RDLA Policy Primer
Understanding Medicaid Coverage

Providing Information about Medicaid in a Post-H.R.1 World

Medicaid is a joint federal and state program that helps cover medical costs for people with limited income and resources.

The federal government has general rules that all state Medicaid programs must follow, but each state runs its own program. Medicaid eligibility and benefits vary from state to state, and based on characteristics such as age, income, disability status, or pregnancy status.[1]

Why Does Medicaid Matter for Rare Disease Patients?

Rare disease patients often have highly complex, chronic health conditions that can require around-the-clock care. The rare disease community relies on Medicaid for access to coverage for diagnosis, treatment, medical equipment, home healthcare, and caregiving services. In many cases, Medicaid is the only insurance program that provides the comprehensive care that rare disease patients need.

Since 70% of rare diseases begin in childhood, many rare disease patients with Medicaid are children.[2] The Children's Health Insurance Program (CHIP) is a related program that provides coverage for children from families with incomes too high to qualify for Medicaid, but too low to access private coverage.

Lastly, Medicaid coverage enables access to rare disease treatments. States are not required to cover prescription drugs, but all states have elected to include a drug benefit. The Medicaid Drug Rebate Program (MDRP) mandates that state Medicaid agencies pay the best available price for prescription drugs. In exchange for this guarantee, Medicaid programs are required to cover nearly all FDA-approved medications. However, Medicaid programs can limit the specific criteria for coverage of a given drug and deploy utilization management strategies like prior authorization and step therapy.[3]

Who is Eligible for Medicaid?

Federal law requires states to cover certain groups of individuals, including low-income families, low-income pregnant women and children, and individuals receiving Supplemental Security Income (SSI).[4] States also have additional options for enrollee coverage and may choose to expand coverage to other groups, such as individuals receiving home and community-based services and children in foster care who are not otherwise eligible. Nearly 2/3 of Medicaid enrollees who qualify based on old age and disability

are eligible through mandatory programs, while the remaining enrollees qualify for expanded coverage programs where requirements for mandatory eligibility (such as income thresholds) have been "waived". In instances in which state budget funding becomes limited, the expanded and more "optional" waiver programs* become most vulnerable to reductions.[5] For more about waiver programs, see below.

Because eligibility criteria vary across states, changes to federal or state Medicaid laws affect states differently and, in some cases, beneficiary groups differently.[6]

What Services are Covered by Medicaid?

Medicaid programs have both mandatory services that must be covered and optional services that a state can choose to cover.

- Mandatory services include inpatient hospital visits, outpatient hospital services, home health services, rural health clinic services, and many others.[7] States must also provide a more comprehensive set of services, known as the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, for children under age 21.[8]
- Optional services include dental, eyeglasses, physical or occupational therapy, and variations in prescription drug coverage.[9]

What is Medicaid Expansion and Why Does it Matter?

The Affordable Care Act (ACA) gave states the option to expand their Medicaid program to adults with incomes up to 138% of the Federal Poverty Level (or $36,777 a year for a family of three).[10] Today, 40 states and DC have expanded Medicaid eligibility, while 10 states (WI, WY, KS, TX, TN, MS, AL, GA, SC, and FL) do not.[11] More than 21 million individuals have gained coverage through Medicaid expansion.

States that expanded coverage to the adult population were given a higher percentage of federal funds (or Federal Medical Assistance Percentage (FMAP) to cover the new population.[12]

Medicaid expansion status is an example of how a federal policy change can affect a state's Medicaid program in different ways. 1 (the One Big Beautiful Bill Act) requires states to implement additional work requirements specifically for the adult expansion population.

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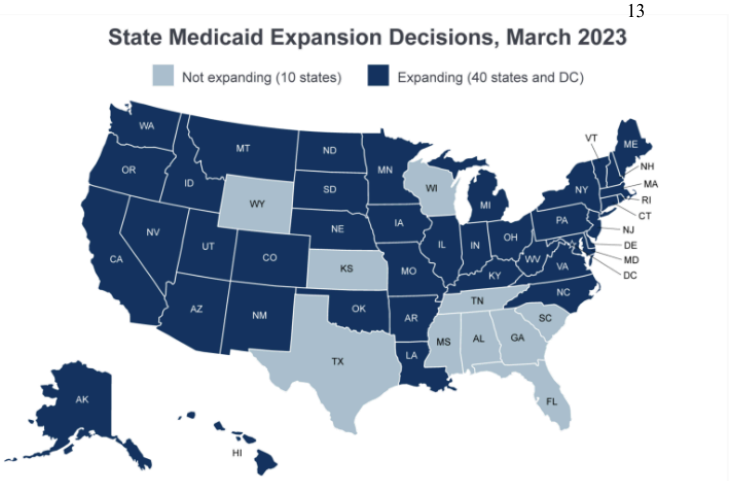


Medicaid Looks Different in Every State

Every state's Medicaid program has a different name. For example, Medi-Cal in California, MassHealth in Massachusetts, and Health First Colorado are all Medicaid programs. You can find the name of your state plan at: https://www.healthcare.gov/medicaid-chip-program-names/

Many states contract with private insurance companies to offer a **Medicaid Managed Care Plan**, which means that a Managed Care Organization (MCO) provides Medicaid benefits and receives payment from the state for each person it serves. Other recipients receive services through **a Fee for Services** system, in which a doctor or other health care provider is paid a fee directly by the Medicaid agency for each service rendered.[14]

If you are looking for clarification on your Medicaid status, you can check with your state's Medicaid agency.

What is a Waiver Program?*

A Medicaid Waiver program is a special set of services that a state can provide after gaining approval from the Federal government. Waiver programs are typically specific to a particular population, need, or service that may not be included in their typical benefits.[15]

There are several types of waiver programs:

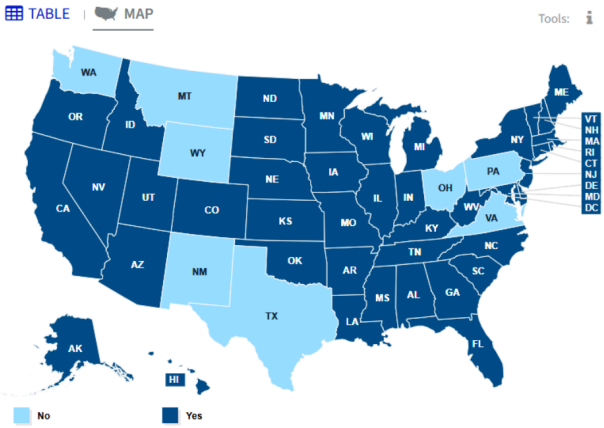
1915 Waivers allow states to provide home and community-based services (HCBS) to individuals who would otherwise require institutional care.

- **Katie Beckett Waivers**, sometimes referred to as TEFRA waivers, are one type of 1915 waiver that provides long-term care benefits for children up to age 19 who qualify for institutional care but live at home.[16] Tax Equity and Fiscal Responsibility Act (TEFRA) waivers are specifically designed to help children with disabilities by excluding the income of a child's parents, allowing the child to qualify for services independently of the family. 43 states offer TEFRA/Katie Beckett Waivers. States without waivers include MT, NM, OH, PA, TX, VA, WA, and WY.

1915 waivers are also among the primary ways enrollees access **home and community-based long-term services and supports (LTSS)**.

- In 2022, 86.6% of Medicaid **long-term services and supports (LTSS)** users received home and community-based services (HCBS), and HCBS accounted for 64.6% of Medicaid LTSS expenditures.[17]
- Medicaid spending per person was nearly nine times higher for people who used LTSS than for those who did not use LTSS ($38,769 vs. $4,480), with particularly high spending for people who used institutional LTSS.[18]

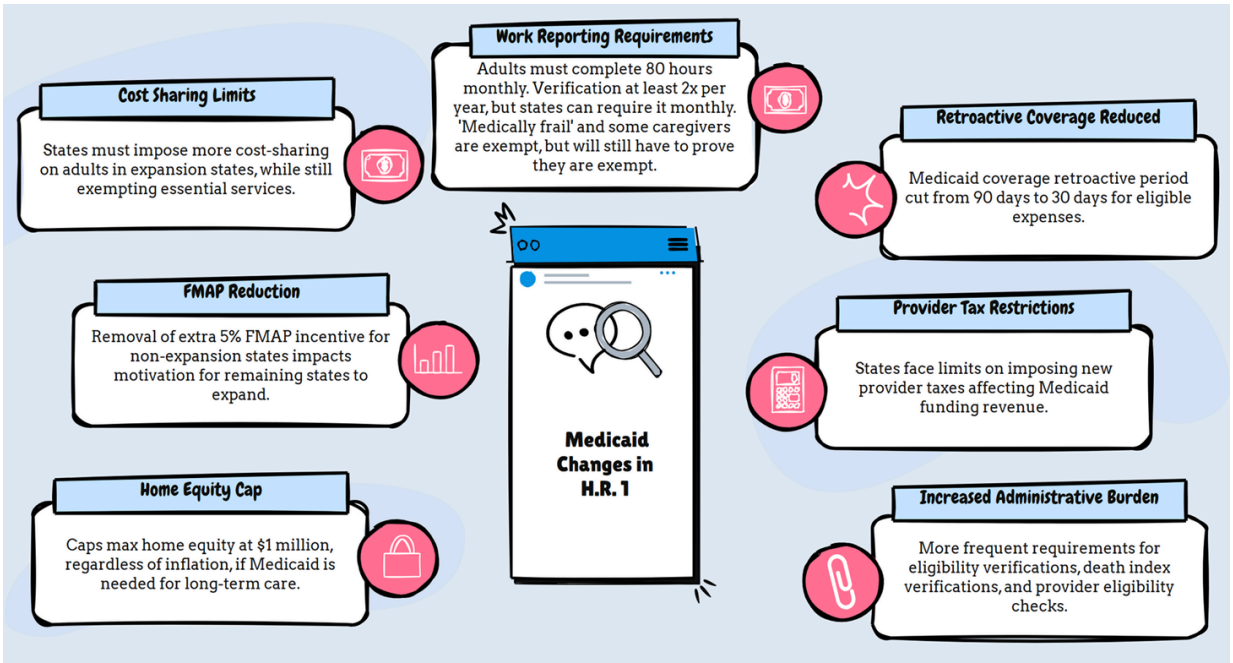
For many patients and their families, HCBS waivers are a key resource for keeping families together and providing high-quality health care services for children with rare conditions. Some states also offer Katie Beckett programs through expansions to their state health care plan or have both a waiver program and a state plan expansion.



1115 Waivers allow states to test new or experimental approaches to their Medicaid or CHIP programs that go beyond what is typically allowed.

- Work Requirements for able-bodied adults are an example of an 1115 Waiver, although recent changes in H.R.1 have codified the requirements into law. However, non-expansion Medicaid states, who would not be subject to H.R.1, can still apply for work requirements through an 1115 Waiver.
- One example is The Georgia Pathways program, which was created by an 1115 Waiver program, requiring adults in the state to work to receive benefits. The program resulted in substantial administrative costs for the state, but has been renewed into 2026.[20]
- Another example is an Arkansas program, which a federal judge halted due to the high level of disenrollments. Arkansas providers reported that the most vulnerable enrollees (e.g., people with disabilities or those experiencing homelessness) were the most likely to face barriers in complying with the requirements.[21]

How did H.R.1 Change Medicaid Policy?



H.R.1, or the One Big Beautiful Bill Act, is a reconciliation spending bill passed in mid-2025 that contained several important changes to Medicaid.[22] H.R.1 reduces federal spending on Medicaid by shifting the cost of Medicaid services to states and imposing new program requirements that are estimated to cause about 10 million people to lose coverage. Over the next 10 years, federal spending on Medicaid will decrease by $900 billion.[23]

Work Requirements and Eligibility Determinations

H.R.1 requires any adult in an expansion state, ages 19-64, to work at least 80 hours a month to maintain coverage.[24] The law also increases the frequency of eligibility determinations to at least once every six months, resulting in higher administrative costs and more opportunities for disenrollment.[25]

One common misconception about adults on Medicaid is that they do not work; however, 64% of adults on Medicaid work full- or part-time. The two largest categories of adults who do not work are caregivers (12%) and those who are ill or disabled (10%). Any implementation of work requirements risks disenrolling individuals from Medicaid, including caregivers and people with disabilities.[26]

State Medicaid Financing

H.R.1 affects Medicaid financing by changing the way that state provider taxes are levied and limiting state-directed payments.

State Provider Taxes are taxes levied on providers to pay for additional hospital services and can be used to draw down additional federal funds.[27] H.R.1 limits the amount of taxes a state can levy, resulting in a loss of Medicaid funding for the state.

State Directed Payments are a way for state Medicaid agencies to direct managed care organizations (MCOs) to make specific provider payments to support state policy goals such as improving the quality of care, enhancing access to services, or addressing priority healthcare needs.[28] H.R.1 limited state directed payments, further limiting payments to specific types of care.[29]

What's Next?

The changes included in H.R.1 will require states to make difficult choices to balance their budgets in the coming years. There are minimal ways for a state to lower its Medicaid spending since federal rules require eligibility and coverage for the mandated groups and services. The changes will be implemented over time. In some cases, states will have flexibility in implementing the new requirements, creating opportunities for the rare disease community to advocate to protect the benefits that matter most.

Resources

- **H.R.1 & What it Means for Rare Diseases -** EveryLife Foundation for Rare Diseases. (2025, July 10). *July RDLA webinar* [Video]. YouTube. https://www.youtube.com/watch?v=tu73-zUD0wk
- **Medicaid Work Requirements:** *A summary of Federal Medicaid Work Requirements - Center for Health Care Strategies*. (2025, October 1). Center for Health Care Strategies. https://www.chcs.org/resource/a-summary-of-national-medicaid-work-requirements/
- **Medicaid Eligibility -** *Eligibility Policy - Medicaid*. (2025). https://www.medicaid.gov/medicaid/eligibility-policy
- **Introduction to Medicaid -** Rubin, I. (2025). Introduction to Medicaid. *Center on Budget and Policy Priorities*. https://www.cbpp.org/research/health/introduction-to-medicaid
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- **Medicaid spending on therapies for rare conditions -** Odouard, I. C., Ballreich, J., & Socal, M. P. (2024). Medicaid spending and utilization of gene and RNA therapies for rare inherited conditions. *Health Affairs Scholar*, *2*(5), qxae051. https://doi.org/10.1093/haschl/qxae051
- **What is Medicaid Home Care?** - Mohamed, M., Burns, A., & Watts, M. O. (2025, September 16). *What is Medicaid Home Care (HCBS)?* KFF. https://www.kff.org/medicaid/what-is-medicaid-home-care-hcbs/
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[9] See Footnote 8

[10] This Federal Poverty Level is based on 2025. For updated numbers, see: Federal Poverty Level (FPL) - Glossary | HealthCare.gov

[11] MACPAC (2023) Medicaid expansion to the new adult group. https://www.macpac.gov/subtopic/medicaid-expansion/

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