Analyzing the Past, Planning for the Future

Spoiler: *There's going to be change*

2026 AAIDD Texas Chapter

50th Annual Convention

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Starting with the Past

- Effective advocacy uses storytelling very well
- Sometimes we remember **the stories we tell ourselves better than the actual facts**.

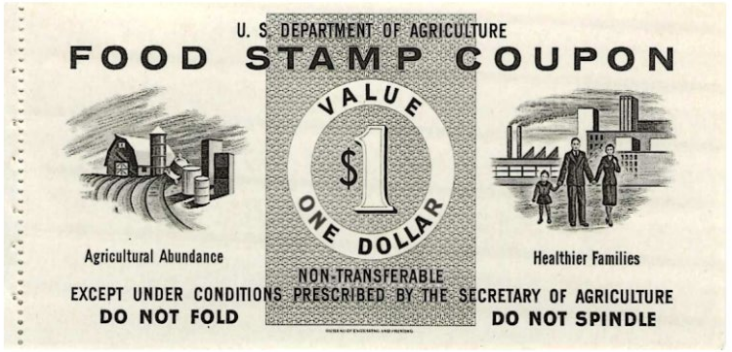
The Last Consultation
Gustave Doré (1865)

What was Medicaid Created for?

- Medicaid was created in 1965 as an ***optional*** federal program to be administered by states as a ***medical assistance program for "needy persons"***, who were defined as

  (a) the elderly, blind, or permanently and totally disabled, and low-income families with dependent children who
  (b) were receiving public assistance for basic maintenance (**cash welfare**, e.g., "the impoverished")

- It required
  - *states to provide core services* with the
  - *cost to be shared* between the federal government and the state.



What is Medicaid and How has it Evolved

- Enacted in 1965 by the federal government as an **optional** program
  - It took until the 1980s before **all states** opted in.
  - If a state opts in to the program, it **must** agree to **core** federal requirements (**state plan** requirements), which are
- **Essential services** (doctor, inpatient and outpatient care, lab tests, and institutional care)
- Additional definitions:
  - **EPSDT (**Early and periodic (health) screening, diagnostic, and treatment) for children under 21. Provides comprehensive preventive, dental, mental health, and developmental health services.
  - **Institutional care** under Medicaid includes (a) nursing homes, (b) **ICFs**, (c) inpatient/residential psychiatric facilities, and (d) **long-term acute, rehab, or chronic care hospitals**.
    - Medicaid ***waiver programs*** (authorized in 1982) are the mechanism by which the federal government allows states to "waive" the **core (state plan)** requirement to provide institutional care and instead use provide home and community based services (HCBS).

What is Medicaid and How has it Evolved

- Authorized under **Title XIX** of the Social Security Act
  - Medicaid eligibility was originally tied to *each individual state's* anti-poverty programs, then later *federal* anti-poverty programs (Aid to Families with Dependent Children [ADFC], Supplemental Social Security Income [SSI])
  - Over time, Congress expanded the eligibility and options to include children, pregnant women, and a more expansive list of people with disabilities
  - In 1996, AFDC was replaced with TANF and Medicaid eligibility was no longer tied to eligibility for cash assistance programs (welfare).
  - In 1997, the CHIP program was established with an enhanced FMAP.
  - In 2010, the ACA provided an option for states to expand Medicaid coverage for nonelderly adults with incomes up to 138% of the poverty line "expansion enrollees". 10 states did not expand coverage.

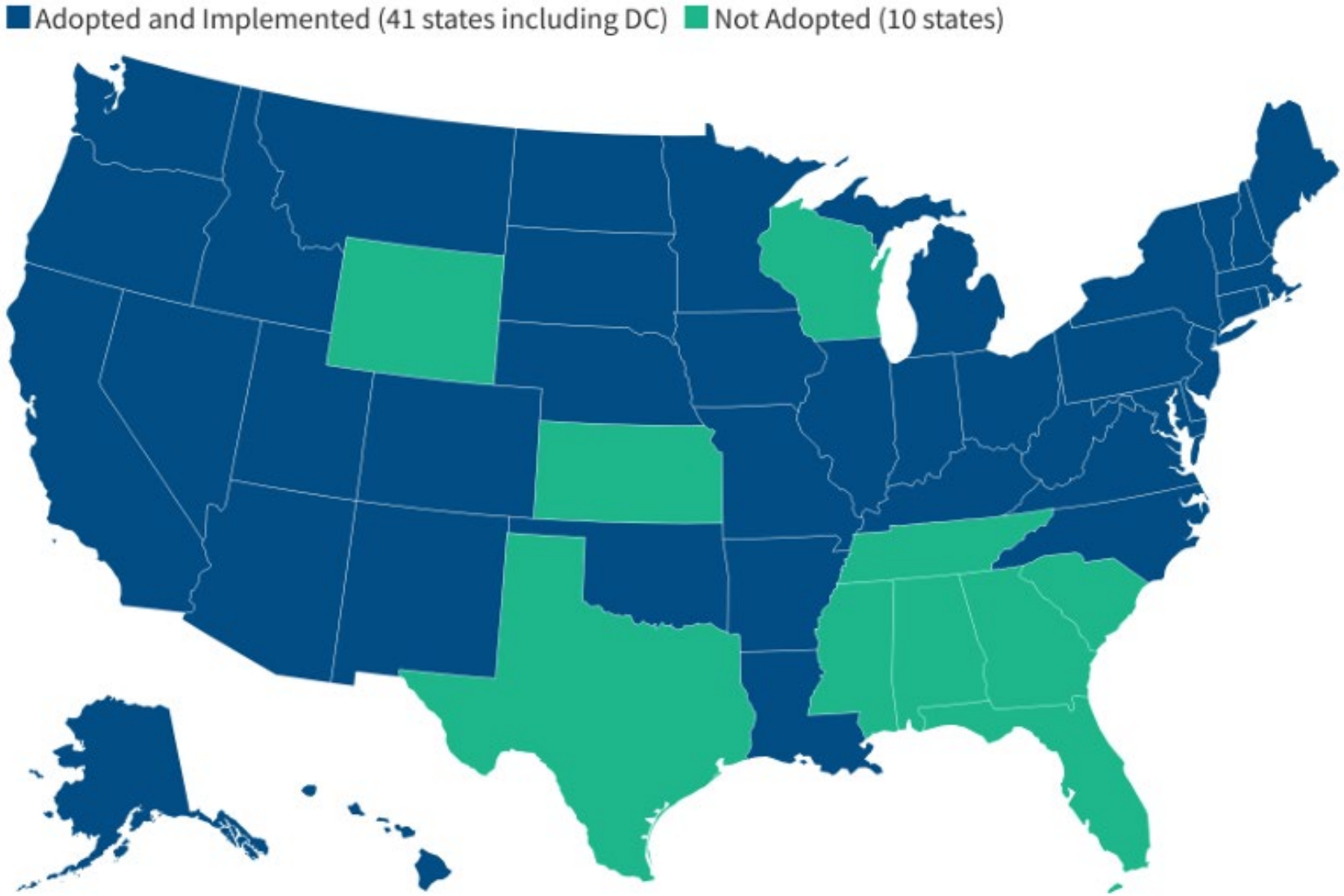
10 States Without Medicaid Expansion:

1. Alabama
2. Florida
3. Kansas
4. Mississippi
5. South Carolina
6. Tennessee
7. **Texas**
8. Wyoming

9. Georgia &
10. Wisconsin

have partial or limited waiver set ups that created a non-expansion “expansion group”

40 States and the District of Columbia Have Expanded Medicaid as of 2026

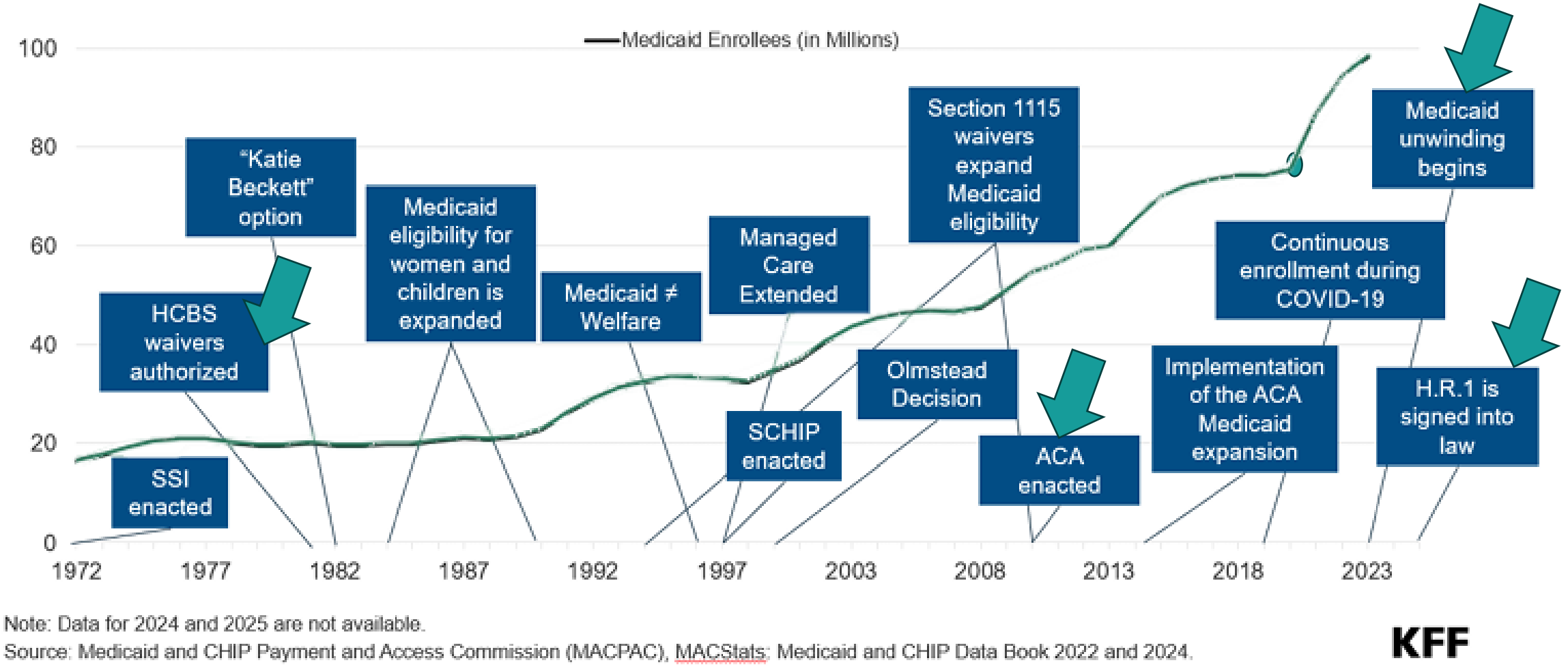


Source: Kaiser Family Foundation

What is Medicaid and How has it Evolved

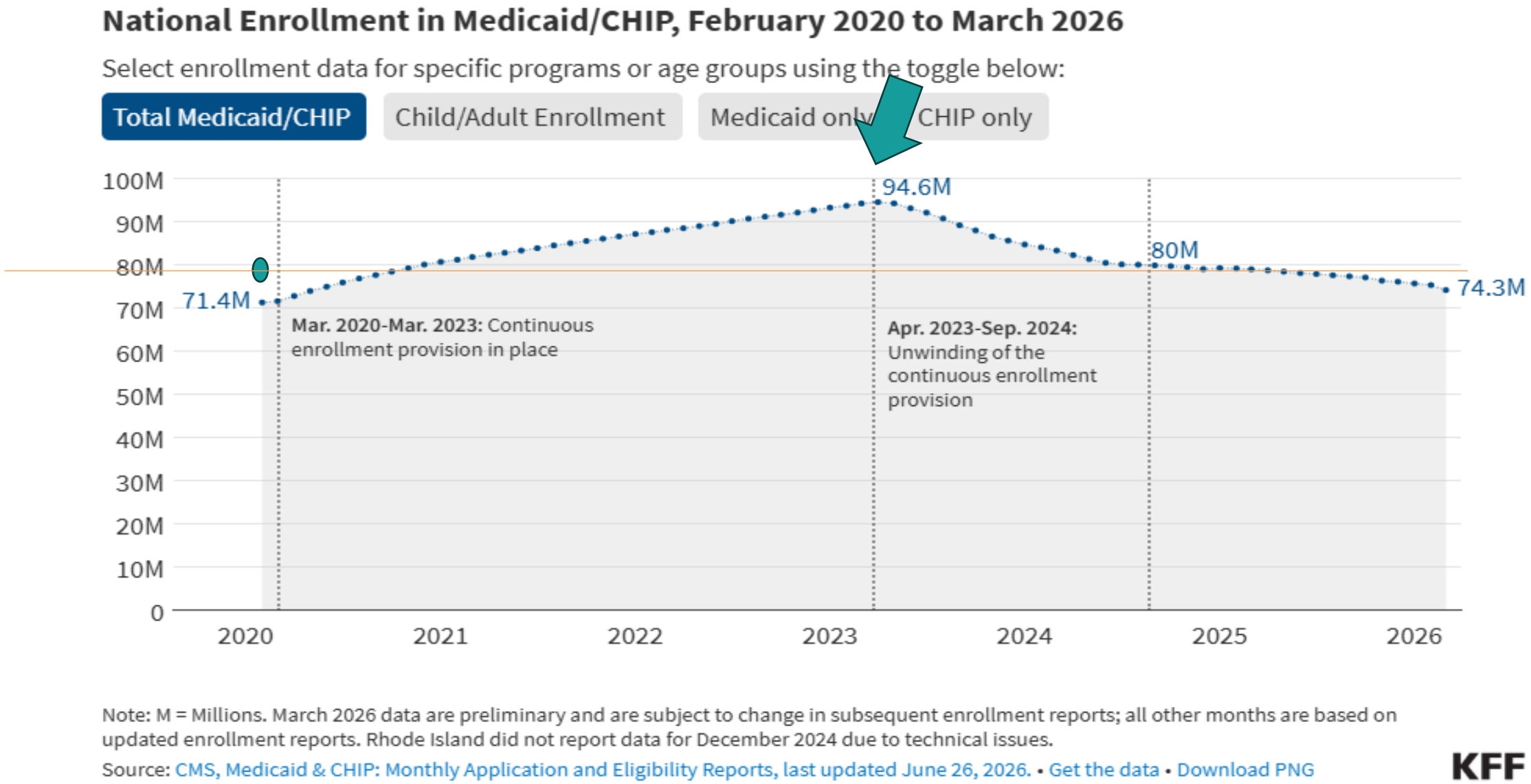
- Covid profoundly affected Medicaid spending and enrollment.
  - At the start of the pandemic, Congress required states to keep people *continuously enrolled* in exchange for enhanced federal funding.
  - As a result, Medicaid/CHIP enrollment grew substantially, and the uninsured rate dropped.
  - On April 1, 2023, the **unwinding** of these requirements began, and millions were disenrolled from Medicaid, but Medicaid enrollment remains higher than prior to the start of the pandemic (February 2000).

What is Medicaid and How has it Evolved



Source: Kaiser Family Foundation

What is Medicaid and How has it Evolved



Source: Kaiser Family Foundation

What is Medicaid and How has it Evolved

- In July 2025, HR1, the Federal Budget Reconciliation Bill (One Big Beautiful Bill Act, OBBBA) was passed, and goes into effect January 1 2027 (or sooner at state option) which is expected to reduce (a) Medicaid enrollment and (b) federal spending over the next 10 years.
  - Conditions Medicaid eligibility for Medicaid *expansion enrollees* on meeting work and reporting requirements
  - Reduces and limits provider taxes* (a mechanism that all but one state uses to finance the state share of Medicaid)
    - KFF's 2025 Medicaid FY2026 budget survey found that although there was considerable variation across states, on average **provider taxes accounted for 18%** of state's contributions to Medicaid.
  - Reduces payments states require managed care organizations to make to health care providers
  - Increases the frequency of eligibility redeterminations for *expansion enrollees*

What are Medicaid Provider Taxes?

All states except Alaska use provider taxes to help finance the state's share of Medicaid costs.

- Taxes on providers of health care items, health care services, or the entities that provide or pay for health care items or services.
- States use these provider takes to fund Medicaid "base" rates and supplemental payments; to finance eligibility expansions, including the ACA Medicaid expansion; or to more generally support the Medicaid program.
- Such taxes are most common for institutional providers, including hospitals (47 states), nursing facilities (45 states), and ICFs (33 states), but also managed care providers (22 states), ambulance providers (21 states).
- Most states collect more than one provider tax.
- The federal government has regulated the use of provider taxes to fund the state's share of Medicaid costs since the 1990s. You might ask yourself *why* provider taxes *in particular* are regulated.
- KFF's 2025 Medicaid FY2026 budget survey found that although there was considerable variation across states, an average of 70% of state's non-federal share came from their general fund, provider taxes accounted for 18%, and funds from local governments or other sources accounted for 6%.

What are Medicaid Provider Taxes?

- Changes to federal rules for provider taxes are estimated to cut federal Medicaid spending by $226 billion over 10 years by
  - Prohibiting new provider taxes or increasing existing provider taxes ($89 Billion)
  - Reducing tax limits in the 41 states that adopted ACA expansion enrollment options ($102 Billion)
  - Revising conditions for approving uniformity waivers ($35 Billion)
- The Congressional Budget Office estimates that changes to the federal rules for provider taxes Is expected to increase the number of uninsured people by 1.2 million by 2034 as
  - To maintain current enrollments, other state resources would be needed to replace the lost tax revenue
  - Replacement revenue can be only be achieved through **tax increases or cuts to other programs**. Reducing Medicaid spending can be only be achieved through lower payment rates to providers, **covering fewer services, or more restrictive eligibility.**

What are Medicaid Provider Taxes? Understanding the Churn

	Without Provider Tax	With Provider Tax	Difference
Cost of Services	$100.00	$100.00	
Provider Tax	$0.00	$5.50	
Total	**$100.00**	**$105.50**	
FMAP 57%	$57.00	$60.14	$3.14
State share 43%	$43.00	$45.36	$2.37
	$100.00	**$105.50**	

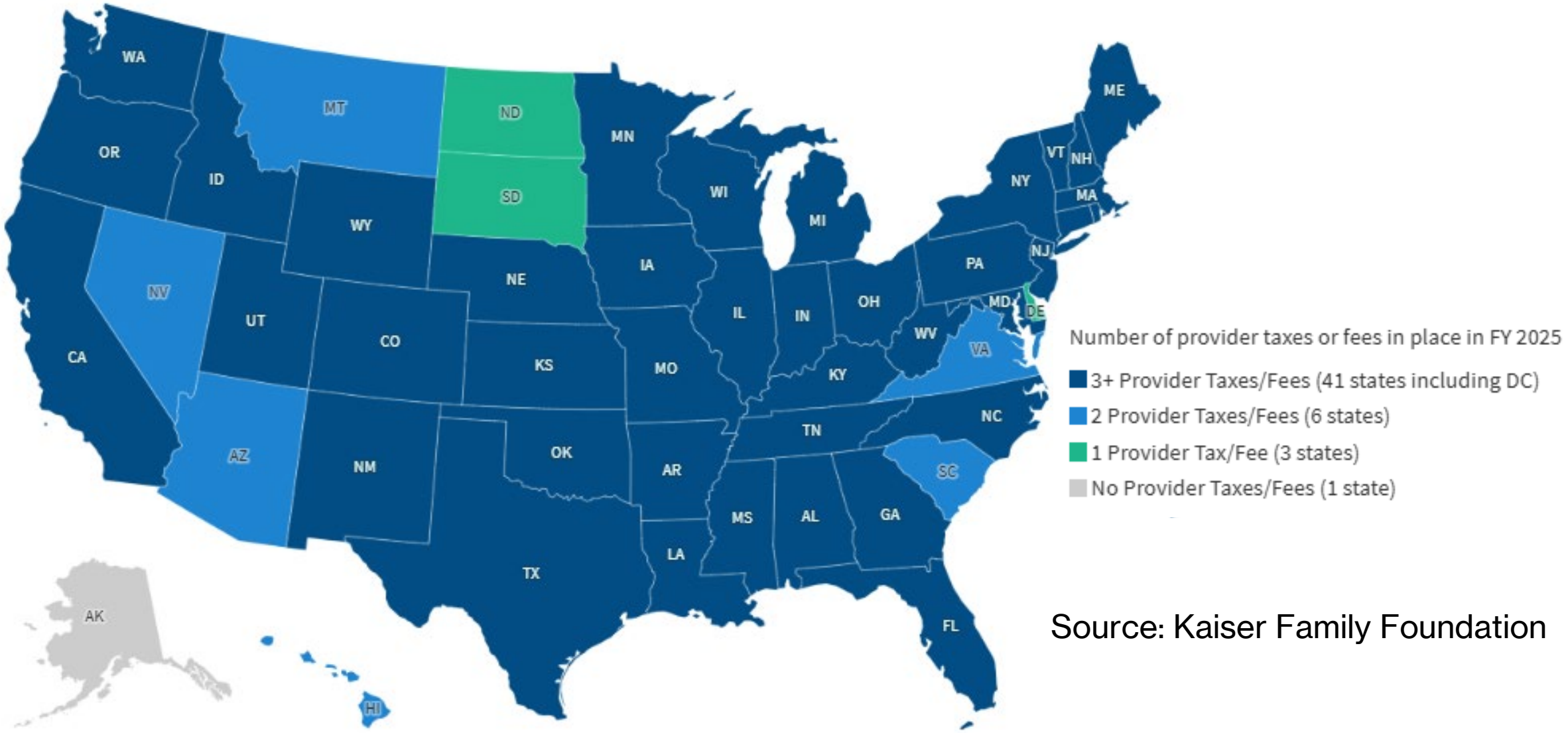
The average annual combined state and federal Medicaid budget is roughly **$16 billion to $18 billion**

(Texas' Medicaid budget is over $50 billion)

Annual Medicaid Cost		$17,000,000,000
FMAP	57%	$9,690,000,000
State Share	43%	$7,310,000,000
Sources of State Share		
State General Fund	70%	$5,117,000,000
Provider Taxes	18%	$1,315,800,000
Local Gov	6%	$438,600,000
Other	6%	$438,600,000
	100%	$7,310,000,000

What are Medicaid Provider Taxes?

All States but Alaska Use Provider Taxes to Help Finance the State Share of Medicaid Spending



Source: Kaiser Family Foundation

Why is Medicaid Under Attack?

- Medicaid has become increasingly expensive
- Some critics see Medicaid as a “low-hanging fruit” opportunity to limit or eliminate entitlement programs

“Are there no workhouses? Are there no benefit fraud hotlines?”

What is an Entitlement Program?

- A government initiative that guarantees specific benefits to any person or entity that meets fixed legal rules*
  - Based in **rights**: If you meet the rules, you have a right to the benefit.
  - Spending is **mandatory**: Funding is automatic. Every eligible person must be paid, unlike programs with spending caps.*
  - Budgets are **open-ended**: Costs are based on how many people qualify, rather than on a fixed budget set by lawmakers.*

What are the Largest U.S. Entitlement Programs?

By mandatory spending:

- Social Security (Retirement) 38%
- Medicare 24%
- **Medicaid 16%**

78%

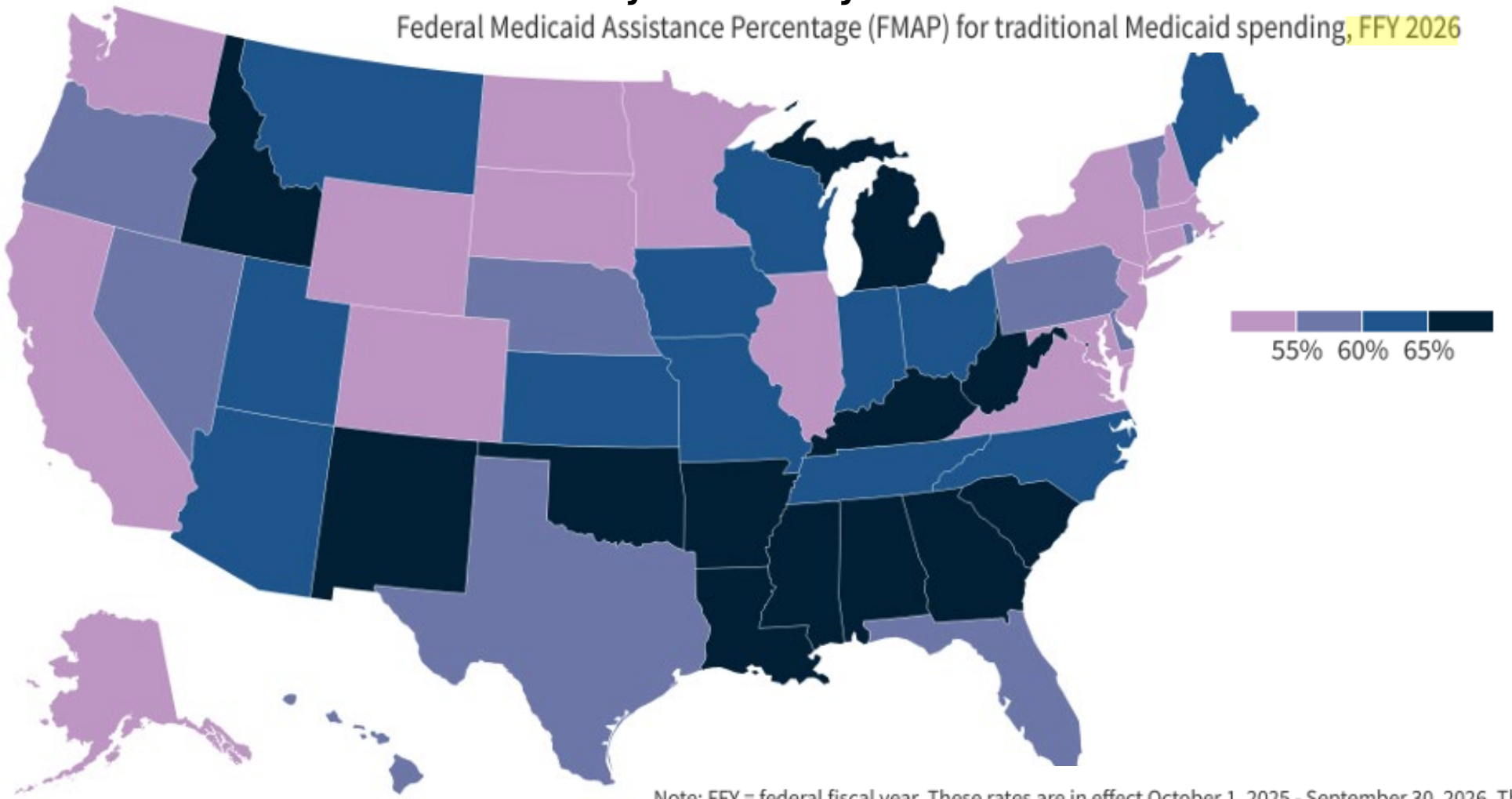
- Income Security 10%
- Veterans' Benefits 6%
- Fed Civilian and Military Retirement 5%
- Other 2%

***technically**

How is Medicaid Financed Today?

- States are guaranteed federal matching funds (FMAP) without a cap for qualified services provided to eligible enrollees.
- The match rate is determined by a formula in the law that provides a match of **at least 50%**
- The match is designed so that the federal government pays a larger share of program costs in states with a lower per capita income.
- States may also receive a higher FMAP for certain services and populations.
  - The ACA *expansion group* is financed with a 90% FMAP (so states pay 10%)

Medicaid is Jointly Financed by the Federal Government and States

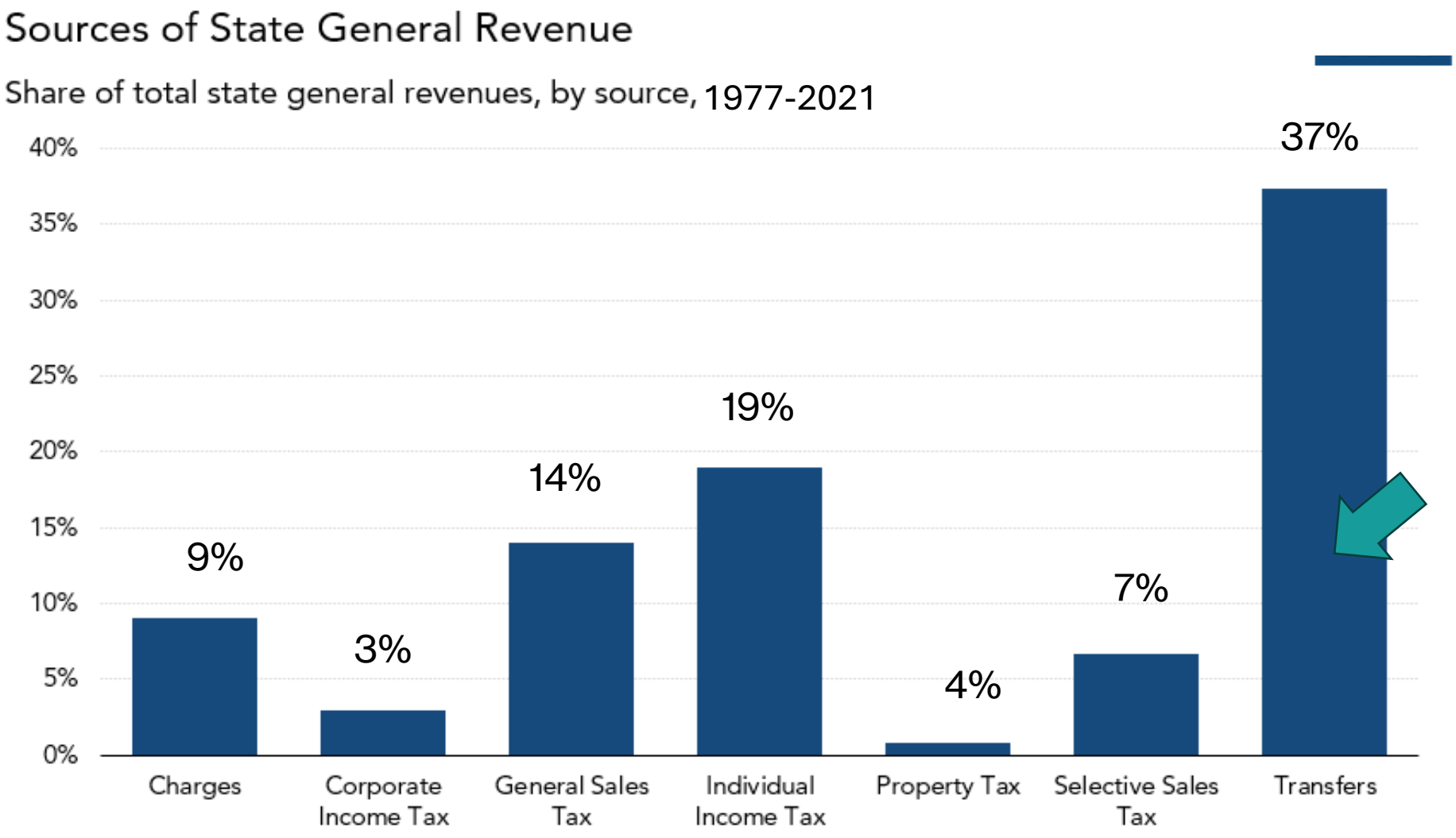


Note: FFY = federal fiscal year. These rates are in effect October 1, 2025 - September 30, 2026. These FMAPs are determined by a formula set in statute and are for services used by people eligible through traditional Medicaid, which includes individuals who are eligible as children, low-income parents, because of disability, or because of age (65+). The formula is designed so that the federal government pays a larger share of program costs in states with lower average per capita income.

Source: Federal Register, November 29, 2024 (Vol 89, No. 220), pp 94742-94745

Source: Kaiser Family Foundation

Where does State Revenue Come From?



Source: US Census Bureau Annual Survey of State and Local Government Finances, 1977-2021 (compiled by the Urban Institute via State and Local Finance Data: Exploring the Census of Governments; accessed 14-Jul-2022 10:05), https://state-local-finance-data.taxpolicycenter.org.

Charges: tuition to state universities, highway tolls, public hospital payments, special assessments, etc.

Selective sales tax: alcohol, tobacco, gas

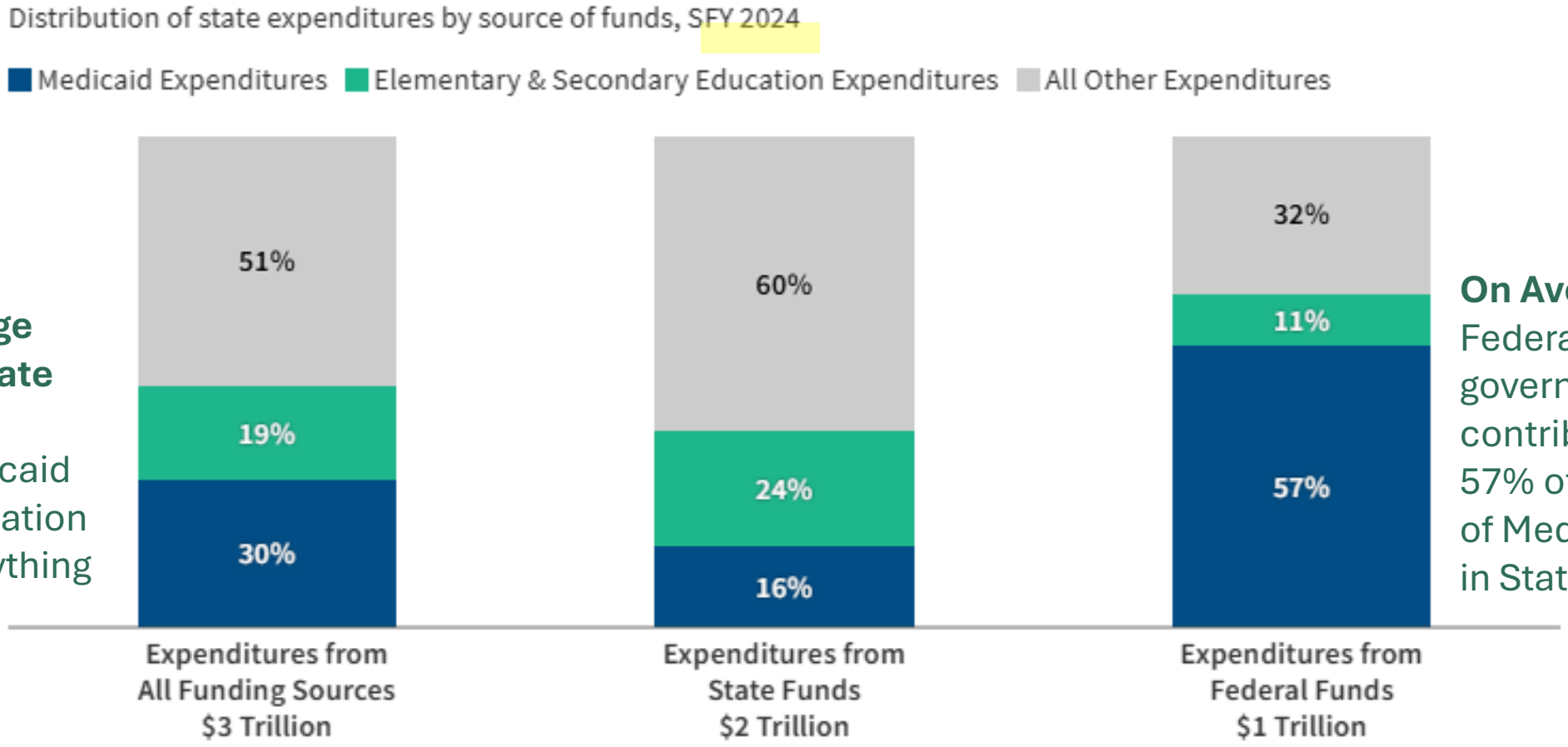
Intergovernmental ***Transfers***:

- Medicaid 65-69%
- Income Security and Social Services
- Transportation
- Education

Source: Tax Policy Center

Where does the Money Go?

On Average
A Total State Budget
30% Medicaid
19% Education
51% Everything else



On Average
Federal government contributes 57% of cost of Medicaid in States

Note: SFY = state fiscal year. Expenditures from state funds include state general funds and other state funds. Expenditures from all funding sources include both expenditures from state funds and federal funds as well as bond funds. Expenditures from state funds and federal funds may not total to expenditures from all funding sources due to the exclusion of bond funds from state and federal funds. For additional information and state-specific notes, see data source.

Source: Kaiser Family Foundation

Why are Medicaid IDD Services Under Such Scrutiny?

"Are you a deserving or undeserving person with disabilities?"

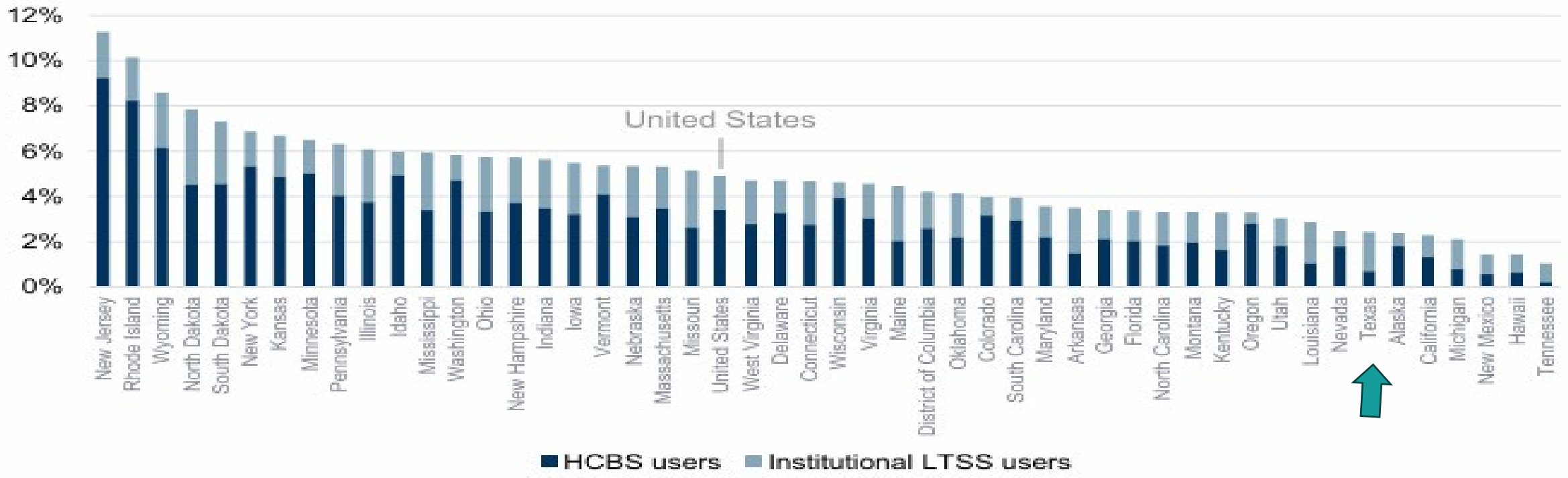
1. Critics believe HCBS is beyond the scope of Medicaid's Intended Purpose

- Medicaid is designed to be a safety net program to provide **medical care assistance** to **impoverished people**
  - Most of Medicaid's mandatory benefits are for acute care
  - Although **institutional care** is a *mandatory* benefit, long term supports and services (HCBS, i.e., waiver services) are *optional* and predominantly used for **non-medical assistance**
  - According to KFF, in 2023 across all beneficiaries, 77% of Medicaid LTSS spending was community based, 23% was institutionally-based

*Have we **advocated** ourselves into this position?*

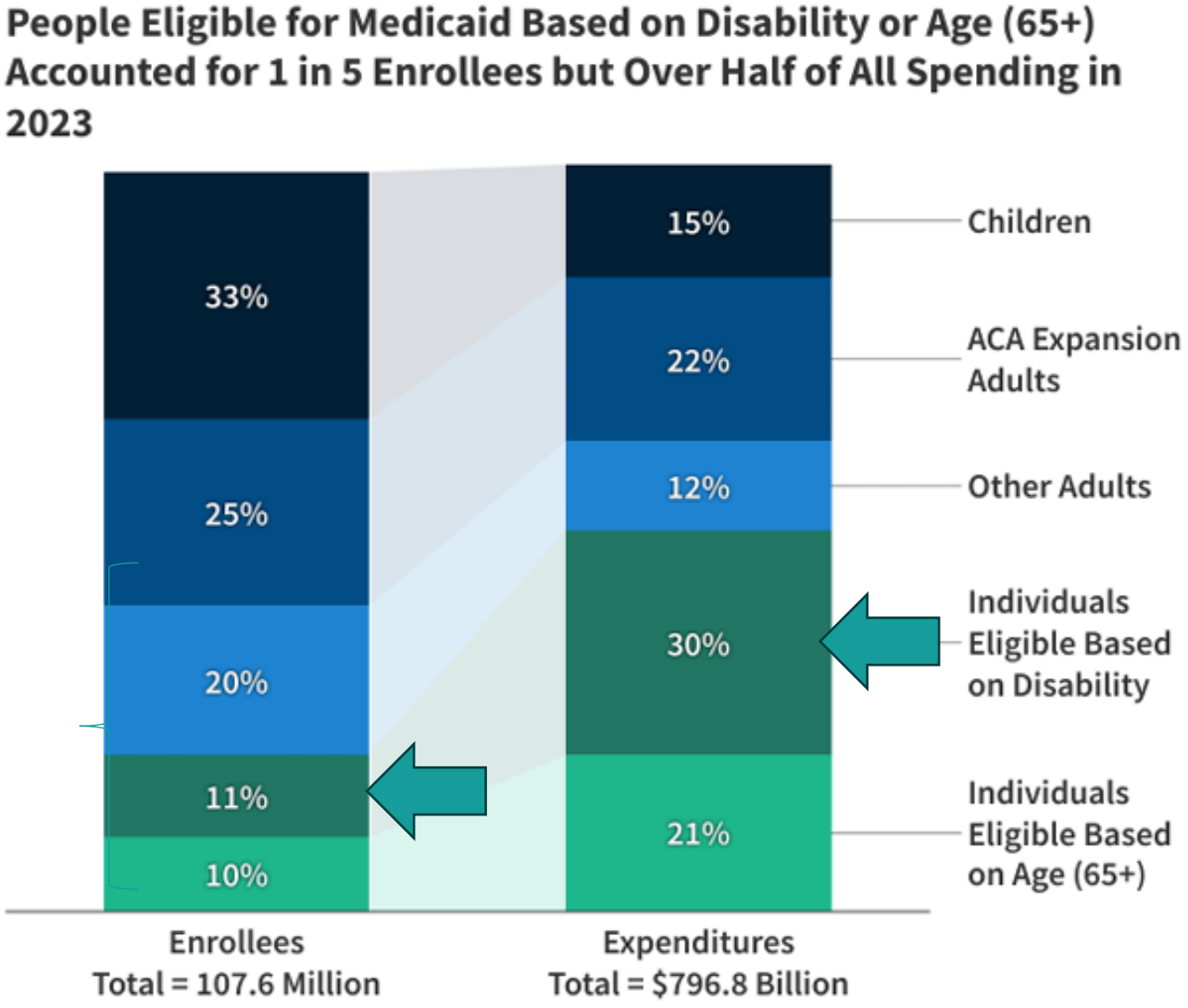
1. Critics believe HCBS is beyond the scope of Medicaid's intended purpose

FIGURE 1. State Distribution of HCBS and Institutional LTSS Users as a Share of All Medicaid Beneficiaries, CY 2021



Source: macpac.gov, Alabama and Arizona excluded due to reporting issues

2. People with Disabilities are the *Most Expensive* Medicaid Beneficiary Group



Note: Includes full and partial benefit enrollees enrolled in at least one month of Medicaid during 2023. Total may not sum to 100% due to rounding.

Source: Kaiser Family Foundation

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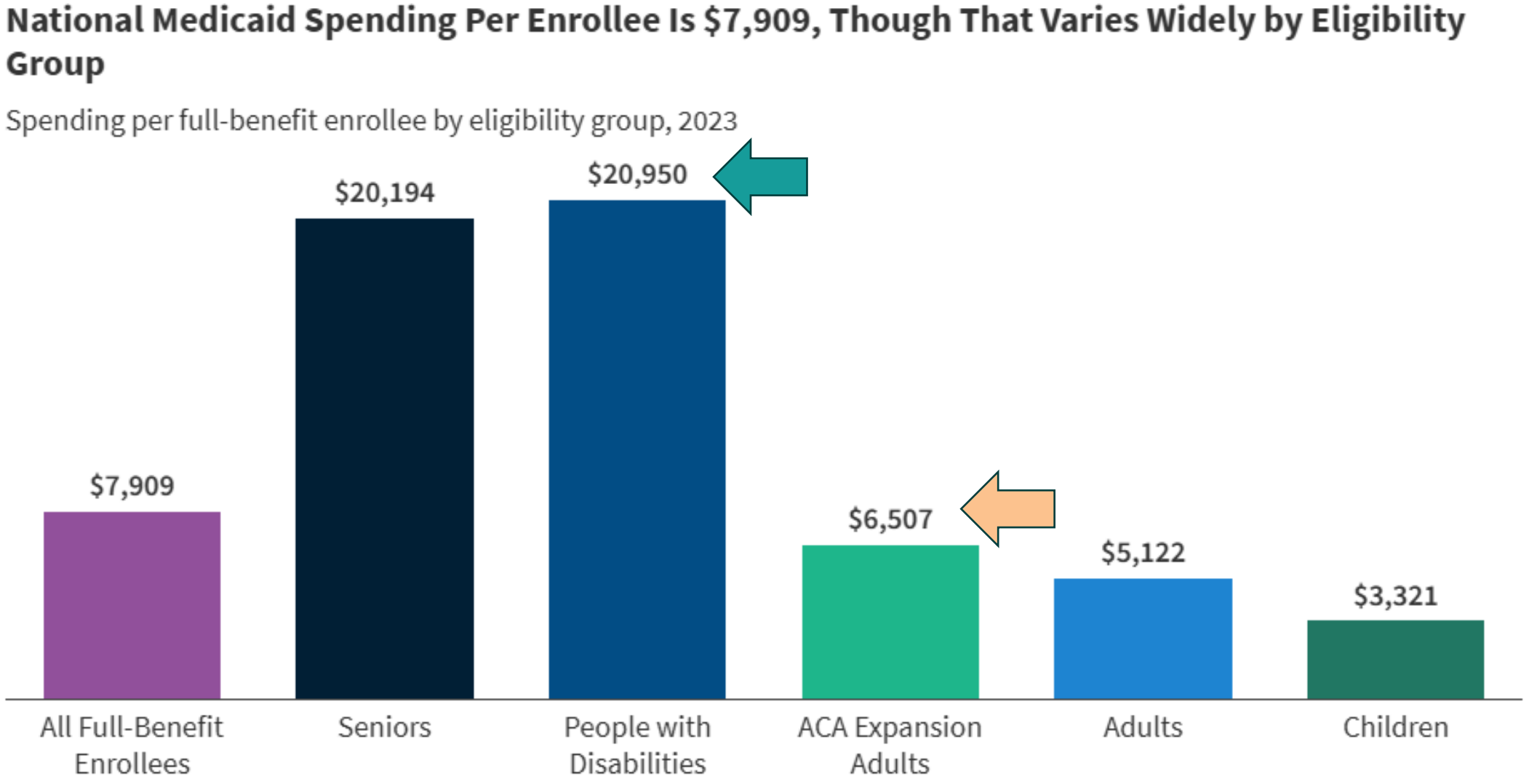

Note: Data include full-benefit enrollees who were enrolled in at least one month of Medicaid in 2023. They may not have actually used any services during this period, but they are reported as enrolled in the program.

Source: Kaiser Family Foundation

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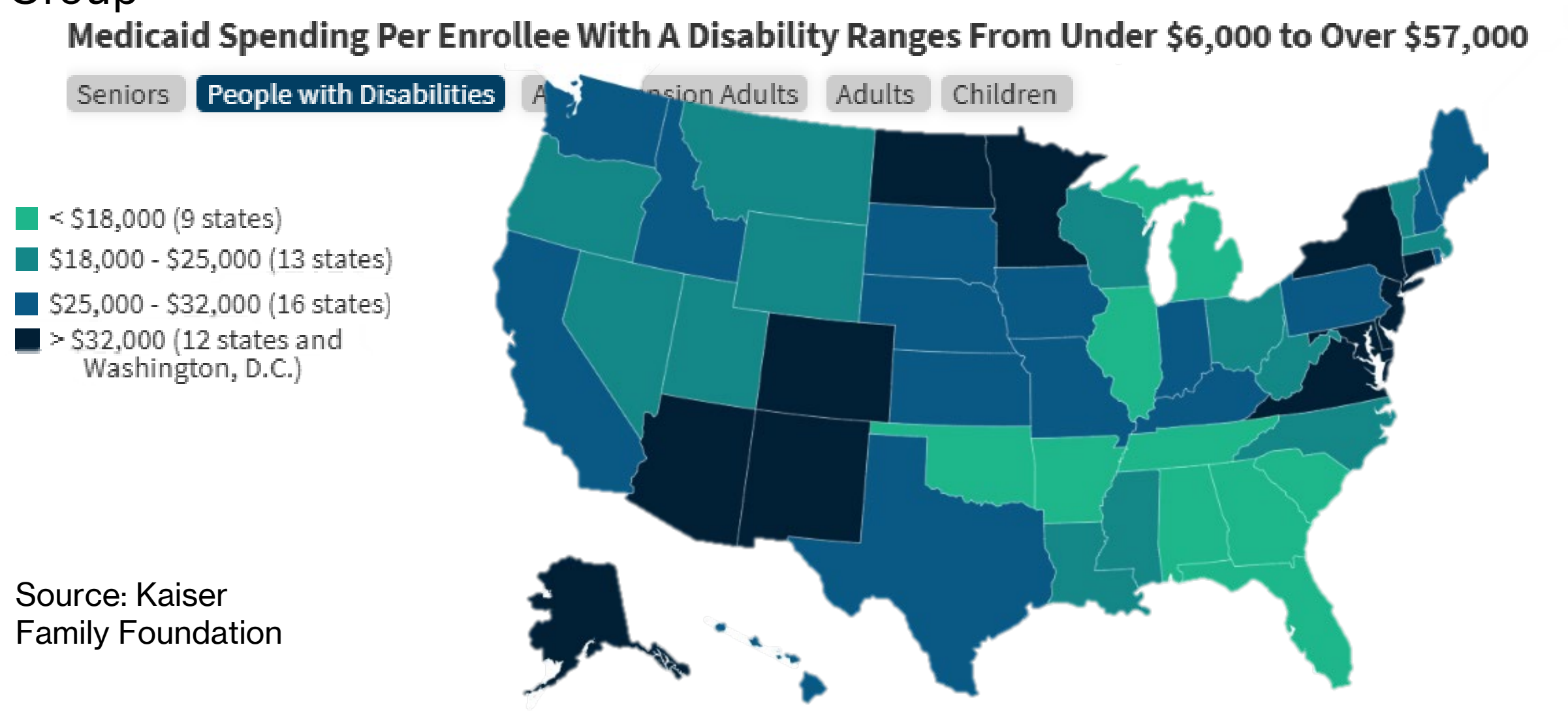


Source: Kaiser Family Foundation

Note: National per-enrollee spending for Medicaid full-benefit enrollees with a disability is $20,950. Data include people who were enrolled in at least one month of full-benefit Medicaid in 2023. They may not have actually used any services during this period, but they are reported as enrolled in the program. Washington, D.C. (not reflected in the figure) spent $45,952 per full-benefit enrollee with a disability.

3. Critics have noticed that HCBS are *optional*, not mandatory, services

- In order to participate in the Medicaid program,
  - States **are** required to pay for ***institutional care*** (nursing homes, etc.)
  - States **are not** required to force people to use them. I have not found any requirement for states to *assure any minimum capacity of such care*.
- People with disabilities have clearly said "no thank you" to long-term inpatient facilities.
  - What do states ***actually have to do*** in order to participate in the Medicaid program? **Agree to pay a cost share for essential services** (doctor, inpatient and outpatient care, lab tests, and institutional care*).
  - States ***do not*** have to build institutions for people with IDD.
  - Optional services ***can be discontinued*** and doing so **will save States money**.
- What does the DOJ Olmsted memo ***actually*** say?

Medicaid funding is going to radically change (decrease)

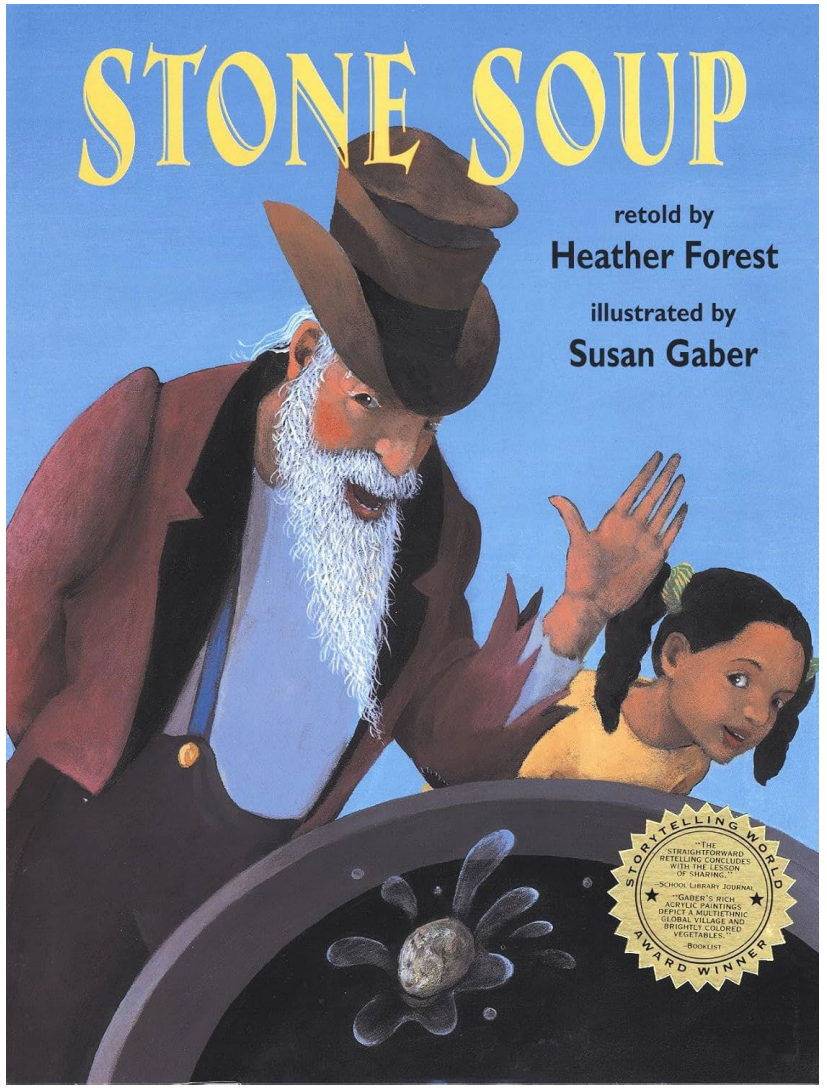
- Current federal strategy is focused on reducing the number of and FMAP **for *expansion enrollees*** *(and others)* ***and restricting provider taxes***
  - Prohibiting new taxes or increasing existing taxes ($89 Billion)
  - Reducing tax limits in the 41 states that adopted the ACA expansion ($102 Billion)
  - Revising conditions for approving uniformity waivers ($35 Billion)

    Restricting or banning taxes that place heavier tax burdens when Medicaid *volume* is considered (hospitals, nursing homes, MCOs)
- The net results are that the
  - Portion of the funds that states have been using to pay for their share of Medicaid are being reduced.
    - States have to find other sources to make up the difference **or cut costs.**
  - States face an increased administrative burden for maintaining *expansion enrollees* (more frequent eligibility recertifications, work requirement monitoring, etc.), which is not free.
- Could it the federal strategy continue to change in the future? Yes.

Reading the Tea Leaves

- The OBBA **will** go into effect in 2027
  - A combination of factors will contribute to
    - Decreased Medicaid enrollment numbers/ increased uninsured
    - Decreased Medicaid service offerings
  - Lower *intergovernmental transfers* (provider tax restrictions, FMAP reductions) will likely
    - Negatively affect state health care systems and the economies dependent upon those systems
    - Those with the **highest support needs** will retain the greatest level of services,
    - Those with **moderate to low support** needs will see substantial reductions in support over the coming years.
  - Will states try provider “rate cuts”?

Reading the Tea Leaves:
Is it Time to Make Stone Soup?



A folk story in which hungry strangers convince the all people of a town to each share a small amount of their food in a soup pot in order to make a meal.

Finally, the stone is removed from the pot, and a delicious and nourishing pot of soup is enjoyed by travelers and villagers alike.

Voluntary Organizations

Clubs, organizations, societies, churches/temples, leagues, teams affiliated with business, employers, or schools, etc.

What do These Have in Common?

Independent Living Movement

Response to ICE Shooting in MN

Reading the Tea Leaves: Possible Futures

- **For people with moderate and low support needs**
  - **Medicaid healthcare,** case management, family-based living, and *voluntary communities* rather than paid services may become the new normal
  - Pros: More innovation, individualization, & choice, plus the dignity of risk
  - Cons: Less oversight, more family burden, depressed outcomes
- **For people with high support needs**
  - **Medicaid essential services** (doctor, inpatient and outpatient care, lab tests, and institutional care)
  - Group homes serving this population may find it practical to be certified as ICFs
  - Pros: People with high support needs people live the community
  - Cons: Substantial non-medical community supports not covered.

Reading the Tea Leaves: *Rebuilding* Voluntary Communities

- Watch the documentary: ***Join or Die*** (2024), based on the work of Harvard Professor Robert Putnam (*Bowling Alone*).
  "A film about why you should join a club…and why the fate of America depends on it."
- The opportunity is in front of us **now** to build generic, community supports *outside* Medicaid (voluntary organizations but also entities based in commerce with seed money grants) that support our goals for inclusion.
- Do you have resources to dedicate to rebuilding local voluntary communities?

  Most neighborhoods **don't** have
  - A website to share information on *activities* or anyone that *coordinates* available spaces for rental/meetings.
  - A physical community center or an accessible location for
    - Drop off/pick up site for donations
    - Meet up site for service/club activities

Reading the Tea Leaves: *Rebuilding* Voluntary Communities

- Local **chapters of service organizations** (Lions, Kiwanis, GFWC, Odd Fellows, Rotary, etc.) have dwindling membership or closed down.
  - These chapters could be re-formed as *inclusive* service organizations to provide community engagement, entrepreneurial, employment, service, and leisure activities.
  - *Could you form a chapter?*
- **Clubs** and **Leagues** for adults are experiencing a tentative resurgence.
  - Clear leadership and opportunity are the only things preventing them from being inclusive.
  - *Could you organize, sponsor, host, or manage community clubs or leagues?*
- **Employment**
  - Participating in the community activities *informs* the development of entrepreneurial kitchen table/garage **businesses** needed by neighborhoods.
  - Networking through clubs and service organizations are common ways for people to find employment opportunities.

Reading the Tea Leaves: *There's going to be change*

- Substantial Medicaid cost cutting is coming – not overnight, but it *is* coming.
- IDD services knows how to pivot pretty well – particularly when we've been given advance notice.
- We need to take advantage of the time we have and act now to build another system under the radar.