


Georgetown University
McCourt School of Public Policy
CENTER FOR CHILDREN
AND FAMILIES

Johnson Policy Consulting

# Medicaid Connections: Health and Justice for Children and Youth with Special Health Care Needs

*Webinar hosted by:*
*Anka Consulting*
*Georgetown University Center for Children and Families*
*Johnson Policy Consulting*

*August 18, 2026*


MEDICAID
CONNECTIONS
WEBINAR SERIES
Every Third Tuesday
AT 2PM ET

# Medicaid Connections Series

Medicaid is the invisible backbone of advocacy, promoting health and well-being for low-income people. It covers birthing for moms and babies, comprehensive benefits for children, coverage for low-income adults, and it helps keep the lights on at many hospitals that accept all types of insurance. Deep cuts to the program could significantly affect people's lives.

Medicaid Connections webinars are a place for those who are not long-time health advocates, as well as those who are, to come together to help ensure all people can access and benefit from the services they need to improve their health and well-being.

# Future Topics

- **Substance Use: Health & Justice** – September 15, 2026 at 2 pm ET
- **Immigration: Health & Justice** – October 20, 2026 at 2 pm ET
- **Mental Health and Well-being: Health & Justice** – December 15, 2026 at 2 pm ET
- **Family Preservation: Health & Justice** – January 19, 2027 at 2 pm ET

# Meet our Speakers

*Moderator:*
**Elisabeth Wright Burak**
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Georgetown CCF

**Kay Johnson**
President,
Johnson Policy Consulting

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Anka Consulting

**Kasey Dudley**
Director, Parents as Champions, SPAN Parent Advocacy Network

**Dr. Allysa Ware**
Executive Director,
Family Voices

**Caitlin Feasby**
Managing Director of Policy,
Groundwork Ohio

# Today's Plan

1. Brief History of Medicaid & Children and Youth with Special Health Care Needs (CYSHCN)
2. Medicaid's role for CYSHCN
   - Medicaid financing
   - Overview of major threats to Medicaid
3. Panel Discussion
4. Audience Q & A

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# Perspectives on Child Disability Policy and Politics

Kay A. Johnson
Johnson Policy Consulting
Medicaid Connections Webinar
August 18, 2026

*"To begin to understand why, it's important to acknowledge where we started. Our nation's disability history is daunting. Every single state has at some point enforced legalized segregation of persons with disabilities; disabled children were excluded from public schools; people with only minor disabling conditions were routinely shut away for life in custodial institutions; and states prohibited marriage between disabled people and forced them to be sterilized….*

*Certainly, part of the solution will require new laws and better enforcement of the existing ones…. It is just one tool. Our goal is to enact a broader, more nuanced approach, extending beyond the legal abolishment of discriminatory practices."*

Judy Heumann and John Wodatch, NYTIMES July 26, 2020

# Drivers of public opinion and policy

## Who pays?

- Direct federal or state program funding
- Local property taxes for education programs
- Families' share of costs

## Which children and conditions?

- Children with special health care needs (CHSCN) definition not consistently used
- Definition of disability has evolved to include biomedical factors, social factors, and functional limitations.
- Definitions, diagnoses, and eligibility are driven by policy, as well as social forces of ableism, racism, and classism.
- Sympathy for "crippled children" vs. antagonism for entitlements to "able bodied" and skepticism re: mental health
- Lists and arbitrary cut offs vs. individualized assessment / determinations

## Role of advocacy and policy entrepreneurs

- Parent advocacy is often at the forefront for children with disabilities
- Specific conditions "in vogue" or have well organized advocacy groups

# Key Disability Policies and Programs

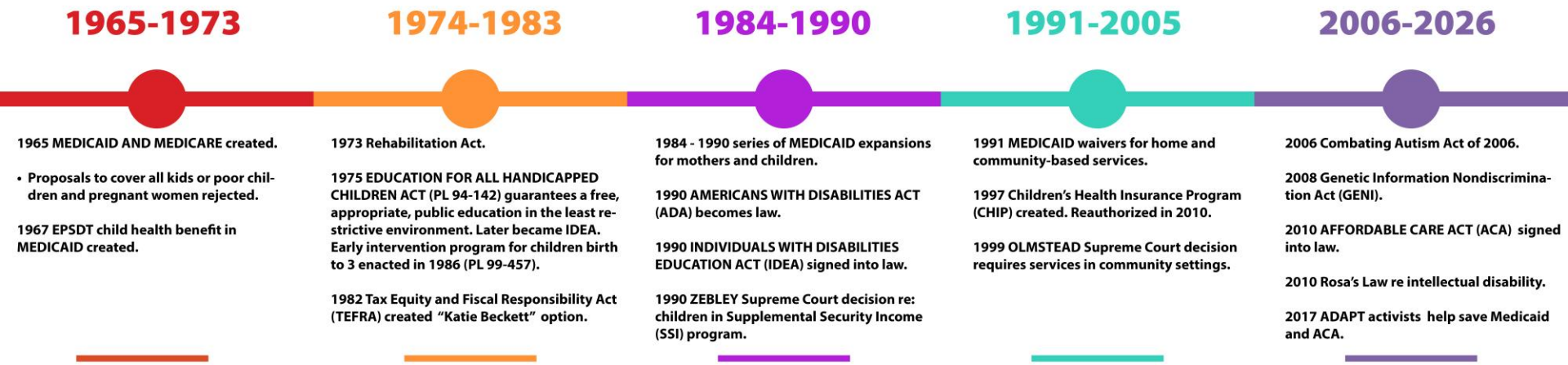
**Directly related to Medicaid**

- Medicaid, including medical necessity standard in **EPSDT** children's benefit
- Supplemental Security Income (**SSI**)
- Individuals with Disabilities Education Act (**IDEA**)
- Affordable Care Act (**ACA**)
- **Olmstead** Supreme Court decision on right to live in the community
- Title V Children with Special Health Care Needs (**CSHCN**) programs

**Related to rights, health, and well-being**

- Americans with Disabilities Act (**ADA**)
- Rehabilitation Act and 508 amendment
- **Family-to-Family** Information Centers
- State **Newborn Screening** and Genetics Programs
- Genetic Information Nondiscrimination Act (**GINA**)
- Health Insurance Portability and Accountability Act (**HIPAA**) protections

# Milestones in Disability Policy related to Child Health



# SSI Policy and Children: 4 phases

- 1st Phase 1974-1990: **SSI not designed for children.**
  - Adult standard based on inability to engage in gainful activity / employment.
  - For children a "comparable severity" standard, lists of impairments and no functional assessment.
- 2nd Phase 1990-96: **Child-appropriate standard (Zebley).**
  - A 1990 Supreme Court decision Sullivan V. Zebley found that SSI approach for children was unfair.
  - SSA revised and expanded eligibility criteria for children – with individualized functional assessment required for children, in addition to list improvements.
  - **Number of children in SSI doubled.**
- 3rd Phase 1996-2009: Congress **returned to pre-Zebley SSI child standard** in Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA).
  - Replaced the "comparable severity" standard with a specific definition of childhood disability.
  - Eliminated individual functional assessment.
  - Required the child suffer from "*a medically-determinable physical or mental impairment, which results in marked and severe functional limitations*…".
  - As a result of policy change, **>90,000 child beneficiaries lost SSI benefits.**
- 4th Phase 2010-present: Focus **on who is "deserving" and accusations of "fraud"** – familiar themes in politics and policy today.
  - Plus, today PRWORA continues to have impact on children with disabilities, on access to publicly funded services, for families with mixed immigration status, and more.

# Indefatigable Parent Advocate: Julie Beckett

- As an infant, Katie Beckett contracted encephalitis, which limited her ability to breathe without support.
- Law then required that Katie live in an institution to qualify for Medicaid.
- Her mother, Julie Beckett, fought successfully to keep Katie at home and continued to advocate for improving care for CSHCN for more than 35 years.

*Photo caption: In 1984, President Ronald Reagan (seen holding Katie Beckett) met with the Beckett family on the tarmac of Cedar Rapids Municipal Airport in Iowa. Representative Tauke (R-IA-2) is standing behind the President. Credit: Courtesy of the Ronald Reagan Library.*

*Photo caption: Julie Beckett, with Katie, when Katie was released from a hospital in Iowa in 1981. Ms. Beckett became a leading disability-rights advocate, fighting for changes in Medicaid coverage of in-home care. New York Times. Photo Credit: United Press International*

- In the 1982 Tax Equity and Fiscal Responsibility Act (TEFRA), Congress created the **"Katie Beckett" state option.**
- The advocacy of one parent led to creation of the Katie Beckett option and to other Medicaid home- and community-based services (HCBS) waivers.
- With Polly Arango and Josie Woll, Julie Beckett co-founded **Family Voices**.

Learn more: https://familyvoices.org/juliebeckett/ and https://www.nytimes.com/2022/05/25/us/julie-beckett-dead.html

# We can do better

- Stop slicing and dicing children
  - Physical versus developmental conditions
  - Complex or chronic illness versus disability
  - Detected via newborn screening, by medical system (EPSDT), in education system, or other
- Develop a unified front
  - Engage families, providers, payers, and public agencies
  - Move beyond old rhetoric and framing
  - Avoid debates about adults versus children
  - **Apply a broad, uniform definition for children with disabilities and special health needs**

# Medicaid's Role for Children and Youth with Special Health Care Needs

Elisabeth Burak
Senior Fellow
Center for Children and Families

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An estimated **99%** of children in foster care have Medicaid coverage.

Medicaid finances **more than 4 in 10** births across the nation

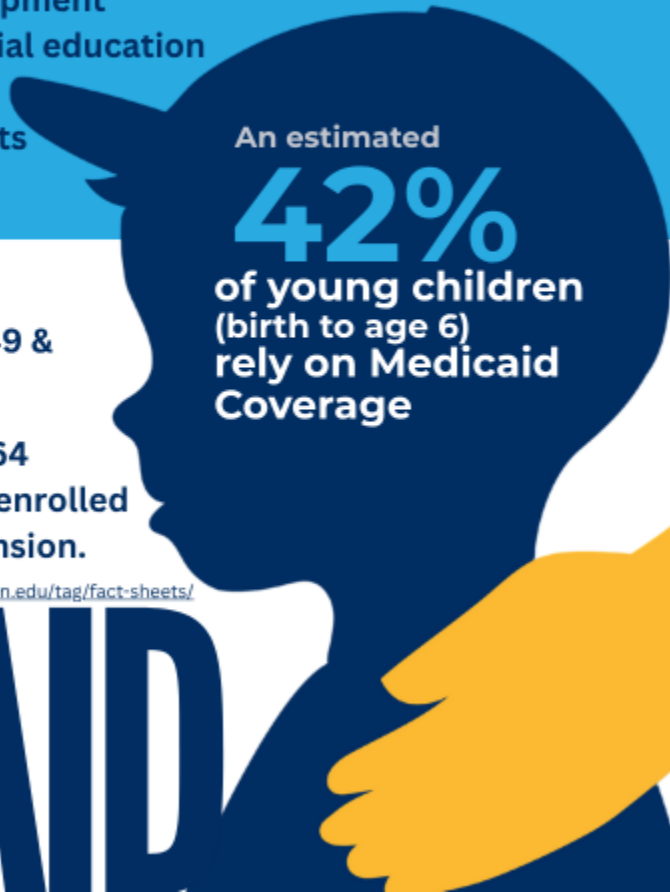
Medicaid covers **more than 1 in 4** childcare staff in the US

**INFANTS & TODDLERS WITH DISABILITIES ENROLLED IN MEDICAID AND PART C:**

- Show improvements in early development
- Show reduced need for school special education
- Grow up with better health
- Have less severe disabilities as adults

**NEARLY HALF** of adult women ages 19-49 &

**MORE THAN 60%** of older women ages 50-64 covered by Medicaid are enrolled under the Medicaid expansion.

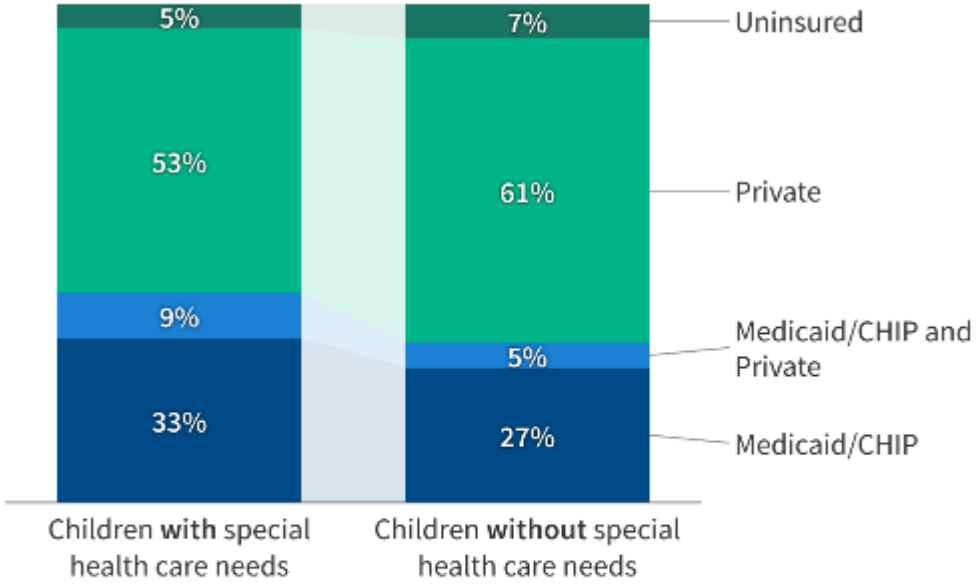


An estimated **42%** of young children (birth to age 6) rely on Medicaid Coverage

See Georgetown CCF fact sheets for more information: https://ccf.georgetown.edu/tag/fact-sheets/

# Medicaid is a Lifeline for CYSHCN

- More than 4 in 10 CYSHCN are covered by Medicaid and/or CHIP
- Medicaid/CHIP are the ONLY source of coverage for one third of CYSHCN




Note: An estimated 19 million (or 26% of children ages 0-17 years) have special health care needs. Totals may not sum to 100% due to rounding. Statistically significant difference between the share of children with special health care needs and children without special health care needs for each group at the $p<0.05$ level.

Source: KFF analysis of 2023 National Survey of Children's Health.

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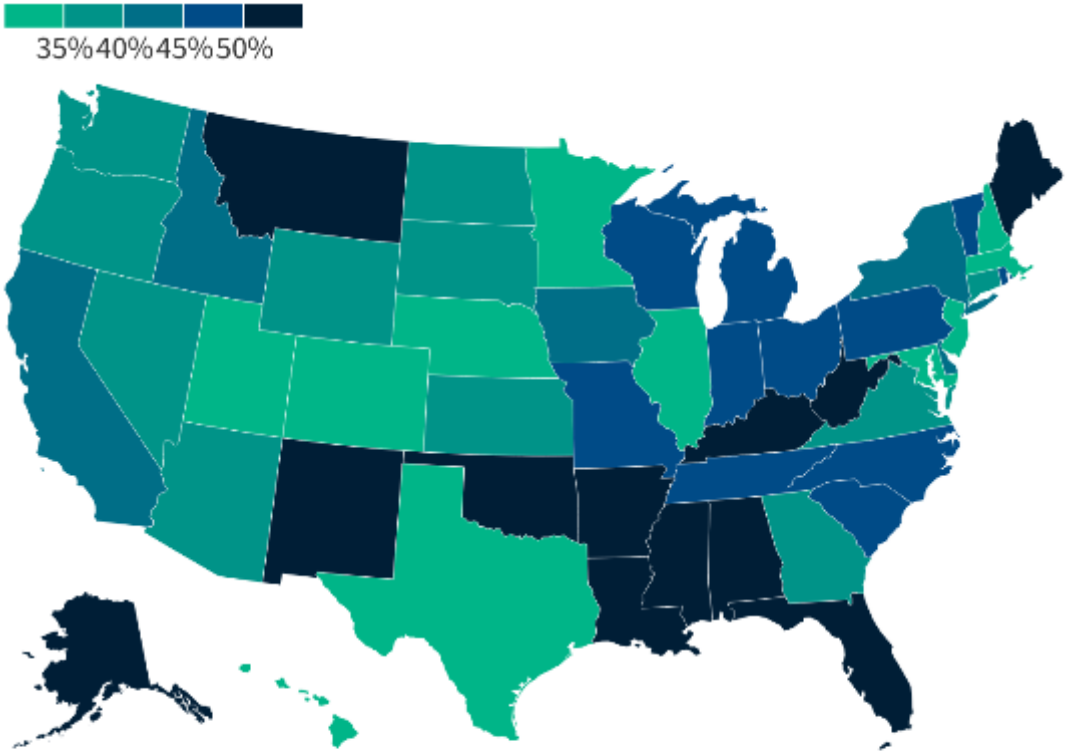
# Share of CYSHCN Medicaid Covers By State




Note: An estimated 19 million (or 26% of children ages 0-17 years) have special health care needs. Includes children with Medicaid/CHIP as sole source of coverage and children with both Medicaid/CHIP and private insurance.

Source: KFF analysis of 2023 National Survey of Children's Health

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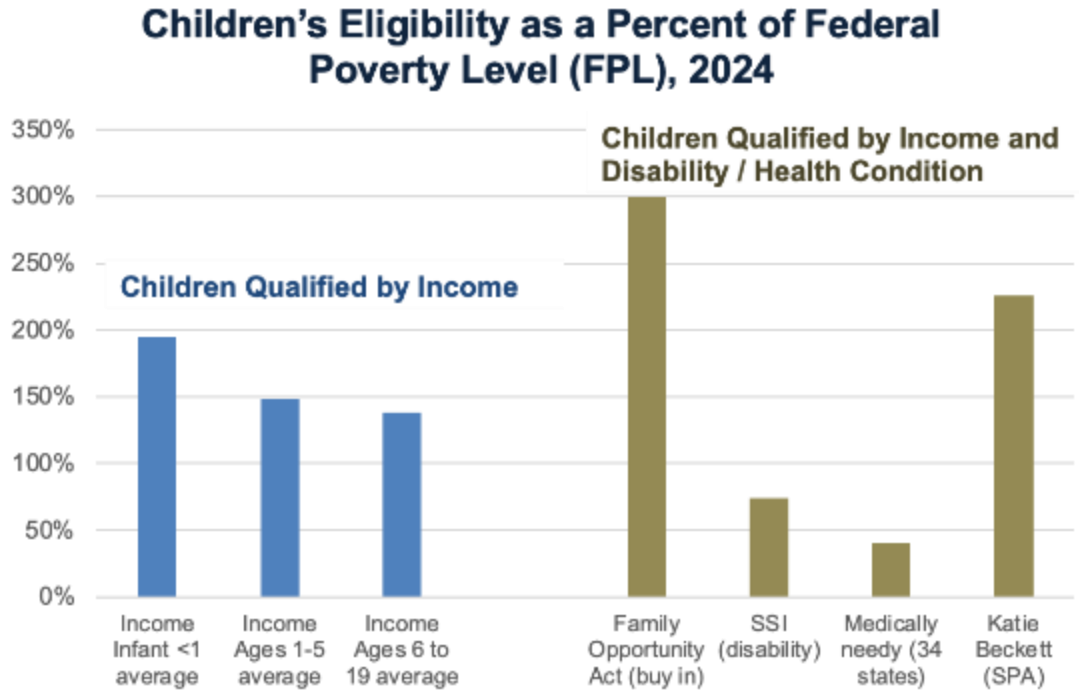
# Pathways to Medicaid for Children with Disabilities

**Medicaid eligibility pathways include:**

- **Income alone**
- **Income PLUS disability**
  - Family Opportunity Act "buy in"
  - SSI disability
  - Medically Needy
  - Katie Beckett
  - Other waivers for people with disabilities (e.g., home- and community- based services-HCBS)




*Sources: Kaiser State Health Facts* Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level, Medicaid Eligibility for Medically Needy Populations and Medicaid Financial Eligibility in Pathways Based on Old Age or Disability in 2022: Findings from a 50-State Survey

# Medicaid Provides Coverage for a Wide Range of Medical and Long-Term Services and Supports

Among CYSHCN covered by Medicaid and CHIP:

- 2/3 have a physical disability, and
- 44% have 4+ functional difficulties
- Many require specialized health services and supports
- Private insurance often offers limited or no coverage

| Examples of Services Covered by Medicaid for CYSHCN |
| --- |
| Primary Care |
| Screenings |
| Prescription Medicines |
| Needed Therapies |
| Transportation |
| Specialized Equipment |
| Assistive Technology |
| Long-Term Care and Home Care |

# Medicaid and Individuals with Disabilities Education Act (IDEA)

| Topic | Medicaid | IDEA |
|---|---|---|
| **Purpose** | For the purpose of enabling each State to **furnish medical assistance** for individuals whose income and resources are insufficient to meet the costs of necessary medical services. The goal of (Medicaid's child benefit) EPSDT is to **ensure that individual eligible children get the health care they need,** when they need it, in the most appropriate setting. | To ensure that all children with disabilities have available to them a **free appropriate public education** that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living; ensure that the rights of children with disabilities and parents of such children are protected; and to assist States, localities, [districts and schools] to provide for the education of all children with disabilities. |
| **Eligibility** | **Income and categorical eligibility criteria including disability status, which vary by state.** | **No income criteria, eligibility based on health and disability status or developmental delay.** |
| **Benefits / entitlement to services** | **Child health benefit = Early, Periodic, Screening, Diagnostic and Treatment (EPSDT)**. Broad set of screening, diagnosis and treatment/intervention services. | **Services outlined in Individualized Education Plan (IEP) (IDEA Part B) or Individualized Family Services Plan (IFSP, IDEA Part C).** |
| **Financing** | **Open-ended federal matching contribution for a percentage of costs for services.** | **Federal formula grants to states. Studies suggest federal grants cover a small fraction of the cost of needed services.** |

# Medicaid's Child Health Benefit: EPSDT

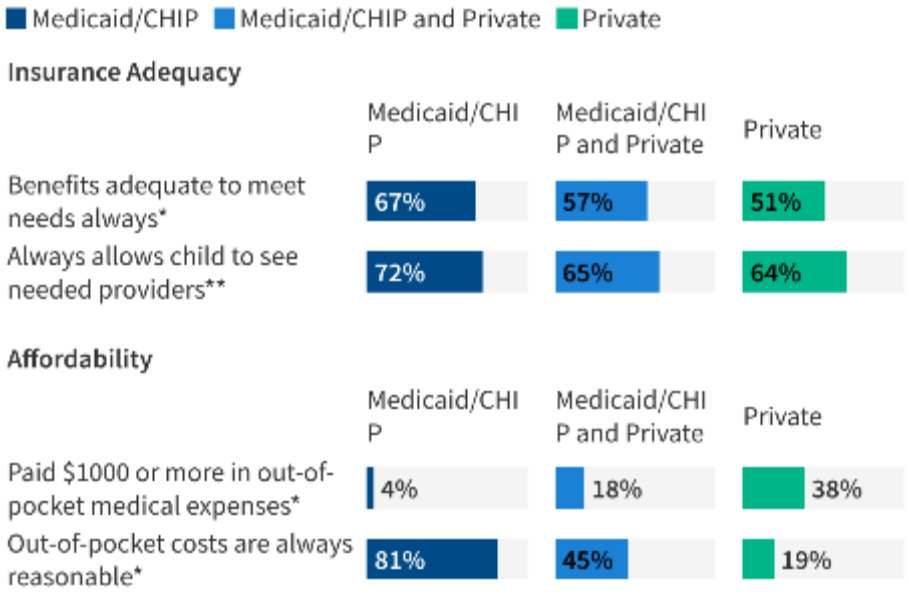
| Building Blocks of Medicaid's Early, Periodic, Screening, Diagnostic, and Treatment Benefit |
| --- |
| Identify problems early, starting at birth |
| Check children's health and development at periodic intervals |
| Provide development, vision, and hearing screenings to detect problems |
| Perform diagnostic tests to identify risks |
| Provide treatment for any problems found |

- Covers **ALL** Medicaid-allowable services when "medically necessary" to correct and ameliorate physical and mental health conditions
- Optional benefits are mandatory for children if medically necessary

# EPSDT Helps CYSHCN Receive Full Range of Care

*"Medicaid is important to me and my family because it helped us get an accurate diagnosis for my 3-year-old daughter. This helped her access services and programs she would not have qualified for otherwise. Since then, she's went from non-verbal to speaking, reading, counting, etc. Her progress would have been stifled without Medicaid."* *South Carolina family*

Source: Georgetown Center for Children & Families and Family Voices. Responses from a 2025 Family Voices survey of families and caregivers of CYSHCN. (https://ccf.georgetown.edu/2025/03/24/medicaid-helps-families-of-children-and-youth-with-special-health-care-needs/)




Note: Includes children age 0-17 years. Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides a set of comprehensive health care services to Medicaid enrollees under age 21. *Indicates statistically significant difference between all groups at the p<0.05 level. **Indicates statistically significant difference between Medicaid alone and the private insurance alone and Medicaid + private insurance groups at the p<0.05 level.

Source: KFF analysis of 2023 National Survey of Children's Health

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# Medicaid is the Primary Source of Financing for Home and Community-Based Services

***"Medicaid & the [HCBS] program have been life changing for my family. Without its support my child would have ended up in a residential program. Instead, because of [home and community-based services] support, she is home and thriving." – Parent Gina***

- HCBS allow CYSHCN to thrive at home with their families, in their communities
- As of 2024, 43 states covered some children with significant disabilities living at home under the "Katie Beckett" Medicaid option or comparable waiver

Source: Georgetown Center for Children & Families and Family Voices. Responses from a 2025 Family Voices survey of families and caregivers of CYSHCN. (https://ccf.georgetown.edu/2025/03/24/medicaid-helps-families-of-children-and-youth-with-special-health-care-needs/)

# Medicaid Can Reduce Health Care Costs and Disabilities for CYSHCN Over Time

*"Medicaid allowed our son to receive necessary therapy… even after our primary insurance would not pay. These therapies have helped him learn new skills to become an independent adult."*
*- North Dakota family*

*"Having Medicaid means that our daughter has access to healthcare without hesitation… As a result, she is the healthiest she has ever been! She is back in public school, competing in archery tournaments and robotics, making straight A's and looking at colleges. Without Medicaid she was essentially bedridden about 4-5 days a week."*
*- Parent Courtney*



Source: Georgetown Center for Children & Families and Family Voices. Responses from a 2025 Family Voices survey of families and caregivers of CYSHCN. (https://ccf.georgetown.edu/2025/03/24/medicaid-helps-families-of-children-and-youth-with-special-health-care-needs/)

# Medicaid Allows Families to Avoid Medical Debt and Meet Other Basic Needs

*"Medicaid is crucial for accessing care and therapy that would otherwise be unavailable for my special needs child! In his first year of life, prior to getting approved for Medicaid, we depleted our savings paying for just his medical care!"*

- *Wisconsin family*

*"Without Medicaid, my 5-year-old wouldn't be able to attend school. [Due to medical costs] We as a family would lose our home and also not be able to afford to rent."*

- *Wisconsin family*

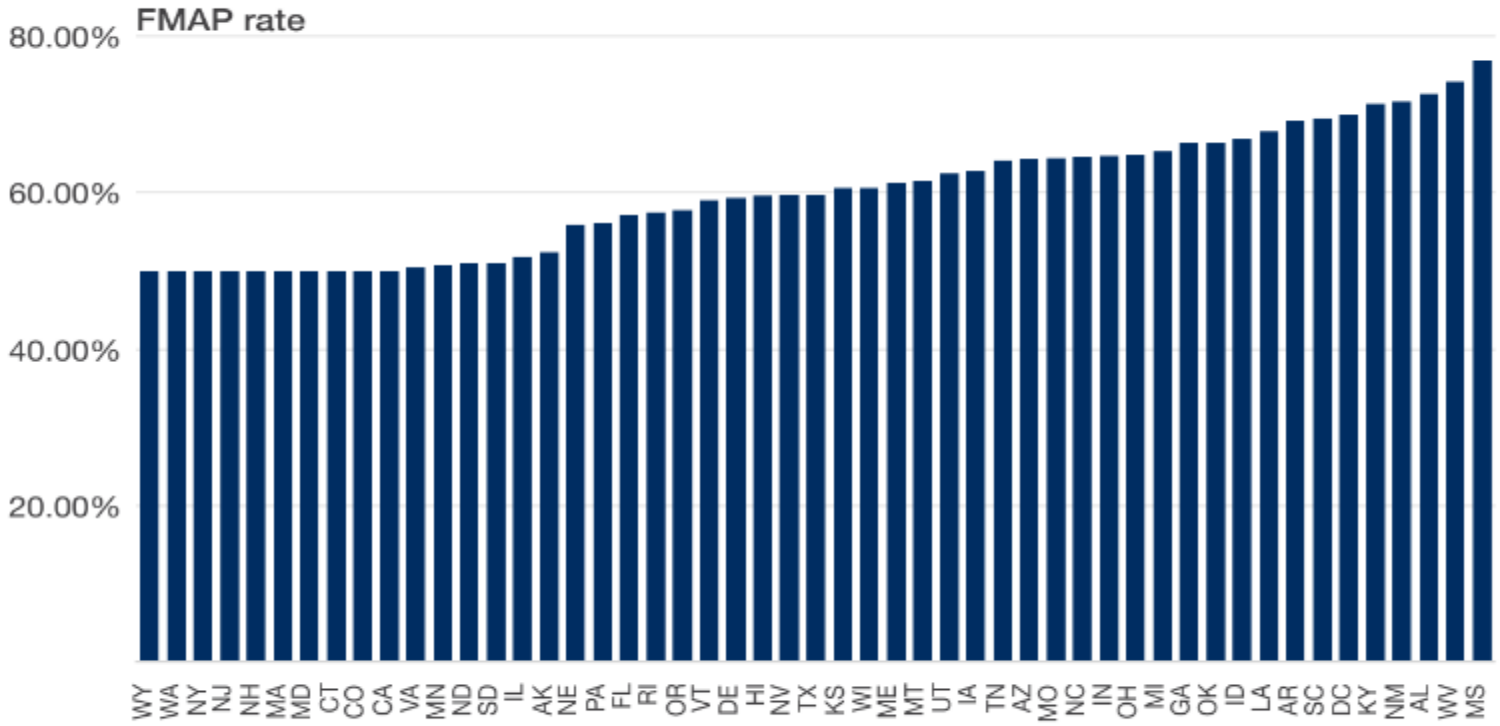
Source: Georgetown Center for Children & Families and Family Voices. Responses from a 2025 Family Voices survey of families and caregivers of CYSHCN. (https://ccf.georgetown.edu/2025/03/24/medicaid-helps-families-of-children-and-youth-with-special-health-care-needs/)

# Medicaid Financing

# Overview of Current Medicaid Financing

- Mandatory federal funding not subject to annual Congressional appropriations
- Open-ended entitlement funding
- Federal government covers a percentage of state Medicaid costs – Federal matching rate (FMAP) – varies by state, based on per capita income
- Federal-state partnership requires state matching contributions

# FMAP Rates by State, FY2026

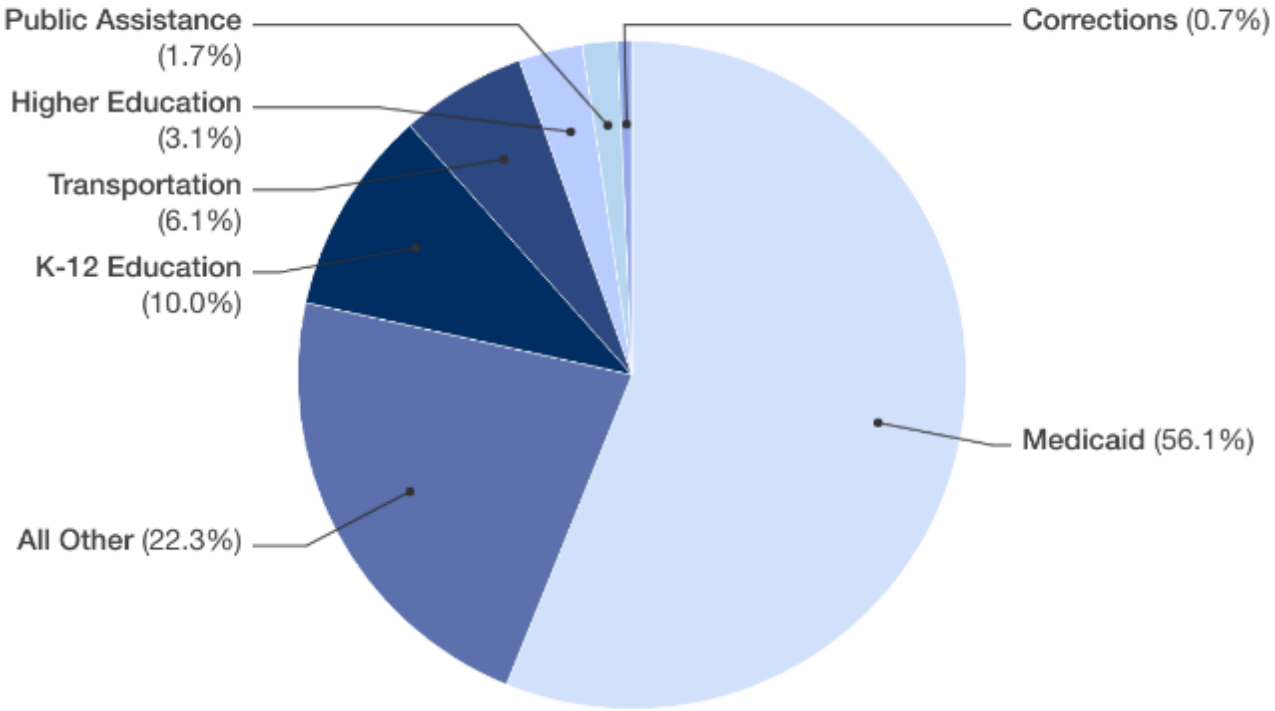



*US federal minimum FMAP is 50%.*



Source: KFF estimates of increased FY 2026 FMAPs based on Federal Register, November 29, 2024 (Vol 89, No. 230), pp 94742-94746.

## Federal Funds for States, FY2024




# Medicaid is the Largest Source of Federal Funds to States

Source: CCF analysis of National Association of State Budget Officers (NASBO) data for state fiscal year 2024 (estimated).

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# Threats to Medicaid

# One Big Beautiful Bill Act (OBBBA, H.R. 1): What was preserved

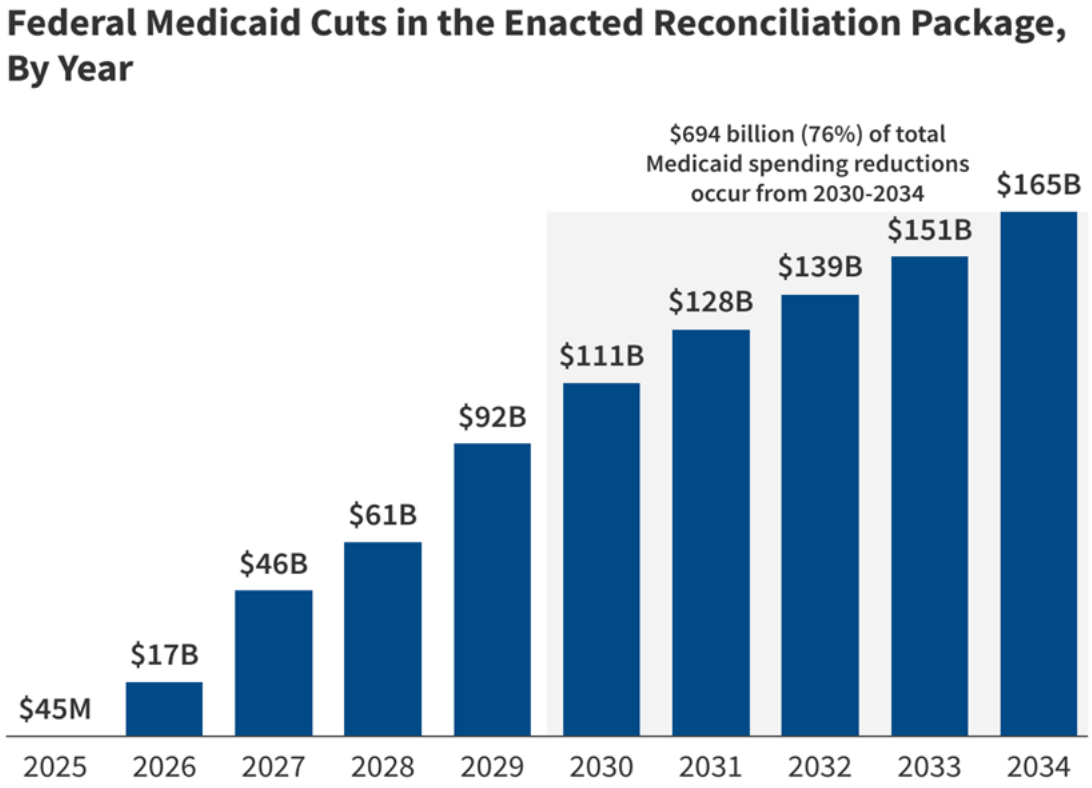
- Medicaid entitlement – NO CAP
  - Funding for states, benefit for individuals
  - Including pediatric benefit (EPSDT)
- Federal 90% matching rate for Medicaid expansion
- Strong public support for Medicaid

# OBBA: Major Medicaid Provisions

- Nearly $1 trillion in Medicaid cuts over the next decade
- Cuts targeting the Affordable Care Act (ACA) Medicaid Expansion – notably new work reporting requirements
- Restrictions on states' ability to finance Medicaid match
- Restrictions on provider payments that could impact access to care
- Red tape enrollment/renewal barriers for all
- Immigrant eligibility rollbacks

Source: E. Park and S. Corlette, "Medicaid, CHIP, and Affordable Care Act Marketplace Cuts and Other Health Provisions in the Budget Reconciliation Law, Explained, (Washington: Center for Children and Families), available here.

# Cuts will grow over time, each state impacted differently




Note: Estimated interaction effects are included each year. Over the 10-year period, the Medicaid spending reductions total $911B, including $79B in estimated Medicaid spending interactions. Without accounting for interactions, the total is $990B. See Methods in "Allocating CBO's Estimates of Federal Medicaid Spending Reductions Across the States: Enacted Reconciliation Package" for more details.

Source: KFF analysis of CBO estimates of the enacted reconciliation package

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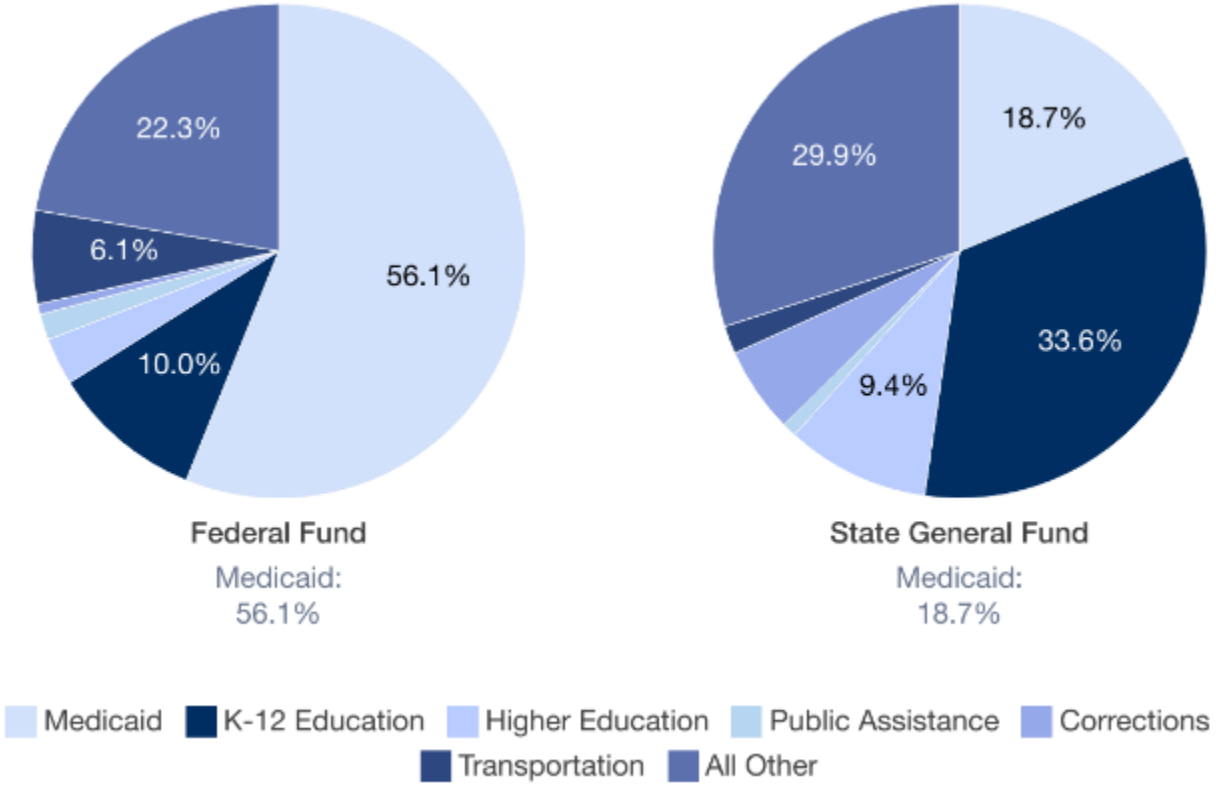
Source: Kaiser Family Foundation (2025) Allocating CBO's Estimates of Federal Medicaid Spending Reductions Across the States: Enacted Reconciliation Package

# A Second Look: Medicaid in State Budgets




Source: CCF analysis of National Association of State Budget Officers (NASBO) data for state fiscal year 2024 (estimated).

# State Choices to Offset Federal Funding Losses (within the Health System)

OR Boost State Revenues


Close or cap enrollment

Impose more red tape to suppress enrollment and retention



Reduce Eligibility

Cut Benefits

Increase Out-of-Pocket Costs

Lower Reimbursement for Providers

**And/or….cut other areas of the state budget**

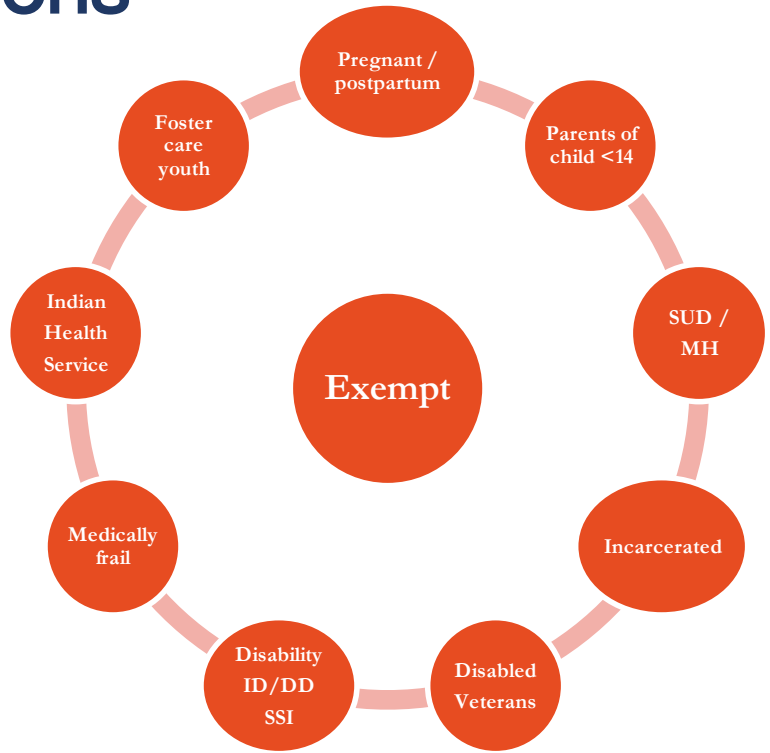
# Why Medicaid Work Requirements Matter

- Policy is intentionally designed to reduce the number of people covered under Affordable Care Act (ACA) Medicaid expansions.
- No child is subject to work requirements, but:
  - Older youth may may age into Medicaid expansion
  - Many parents and caregivers of CYSHCN could be impacted
- Work requirement exemptions are complex, not all well defined or aligned with eligibility categories.
- ***Kids could incorrectly lose coverage as their parents or other adults in their family are disenrolled***

Sources: Buettgens et al. *Projected Reductions in Medicaid Expansion Enrollment Under OBBBA's Work Requirements and Six-Month Redeterminations.* Urban Institute. March 25, 2026; Sara Rosenbaum. A 'Shift in Kind': A Medicaid Work Requirement Would Radically Change Health Policy. Health Affairs Forefront. June 16, 2025. DOI 10.1377/forefront.20250612.628094; Joan Alker. CMS Guidance on Medicaid Work Requirements Leaves States Hanging. Center for Children and Families. December 11, 2025. https://ccf.georgetown.edu/2025/12/11/cms-guidance-on-medicaid-work-requirements-leaves-states-hanging; Gaffney, Himmelstein, & Woolhandler. Projected Effects of Proposed Cuts in Federal Medicaid Expenditures on Medicaid Enrollment, Uninsurance, Health Care, and Health. DOI:10.7326/ANNALS-25-00716

# Work Requirement Exemptions

- Despite exemptions, people will lose coverage due to administrative barriers.
  - Everyone has to verify work or exemption status at application or renewal of eligibility.
  - Reporting required every 6 months or perhaps monthly.
  - Documentation required for many.
  - States will need to set up systems and technology for efficient processes.
- Parents, pregnant and postpartum people, and others will be affected.




Sources: Burak & Johnson. *Medicaid Work Reporting Requirements: How Can States Protect Pregnant and Postpartum Women from Losing Health Coverage?* Report. Center for Children and Families, July 17, 2026. https://ccf.georgetown.edu/2026/07/17/medicaid-work-reporting-requirements-how-will-states-protect-coverage-for-pregnant-and-postpartum-women/; ; Alker & Kohler. Which parents will be impacted by Medicaid work reporting mandate? Center for Children and Families. April 2, 2026. https://ccf.georgetown.edu/2026/04/02/which-parents-will-be-impacted-by-medicaid-work-reporting-mandate/; CMS. Medicaid Community Engagement Requirement for Certain Individuals Interim Final Rule with Comment Period (CMS-2454-IFC). June 1, 2026. https://www.cms.gov/newsroom/fact-sheets/medicaid-community-engagement-requirement-certain-individuals-interim-final-rule-comment-period-cms

# What You Can Do


- ✔ **Help highlight the harmful impacts Medicaid cuts would have on individuals and families, communities, providers, state budgets and economy**
- ✔ **Tell your story about Medicaid**
- ✔ **Join state or local parent advocacy education efforts to educate policymakers**
- ✔ **Recruit a friend**

# Now let’s hear from our panel!