § 1115 waivers to go outside the boundaries of their state Medicaid plans to implement experimental projects designed to expand Medicaid eligibility and services and to improve access to health care. Waiver requests must be approved by the Centers for Medicare & Medicaid Services (CMS), are to have robust evaluation components, and must be budget neutral. CMS's authority to approve waivers is limited:

1. The waiver must implement an “experimental, pilot, or demonstration” project;
2. The waiver must be limited to Medicaid provisions in 42 U.S.C. §1396a;
3. The experiment must be likely to promote Medicaid’s objectives; and
4. The waiver of Medicaid’s requirements must be limited to the extent and period needed to carry out the experiment.²

A. Waiver Approvals Over Time

Early § 1115 Medicaid waivers focused on experimenting with nominal cost sharing.³ Congress later amended the Medicaid Act to add detailed provisions—outside of § 1396a—establishing states’ options for imposing premiums and cost sharing and stated its belief that this would “give[] the Secretary sufficient flexibility in this regard to make further exercise of the Secretary’s demonstration authority unnecessary.”⁴

During the 1990s, the Clinton administration approved a number of states’ requests to implement § 1115 waivers to expand Medicaid coverage to childless adults while transitioning the service delivery system from fee-for-service provider payments to capitated managed care.⁵ Congress subsequently amended the Medicaid Act to describe, in detail, the states’ options for using managed care for providing medical assistance.⁶

The Obama administration approved waivers for Delivery System Reform Incentive Programs designed to improve health outcomes while controlling costs.⁷ Such reforms included quality and value controls in managed care contracts, implementation of health homes for individuals with chronic conditions, and new delivery and payment models for individuals dually eligible for Medicaid and Medicare.⁸ The administration also used § 1115 waivers as a tool for limited Medicaid expansion after the U.S. Supreme Court decided *National Federation of Independent Business v. Sebelius* in 2012.⁹ For example, Arkansas expanded Medicaid coverage using private insurance exchanges and subsidies. Indiana expanded coverage but added conditions on eligibility, including premium payments.¹⁰

Over the years, § 1115 waivers have also been used during emergencies, such as 9/11 and Hurricane Katrina, to enable affected states to get Medicaid to needy individuals quickly and continuously.¹¹

In the reproductive and sexual health context, some states have used or are using § 1115 demonstration projects to expand family planning coverage to certain groups of individuals who were not otherwise eligible for Medicaid. Ten states currently operate expanded family planning programs through § 1115, which have been a critical source of limited Medicaid coverage for individuals seeking a range of reproductive and sexual health care services.¹² These experiments were so effective that Congress included a provision in the ACA allowing states to permanently add coverage of family planning services as a state plan amendment (SPA). As a result, states have been phasing out their use of § 1115 waiver authority in favor of the SPA option to provide family planning services.¹³

States have also used § 1115 to redesign service delivery systems and/or cover services that were not typically covered under a state's Medicaid plan. For example, several states conducted or are currently conducting demonstration projects to provide earlier access to treatment for people living with HIV.

INNOVATIVE APPROACH:

Six states—Arizona, California, Colorado, Maine, Massachusetts, Oregon, and the District of Columbia—have approved § 1115 waivers to provide care for people living with HIV.¹⁴ Each state has taken a different approach to conducting its demonstration, but all sought to provide earlier access to treatment. Maine assigns each enrollee a nurse coordinator to coordinate the social, pharmacy, and medical needs of people living with HIV. The District of Columbia used Department of Defense drug pricing to provide less costly antiretroviral HIV medication.¹⁵

B. Waivers Used to Limit Eligibility and Enrollment

Recent § 1115 waivers under the Trump administration have looked very different compared to past waivers. Several states have applied for—and CMS has approved—projects that impose unprecedented and harmful restrictions on Medicaid enrollees.

If allowed to stand, these waivers could fundamentally transform the nature of the Medicaid program and exacerbate health inequities. Research has shown that Medicaid coverage enables individuals to obtain care and use preventive services such as cervical cancer screenings and family planning.¹⁶ Waivers that limit coverage put women of color, people with disabilities, LGBTQ people, and other underserved populations who rely on Medicaid as their only source of affordable health care coverage at risk.

1. Work requirements

On January 11, 2018, for the first time in the 50-year history of the Medicaid program, the Trump Administration released a policy encouraging states to apply “work and community engagement” requirements to a segment of the state’s Medicaid population. Those subject to the requirement will be terminated from health care coverage unless they meet a monthly minimum of work or volunteer hours and show proof that they worked, looked for work, volunteered, went to school, or participated in a job-training program.

As of January 2019, CMS has approved seven waiver projects with work requirements—Arkansas, Indiana, Kentucky, New Hampshire, Maine, Michigan, and Wisconsin—although most have not yet gone into effect.¹⁷ In early 2018, sixteen Kentucky Medicaid enrollees challenged Kentucky’s demonstration project, the first one CMS approved under the new policy. On June 29, 2018, the D.C. federal court vacated the approval of Kentucky’s waiver project and remanded the matter to HHS for further review.¹⁸ A group of Medicaid enrollees in Arkansas have also filed a lawsuit challenging their state’s CMS-approved project.¹⁹ Ten states have pending waiver proposals that seek to impose work requirements on Medicaid enrollees.²⁰

Work requirements undermine reproductive health and economic security. They are unnecessary and have been shown to be ineffective in other public benefits programs.²¹ Work requirements also create an unnecessary burden on Medicaid enrollees. While the waivers exclude some populations—such as pregnant people, caretakers of dependents or people with disabilities, and people with disabilities—excluded individuals will still be subject to the waiver’s reporting and documentation requirements. These requirements may be so confusing and complex that some will lose their Medicaid coverage because they are unable to navigate these processes and/or unable to meet the administrative requirements to qualify for exemptions. Work requirements are

also unworkable for many low-income workers. For example, women are concentrated in certain low-wage jobs with inconsistent work hours and/or have jobs in the informal economy that do not provide proof of employment. Work requirements also recycle historical stereotypes that stigmatize poor people, people of color and people with chronic and disabling conditions.²²

2. Lockout periods

As of January 2019, seven states—Arkansas, Indiana, Kentucky, Maine, Michigan, New Mexico, and Wisconsin—include lock out penalties in their § 1115 projects. Another two states have pending applications that include this penalty.²³ Lockouts bar otherwise eligible individuals from receiving Medicaid coverage during the lockout period. The length of the lockout period varies from state-to-state and ranges from three to nine months. Lockout periods can apply to individuals who fail to pay premiums, meet work requirements, complete paperwork or report changes in circumstances. For those locked out as a result of failing to meet work requirements, this complication only increases the barriers to finding a stable job that meets the criteria of the state. For most Medicaid enrollees, being locked out of the program means they have no other viable and affordable health care coverage option. Many individuals rely on Medicaid coverage because they do not have access to marketplace coverage. Thus, the disruption of a lockout period can be all the difference in accessing life-saving care.

3. Enrollment Limits

There currently are no time limits in the Medicaid program. However, two states submitted waivers requesting authority to place limits on how long an individual can be enrolled in Medicaid (known as an “enrollment cap”) or how long an individual can receive Medicaid coverage over the course of their lifetime (known as “lifetime limits”).²⁴

Enrollment caps add an unnecessary restriction on eligible individuals seeking Medicaid coverage. These restrictions impose an arbitrary limit on the number of people who can access coverage that has nothing to do with meeting program requirements. Enrollment caps will have a disproportionate impact on women of color, who are more likely to have low incomes and more likely to be enrolled in Medicaid coverage for longer periods of time.

In May 2018, CMS announced it would not approve state requests to impose lifetime limits on Medicaid coverage.²⁵ If, however, CMS were to reverse its policy, approval of the requests would allow those states to limit enrollees to only 36 to 60 months of Medicaid coverage. This means that a single parent working full time at minimum wage and qualifying for Medicaid might lose access to health care for up to five years, even if their job does not offer coverage.

C. Waivers Used to Exclude Abortion Providers

While states are phasing out their use of § 1115 authority to provide family planning services, ten states currently use this authority to expand coverage for individuals seeking family planning services and supplies who are not otherwise eligible for Medicaid.²⁶ Advocates should be troubled, however, that some states are seeking to use family planning waivers to restrict reproductive and sexual health services under Medicaid.

Texas, the first state to apply for such a waiver, submitted a demonstration project application to waive the “freedom of choice” of family planning provider protection in order to exclude abortion providers.²⁷ As of January 2019, Tennessee has also applied for an exclusion, and South Carolina submitted a similar application to CMS. These waivers are a clear attack on Planned Parenthood and other abortion providers. They ignore the longstanding “freedom of choice” protection that allows Medicaid enrollees to seek family planning services from any Medicaid provider, whether or not the provider is in the enrollee’s managed care network.²⁸ If implemented, the Texas waiver would not cover counseling for or provision of emergency contraception and would not pay for family planning services that include a “diagnosis related to elective termination of pregnancy or emergency contraception.”²⁹

D. Waivers Used to Limit Benefits and Increase Costs

1. Elimination of vital services

Several state waiver applications also include proposals to eliminate coverage of key Medicaid benefits, such as non-emergency medical transportation (NEMT) and Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) services for 19 and 20 year-olds.³⁰ NEMT is an important benefit because it provides a means for Medicaid enrollees—such as people with disabilities and people living in rural communities and other areas with limited public transportation options—to travel to their providers to access care.³¹ EPSDT is a comprehensive health care benefit for children and youth under 21 years old who are enrolled in Medicaid or enrolled in CHIP when a state operates its program as an extension of Medicaid.³² EPSDT covers medical, vision, hearing, and dental screenings, including age-appropriate health education.³³ The elimination of such benefits undermines the Medicaid program and will exacerbate existing health and health care disparities within waiver states.

For example, in an evaluation of Iowa’s NEMT waiver, implemented in 2014, fourteen percent of new Medicaid enrollees with incomes under the federal poverty level (FPL) reported they could not obtain transportation to or from a health care visit.³⁴ An evaluation of Indiana’s NEMT waiver that went into effect in 2015 found six percent of enrollees without state-provided NEMT cited transportation as a reason for missing an appointment in the six months prior to their participation in the survey.³⁵

2. Premiums and co-pays

Several states are also seeking to impose premiums and heightened co-pays on individuals enrolled in Medicaid.³⁶ Under federal Medicaid law, premiums are generally prohibited for individuals with incomes below 150 percent FPL, and certain groups are exempt. Medicaid includes flexibility for states to use copayments, but they must generally be nominal in amount. These protections are in place because individuals enrolled in the Medicaid program lack the financial resources to pay high fees to access care.

Other states have submitted waiver applications to impose emergency department co-pays and/or missed appointment fees on Medicaid enrollees. Kentucky and Wisconsin have received approval for such changes.

Premiums and co-pays impede an individual's access to health care services and their ability to enroll in health insurance. In one study of the Alabama Children's Health Insurance Program, the increase in premiums reduced the number of Black parents who renewed their child's enrollment by 5.9 percent.³⁷ Co-pays deter individuals from seeking the care they need. Studies demonstrate that even small levels of cost-sharing are associated with reduced use of *necessary* health services by low-income people, including preventive and primary care.

E. Public Participation and Transparency

§ 1115 of the Social Security Act and its implementing regulations include detailed requirements regarding transparency and public participation during the development, approval, and monitoring of a demonstration project.³⁸ These requirements were put in place by the ACA, which also directed HHS to promulgate regulations outlining a public notice and comment period at both the state and federal levels that is "sufficient to ensure a meaningful level of public input."³⁹ HHS regulations clarified that the public notice and comment period must include public hearings and written comments.

ADVOCACY TIP:

States and CMS must follow a particular public comment process when developing, reviewing, and approving a waiver request under § 1115. This process includes a 30-day state public notice and comment period before a state submits an application for an initial demonstration or an application to extend an existing demonstration.⁴⁰ After receiving an application, CMS must also provide a 30-day federal public notice and comment period. Thus, advocates have more than one opportunity to get involved with the design and review of § 1115 waiver requests.⁴¹ Make sure to submit written comments, supported by expert opinions and research to the state Medicaid agency, and resubmit your comments again during the federal process.

F. Reduced Oversight and Monitoring

Section 1115 waiver approvals typically include special terms and conditions that require states to submit periodic monitoring and performance reports to CMS. These reports allow CMS and other public stakeholders to oversee and track the effects of the project throughout the demonstration period.

On November 6, 2017, CMS announced a set of “Section 1115 Demonstration Process Improvements” that included expediting the approval of certain proposals and reducing the number and frequency of monitoring reports.⁴² CMS’s new efforts to reduce the state’s administrative burden and “streamline” monitoring and reporting requirements are concerning. Congress intended for approved 1115 waivers to include “a detailed research methodology and comprehensive evaluation for the demonstration.”⁴³ Implementing regulations establish reporting and monitoring procedures designed to ensure that CMS has adequate information concerning both a state’s compliance with these requirements and the effectiveness of the demonstration. The expedited processes announced by CMS threaten to undermine both Congressional intent and CMS’s duly promulgated regulations.

For detailed information about how states are using § 1115 demonstration projects, see NHeLP’s webpage on Medicaid waivers at <http://www.healthlaw.org>

Endnotes

- 1 42 U.S.C. § 1396-1.
- 2 42 U.S.C. § 1315(a).
- 3 Jane Perkins, Nat’l Health Law Prog., *Fact Sheet: Legal Issues in Section 1115 Medicaid Waivers* (2018), <https://healthlaw.org/resource/fact-sheet-legal-issues-in-section-1115-medicaid-waivers/>.
- 4 *Id.* See also Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, 96 Stat. 324, 367 (enacting § 1396o and amending § 1396a(a)(14) to its current form); H.R. Rep. No. 97-757, pt. 1, at 6, 97th Cong. 2nd Sess. 1982, Report on Medicaid and Medicare Part B Budget Reconciliation Amendments of 1982 (August 17, 1982).

- 5 *Id.*
- 6 Balanced Budget Act of 1997, Pub. L. No. 105-33, 111 Stat 251 (amending 42 U.S.C. §§ 1396n and enacting 1396u-2).
- 7 *Id.*
- 8 Alexandra Gates et al., Kaiser Fam. Found., *An Overview of Delivery System Reform Incentive Payment Waivers* (Sep. 29, 2014), <https://www.kff.org/medicaid/issue-brief/an-overview-of-delivery-system-reform-incentive-payment-waivers/>.
- 9 *See Nat'l Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519 (2012) (finding states could not be denied federal funding if they refused to implement the Affordable Care Act's expansion of Medicaid to adults with incomes below 133% of the federal poverty level).
- 10 Perkins, *supra*, note 3.
- 11 *Id.*
- 12 Alabama, Georgia, Florida, Maryland, Mississippi, Montana, Oregon, Rhode Island, Washington, and Wyoming currently have § 1115 family planning waivers. Utah has submitted a § 1115 application to expand their family planning program.
- 13 For information about eligibility for family planning expansion programs, see Chapter II, Section 5.
- 14 *See* HHS, Health Res. and Serv. Admin., *Impact of Medicaid 1115 Waivers on the Ryan White HIV/AIDS Program: Case studies on Experiences of RWHAP Providers and Clients* (2015), <https://hab.hrsa.gov/sites/default/files/hab/Global/medicaidwaivers.pdf>; Jamille Fields & Deborah Reid, Nat'l Health Law Prog., *Earlier Access to Treatment for Women Living with HIV: The Affordable Care Act's Medicaid Expansion and Section 1115 Demonstration Projects* (2015), <https://healthlaw.org/resource/earlier-access-to-care-for-uninsured-women-living-with-hiv-and-the-aca/>.
- 15 Fields & Reid, *supra* note 14.
- 16 Medicaid and CHIP Payment and Access Commission, *Access in Brief: Use of Cervical, Breast, and Colon Cancer tests*, 3 (2016) <https://www.macpac.gov/publication/access-in-brief-use-of-cervical-breast-and-colon-cancer-tests-among-adult-medicaid-enrollees/>; Guttmacher Inst., *Publicly Funded Family Planning Services in the United States* (Sept. 2016), <https://www.guttmacher.org/fact-sheet/publicly-funded-family-planning-services-united-states>.
- 17 Sarah Grusin, Nat'l Health Law Prog., *Sec. 1115 Waiver Tracking Chart* (Jan. 9, 2019) [hereinafter Waiver Tracker], <https://healthlaw.org/resource/sec-1115-waiver-tracking-chart-3-2/>.

- 18 *Stewart v. Azar*, 2018 WL 3203384 (D.D.C. June 29, 2018) (holding the Secretary of HHS's approval was arbitrary and capricious). Nat'l Health Law Prog., Kentucky Equal Justice Center, the Southern Poverty Law Center, and Jenner & Block LLP are representing the Kentucky plaintiffs.
- 19 Nat'l Health Law Prog., Legal Aid of Arkansas, and Southern Poverty Law Center are representing the Arkansas plaintiffs.
- 20 As of January 2019, Alabama, Arizona, Mississippi, North Carolina, Ohio, Oklahoma, South Dakota, Tennessee, Utah, and Virginia have pending waiver requests. Waiver Tracker, *supra* note 17.
- 21 MaryBeth Musumeci & Julia Zur, Kaiser Family Found., *Medicaid Enrollees and Work Requirements: Lessons From the TANF Experience* (Aug. 18, 2017), <https://www.kff.org/medicaid/issue-brief/medicaid-enrollees-and-work-requirements-lessons-from-the-tanf-experience/>.
- 22 Vanita Gupta & Fatima Goss Graves, USA TODAY, *Medicaid Work Requirements Are A Throwback to Rejected Racial Stereotypes* (2018), <https://www.usatoday.com/story/opinion/2018/01/11/medicaid-work-requirements-throwback-rejected-racial-stereotypes-gupta-graves-column/1024134001/>.
- 23 As of January 2019, South Dakota and Utah have submitted 1115 waiver applications that include lockouts. Waiver Tracker, *supra* note 17.
- 24 As of January 2019, AZ and UT have pending applications for a limit on the total number of months an individual can received Medicaid over the course of a lifetime. Utah is also seeking an enrollment cap in their waiver application. Kansas included a lifetime limit in their waiver application, however it was rejected. Waiver Tracker, *supra* note 17.
- 25 Nathaniel Weixel, *Trump administration won't approve lifetime limits on Medicaid*, THE HILL, Mar. 15, 2018, <https://thehill.com/policy/healthcare/medicaid/387760-trump-administration-wont-approve-lifetime-limits-on-medicaid>.
- 26 Guttmacher Inst., *Medicaid Family Planning Eligibility Expansions*, <https://www.guttmacher.org/state-policy/explore/medicaid-family-planning-eligibility-expansions> (Jan. 1, 2019).
- 27 Tex. Health & Human Services Comm'n, *Healthy Texas Women Section 1115 Demonstration Waiver Application*, 3, (2017), <https://hhs.texas.gov/laws-regulations/policies-rules/waivers/healthy-texas-women-1115-waiver> [hereinafter Tex. Healthy Texas Women Waiver]. In 2011, Indiana was the first state to seek CMS approval to exclude Medicaid participation of abortion providers through a state plan amendment. CMS denied the request citing the state's violation of the free choice of family planning provider requirement. See CMS, Letter from Donald Berwick, Administrator, to Patricia Casanova, Director of the Indiana Office of Medicaid Policy and Planning (June 1, 2011). Letter on file at NHeLP.

- 28 42 U.S.C. § 1396a(a)(23).
- 29 Tex. Healthy Texas Women Waiver, *supra* note 27, at Attachment B: Benefit Specifications and Provider Qualifications.
- 30 CMS approved waivers of NEMT coverage from Kentucky and Indiana, and is considering waivers from Arizona and Massachusetts. UT has a pending waiver application to eliminate EPSDT requirements for young people under 21 years of age. Waiver Tracker, *supra* note 17.
- 31 42 C.F.R. § 431.53.
- 32 States can establish their version of CHIP as a separate program, as an expansion of Medicaid, or as a combination of those two options. See 42 C.F.R. § 457.70(a). As of the writing of this guide, nine states and the District of Columbia operate CHIP as an expansion of Medicaid, two states operate CHIP as a separate program, and 39 states, as a combination of the two approaches. See Medicaid & CHIP Payment & Access Comm’n, *FactSheet: State Children’s Health Insurance Program (CHIP) 1* (2017), <https://www.macpac.gov/publication/state-childrens-health-insurance-program-chip-fact-sheet/>.
- 33 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(b), 1396d(r). For a comprehensive overview of EPSDT, see CMS, *EPSDT—A Guide for States: Coverage in the Medical Benefit for Children and Adolescents* (2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf.
- 34 Suzanne Bentler et al., Univ. of Iowa Public Policy Center, *Non-Emergency Medical Transportation and the Iowa Health and Wellness Plan at 23* (March 2016), https://ir.uiowa.edu/cgi/viewcontent.cgi?article=1131&context=ppc_health.
- 35 The Lewin Group, *Indiana 2.0: Evaluation of Non-Emergency Medical Transportation (NEMT) Waiver*, Prepared for Indiana Family and Social Services Administration, Executive Summary, 4 (2016), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-nemt-final-evl-rpt-11022016.pdf>.
- 36 As of January 2019, Kentucky, Indiana, Maine, Michigan, New Mexico, and Wisconsin have received approval to impose premiums on individuals with incomes under 150 percent FPL. North Carolina and Virginia are seeking similar proposals. Waiver Tracker, *supra* note 17.
- 37 Michael A. Morrissey et al., *The Effects of Premium Changes on ALL Kids, Alabama’s CHIP Program*, 2 MEDICARE & MEDICAID RES. REV. E12 (2012), https://www.cms.gov/mmrr/Downloads/MMRR2012_002_03_A01.pdf.
- 38 42 U.S.C. § 1315(a). For more information, see Catherine McKee & Jane Perkins, Nat’l Health Law Prog., *Waiver Requests: Transparency & Opportunity for Public Comment* (2017), <https://healthlaw.org/resource/sec-1115-waiver-requests-transparency-opportunity-for-public-comment/>.

- 39 42 U.S.C. § 1315(d)(2)(A), (C).
- 40 42 C.F.R. § 431.408(a).
- 41 Jane Perkins & Catherine McKee, Nat'l Health Law Prog., *Section 1115 Waiver Requests: Transparency and Opportunity for Public Comment* (Apr. 2017), <https://healthlaw.org/resource/sec-1115-waiver-requests-transparency-opportunity-for-public-comment/>.
- 42 CMS, CMCS Informational Bulletin, Section 1115 Demonstration Process Improvements (Nov. 6, 2017), <https://www.medicaid.gov/federal-policy-guidance/downloads/cib110617.pdf>.
- 43 H. R. Rep. No. 3982, pt. 2 at 307-08 (1981).