Medicaid 101

What's at stake for people with disabilities, and the people who care for them

OVERVIEW

What we'll cover

1

What Medicaid is

Who it covers, what it pays for, and how

2

Why it matters for care

The main way people pay for care at home

3

What's changing now

How H.R. 1 and other changes are hurting people

4

What we can do

Where advocates can make a difference

PART 1 · WHAT MEDICAID IS

Medicaid covers nearly 80 million people

It's more than health insurance. It covers 2 in 5 children and more than 40% of births.

It pays for the care people need

If you qualify, your care is covered. There's no set spending cap. This is what "entitlement" means.

States and the federal government split the cost

The federal share averages about 63%, from 50% to 75% by state. A formula called FMAP sets it.

It's a big piece of every state budget

Medicaid is states' largest source of federal money, about one-third of most state budgets.

PART 1 · WHAT MEDICAID IS

Required services vs. optional services

Required in every state

- Nursing homes
- Doctor visits and primary care
- Lab tests and X-rays
- Rides to medical appointments
- Community health centers
- Family planning

Optional: each state decides

- **Care at home and in the community**
- Dental care
- Physical therapy
- Glasses and dentures
- Private duty nursing
- Chiropractic care

> **Nursing homes are required. Care at home is not. So when states cut, care at home is at risk first.**

PART 1 · CARE AT HOME

Care at home helps people live their own lives

These are called home and community-based services, or HCBS.

At home

- Cooking meals
- Taking medications
- Bathing, dressing, and personal care
- Managing money
- Staying connected with others

At work and in the community

- Job coaching
- Volunteering
- Day programs

PART 2 · WHY IT MATTERS FOR CARE

Medicaid is the main way people pay for long-term care

Long-term care means ongoing help with everyday life, at home or in a facility.

11M+

people with disabilities rely on Medicaid for health care and to live independently

6M+

adults get long-term care paid for by Medicaid

Medicare and most private insurance don't cover long-term care.
Medicaid fills that gap.

Sources: Community Living Equity Center; KFF

PART 2 · WHY IT MATTERS FOR CARE

A small group of people with big care needs

6%

of Medicaid enrollees use long-term care

→

37%

of Medicaid spending goes to their care

That's why Medicaid cuts hit older adults and people with disabilities hardest.

Source: KFF, 2020 data

PART 2 · WHY IT MATTERS FOR CARE

Without Medicaid, care at home is out of reach

$60,000+

a year for 40 hours of help each week

$288,000+

a year for care around the clock, like for someone living with ALS or Alzheimer's

Very few families can pay that on their own.

Source: KFF, 2024

PART 2 · WHY IT MATTERS FOR CARE

Caregivers and care workers rely on Medicaid too

Most direct care worker wages are paid for by Medicaid

37% of direct care workers get their own health coverage through Medicaid

13%+ of family caregivers rely on Medicaid for their own coverage

25%+ of family caregivers' income already goes to care costs

PART 3 · WHAT'S CHANGING NOW

In 2025, H.R. 1 cut more than $1 trillion from programs people rely on

Many programs were cut

Medicaid, Medicare, ACA marketplace coverage, SNAP, and more

Costs moved to others

States, families, and care providers now have to cover more

States decide what happens next

Most choices about how to carry out the cuts are now up to states

PART 3 · WHAT'S CHANGING NOW

How federal cuts reach people

Federal funding is cut

→

States face budget gaps

States must balance their budgets

→

Cut optional services

Care at home is optional, so it's at risk first

Cut payments to providers

Lower pay means fewer care workers

Cut who can enroll

Waitlists, stricter rules, and people losing coverage over paperwork

> **There is no way to shield older adults and people with disabilities from these cuts.**

PART 3 · WHAT'S CHANGING NOW

The harm is already showing up

18+
states have proposed or passed cuts to home care

1,100+
hospitals and clinics face closure or cuts

2M+
children have lost Medicaid since January 2025

1.65M
jobs expected to be lost in three years, nearly half in health care

Home care cuts: Home and Community Based Services Impacts Tracker Project, 2026

PART 3 · WHAT'S CHANGING NOW

Work requirements will push millions off Medicaid

5M+ would lose coverage under the law, according to the Congressional Budget Office

9M+ are now expected to lose coverage under a stricter federal rule from CMS

Most at risk

- Adults ages 50 to 64
- Caregivers who get coverage through Medicaid
- People with disabilities and chronic health conditions

The rule makes people with health conditions prove their condition "significantly impairs" their ability to work, volunteer, or go to school 80 hours a month.

PART 3 · WHAT'S CHANGING NOW

Health coverage costs more since ACA tax credits ended

3M
fewer people have ACA marketplace plans than last year

58%
more in premiums for the average enrollee, plus about $1,000 more in deductibles

2×
higher premiums for the typical direct care worker with a marketplace plan

10%+
expected premium increase next year

PART 4 · WHAT WE CAN DO

Speaking up in the states is working

State	What happened
Nebraska	Stopped cuts to home care programs
Florida	Delayed work requirements
Colorado	Reversed caps on paying family caregivers
New Mexico	Created a Medicaid trust fund
Michigan	Moved forward new ways to raise revenue

Public education by advocates helped make each of these wins possible.

PART 4 · WHAT WE CAN DO

How advocates can help

Educate lawmakers

Help legislators and their staff understand what's at stake

Testify

Give written or spoken testimony at hearings

Watch new rules

Track work requirements, eligibility checks, and how exemptions are used

Document the harm

Keep records of people who are denied or cut off

PART 4 · A CHOICE FOR STATES

State leaders face a choice

Cut care to close budget gaps

or

Raise revenue, like taxes, and protect care

Families need stability and investment, not more cuts.

PART 4 · THE PATH FORWARD

There's a better way forward

Right now

- Prevent harm wherever we can
- Watch closely how states respond to H.R. 1
- Explore fair ways to raise revenue
- Bring more of the public into the fight for care

For the long term

- Repeal H.R. 1 in full
- Invest in Medicaid home care
- Expand home care through Medicare, and for people who qualify for neither Medicare nor Medicaid