

NAEC Update – Washington and Advocacy Update

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Agenda

- What is the reconciliation bill?
- What policies does it include that would impact people with epilepsy and epilepsy centers?
- What comes next – timing/process?
- How can you advocate for your center and your patients?
- What about other issues?



Budget Reconciliation Background

- Congress is working on a reconciliation bill – legislation which can only include provisions related to federal spending or revenues and only requires a simple majority to pass.
- This is the vehicle President Trump wants Congress to use to pass his priority issues – extend the 2017 tax cuts, increase border security and reduce the deficit.
- Congress needs to find a way to pay for these policies.
- The bill language released to date would have significant impacts on epilepsy community



What has happened so far?

House passed its bill,
H.R.1, the One Big
Beautiful Bill Act, on
May 22 by a vote of 215
to 214



Action moves to Senate;
relevant Committees
release text of their bills
in mid June



What Medicaid policies are in the House bill?

Work reporting requirements for Medicaid expansion **applicants and enrollees**


Moratorium on states' use of provider taxes as funding mechanism

Mandated cost-sharing (services and Rx) for Medicaid expansion enrollees

Repeal streamlined redetermination and enrollment processes

Sunset the 5% FMAP incentive for new uptake of Medicaid expansion

FMAP penalty for states that use state \$\$ to provide benefits to immigrants

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- 10.3 million people lose Medicaid coverage by 2034
 - about ½ of those losses attributable to work reporting requirements
 - 7.7 million fewer people have insurance by 2034
 - Medicaid policies yield \$625 billion in federal savings over 10 years

How does the Senate version compare?

- Deeper Medicaid cuts for provider taxes and state-directed payments
- Extends work reporting requirements to parents with children over 14
- Expands limit on retroactive coverage for all people on Medicaid



What are work reporting requirements?

- By Dec 2026, states must implement policies that require people who qualify via Medicaid expansion to meet at least 80 hours per month working, or engaging in other qualifying activities, to keep their coverage.
- If people don't comply with the requirements – because they don't meet work or other activity thresholds, or because they get caught up in red tape– they will lose access to Medicaid.
- The bills call for certain exemptions – including for people living with complex and serious medical conditions – but they exempt people from having to work, NOT having to do reporting and paperwork processes.



What do we know about work reporting requirements?

Studies show that more than 90% of individuals in the Medicaid expansion group either work or should qualify for an exemption; 44% have a chronic health condition

One mistake on a form
could mean losing your
health coverage.



Past experience (Arkansas, Georgia) demonstrates that red tape → significant coverage losses, more costs for states and no increases in people working



Impact on Epilepsy Community

- About 40% of adults with epilepsy and more than one-third of children and youth with special health care needs are insured by Medicaid
- Losing Medicaid coverage would be devastating for people with epilepsy, interrupting treatment regimens and access to epilepsy centers
- Centers will need to spend more time and resources helping people access coverage
- Loss of Medicaid \$\$ for states would make care for people with chronic conditions likely targets for state cost-cutting efforts.



What ACA policies are in bill?

- Reminder: ACA created Marketplaces /exchanges for people to buy individual plans that meet certain standards and processes
 - With sliding scales based on income, people can access tax credits to help them afford their premiums and cost-sharing reductions to lower their out-of-pocket costs
- Bill would make lots of technical changes that would have a big impact –
 - Changes to tax credits – who is eligible, processes for reconciliation
 - Changes to enrollment timing and processes
 - Changes to ACA regs



What ACA policy changes are **NOT** included in the bills?

- No extension of enhanced advanced premium tax credits (eAPTCs)
 - In law since 2021, they will expire at the end of 2025 unless Congress extends
 - Enhanced = more people qualify and they are more generous for everyone
- If they are allowed to expire: premiums spike on average by 75% → loss of coverage for 4.4 million people



What do these policies mean?

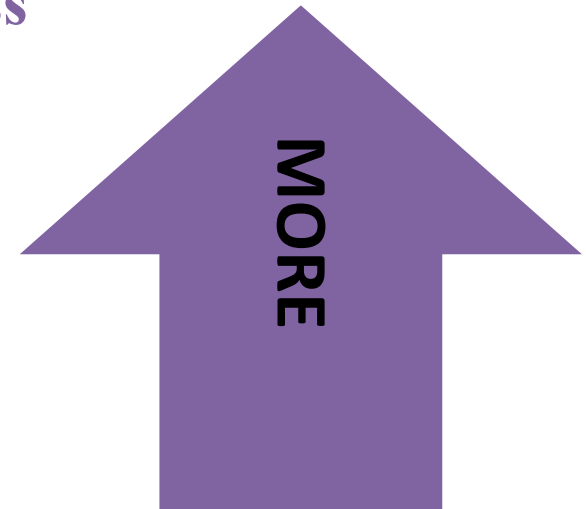
- Significant coverage losses – Kaiser Family Foundation estimates they could cause Marketplace enrollment to shrink by 1/3 (8 million people)
- For people who stay in Marketplace coverage:
 - Insurance will be **less affordable**
 - Insurance will be **less accessible**



Impact if people with epilepsy lose coverage

- Time and resources to help people access coverage
- Uncompensated care
- Adverse health events – hospitalizations and ED visits
- Patient out-of-pocket costs

- Access to treatment
- Access to epilepsy center services
- Reimbursement for health care services



What other policies are included?

- Streamlined Medicaid enrollment for out-of-state pediatric providers to facilitate access to expert providers in Medicaid and CHIP for kids with complex health conditions (House bill)
- Interim fix to physician fee schedule (House bill)
 - Increase to Medicare conversion factor in 2026 to about 2.25% (which is 2% above current law)
 - Tying future updates to the Medicare Economic Index for 2026-2035



Widespread concern from health community

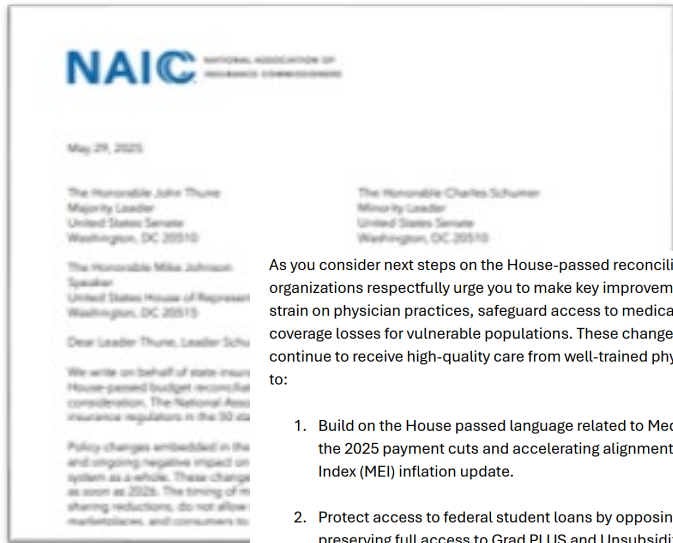
AHIP Statement on the Senate Finance Committee's Reconciliation Proposal

Press Release

PUBLISHED JUN 17, 2025 • BY AHIP

Washington, D.C. – Following the release of the Senate Finance Committee's reconciliation proposal, AHIP issued the following statement:

"At a time when Americans are looking for stability and certainty with their health care, the latest budget proposal would jeopardize the coverage and access to care that millions of Americans rely on in Medicaid and the individual market. Enactment of these policies combined with potential inaction on expiring health care tax credits would mean millions of people losing Medicaid coverage would find a disrupted individual market with less competition, diminished choices and higher premiums. All of these impacts will be magnified in rural communities.



As you consider next steps on the House-passed reconciliation bill, the undersigned physician organizations respectfully urge you to make key improvements that are necessary to avoid further strain on physician practices, safeguard access to medical education, and prevent potential coverage losses for vulnerable populations. These changes are essential to ensuring that patients continue to receive high-quality care from well-trained physicians. Specifically, we urge the Senate to:

1. Build on the House passed language related to Medicare physician payment by addressing the 2025 payment cuts and accelerating alignment with a full annual Medicare Economic Index (MEI) inflation update.
2. Protect access to federal student loans by opposing proposed borrowing caps and preserving full access to Grad PLUS and Unsubsidized Direct Loans.
3. Prevent coverage losses by addressing provisions in the reconciliation bill that could increase the number of uninsured and protect Medicaid access for individuals without other coverage options.



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PRESS RELEASES

AMA statement on House passing reconciliation bill

May 22, 2025 | 2 Min Read

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The following statement is attributable to:

Bruce A. Scott, M.D.

President, American Medical Association

"The AMA appreciates that the bill adopted today addresses the problem of **decreasing Medicare payment** (PDF) for physician services. Continued cuts threaten access to care for America's seniors, and the inclusion of an update for 2026 that partially accounts for inflation is an important step. This must, however, represent only the first step to ensuring that Medicare payments keep up with inflation over the long term, as they do for other Medicare providers.

"While we are also pleased that the bill did not include more severe Medicaid provisions such as direct FMAP cuts or per capita caps, we remain concerned that many of the Medicaid and ACA savings provisions will have a significant and negative impact on the ability of eligible individuals to access and maintain coverage. Federal programs should seek to facilitate and maintain enrollment of eligible individuals, not erect bureaucratic barriers to care. As the bill moves forward, we urge the Senate to take the necessary steps to ensure that efforts to address waste, fraud and abuse do not result in millions of patients affected by these changes.

"Also, as currently drafted, this legislation



Patient Coalition Condemns House-Passed H.R. 1 for Stripping Coverage from Millions

Hospitals Speak Out

AHA POSITION

AHA urges Congress to reject reductions to the Medicaid program that would not only strip access to health care from some of the most vulnerable populations but also destabilize hospitals and health systems, leading to a loss of services that would impact patients and communities nationwide.



Medicaid is more than just health care coverage in rural communities – it plays a significant role in sustaining the viability of rural health care systems, including hospitals, rural health clinics, long-term care, EMS agencies, and community health centers. Rural areas will suffer the most if these policies are enacted as rural residents rely upon Medicaid for health care coverage more than their urban counterparts, and public payers, including Medicaid, comprise a larger share of rural hospital services. Cuts, such as those passed by the House of Representatives, will force many rural facilities to reduce or cut service lines or close their doors entirely, impacting access to care for everyone who lives in in the community.

NRHA urges rural champions in the Senate to reject cuts to the Medicaid program and protect rural health care.



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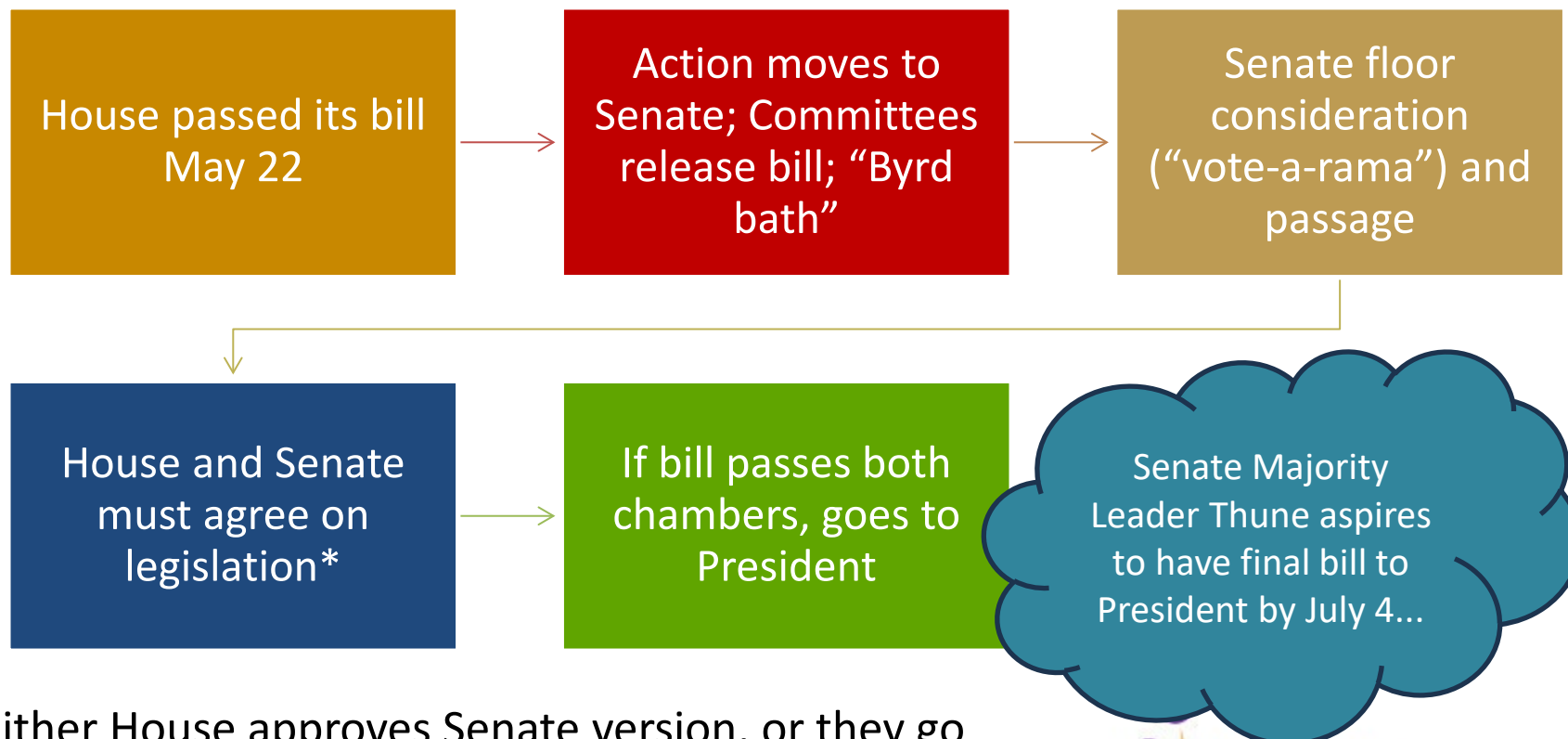
Medicaid Cuts Put Kids' Health at Risk

Proposed changes to Medicaid policies in Congress's budget reconciliation bills threaten all children's access to health care.

[LEARN MORE](#)



What happens next?



*Either House approves Senate version, or they go to conference.

Easy ways to take action

- Epilepsy Foundation [action alert](#):



Call Congress

- Call your Senators... or use Capitol switchboard: (202) 224-3121
- Only need a few points:
 - My name is X and I live in Y place.
 - I am calling because I'm an epileptologist who cares for people with epilepsy in our state.
 - I am very worried that the health care cuts in the reconciliation bill will lead to my patients losing coverage.
 - Loss of coverage means people won't be able to access treatments and expert care, leading to more seizures, worse outcomes for patients, and higher health care costs.
 - As your constituent, I'm asking you to please reject these cuts.



Other tools / other issues

Federal Cuts & Changes: Impacting the Epilepsy Community:
Advocacy Toolkit

Federal Cuts & Changes Impacting the Epilepsy Community

Now more than ever, it is critical for the epilepsy community to SPEAK UP and speak with ONE VOICE to try and protect epilepsy programs and research. On April 14, 2025, 118 epilepsy organizations—representing people living with epilepsy; caregivers and loved ones; physicians, care providers, and epilepsy centers; epilepsy researchers; and others—issued [a statement](#), united in opposition to recent actions by the Administration and Congress to cut vital federal epilepsy programs (Note: Organizations that signed on after the deadline are added to the version on [epilepsy.com](#); if you still want to sign on, email lweidner@efa.org).

This toolkit builds on that statement by offering resources and information to support people and organizations in the epilepsy community who want to educate and advocate about recent and looming federal cuts and other changes that are negatively impacting the epilepsy community. This toolkit has resources you need to get started, including background on the issues and action steps you can take — whether you only have a few minutes or have a few hours. Actions range from emailing your members of Congress through an action alert (very quick!) to posting on social media (kind of quick!) to ~~requesting and holding meetings with your members of Congress (this will take a while).~~

- [Advisory Committee on Heritable Disorders in Newborns and Children](#)
- [CDC Epilepsy Program](#)
- [CDMRP](#)

- [Department of Education](#)
- [Medical Research](#)
- [Medicaid](#)
- [National Plan for Epilepsy](#)



Remember...

- The bill is not yet law!
 - Senate has narrow path to 51 votes – and multiple groups have concerns
- Advocacy has already had an impact in shaping bill
- Protecting coverage is a top priority for many advocates within and beyond the epilepsy community



July 27, 2017 – final attempt at ACA “repeal and replace” goes down to defeat



Questions and Discussion

