NORD®
National Organization
for Rare Disorders

ADVOCACY PRIORITY
MEDICAID

Any cuts to Medicaid will reduce access to individuals with rare diseases.

Current issues being considered by Congress:

- Work/community engagement reporting requirements
- Limiting funding for certain types of adults on Medicaid
- Cutting the Federal government's financial responsibility across the board for Medicaid

What is Medicaid?[1]

Medicaid is a government health program that provides comprehensive coverage of health care and long-term services for low-income individuals, children and families in the United States. Medicaid was established by the Social Security Amendments of 1965, the same law that established Medicare. While both of these government programs provide publicly funded health care coverage, Medicaid is a joint federal-state program that supports a range of low-income individuals, while Medicare is a federal program that provides health care coverage for adults over the age of 65.

What does Medicaid cover?

The services that Medicaid programs cover vary from state to state, but there are minimum standard benefits all Medicaid programs are required to offer. These include physician services, laboratory and x-ray services, inpatient and outpatient hospital services, among other benefits. One important requirement of note is the Early Periodic Screening Diagnosis and Treatment (EPSDT) services benefit for Medicaid enrollees under the age of 21. EPSDT is especially important for children with rare conditions, because it allows children access to a broader set of benefits to address complex health needs than what is traditionally covered by private insurance.[5] States can also elect to cover some benefits that are not mandatory. For example, all state Medicaid programs cover prescription drugs.[5]

Why is Medicaid important for people with rare diseases?

While many think of Medicaid primarily as a program for children and families with limited income, Medicaid is also a critical resource for more than 10 million children and adults impacted by disabilities and complex medical conditions, including rare diseases.[6] Living with a rare disease often results in barriers to full time employment due to disability and for families with children or other loved ones who require full-time care. Medicaid can provide individuals with coverage when Medicare or employer-sponsored benefits are not available, as well as facilitate access to services not covered by Medicare or private insurance. Additionally, Medicaid is the primary payer of long-term care services, ranging from institutional care to home and community-based long-term services and supports. These services are a fundamental component of daily life for many people impacted by rare diseases and their families, so it is critical that Medicaid programs are supported and well-funded.

How is Medicaid funded?[1]

Medicaid is jointly funded by federal and state governments and administered at the state level. States are guaranteed federal matching dollars to provide qualified services to eligible enrollees. How much the federal government matches state contributions to Medicaid, known as the Federal Medical Assistance Percentage (FMAP), is determined by a formula laid out in law that accounts for the populations covered by the program and per capita income in the state.

Who is eligible for Medicaid?

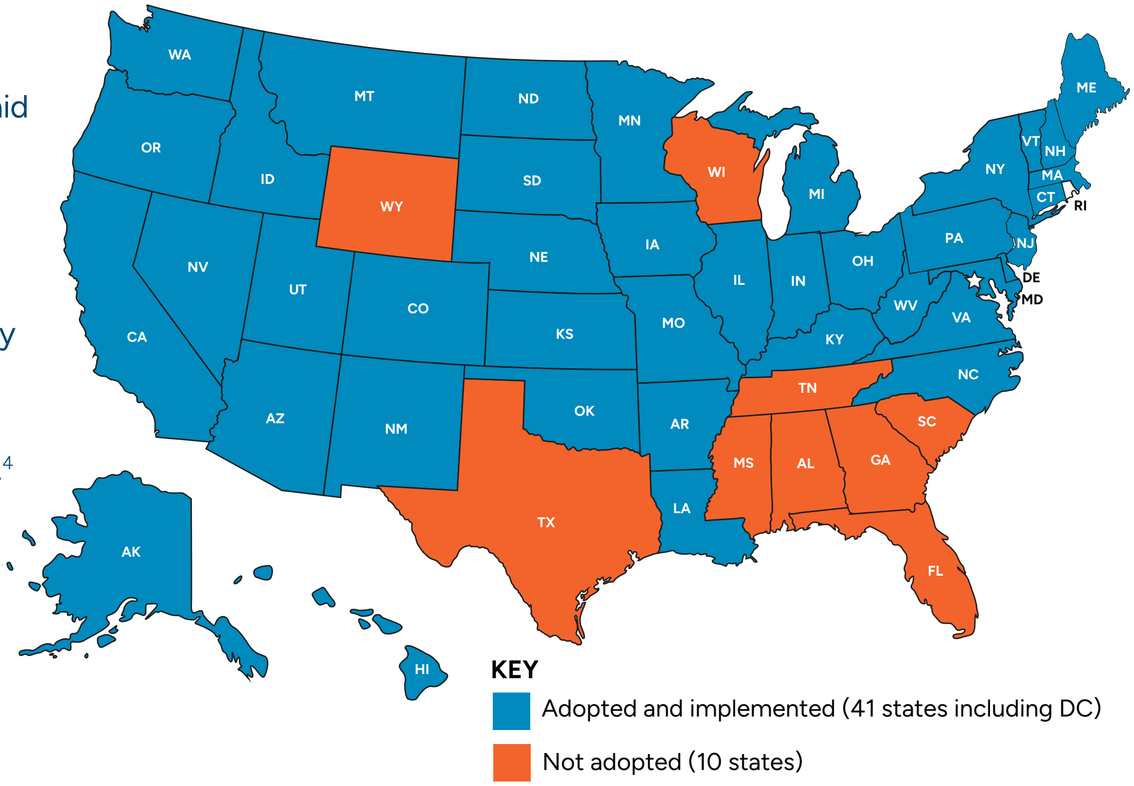
Medicaid is an entitlement program, which means that all people who meet eligibility criteria are guaranteed coverage. The federal government sets minimum eligibility requirements, but states determine their own eligibility criteria. Medicaid eligibility varies from state to state depending on factors such as income, household size, and other criteria, but generally covers children, parents, people who are pregnant, people with disabilities and people over the age of 65 who have limited income.[1]

Medicaid Expansion

In 2010, The Patient Protection and Affordable Care Act (ACA) gave states the option to expand Medicaid eligibility to all adults with income up to 138% of the federal poverty level (FPL).[3] Prior to this expansion, most childless adults were ineligible for Medicaid and many remained uninsured. As of March 2025, 40 states and the District of Columbia have chosen to expand Medicaid, while ten states have chosen not to expand Medicaid.[3] In a comparison of expansion versus non expansion states from 2013 to 2022, expansion states saw uninsured rates drop from 35% to 15% while non expansion states only saw a decrease from 44% to 30%.[4]

States Adopting Medicaid Expansion

> To incentivize state participation in Medicaid expansion, the federal government covers 90% of the costs for this population, providing a significantly higher FMAP than the typical state-federal cost-sharing structure.[4]



KEY

🟦 Adopted and implemented (41 states including DC)

🟧 Not adopted (10 states)

Sources

[1] https://www.kff.org/health-policy-101-medicaid/?entry=table-of-contents-introduction

[2] https://www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html

[3] https://www.kff.org/status-of-state-medicaid-expansion-decisions/

[4] https://www.cbpp.org/research/health/medicaid-expansion-frequently-asked-questions-0.

[5] https://www.kff.org/health-policy-101-medicaid/?entry=table-of-contents-what-benefits-are-covered-by-medicaid

[6] https://www.medicaid.gov/about-us/program-history/medicaid-50th-anniversary/entry/47691

Share your experiences with Medicaid at rarediseases.org

About NORD®

Since 1983, the National Organization for Rare Disorders (NORD®) has fought to improve the health and well-being of people with rare diseases by driving advances in care, research, and policy. We're an independent and nonpartisan nonprofit dedicated to reimagining a future where every person with a rare disease and their families live their best lives.

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