Today we will talk about:

- Federal Administration: State Governors object to U.S. DOJ memo reinterpreting community integration; CMS posts information on Medical Frailty exemption; CMS Rule Restricts State Use of Medicaid Provider Taxes beyond HR 1 requirements; HR 1 Caps on State-Directed Payments Could Cut Medicaid Spending Up to 25% in 17 States; National advocates say HR 1 will result in higher Medicaid improper payment penalties for states; Parents unsure if special education move will help or harm students with disabilities; Special education head at Education Department abruptly resigns; What to do in Wisconsin if you don't think your school is complying with IDEA.
- Impact of HR 1: Congress will not act in time to prevent home care cuts in states; California's Next Governor Will Face Destabilizing Surge in Uninsured; Oregon Faces $1.3 Billion Medicaid Budget Hole From HR 1; The parent caregiver 'savings' Arizona is chasing don't exist — unless care disappears; Michigan Free Clinics See 54% Patient Surge as Medicaid Work Requirements Loom; Ohio: 50% food bank users have had to choose between paying for rent or food; Indiana, long term power outage cost families their food stocks; then SNAP benefits were denied.

Weekly Update

Sept 11th, 2026

Federal Funding Fallout 2026

Administration

Federal Agency Actions

60 years of disability progress helped my brother. I fear we're reversing it | Opinion

- "When Steve turned 5, the Kansas City public school district, and then later Shawnee Mission schools, refused to educate him. They were not required at the time to provide an education to children with disabilities.
- "At 9, he was sent to a state institution, and later moved in and out of community programs and state institutions for the next 25 years.
- "In 1966, institutional care for someone like Steve was predominantly custodial. Without the right to public education, people like Steve got little more than three hots and a cot. There was little expectation that he could ever have much of a life. Painfully, our family learned what millions of other disability families already knew: Whatever Steve needed, we were going to have to fight for it."
- "Today, he lives in a Medicaid-funded Home and Community Based Services program.
- "Steve's journey — from exclusion, segregation and institutionalization to life in the community — took more than half a century. Now I am deeply frightened that America is beginning to move backward.

https://www.kansascity.com/opinion/article317106206.html#storylink=cpy

He lost 10 years in a Georgia nursing home. It's becoming more common

- There is a nightmare lived by millions of disabled and elderly Americans who rely on Medicaid: Instead of receiving in-home care to live independently, they are often forced to live in institutions.
- It could become more common.
- On Aug. 31, the Trump administration moved to make it easier for states to place disabled and elderly people in institutions.
- To appease a lawsuit from several states, government lawyers told a federal judge they were willing to erase a 50-year-old provision requiring federal funds be used to care for people in their homes, whenever possible.
- Advocates say the government's concession erodes hard-fought civil rights under the Americans with Disabilities Act. And it threatens the return of a system where disabled people are locked in institutions instead of being allowed to live in their homes.

https://www.usatoday.com/story/news/investigations/2026/09/07/disability-rights-undermined-by-trump-doj-as-georgia-man-seeks-freedom-under-olmstead/91584075007

He lost 10 years in a Georgia nursing home. It's becoming more common

- “Nick lived independently with cerebral palsy using home-based supports until 2016 when he entered the hospital with a common wound. He thought he would go home after a short nursing home stay.
- “Instead, he was put at the end of Georgia’s list of 6,000 people waiting for disability services. He lost his job, his house and, eventually, his independence.
- “For 10 years, he remained locked away in Room 130 at Brown Health & Rehabilitation, more than 30 miles from his Athens home.
- “On paper, he had the right to live where he wanted, but he fell into a services gap
- “When he lost his home services, Papadopoulos could choose to live on the streets or in a nursing home – it wasn’t a real choice.”

https://www.usatoday.com/story/news/investigations/2026/09/07/disability-rights-undermined-by-trump-doj-as-georgia-man-seeks-freedom-under-olmstead/91584075007

He lost 10 years in a Georgia nursing home. It's becoming more common

- “Nick could not leave, not even for a day trip.
- “Just to get out of bed, facility rules said he needed a medical lift and two aids.
- “He had to wait until they were done with more than 20 other patients.
- “Nick spent so much time in bed, he lost muscle mass and developed osteoporosis.
- Sometimes, he sat in a soiled diaper for hours before help arrived.”

https://www.usatoday.com/story/news/investigations/2026/09/07/disability-rights-undermined-by-trump-doj-as-georgia-man-seeks-freedom-under-olmstead/91584075007

He lost 10 years in a Georgia nursing home. It's becoming more common

- “They did their best,” he said, acknowledging nurses and aids had to care for too many people.
- “While in the nursing home, Nick missed his mother’s funeral.
- “He missed his dad’s funeral.
- “He missed a cousin’s wedding and the birth of his nephew.
- “Concerts and dinners and movies with friends were a thing of the past.
- “He was exposed to diseases he never would have been at home, and scabies mites burrowed into his skin”

https://www.usatoday.com/story/news/investigations/2026/09/07/disability-rights-undermined-by-trump-doj-as-georgia-man-seeks-freedom-under-olmstead/91584075007

He lost 10 years in a Georgia nursing home. It's becoming more common

- “Regardless of what the Supreme Court case said about his rights, he could not get out.
- “And on Aug. 31, federal lawyers sided with the suing states, offering to erase the integration mandate from federal health regulations as part of a settlement.
- “They said it’s not discrimination to treat someone in an institution if there are “legitimate” reasons for states to prefer it over caring for them in their homes.”

https://www.usatoday.com/story/news/investigations/2026/09/07/disability-rights-undermined-by-trump-doj-as-georgia-man-seeks-freedom-under-olmstead/91584075007

18 Governors send letter to U.S. DOJ objecting to memo

- “As Governors, we are deeply concerned by the federal government’s retreat from its longstanding role in protecting the right to community integration and that such actions signal changes to programs serving individuals with disabilities.
- “We strongly oppose any federal actions that would weaken protections against unnecessary segregation or diminish the right of people with disabilities to receive services in the most integrated settings appropriate to meet their needs, consistent with established Olmstead precedent. Community integration is not an abstract legal concept. It means having a home, being able to work, attend school, shop, worship, build relationships, and participate in an ordinary civic life.”

https://www.governor.ny.gov/sites/default/files/2026-09/Governors_Letter_on_Olmstead_9-2026.pdf

BPDD statement on Governor's letter to U.S. DOJ

- All states have spent decades investing in home care as a strategy to avoid costly Medicaid funded nursing home and institutional placements because people with disabilities, older adults, and families want to be able to age in place and contribute to their communities.
- Former Wisconsin Governor Tommy Thompson initiated what became Family Care and IRIS to prevent expensive and unnecessary nursing home placements, starting with a few counties.
- Former Wisconsin Governor Scott Walker extended the programs to all counties and made sure people who qualified for care did not have to wait to get it.
- Today, the home care infrastructure Wisconsin has spent decades building supports for 30,000 children with disabilities and 90,000 older adults and adults with disabilities through its Medicaid home care waiver programs, as well as many other older adults and families who need care to stay in their homes.

https://wi-bpdd.org/.../BPDDStatement_Gov-Letter_9.8.26.pdf

Wisconsin Board for People
With Developmental Disabilities

vers among 18 governors opposed to federal actions threatening home care nd the right of people with disabilities to live in their communities

eptember 8, 2026

ress Contact: Jenny Price, jenny.price@wisconsin.gov (608-220-2924)
Sydney Badeau, badeausydney@gmail.com

Wisconsin Governor Tony Evers joined a group of 18 governors who called on the federal government to return to its "fundamental national commitment that disability should not be a basis for exclusion or diminished opportunity."

The Governor's letter to the U.S. Justice Department is in response to a U.S. DOJ opinion released in June that argues core civil rights laws—the Americans with Disabilities Act, the Rehabilitation Act, and the 1999 Supreme Court Olmstead decision—do not require states to integrate people with disabilities into the community. The opinion is contrary to decades of interpretation and long-standing legal precedent. It undermines the core civil rights laws that protect people with disabilities from being forced into institutions.

"As Governors, we are deeply concerned by the federal government's retreat from its longstanding role in protecting the right to community integration and that such actions signal changes to programs serving individuals with disabilities," the governors said in the letter released Friday.

Wisconsin disability organizations have responded to the opinion and the subsequent revocation of ADA guidance.

The Governors' letter states: "We strongly oppose any federal actions that would weaken protections against unnecessary segregation or diminish the right of people with disabilities to receive services in the most integrated settings appropriate to meet their needs... Community integration is not an abstract legal concept. It means having a home, being able to work, attend school, shop, worship, build relationships, and participate in an ordinary civic life."

"People with disabilities want to learn. We want to work. We want the same things everyone does, the chance to follow our dreams and live the life we want." said Sydney Badeau, Wisconsin Board for People with Developmental Disabilities Board Chair. "We know what happened when people with disabilities were locked away. Abuse. Neglect. A life limited by what someone else decided was your potential, not what you want."

Wisconsin still has 3 state run institutions

Table 1: People with Developmental Disabilities in Institutions, as of December

Institution Type	2020	2021	2022	2023
State Centers	296	289	268	257
Nursing Homes*	21	24	23	19
Non-State ICF-IIDs*	65	43	38	35
Total	382	356	329	311

Table 2: State Centers Population and Daily Rates

Facility	Population*	Private Pay Rate**	Intensive Treatment Services Rate**
CWC	150	$1,740	$1,985
NWC	11	2,571	1,985
SWC	92	1,568	1,985
Total	253		

*Population as of July 1, 2024, including long-term and intensive treatment populations.
**2024-25

https://docs.legis.wisconsin.gov/misc/lfb/informational_papers/january_2025/0052_services_for_persons_with_developmental_disabilities_informational_paper_52.pdf

https://mn.gov/mnddc/parallels2/pdf/80s/83/83-COM-WCD.pdf

Wisconsin still has 3 state run institutions

Table 3: State Centers Budget and Authorized Full-Time Equivalent Positions, 2024-25

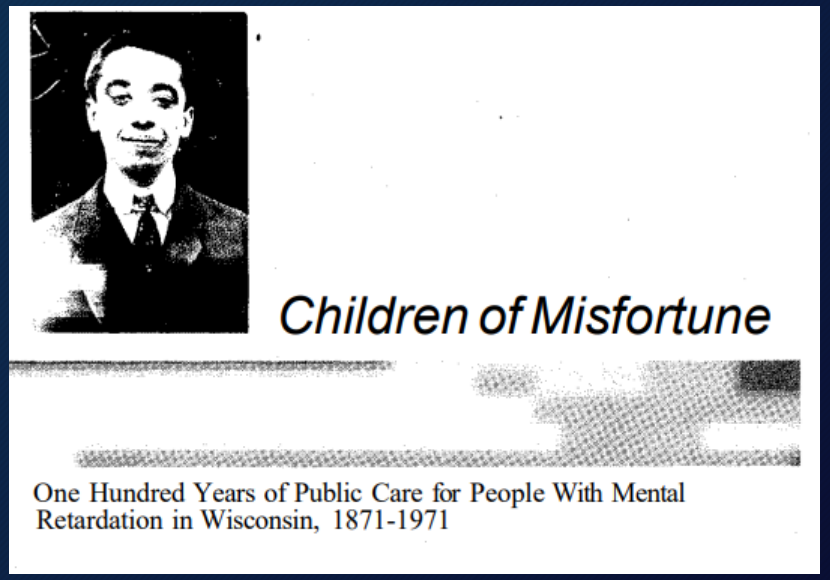
	CWC	NWC	SWC	Total
Program Revenues - MA				
State Operations	$100,554,400	$16,200	$49,983,300	$158,237,600
Utilities & Fuel	2,160,900	1,346,300	2,032,600	5,539,800
Institutional Repair and Maintenance	496,500	0	423,100	919,600
Institute Operations	298,700	0	1,700	300,400
Electric Energy	36,600	28,000	42,300	106,900
Subtotal	$103,547,100	$1,390,500	$52,483,000	$165,104,300
Program Revenues - Other				
Alternative Services	$228,200	$11,862,300	$24,100	$12,128,400
Extended Intensive Treatment Surcharge	50,000	0	50,000	100,000
Farm Operations	0	0	50,000	50,000
Activity Therapy	77,400	17,800	17,500	112,700
Gifts and Grants	20,000	39,600	18,000	77,600
Interagency and Intra-agency Programs	176,200	1,378,500	186,900	1,982,100
Subtotal	$551,800	$13,298,200	$346,500	$14,450,800
Total Funding (All Sources)	$104,098,900	$14,688,700	$52,829,500	$179,555,100
Total Authorized FTE Positions (All Sources)	777.30	131.50	480.25	1,389.05

https://docs.legis.wisconsin.gov/misc/lfb/informational_papers/january_2025/0052_services_for_persons_with_developmental_disabilities_informational_paper_52.pdf

https://mn.gov/mnddc/parallels2/pdf/80s/83/83-COM-WCD.pdf

Wisconsin policy history tracks evolution into and out of institutions (1984)

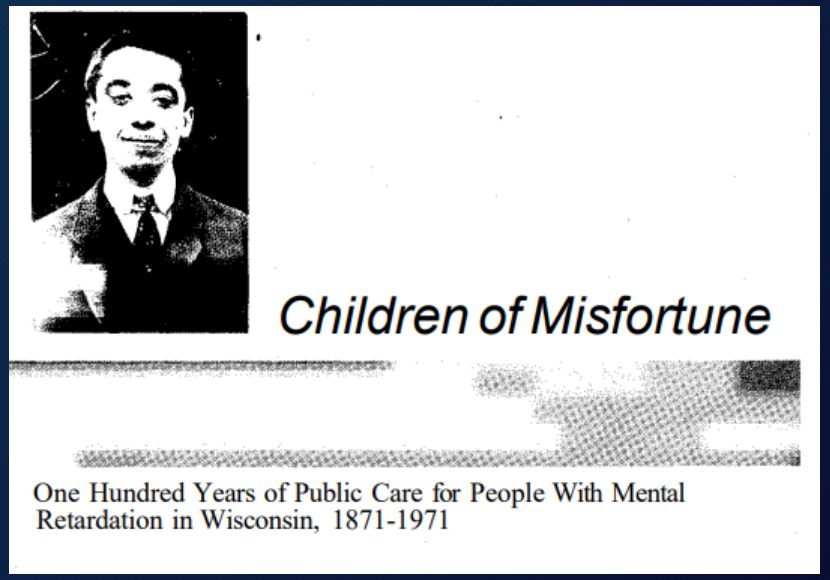
- Conserving money was the ultimate motivation for legislative and bureaucratic initiated change.
  - When county care was cheaper than state institutional care, the "Wisconsin System" of county mental hospitals was created in 1878.
  - When sterilization and subsequent release was cheaper than lifelong segregation, nearly 1,000 persons were sterilized.
  - When establishing community day services and group homes was cheaper than expanding institutional services, hundreds of community programs were developed.



https://mn.gov/mnddc/parallels2/pdf/80s/83/83-COM-WCD.pdf

Wisconsin policy history tracks evolution into and out of institutions (1984)

- While the outward appearances of institutions changed, the substance remained the same.
  - They were still large, overcrowded, isolated facilities with inadequate staff and insufficient resident programming, and there were repeated investigations of alleged resident abuse at the centers
- Many, if not all, of the improvements in public policy regarding persons with mental retardation were the result of the lobbying efforts by grassroots advocacy groups.
- In 1970, there were 3690 people with I/DD in state centers. In 2026, there are 257.



https://mn.gov/mnddc/parallels2/pdf/80s/83/83-COM-WCD.pdf

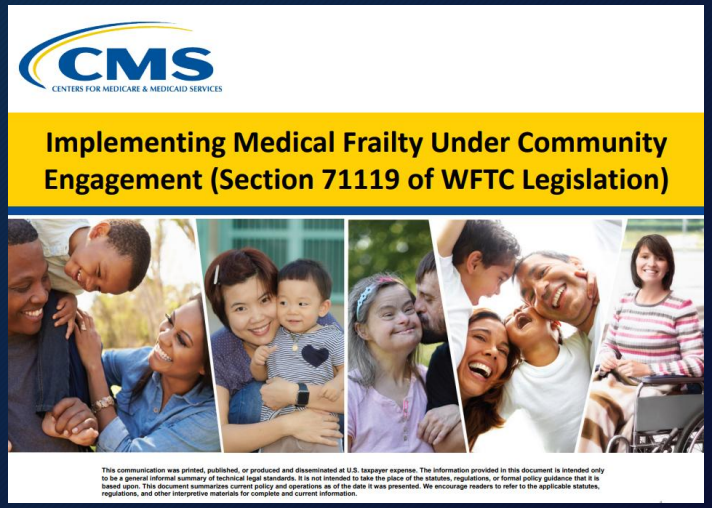
Defend Community Integration Coalition established

- “For people with disabilities, there is no right more foundational than the right to make our own choices.
- Far too often, we find ourselves in the position where others decide our lives for us.
- It takes a lot to ensure that the choices we have are real choices.
- It has taken years to build the supports we need to go to school, work, eat, stay housed, and raise our children.
- “Life is not just about getting three square meals a day and getting our meds on time. It is about growing, working, loving, dreaming, failing and reaching our potential. It is about deciding when to get up, when to go out, what to eat, and with whom to live.
- “It is hard to do these things when we are forced to stay in congregate settings where we have no say over most aspects of our lives.”

Join the Defend Community Integration Coalition: https://bit.ly/3V8Nfly

CMS posts information on Medical Frailty exemption

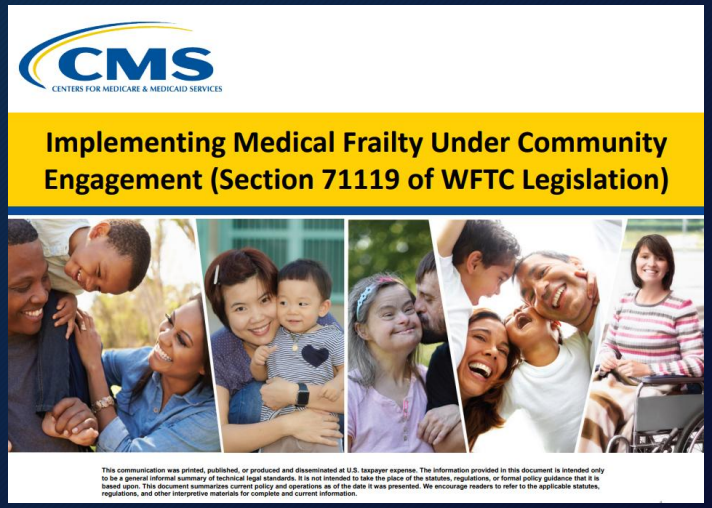
- CMS has posted a slide deck that gives states and advocates an idea of how CMS is thinking about how people can fit into the Medical Frailty exemption categories in the HR 1 work requirement rule.
- While national advocates do not think the CMS information is the only way states can choose to implement the Medical frailty exemption, it gives a general sense of the direction states can go that will be ok with CMS.
- CMS suggests states could use a tiered framework for evaluating medical frailty based on reliable diagnosis codes and claims and encounter data.



https://www.medicaid.gov/resources-for-states/working-families-tax-cut-legislation/community-engagement/ImplementingMedicalFrailtyDeck.pdf

CMS posts information on Medical Frailty exemption

- The tiers suggested by CMS (but states aren't required to follow) are:
  - Tier 1: conditions that demonstrate significant impairment based on International Classification of Disease codes
  - Tier 2: conditions that may indicate an individual is medically frail but more information is needed to show the condition significantly impairs the individual's ability to comply with work requirements (e.g., elevated acute care utilization, high-risk polypharmacy, use of certain durable medical equipment) or other factors indicating impairment (e.g., co-morbidities, chronic conditions, acute or temporary conditions like injuries or surgery).
  - Tier 3: conditions where there is insufficient information or no data to evaluate medical frailty based on Tier 1 and 2 criteria and requires an individualized assessment



https://www.medicaid.gov/resources-for-states/working-families-tax-cut-legislation/community-engagement/ImplementingMedicalFrailtyDeck.pdf

CMS Rule Restricts State Use of Medicaid Provider Taxes beyond HR 1 requirements

- CMS's proposed provider tax rule goes beyond what's required in HR 1
- That is true of other CMS rules implementing H.R. 1 Medicaid cuts — including state-directed payments, work reporting requirements, and section 1115 waiver budget neutrality.
- The proposed Provider tax rule restricting state use of provider taxes more.
- This will shift more costs to states, and make it more difficult for states to finance Medicaid and other state health priorities.

https://ccf.georgetown.edu/2026/07/27/cms-issues-new-rule-again-going-beyond-h-r-1-requirements-to-further-restrict-state-use-of-medicaid-provider-taxes/

CMS Rule Restricts State Use of Medicaid Provider Taxes beyond HR 1 requirements

- Ways the proposed rule goes beyond HR 1 include:
  - Making H.R. 1 restrictions and general provider tax rules apply to health insurer premium taxes (even if they are unrelated to Medicaid).
  - If CMS says health insurer premium doesn't comply with the provider tax rules and restrictions, states will have to eliminate or reduce such taxes or be subject to financial penalties in their Medicaid program (even if such taxes are unrelated to Medicaid).

https://ccf.georgetown.edu/2026/07/27/cms-issues-new-rule-again-going-beyond-h-r-1-requirements-to-further-restrict-state-use-of-medicaid-provider-taxes/

CMS Rule Restricts State Use of Medicaid Provider Taxes beyond HR 1 requirements

- Ways the proposed rule goes beyond HR 1 include:
  - Requiring states to do a lot of work to get through a reporting process and compliance system.
  - Giving CMS authority to review all state provider taxes and make sure the taxes aren't too big.
  - If states have any provider tax that is bigger than what HR1 allows, then CMS can require states to refund provider, give money back to the feds, or be subject to federal deferrals or disallowances.
  - The rule also signals that intergovernmental transfers will be watched more closely and potentially restricted.

https://ccf.georgetown.edu/2026/07/27/cms-issues-new-rule-again-going-beyond-h-r-1-requirements-to-further-restrict-state-use-of-medicaid-provider-taxes/

CMS Rule Restricts State Use of Medicaid Provider Taxes beyond HR 1 requirements

- The CBO originally estimated HR 1's Provider Tax provision would cut federal Medicaid spending by $191.1 billion over ten years and increase the number of uninsured by 1.1 million by 2034.
- In the proposed rule, CMS estimates federal Medicaid spending would be cut by $245.8 billion over ten years.
- State revenues raised through provider taxes to finance Medicaid (and other health spending) would fall by $198.7 billion over ten years, a reduction of 17.2 percent, compared to prior law.
- But in the tenth year (2035), states would see their provider tax revenues fall by 27.1 percent, compared to the revenues they would have received to pay for Medicaid costs in the absence of H.R. 1 and the proposed rule.
- In addition, health care providers would see their Medicaid payments fall by $220.3 billion over ten years.

https://ccf.georgetown.edu/2026/07/27/cms-issues-new-rule-again-going-beyond-h-r-1-requirements-to-further-restrict-state-use-of-medicaid-provider-taxes/

HR 1 Caps on State-Directed Payments Could Cut Medicaid Spending Up to 25% in 17 States

- A new study predicts 17 states could see Medicaid spending reductions between 10% to 25% under new federal limits on state-directed payments under HR 1.
- Thirty-nine states paid hospitals, nursing facilities or academic medical center professionals more than Medicare rates through state-directed payments
- HR 1 limits state-directed payments to 100% of Medicare rates in expansion states and 110% in non-expansion states for hospital inpatient, hospital outpatient, nursing facility and academic medical center professional services.
- The Congressional Budget Office (CBO) estimated the HR 1 change would reduce federal Medicaid spending by about $149 billion over 10 years.

https://www.beckershospitalreview.com/finance/17-states-could-face-medicaid-spending-cuts-of-10-to-25-under-hr-1/

https://www.kff.org/medicaid/at-least-37-states-have-medicaid-state-directed-payments-for-hospital-services-that-could-be-reduced-by-the-2025-reconciliation-law-limits/

HR 1 Caps on State-Directed Payments Could Cut Medicaid Spending Up to 25% in 17 States

- The report estimates a $51.8 billion reduction in annual Medicaid spending across 36 states (including seven non-expansion states)
- That reflects about 6.4% of those states' total Medicaid spending,
- Lower Medicaid reimbursement will likely increase uncompensated care costs and Medicaid shortfalls, and that providers may limit the number of Medicaid patients they serve or seek higher prices from commercial payers.
- In May CMS proposed an administrative rule that went farther than HR 1 and limited more provider classes to Medicare rates and eliminated uniform fee increases (the most common state-directed payment type).
- If finalized as proposed, the study's estimates the rule would increase the amount of money states lose under the state-directed payment provision.

https://www.beckershospitalreview.com/finance/17-states-could-face-medicaid-spending-cuts-of-10-to-25-under-hr-1/

https://www.kff.org/medicaid/at-least-37-states-have-medicaid-state-directed-payments-for-hospital-services-that-could-be-reduced-by-the-2025-reconciliation-law-limits/

National advocates say HR 1 will result in higher Medicaid improper payment penalties for states

- Beginning October 1, 2029, HR 1 makes changes to the Payment Error Rate Measurement (PERM) program.
- PERM is a performance metric that identifies improper payments in states' Medicaid programs, determines their cause, and uses corrective action to reduce them.
- The overwhelming majority of improper payments are from a lack of documentation or minor administrative mistake

https://healthlaw.org/a-proper-scare-how-obbba-changes-improper-payment-rules-to-expose-states-to-significant-financial-liability/

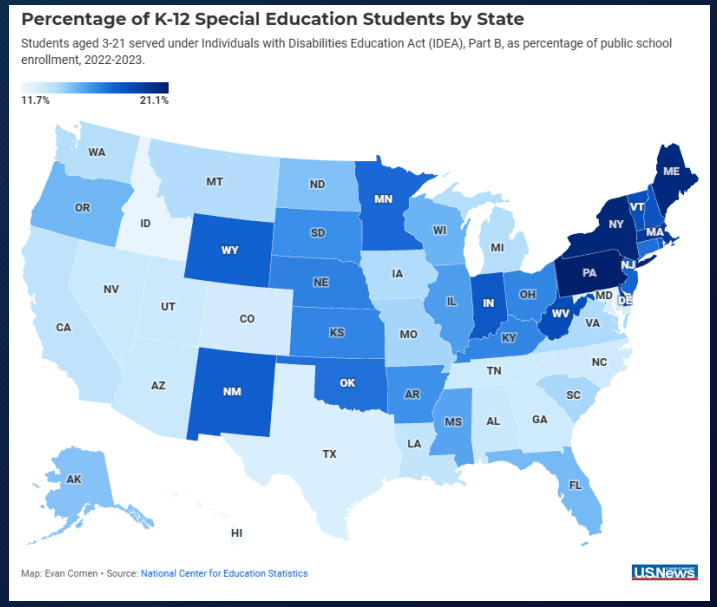
National advocates say HR 1 will result in higher Medicaid improper payment penalties for states

- Under HR 1 states will be required to repay the federal portion of any errors over the 3 percent threshold. (12 states had error rates above 3%)
- HR 1 also makes payments classified as “improper” based on a lack of documentation subject to recovery (i.e. states would have to pay that money back to the feds).
- Importantly, improper payments are not the same as fraud.
- These changes put state budgets at risk.

https://healthlaw.org/a-proper-scare-how-obbba-changes-improper-payment-rules-to-expose-states-to-significant-financial-liability/

Parents unsure if special education move will help or harm students with disabilities

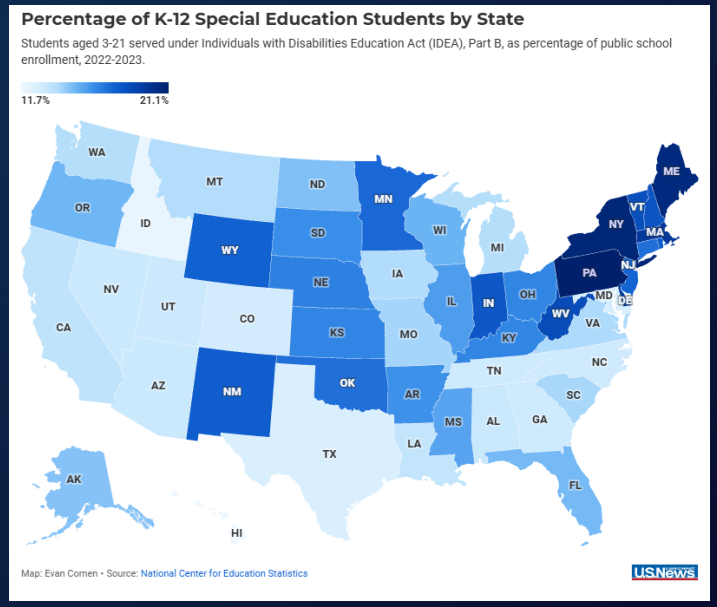
- There are more than 8 million American children with disabilities in the U.S.
- Some parents worry moves at the U.S. Dept of Education moves will mean they will have to fight harder for their children's educational rights protected by the Individuals with Disabilities Education Act, or IDEA.
- Pre 1975, Congress found that more than half of children with disabilities did not receive appropriate educational services and equal opportunities before 1975 and that 1 million were excluded from the nation's public school systems.
- Several states blocked children from school if they were deaf, blind, emotionally disturbed or intellectually challenged.



https://www.usnews.com/news/national-news/articles/2026-09-04/trump-upends-special-education-oversight-stirring-parents-and-advocates

Parents unsure if special education move will help or harm students with disabilities

- Among the worried is Katie Moureau, who has three kids receiving special education services at schools in Cottage Grove, Wisconsin.
- She says the change could be a step toward a scenario in which “all children with disabilities will lose the federal oversight and accountability that makes their rights under IDEA meaningful.”
- She worries that the transfer of special education oversight will force families to face more challenges getting the evaluations, services, accommodations and individualized education programs their children need.



https://www.usnews.com/news/national-news/articles/2026-09-04/trump-upends-special-education-oversight-stirring-parents-and-advocates

Special education head at Education Department abruptly resigns

- The U.S. Department of Education's top special education official unexpectedly resigned just as the agency is putting plans in motion to outsource many responsibilities related to supporting students with disabilities.
- The Education Department has at least 14 ongoing interagency agreements (IAAs) with other federal agencies that will move many employees to other federal agencies.
- Rogers was brought in to oversee the IAA between the special education offices and HHS in May.
- One of the main things OSERS does is support states and schools with programs for people with disabilities, including the implementation of the Individuals with Disabilities Education Act (IDEA).
- It also manages about $15 billion in federal funding supporting students with disabilities.

https://www.npr.org/2026/09/09/nx-s1-5962899/special-education-kelly-rogers-resigns

https://www.disabilityscoop.com/2026/09/10/nations-special-ed-chief-abruptly-resigns-as-education-department-transfers-get-underway/32167/

Special education head at Education Department abruptly resigns

- This week 100 OSERS staffers moved to the Department of Health and Human Services, and 57 Education Department's Office for Civil Rights to the Department of Justice next week
- Beyond the OSERS and OCR changes this month, union officials said that nearly 180 Education Department staffers were transferred to four different agencies this summer.
- The staff moves forward the plan announced in June to shift many special education functions to the health agency and certain civil rights work to the Justice Department.
- It is unclear who will take over for Rogers, whether that person will be part of the Education Department or HHS or how Rogers' departure will impact plans for OSERS,
- On top of the staffing and physical changes to the Education Department, Rummel points out that the president's budget proposal for the coming fiscal year 2027 would cut over 80% of OSERS staff.

https://www.npr.org/2026/09/09/nx-s1-5962899/special-education-kelly-rogers-resigns

https://www.disabilityscoop.com/2026/09/10/nations-special-ed-chief-abruptly-resigns-as-education-department-transfers-get-underway/32167/

What to do in Wisconsin if you don't think your school is complying with IDEA

Steps families should take if they believe their school district is not doing what they should for students with disabilities under IDEA.

Parents should report incidents both to DPI (Wisconsin Dept. of Public Instruction) and to Disability Rights Wisconsin (DRW).

This helps DPI start investigations and assess whether there is a pattern of behavior by a district that they can act upon.

It may not bring immediate relief, but it is important for families to file complaints.

What to do in Wisconsin if you don't think your school is complying with IDEA

If anyone believes a school district is in violation of any Special Education law and the incident occurred in the last year, they can file a complaint using DPI's template or via email idea@dpi.wi.gov.

They can also call DPI's special education main line – 608-266-1781 - and speak with one of our team members regarding their experience(s) with a district and any questions they may have.

People filing complaints should include as much specific and detailed information (dates, state law that was violated, supporting documentation, etc.) as possible.

DRW's phone is 800-928-8778 or email info@drwi.org

Survival Coalition Issue Forum: Medical Aid in Dying laws, implications for people with disabilities

Speakers

Anita Cameron is a disability justice activist who has been involved in social change activism and community organizing for 44 years. From 2017-2025, Anita worked as Director of Community Outreach for Not Dead Yet, a Rochester, NY-based, national disability rights group opposed to medical discrimination against disabled people, medical rationing and assisted suicide. Anita's work and articles were cited in the 2019 National Council on Disability report on the dangers of assisted suicide as public policy.

Barbara Lyons. Following a 40-year career working in public policy, disability advocacy and advocacy for human dignity and healthcare equality, Barbara served as Coalitions Director for PRAF for 7 years. Barbara now works as Special Projects Coordinator focusing on research and legal issues and physician co-ordination for the Patient's Rights Action Fund.

- Survival Coalition is hosting a series of policy issue forums this fall.
- Our first is about Medicaid Aid in Dying laws, and how these policies may impact people with disabilities and families.
- Learn about key issues and areas of concern, what laws look like in other states and countries, and how perceptions of people with disabilities/older adults and cost of care needs can influence who chooses or is offered medical aid in dying options.
- The event will be **September 15th from 12-1 PM.**
- Register here
- The webinar will be recorded and materials will be sent out to people who registered.
- Please share this opportunity with your networks!

Survival Coalition statewide survey on special education experiences in Wisconsin

- Survival Coalition is helping conduct a statewide survey of parents of students with disabilities about their experiences with special education in Wisconsin.
- The survey is intended to help inform schools, legislators, and the press about what parents and students with disabilities are currently experiencing in schools.
- Your experiences help tell an important story about how the amount of staff support, quality of special education and transition services, and how the current way special education is funded impacts students, families, and schools.
- Help us reach our goal of 500 responses from across Wisconsin by adding your voice.
- **Please** share this survey widely on social media and e-mail list servs, and encourage people to take the survey and forward it to others.
- **We are aiming to close the survey this summer** so results can be shared in the fall.

Survival Coalition

of Wisconsin Disability Organizations

Calling all Wisconsin special education families!

Survival Coalition is helping conduct a statewide survey of parents of students with disabilities about their experiences with special education in Wisconsin. The survey is intended to help inform schools, legislators, and the press about what parents and students with disabilities are currently experiencing in schools.

Your experiences help tell an important story about how the amount of staff support, quality of special education and transition services, and how the current way special education is funded impacts students, families, and schools.

We'd like to hear from at least 500 people from across Wisconsin! Help us reach our goal by adding your voice. You can submit anonymously and it should take less than 10 minutes to complete!

Survey QR Code:

Or find the survey on learninmyshoeswi.org

Learn in my Shoes

Continued coverage of impact of Reconciliation bill

Lots of articles to share.

Congress will not act in time to prevent home care cuts in states

Congress has introduced two bills related to home care:

Home and Community Based Services ACCESS act (would make HCBS mandatory Medicaid service)	Medicare at Home (would establish Home care as a service covered under Medicare for first time)

REMEMBER: These pieces of legislation will not pass this Congress (much less be signed into law)

Legislation is often introduced over multiple sessions and can take several sessions to pass. These ideas will not move forward before 2028.

These pieces of legislation will not prevent the Medicaid cuts or state budget holes that are resulting in home care cuts in states now.

Congress will not act in time to prevent home care cuts in states

- States—through state budget process and state agency actions—will make decisions that impact care infrastructure in the next 6 months.
- The near-term action is in the states.
- Grassroots disability advocates focus should be on the state decision makers who will make funding and policy decisions that impact care infrastructure, who can get care, and the kind of care people can get.
- Federal agency actions—like Medicaid deferrals, withholdings, changes to administrative rules etc.—may continue to impact home care and state budgets.

Congress will not act in time to prevent home care cuts in states

After the November elections, Congress will know which party is the majority in the House and Senate.

The period after the election and before the start of the next Congress (Nov-Jan 20th) is called the “lame duck” session.

Congress must make decisions on the federal budget before Dec. 11th

If Republicans do not retain the majority in both Houses, the likelihood of another reconciliation bill increases (may include SAVE Act provisions, fraud/waste/abuse changes, other health care changes).

Even if Democrats have the majority next session, the President can veto legislation they pass (this means ideas like repealing HR 1 will not happen in the next two years).

California's Next Governor Will Face Destabilizing Surge in Uninsured

- By 2030, the number of uninsured Californians under 65 is expected to grow almost 50% from 2.4 million to 4.6 million because of cuts to Medicaid from HR1 and ACA marketplaces.
- It is unclear how the state will backfill as much as $30 billion in federal funding California stands to lose annually.
- The rise in the uninsured population may have big impacts on hospital systems, insurers, and the economy.
- In February, legislators were told the HR 1 and ACA changes could cost California about 200,000 jobs, mostly in the healthcare industry.
- Hospital executives have begun reporting more unpaid medical bills.
- Experts warn health plans will raise premiums further because the remaining people insured are sicker and more expensive to cover.

https://kffhealthnews.org/elections/xavier-becerra-longtime-health-coverage-champion-california-gubernatorial-race-uninsured-rate/

Oregon Faces $1.3 Billion Medicaid Budget Hole From HR 1

- Oregon health officials told state legislators Oregon will need fund nearly $1.3 billion more in the next four years to maintain current Medicaid operations.
- The state budget shortfall is from federal cuts and new restrictions in HR 1, and creates immediate pressure on Oregon's next biennial budget cycle.
- **Why it matters:** State Medicaid agencies must prepare for significant budget cuts or identify new state revenue sources to backfill federal funding losses, likely forcing difficult choices between benefit reductions, provider rate cuts, or eligibility restrictions.

https://www.newsfromthestates.com/article/2025-gop-tax-law-will-cost-oregon-nearly-13b-medicaid-over-next-four-years-officials-say

Oregon Faces $1.3 Billion Medicaid Budget Hole From HR 1

- The state faces a $421 million deficit for the next two-year budget cycle and the following budget cycle the gap grows to $868 million.
- “I also need to be very candid with you,” Pakseresht told lawmakers. “Even with our best work, there are going to be people who lose coverage. We need to know that before we step into this”
- In Oregon, around 200,000 people are estimated to lose their Medicaid coverage as HR 1 is implemented in the coming years.
- Lawmakers gave little indication on Wednesday about how they would work to address the agency’s expected budget gaps.

https://www.newsfromthestates.com/article/2025-gop-tax-law-will-cost-oregon-nearly-13b-medicaid-over-next-four-years-officials-say

The parent caregiver ‘savings’ Arizona is chasing don’t exist — unless care disappears

- An Arizona Auditor General report estimates the state could reduce spending by $133 million to $493 million by implementing age-based standardized assessments that decrease authorized services for children with disabilities.
- The audit found no widespread fraud in Arizona's Parents as Paid Caregivers model, but advocates argue projected savings would come from unfilled care needs rather than program efficiencies.
- **Why it matters:** State Medicaid agencies considering similar assessment tools should note that reduced authorizations may shift costs to emergency and institutional settings rather than generate true savings.

https://azmirror.com/2026/09/04/the-parent-caregiver-savings-arizona-is-chasing-dont-exist-unless-care-disappears/

The parent caregiver ‘savings’ Arizona is chasing don’t exist — unless care disappears

- Arizona’s Parents as Paid Caregivers program expands the existing direct-care workforce by allowing qualified, trained and certified parents to provide services already assessed and authorized for their children.
- If a qualified non-parent caregiver provides an authorized hour of care, Medicaid pays for that service. If a qualified parent provides that same authorized hour, Medicaid pays the same.
- The child’s need didn’t change. The work didn’t change. Only the worker did.
- The care being provided is specialized, beyond what would ordinarily be expected of a parent of a child without a disability.

https://azmirror.com/2026/09/04/the-parent-caregiver-savings-arizona-is-chasing-dont-exist-unless-care-disappears/

The parent caregiver ‘savings’ Arizona is chasing don’t exist — unless care disappears

- “So, if Arizona removed parents from the paid workforce tomorrow and other qualified caregivers filled every shift, where would the savings come from?
- “They wouldn’t.
- “There is, however, a very effective way to make the expenditure disappear: No one provides the necessary service.
- “An unfilled shift generates no Medicaid claim.
- It also generates no care.”

https://azmirror.com/2026/09/04/the-parent-caregiver-savings-arizona-is-chasing-dont-exist-unless-care-disappears/

The parent caregiver ‘savings’ Arizona is chasing don’t exist — unless care disappears

- “Real efficiency reduces unnecessary costs without reducing access to necessary care or destabilizing the workforce that provides it.
- “But if Arizona spends less because necessary care doesn’t reach the child, that is not efficiency. It is unmet need.
- “The cheapest Medicaid service will always be the one someone does not receive.”

https://azmirror.com/2026/09/04/the-parent-caregiver-savings-arizona-is-chasing-dont-exist-unless-care-disappears/

Michigan Free Clinics See 54% Patient Surge as Medicaid Work Requirements Loom

- Michigan's free health clinics reported a 54% patient increase through August 2026 as Medicaid enrollment shrinks to its smallest since 2019.
- That pressure is likely to increase with upcoming cutbacks in Medicaid.
- Free clinics largely operate on shoestring budgets and good will. Doctors, nurses and pharmacists are volunteers. Drugs are donated by manufacturers. Lab tests are the charity work of local hospitals. Fundraising is constant.
- Free clinics are often limited in both the hours they operate and the specialists they provide.
- Still, they can be lifesaving for those who have nowhere else to turn
- **Why it matters:** Michigan Medicaid managed care plans and providers should prepare for significant Medicaid enrollment declines and uncompensated care increases as 650,000 enrollees face new work requirements and non-citizens lose coverage, potentially shifting care to safety-net settings.

https://bridgemi.com/michigan-health-watch/as-health-costs-climb-some-care-shifts-to-michigans-charity-clinics/

Ohio: 50% food bank users have had to choose between paying for rent or food

- 57% of surveyed households who visited an Ohio food bank were forced to choose between paying for utilities or paying for food, according to a new report. In households with children, it was 65%.
- 63% reported choosing between paying for transportation or food.
- 59% said they had to choose between clothes and personal hygiene products or food.
- 48% said they had to choose between affording medicine or food.
- 45% had to decide between paying their rent or mortgage or paying for food.

https://www.newsfromthestates.com/article/nearly-half-households-using-ohio-food-banks-have-had-choose-between-paying-rent-or-food

Ohio: 50% food bank users have had to choose between paying for rent or food

- About half (49%) had Medicaid coverage and 76% had someone in their household living with a health condition including high blood pressure, diabetes, or heart disease.
- A little less than half (45%) received Supplemental Nutrition Assistance Program benefits.
- Of those households receiving SNAP, 24% said their benefits lasted one week or less.
- More than 100,000 Ohioans — including more than 50,000 children — have lost their Supplemental Nutrition Assistance Program (SNAP) benefits since President Donald Trump's "One Big Beautiful Bill Act" made the largest cuts to food stamps in the history of the program.

https://www.newsfromthestates.com/article/nearly-half-households-using-ohio-food-banks-have-had-choose-between-paying-rent-or-food

Indiana, long term power outage cost families their food stocks; then SNAP benefits were denied.

- When Indiana had a power outage that lasted two weeks, people lost weeks of food they couldn’t afford to replace.
- The outage caused additional expenses, like needed to buy drinking water and disrupted people’s employment.
- Applications to replace SNAP benefits were denied.
- Indiana denied SNAP replacement funds based on a policy on the date the household received the benefit not how much food was actually lost.

https://19thnews.org/2026/09/gary-indiana-power-outage-families-snap-benefits/

Indiana, long term power outage cost families their food stocks; then SNAP benefits were denied.

- Federal guidance allows SNAP recipients to receive replacement benefits if they lost food during flooding, power outages or other household misfortunes
- The state said people who received their monthly benefits before the power outage hit on August 11 were eligible for replacement. Those whose benefits arrived after the outage started were not eligible
- Because of the timing of the outages, many SNAP recipients who lost power were not eligible to have their benefits replaced — and had to figure out how to absorb a significant expense.

https://19thnews.org/2026/09/gary-indiana-power-outage-families-snap-benefits/

Indiana, long term power outage cost families their food stocks; then SNAP benefits were denied.

- States can make it easy or hard to report the need for a replacement benefit.
- In Indiana, the question is whether state policy on replacing SNAP benefits is legally more restrictive than it should be.
- Administrative denials and delays do not address real-time hunger needs.
- States with more restrictive policies or systems that make it hard to apply or take a long time to decide on applications will have a bigger group of people who will become even more vulnerable when the unexpected happens.

https://19thnews.org/2026/09/gary-indiana-power-outage-families-snap-benefits/

Resources

People with disabilities and families can use

Disability questions you can ask any candidate

How will you make sure that I *[or my loved one]* can continue to receive care at home, so I am not *[or they are not]* locked up in a Medicaid-funded nursing home or institution that costs more?

What will you do to make sure the state guarantees that people with disabilities and older adults have the right to have the help they need to live at home?

What will you do to make sure public schools receive enough state funding to cover the costs of educating students with disabilities?

Do you believe private schools that receive taxpayer funds to teach students with disabilities should have to follow the same rules as public schools? Why or why not?

How will you make sure people with disabilities are driving the decision making when policies concerning us are discussed and decided?

When constituents call you because they lost food assistance or Medicaid-funded health or home care what will you do to help and how fast will their gaps in health or home care services be resolved?

Do you support removing income caps so people with disabilities can work, earn, and save more without losing the home care they need to keep a job?

Potential HCBS Reductions

Elimination of HCBS programs or services within programs	Reduced waiver slots or service caps	Cuts to HCBS provider rates
Higher eligibility for HCBS programs (esp. Level of Care)	Reduced capitation rates	Policies that force people into more congregate supports

Potential Impacts of HCBS Reductions

Decreased utilization of HCBS and longer HCBS waiting lists	Worsened direct care workforce crisis	Increased number of family caregivers
Higher use of institutional care	Increased physician visits, ER visits, and mortality	Increased use of congregate settings over individualized supports

Home and Community Based Services Impacts Tracker Project

https://hpmmatters.publichealth.gwu.edu/HCBS-impacts-tracker-project

This tracker lists verified changes to home care programs made by states through legislative, budget, or state agency policies.

Participants in Medicaid may be the first to know about agency changes that result in cuts to home care.

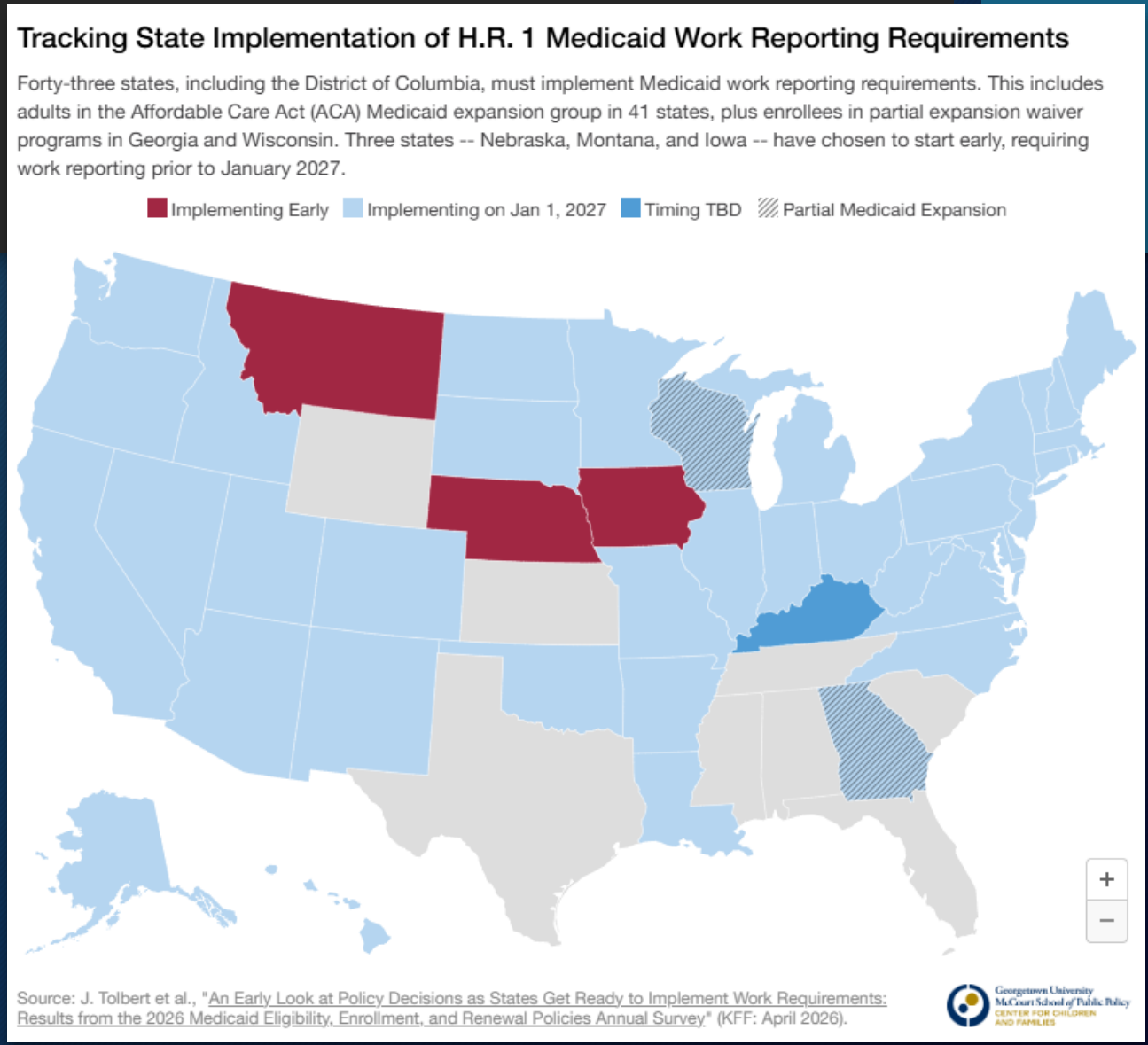
You can report changes and upload documentation using a form on the site.

Share this with your networks, especially friends in other states so they know where to go if they see HCBS cuts in their state.

Tracking how states are implementing “prove you’re working/exempt” requirements

- States will be making different decisions that impact whether people will be able to prove they are exempt or prove they are working enough.
- State data systems, funding, time, and available staffing will impact decisions.
- Different states may have different priorities when it comes to preventing loss of coverage.
- This tracker has a page for each state that is tracking major categories of decisions and what decisions states have made or still need to make.

https://ccf.georgetown.edu/feature/tracking-implementation-of-h-r-1-medicaid-work-reporting-requirements/



Tool to help people understand what small changes in Medicaid could mean for them

Have individuals:

- List the major parts of their care plan,
- How many paid hours/service the plan currently provides,
- How much natural supports unpaid caregivers are currently doing to make the care plan work.

Ask them what would happen if:

- The amount of paid caregiver hours was reduced (what would it mean if you lost 5 hours? 10 hours? More?)
- The amount of services you currently get was reduced?
- Some of the services you have now would not be in your care plan any more.
- Unpaid caregivers could not cover the same hours or weren't able to cover more hours?

https://wi-bpdd.org/wp-content/uploads/2026/04/BPDD_Worksheet_ImpactCarePlanReductions_042026.pdf

WHAT WOULD IT MEAN IF I GOT LESS HELP THAN I HAVE NOW?

	Number of paid hours/amount of service in my care plan	Tasks or time covered by unpaid caregivers in my care plan	Impact of cuts to paid hours or reduction of services in my care plan?
Personal care			
Home health			
Nursing			
Therapies			
Medical Equip. & Supplies			
Mental Health			
Group home			
Employment Services			
Day Services			
Other services or supports			

Here is what my life looks like now. (Ex. I live in my home in the community, not an institution, I work, I volunteer etc.)

With Family Care, IRIS, CLTS as it is now, I am not always able to…) Ex. Find enough caregivers, get transportation in the evenings, get support on my job.)

What are you most worried about if you have less help than you have now?