



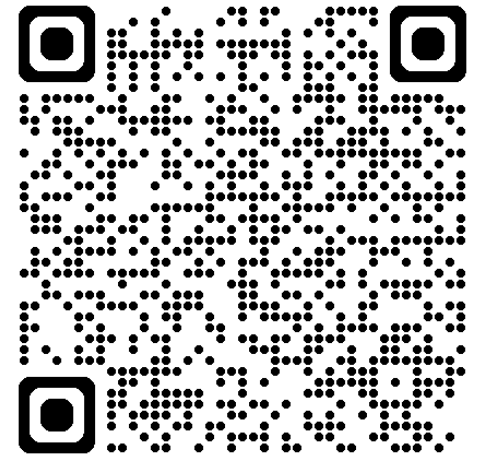
Basics of Medicaid and Reconciliation: Community Living and Policy

**Thursday, June 26, 2025
3:00 – 4:30 PM ET**



Zoom Tips & Accessibility

- ▶ Please stay on mute while presenters are speaking.
 - ▶ There may be time for questions, please add them to the chat.
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AUCD Policy Team Members



Denise Rozell

Director of
Policy Innovation



Lillie Heigl

Senior Policy
Advisor



Liz Weintraub

Senior Advocacy
Specialist



Shoshana Marin

Public Policy
Fellow

Webinar Presenters



Alison Barkoff, JD

Hirsh Health Law and Policy Associate Professor
and Hirsh Program Director



Jennifer Lav

Director of the Disability Practice Area at the
National Health Law Program D.C. Office

Medicaid: Why It is Critical for People with Disabilities

Alison Barkoff, JD

*Hirsh Health Law and Policy Associate Professor
and Hirsh Program Director*

June 26, 2025

HISTORICAL CONTEXT

Segregation as the Norm

- Until the early 1980s, institutionalization of people with disabilities was the norm
 - “Asylums for the lunatics and feeble-minded”
 - Parents were told this was the best option for their children
 - Public outcry after exposés on Willowbrook and Pennhurst
- No funding for community-based supports
- No right to a public education for students with disabilities

Advocacy for Community Services

- Until the 1980s, public disability funding (primarily through the Medicaid program) only paid for care in institutions
- One little girl and her family successfully challenged this policy
- Beginning in 1982, Medicaid created an optional “waiver” program that allowed states to provide community services as an alternative to institutional care
- Now every state provides Home and Community Based Services (HCBS) through a range of different programs

Advocacy for Community Services (cont'd)



Advocacy for the Right to Community Living

- **U.S. Constitution** as a tool for early institutional reform
 - Basic right to safety and adequate treatment when in state custody
 - The **Civil Rights of Institutionalized Persons Act** (passed in 1980) allowed feds to address unconstitutional conditions in public facilities
- **Rehabilitation Act of 1973**
 - Section 504 of the Rehab Act prohibits discrimination by recipients of federal funding; predecessor to the Americans with Disabilities Act
- **Education for All Handicapped Children Act of 1975**
 - Predecessor to the Individuals with Disabilities Education Act (IDEA)
 - Gave children with disabilities a right to public education

The Americans with Disabilities Act

- Congress passed the ADA in 1990 “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”
 - The ADA specifically finds that **segregation, isolation, exclusion and institutionalization of people with disabilities** is a “serious and pervasive problem”
 - ADA’s goal is to **assure equality of opportunity, full participation, independent living, and economic self-sufficiency** for individuals with disabilities.

Title II of the ADA

- Prohibits discrimination by public entities in services, programs and activities
- Integration regulation requires services, programs and activities in **the most integrated setting** appropriate
- Most integrated setting is one that enables people with disabilities to **interact with people without disabilities to the fullest extent possible**

Olmstead v. L.C.: A Right to Community Living

- Two women in Georgia's state hospitals claimed the state was violating the ADA by not providing them services in the community.
- In 1999, the Supreme Court held that **Title II prohibits unjustified segregation of people with disabilities**, relying on “two evident judgments” about institutional placement:
 1. “perpetuates **unwarranted assumptions** that persons so isolated are incapable or unworthy of participating in community life”
 2. “**severely diminishes the everyday life activities of individuals,**” including family, work, education, and social contacts

Olmstead v. L.C. (cont'd)

- Supreme Court held public entities are required to provide community-based services when:
 - Such services are appropriate;
 - Affected persons do not oppose community-based treatment; and
 - Community-based treatment can be reasonably accommodated, taking into account the resources available to the entity and the needs of others receiving disability services
- *Olmstead* created a legal right to community integration

Olmstead v. L.C. (cont'd)



Olmstead Enforcement Over the Last 25 Years

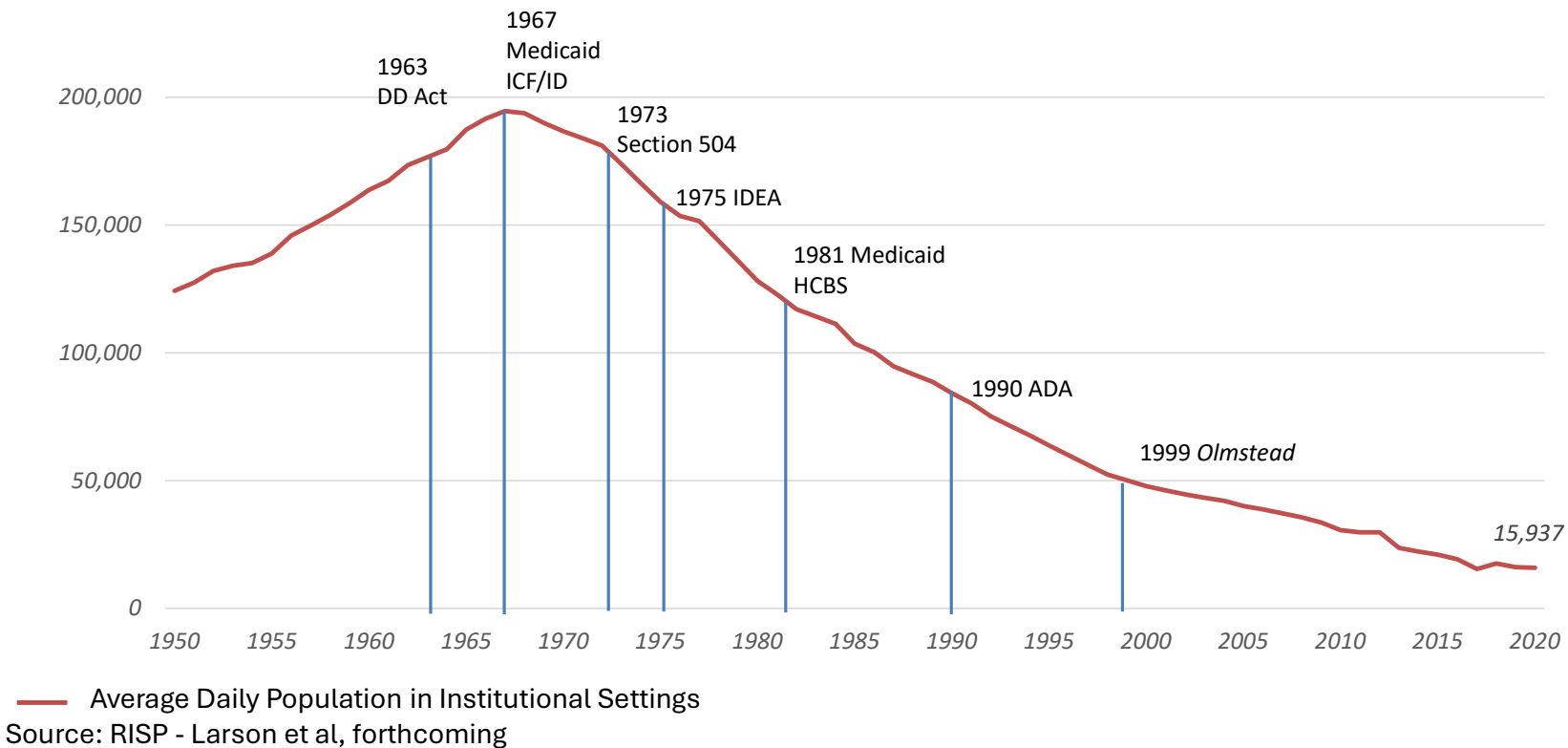
Systemic reform litigation has focused on reshaping states' service systems and expanding the reach of *Olmstead* to:

- People with **all types of disabilities of all ages**:
 - Children, adults and seniors with range of physical and mental disabilities
- **All types of institutional settings**, including:
 - Ex: state operated facilities, private nursing homes and adult care homes
- Both people **experiencing or at serious risk of segregation**:
 - Ex: People with urgent needs on wait lists or experiencing cuts in services
- **All types of segregated settings**:
 - Residential, day programs, and educational settings

Updated Section 504 Regulations and *Olmstead*

- Section 504 has an **integration mandate** that has been interpreted co-extensive with the ADA's
- The US Department of Health and Human Services' Section 504 regulations **apply to all HHS funding, including Medicaid**
- HHS issued **updated 504 regs in spring 2024**, including incorporating in the *Olmstead* decision and caselaw
 - Defines segregated setting
 - Applies to all types of people with disabilities & types of services
 - Applies to people in or at serious risk of segregation

Seeing the Impact of Laws: ICF/IID Census



FURTHERING THE RIGHT TO COMMUNITY LIVING THROUGH THE MEDICAID PROGRAM

Medicaid Act

- Enacted in 1965 as Title XIX of the Social Security Act
- Means-tested entitlement program
- Voluntary federal-state partnership
- Flexibility (with a federal floor)
 - Mandatory and optional coverage groups
 - Mandatory and optional services
- States and the federal government share the costs

Medicaid vs. Medicare

Medicaid

- Joint federal-state program
 - Feds pay part and states pay part
 - Program design varies by state
- Means tested based on income (and sometimes resources)
- Traditional population is low-income children, pregnant women, families, and disabled people; Affordable Care Act expanded to additional low-income individuals at states' option
- Extensive covered services, including long-term services and supports (LTSS)

Medicare

- Federal program
 - Federal government pays 100%
 - Does not vary by state
- Eligibility not based on income or resources
- Covers people 65+ and some people under 65 with certain disabilities and health conditions
- More traditional medical coverage; does not cover LTSS

Medicaid Coverage

- Largest source of health coverage in the country
- Medicaid covers:
 - 1 in 5 people nationally (over 90 million people)
 - 1 in 2 children (kids are nearly half of the Medicaid population)
 - 1 in 3 individuals with disabilities (approx. 15 million people)
 - 62% of nursing facility residents
- People with disabilities and older adults make up 21% of beneficiaries but are nearly half of Medicaid's costs due to their use of LTSS

Medicaid Coverage

Mandatory Services

- Most “traditional” health care services, like physician services, hospital services, etc.
- Home health services
- Early and Periodic, Screening, Diagnosis and Treatment (EPSDT)
- **Nursing facility**

Optional Services

- Rehabilitative services
- Personal care services
- Private duty nursing
- Dental
- Intermediate Care Facilities*
- **Home and community-based services**

Examples of Home and Community-Based Services

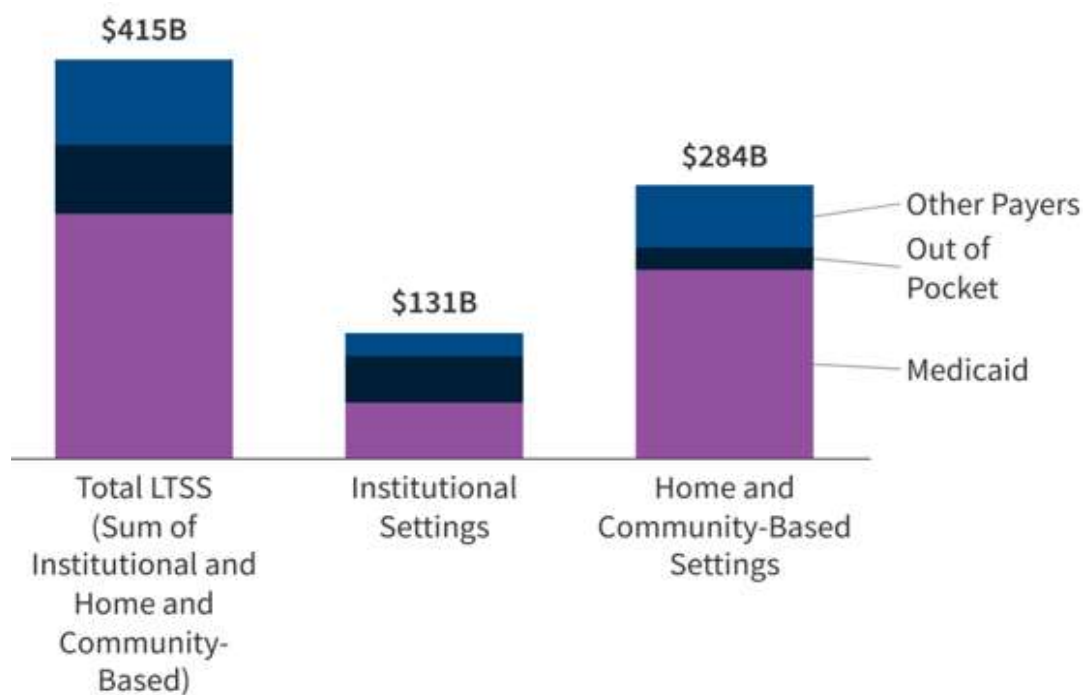
In the Home

- Assistance with self-care
- Help cooking, cleaning, etc.
- Help with budgeting
- Help with medications
- Socialization
- Residential supports

In the Community

- Job coaching
- Community volunteering
- Day programs
- Participating in community activities
- Transportation or assistance using transportation

Medicaid Pays for the Vast Majority of HCBS



SOURCE: Chidambaram P, Burns A. 10 things about long-term services and supports. KFF. July 8, 2024. Accessed Feb. 23, 2025.
<https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/>

Medicaid HCBS: Waivers

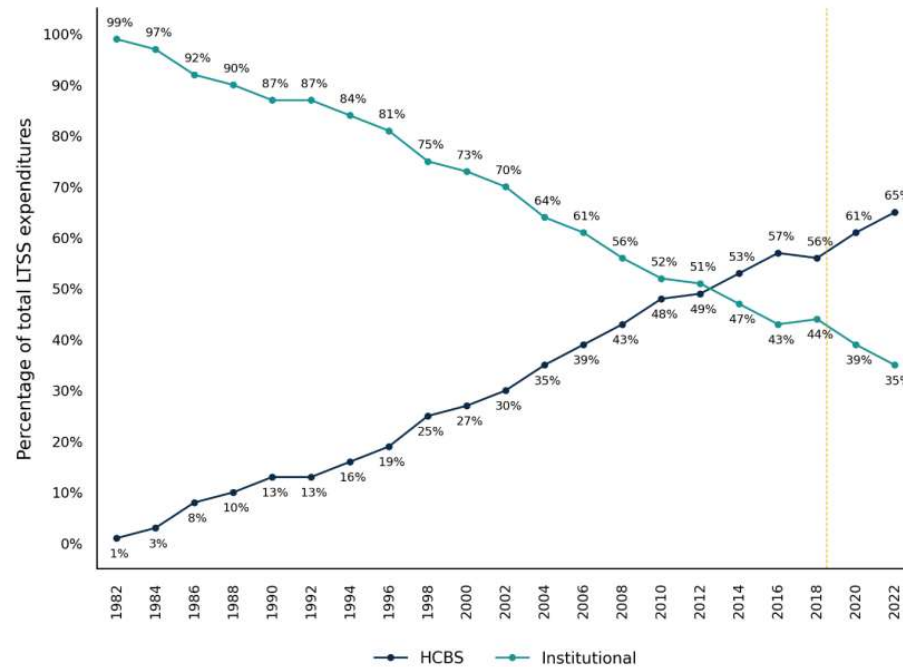
- All states provide HCBS, even though they are optional
- Most states provide HCBS through a 1915(c) waiver
 - Must meet an “institutional level of care”
 - HCBS must cost the same or less than institutional care
 - Typically targeted to a specific population
 - May have higher income limits
 - Can limit enrollment → long waiting lists for HCBS services
 - More than 700,000 people on HCBS waiting lists

Other Medicaid HCBS Authorities and Programs

- 1915i State Plan HCBS
 - Allows for **broader eligibility** than 1915(c) waivers but states cannot limit enrollment
- Community First Choice/ 1915k State Plan HCBS
 - Enhanced FMAP (6%) for **community-based attendant services**
- Money Follow the Person (MFP) Program
 - Significantly enhanced FMAP to **transition people out of institutions** like nursing homes and ICFs to the community
- Balancing Incentive Program
 - Funding to help states **“rebalance;”** created in the ACA but has ended

Progress in Advancing the Right to Community Living Through States' Medicaid Programs

Figure 2. National Medicaid HCBS and institutional LTSS expenditures as a percentage of total Medicaid LTSS expenditures, 1981–2022



SOURCE: Murray C, Stepanczuk, Carpenter A, Wysocki A. Trends in users and expenditures for home and community-based services as a share of total Medicaid LTSS users and expenditures, 2022. Mathematica. Aug. 29, 2024. <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2022.pdf>

But Structural Barriers Remain

Medicaid has an **institutional bias**:

- Institutional services are mandatory; HCBS is optional
 - That's why 700,000 people are sitting on HCBS waiting lists
- Medicaid pays for room and board in institutional settings but prohibits payment for housing the community
 - Lack of affordable, accessible housing is a huge problem

Medicaid's **strict income and asset limits** create significant barriers to accessing HCBS and misaligns incentives

Take Aways



- People with disabilities have a civil right to live and participate in their communities, which for many people requires HCBS
- Disability rights laws have shaped the Medicaid program and states' Medicaid systems
- A threat to Medicaid is a threat to disability rights!

Threats To Medicaid in the 119th Congress: People with Disabilities

Jennifer Lav, Director, Disability Practice Area



About the National Health Law Program

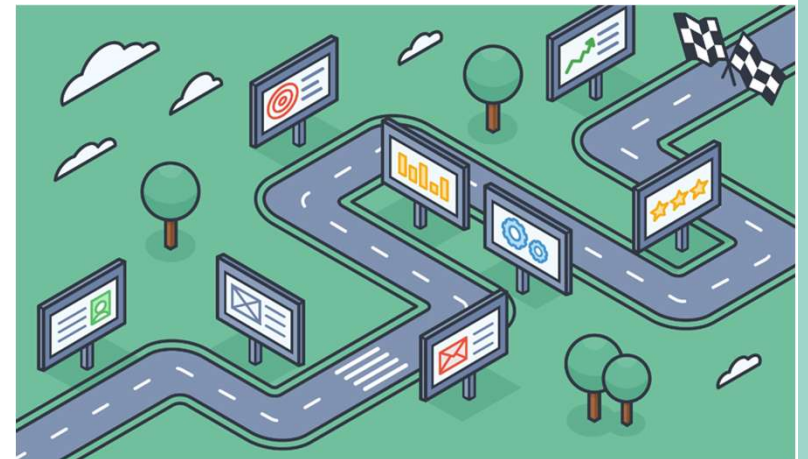
- National non-profit law firm committed to improving health care access, equity, and quality for underserved individuals and families
- State & Local Partners:
 - Disability rights advocates – 50 states + DC
 - Poverty & legal aid advocates – 50 states + DC
- National Partners
- Offices: CA, DC, NC
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Roadmap

- Reconciliation
- Medicaid Cuts
- What Proposed Cuts Mean for HCBS
- How to Help
- Resources



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Reconciliation

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State of Play—Reconciliation Generally

- Reconciliation: a vehicle to pass specific budget and tax related legislation and avert the filibuster (need only 50 Senate votes)
- Congressional Republicans currently trying to push a reconciliation package that uses cuts to health care + other critical programs to pay for harmful tax, immigration, & other objectives

State of Play

- House passed a bill on April 10, 2025.
- Senate released a draft of their version on June 16th, 2025.
- Senate version of the bill is even harsher than House version.
- Senate attempting to pass a bill and force the House to accept it.
- Stated goal is a final bill by July 4, 2025.

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Coverage Losses & Funding Cuts

- Medicaid provisions would result in almost 8 million people losing coverage over a 10 year period.
- The total bill and related processes will result in 16 million uninsured.
- Cutting federal \$\$ for Medicaid by almost \$800 Billion

*** Estimates based on the House bill, as of 6/4/2025 ***

How Republicans Propose to Cut Medicaid

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Four Ways Republicans Proposed to Cut

1. Work Requirements
2. Caps on Provider Taxes & State Directed Payments
3. Making it harder to get and stay on Medicaid
4. Targeting Immigrants

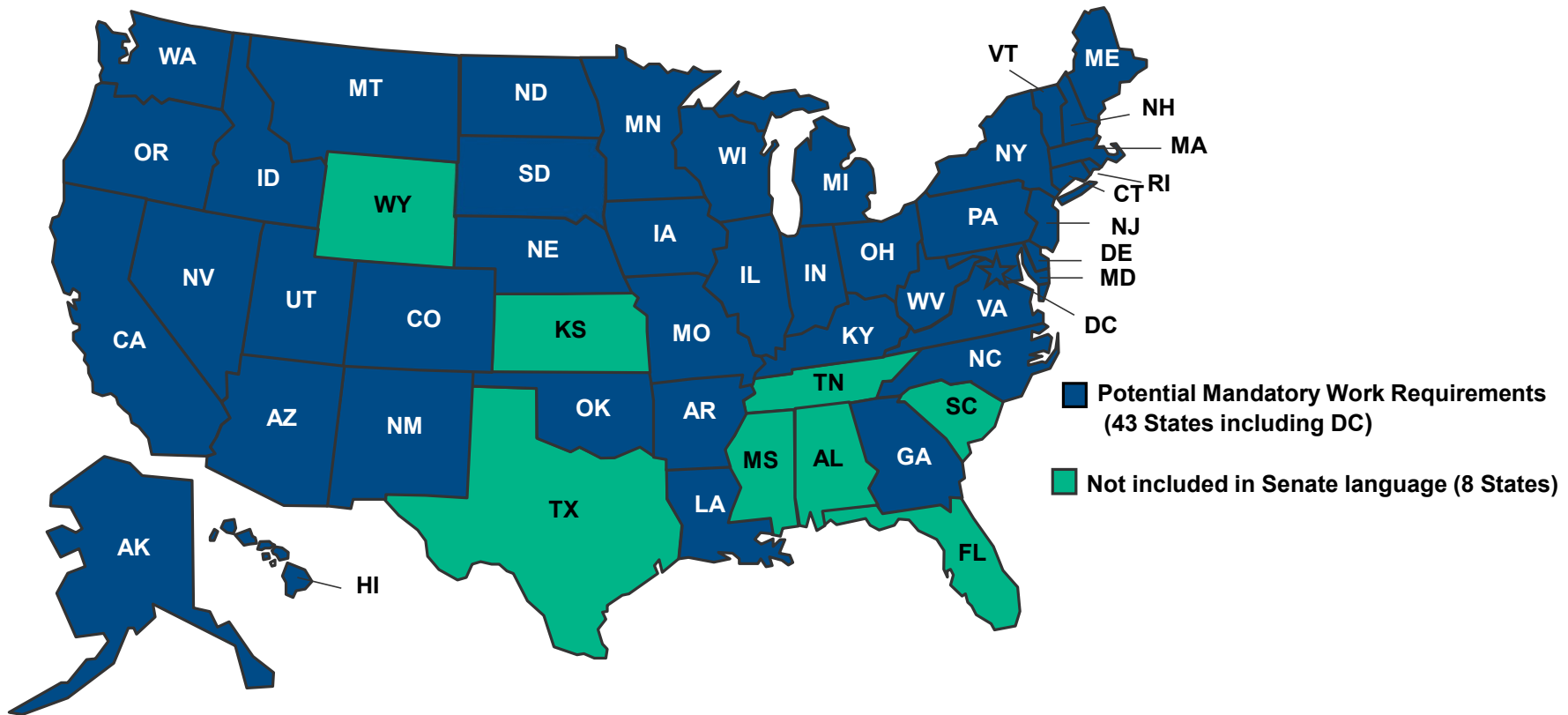
Threat #1: Work Requirements

- Requiring people to work a certain amount to get health care.
- Biggest vehicle for cuts—Estimated 4.8 to 7 million people will lose Medicaid, and federal funding cuts of \$344 billion over 10 years.
- Mandatory.
- Applies only in expansion states (and Georgia and Wisconsin) to “expansion population,” but disabled people will still be harmed!
- Expect large losses due to red tape.

Medicaid Expansion

- Over 40 different “eligibility categories” in Medicaid.
- The “Adult Expansion” category is one of the biggest (20 million people).
- Created by the Affordable Care Act (implemented 2014):
 - Adults 19-64
 - Do not fit into another category (not pregnant, not eligible based on disability)
 - Income less than 138% FPL
 - \$21,597 (single) or \$36,777 (3 person household);
- Nat’l Fed. of Indep. Bus. v. Sebelius, 132 S. Ct. 2566 (2012) effectively gave states option to implement expansion

States Where Federal Work Requirements Would be Mandatory



NOTES: Current status for each state is based on KFF tracking and analysis of state activity. See link below for additional state-specific notes. Modified by NHeLP to add Wisconsin and Georgia, which are included as states with waivers that would be required to implement work requirements under both the House and Senate version of the reconciliation bill.

SOURCE: ["Status of State Medicaid Expansion Decisions: Interactive Map,"](#)

People with Disabilities & Medicaid Expansion

- **Around a fifth to a third of Medicaid expansion adults have disabilities** – especially mental and behavioral health conditions – that can be barriers to work
- **Older adults (50-64) are much more likely to have health barriers** to employment, and more likely to encounter employment related age-discrimination
- **Millions of caregivers are enrolled in the Expansion.**
 - Parents with incomes above the low Parent and Caretaker threshold
 - Family members caring for disabled youth or aging parents
 - Nearly a third of paid caregivers for people with disabilities

Threat #2 Provider Taxes

- Provider and insurer taxes help states generate funding for their portion of Medicaid costs.
- Almost every state has some version of these taxes, they are regulated by federal law, and they have been part of Medicaid for decades.
- Proposal to drastically restrict how much revenue states can raise through these taxes.
- Restricting how states fund their share of Medicaid will create giant holes in state budgets, and cuts to Medicaid. ([CCF](#))

Threat #3 Changing Eligibility Rules to Make it Harder to Stay on Medicaid

- Moratorium on Eligibility and Enrollment Rules
- These rules help people with disabilities and older adults by removing administrative burdens to continuation of coverage and eligibility determinations, and allows people to deduct out of pocket costs for HCBS for purposes of eligibility. ([NHeLP, How E&E rule helps disabled people and older adults stay enrolled](#)).
- Estimated 1.3 million will lose Medicaid coverage.
- Additional proposal to make people recertify every 6 months.

Threat #4 -- Targeting Groups

- Immigrants
 - Reducing federal funding for Medicaid if states use their own state funds to cover certain immigrants.
 - Excluding certain groups of immigrants (including some asylees, refugees, survivors of domestic violence) who have traditionally been covered by Medicaid.
 - Other changes to reduce federal funding when states provide emergency care to immigrants.
- Planned Parenthood
- Gender Affirming Care

A cut is a cut is a cut.

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Impact on People with Disabilities

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Impact of Reconciliation

1. People with disabilities will lose eligibility (work requirements, eligibility changes, immigration, etc).
2. Health care will be less affordable.
3. States will make cuts to balance their budgets.
 - States will cut provider rates.
 - States will reduce optional services (e.g. HCBS).
 - States will restrict eligibility.

Cuts in Medicaid Funding Lead to Cuts in HCBS

- 86% of optional Medicaid spending is on people w/disabilities and older adults.
- HCBS comprises over half of all optional state Medicaid funding.
- In the past, when there was a reduction in Medicaid funding, every single state cut one or more HCBS program.

Cite: Jessica Schubel, et al. [History Repeats? Faced With Medicaid Cuts, States Reduced Support For Older Adults And Disabled People.](#) Health Affairs (April 16, 2025)

How to Help

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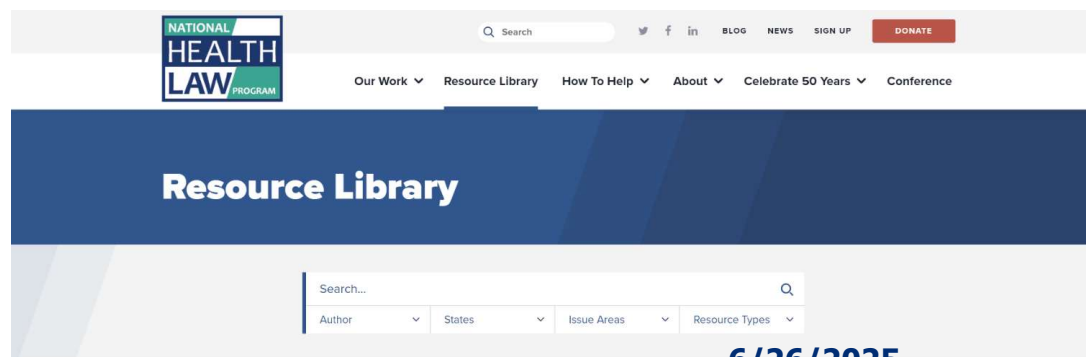
3 Ways Stop this Bill

1. Stay on message.
2. Stay united.
3. Stay connected.

Join the “[Protect Medicaid Space](#)” for regular updates/actions.

Resources

- NHeLP, [Medicaid Defense landing page](#) & [Disability Practice Area](#).
- Consortium for Constituents With Disabilities (CCD), [Protect Medicaid landing page](#).
- KFF, [Health provisions reconciliation tracker](#).



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Thank you for joining us

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Jennifer Lav
Director
Disability Practice Area
lav@healthlaw.org

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