



Medicaid: A Critical Lifeline to Care for Many People with Cystic Fibrosis

Laurie 53, Vermont

- Public employee; Married to small business owner
- Two teenage daughters with CF
- Private insurance; Medicaid as secondary coverage

Though privately insured, Laurie says that Medicaid has been critical in paying for her daughters' care. By filling in the gaps left by their private insurance plan, Medicaid helps ease the financial challenges of caring for someone with CF, even covering the \$30 co-pays for each of her daughters' 40 specialist visits each year. "I don't know what we would do without Medicaid," she says. "Our daughters' care is incredibly expensive but it keeps them alive. Without the vital coverage that Medicaid provides, I can't imagine how we could get our daughters the care they need and make ends meet."

Medicaid provides a vital source of coverage for **half of children and one-third of adults with cystic fibrosis**. For many individuals with CF, Medicaid serves as a payer of last resort by filling important gaps left by private health plans.

HOW MEDICAID CURRENTLY WORKS

Medicaid is a health care program funded jointly by the federal government and state governments. It provides free or low-cost health care coverage for low-income individuals and those who qualify through certain eligibility categories, such as individuals with disabilities. For people with CF, Medicaid helps them afford the treatments, medications, and inpatient and outpatient care they need.

It is the largest source of medical and health-related services for people with low incomes in the United States. In most cases, individuals with cystic fibrosis who are on Medicaid can get all of their CF medications and visits covered. Under current law, the federal government guarantees matching funds to states for covered services, providing funds based on actual costs and needs as economic circumstances change and medicine advances.

A MAJORITY OF THE CF COMMUNITY RELIES ON MEDICAID

The Cystic Fibrosis Foundation supports:

- Retaining expanded Medicaid eligibility, as Medicaid provides a critical source of coverage for half of children and one-third of adults with CF
- Protecting funding for Medicaid, as capping the federal government's contribution to this program would limit a state's ability to provide access to ground-breaking, lifesaving treatments



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Medicaid and Its Implications for the CF Community

Broad structural changes to Medicaid eligibility and financing would likely cause **SIGNIFICANT CHALLENGES FOR PEOPLE WITH CF** trying to access treatments and care that they need to stay healthy.

ENROLLMENT BARRIERS

Barriers to accessing and maintaining coverage through Medicaid make it more difficult for many people with CF to access the treatments they need to stay healthy. Limiting access to Medicaid through work requirements, premiums, lockout periods, and lifetime limits would likely cause some beneficiaries to lose coverage. Further, any exemption process for people with CF or other complex conditions would impose undue burden on beneficiaries and create an additional barrier to coverage for the people who rely on Medicaid to get the care they need.

BLOCK GRANTS AND PER CAPITA CAPS

Two common proposals to alter Medicaid hinge on restructuring Medicaid's funding. Under a block grant, states would receive an annual lump sum payment and under per capita caps, the payment would be a fixed dollar amount per beneficiary. Because these funding changes would be tied to historical costs, neither policy would be responsive to new therapies or technologies. Such rigid funding structures would limit a state's ability to keep pace with providing access to groundbreaking, lifesaving treatments.

Moreover, both approaches would cut overall Medicaid funding, forcing states to make tough decisions about how to allocate benefits and how to cover costly, lifesaving therapies. In this situation states may choose to curb benefits or add additional barriers to enrollment, which could prevent people with CF from accessing the breakthrough therapies and specialized care they need to live longer, healthier lives



Morgan 38, Montana

- Full-time mother; Married to a small business owner
- 3-year-old daughter with CF and 8-year-old son
- Adults covered by private insurance; Children covered by Medicaid

After Morgan's daughter was diagnosed with cystic fibrosis, they structured their life around making sure she gets the care she needs — which has meant making sure that she can retain her Medicaid coverage. They left Montana for Utah briefly, but returned a year later because they didn't qualify for Utah's Medicaid program and couldn't afford to keep paying out-of-pocket for expensive private insurance. "One of the big reasons we moved back was because of the support we received through Medicaid," she says. "It's the only way we're able to do what needs to be done to keep our daughter healthy."