MEDICAID MATTERS

What's Changing with Medicaid?

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On July 4, 2025, President Trump signed the One Big Beautiful Bill Act (OBBBA) into law. This bill was primarily aimed to extend tax cuts from the first Trump Administration, but contained a number of other policy changes, including a reduction of $1 trillion in federal spending on the Medicaid program.

KEY TAKEAWAYS

- The OBBBA made big changes to the Medicaid program.
- However, there are two big caveats to keep in mind:
  - Most of the biggest changes won't begin to go into effect until 2027.
  - Each state will implement changes differently, so it will be important to follow what is happening in your own state.
- State variation will be especially true in regards to the changes to how states can finance their programs. Depending on state budgets and priorities, states may choose to make different eligibility or benefits changes. States may or may not make any changes that would impact those that qualify for Medicaid due to disability.

What is Medicaid?

Medicaid provides health coverage for millions of low-income people in the U.S. and helps millions of people with disabilities get access to long-term services and supports (LTSS) including home-and community-based services (HCBS). Medicaid is a federal-state program; states access federal Medicaid dollars by putting up a nonfederal share of funds, which the federal government then matches at the applicable matching rate. There is no limit on the amount of federal Medicaid dollars states can "draw down" as long as they put up their own share of funds. States and the federal government also share decision-making as to how Medicaid programs are operated. The federal government sets baseline parameters around eligibility, benefits, financing, and other requirements that states must follow. Within those parameters, states have flexibility to design their programs. This means that each of the 56 state, district, and territory Medicaid programs has its own unique features and characteristics.

Who qualifies for Medicaid?

There are different ways to qualify for Medicaid. Some eligibility populations are required in every state; others vary by state. Federal policies changing Medicaid requirements may change the requirements based on specific qualifying populations. For example, some of the changes made by the OBBBA outlined here affect only the "ACA expansion population".

Groups that qualify for Medicaid

All States

- Low-income families
- Qualified pregnant women and children

Some States

- Individuals receiving home and community-based services
- Children in foster care
- ACA expansion population – low-income adults who don't otherwise qualify

Generally, individuals with AS will qualify for Medicaid due to their disability status.

What is changing under the new law?

Many of the changes in the OBBBA such as work requirements, should not impact people with AS. However, overall reduced federal funding for Medicaid could lead to changes in benefits or increased wait times, depending on your state.

More frequent eligibility redeterminations

For individuals who qualify for Medicaid, states must periodically conduct "eligibility redeterminations" to verify if those individuals still qualify for Medicaid or if their circumstances have changed such that they no longer qualify. Generally, states are required to conduct eligibility redeterminations at least annually and must disenroll those found to no longer qualify.

- Beginning January 1, 2027, OBBBA requires that for ACA expansion Medicaid beneficiaries, states must conduct eligibility redeterminations every 6 months rather than once a year.
- This change will not directly affect beneficiaries who qualify on the basis of disability; however, it is likely to increase overall renewal volume for the state Medicaid agency, and as a result, may cause delays in application and renewal processing.

Limitations on provider taxes

Medicaid provider taxes are imposed by state or local government on health care entities, such as hospitals, nursing homes, or managed care organizations. Revenue collected from these taxes is used to draw down additional federal Medicaid funds. Provider tax arrangements can be beneficial to both states and providers, because providers are often "paid back" in the form of higher base or supplemental payments. Under current law, this is permissible within certain boundaries. Nearly all states use some form of provider tax or fee to help finance their Medicaid programs. Critics argue that provider taxes are a budget gimmick that can distort Medicaid finances and obscure the true cost of the program; supporters say they are a necessary tool for states to maintain Medicaid coverage and provider payments, especially during budget shortfalls.

- The OBBBA freezes existing provider taxes effective immediately upon enactment. This means that states cannot impose any new provider taxes or increase existing ones.
- From October 2027 to October 2033, for ACA Medicaid expansion states only, provider taxes must be reduced by a certain amount each year. Ultimately, the effect of these limitations will reduce the amount of revenue (both federal and state) available for states to use for Medicaid. However, the degree of impact will vary by state depending on their current provider tax structure and state budgetary options for replacing lost revenue.

Work requirements

- The OBBBA requires states to adopt work requirements as a condition of Medicaid eligibility for ACA expansion beneficiaries who do not meet an exception starting in January 2027. To comply with work requirements, an individual must spend 80 hours a month working and/or participating in community service activities or educational programs.
- Several groups are exempt from work requirements. They include parents and caretakers of children under age 14 or disabled individuals; individuals who are "medically frail" or otherwise have special medical needs; those with substance use disorders; and pregnant or postpartum individuals.
- Given the short implementation timeline, states will need to begin planning for implementation soon. This includes planning for upgrades to eligibility & enrollment systems, outreach, and defining additional parameters (for example, what kind of documentation will be required of beneficiaries requesting an exemption).

HCBS

Home- and community-based services (HCBS) allow people with significant physical and cognitive limitations to live in their home and remain integrated with the community, rather than receiving LTSS in an institutional setting (such as a nursing facility). HCBS, unlike nursing facility care, is an optional benefit, meaning states are not required to offer it. States often use waiver authorities (know as Section 1915(c) HCBS waiver authority or Section 1115 demonstration authority) to offer HCBS, which give states flexibility to limit the number of beneficiaries receiving services, target specific populations, or limit availability to certain parts of the state. With some exceptions, HCBS is usually available only to people with an institutional level of care need – that is, people whose needs are such that they would be eligible for care in a nursing facility or other institutional setting.

- The OBBBA does not directly cut or change HCBS services. However, the OBBBA, which includes cuts to Medicaid amounting to nearly $1 trillion, is expected to put a significant strain on state resources for Medicaid. Because HCBS services are optional, and costly (albeit less costly than most institutional care), they are at high risk for being cut, either in terms of eligibility, scope of available benefits and services, or provider payment cuts. Historically, when states have faced budget constraints, they have cut HCBS services in some way.
- In addition, the OBBBA creates a new Section 1915(c) waiver option allowing states to cover HCBS for peoples whose needs do not rise to an institutional level of care need. CMS can approve these new 1915(c) waivers beginning in 2028. It is not clear how many states will take up this option, given the budget constraints discussed above.

Implementation timeline

Today	• Provider tax freeze and new state directed payments limited upon enactment • ABLE Account flexibilities remain available in 2025 and future years
January 2026	• Enhanced ACA marketplace tax credits expire • Medicare sequestration cuts
October 2026	• Restrictions on immigrant eligibility for Medicaid • Rural fund available
January 2027	• State implementation deadlines, including work requirements and 6-month eligibility redeterminations
October 2027	• Provider tax reductions begin
2028	• Revised home equity limit for LTC eligibility • Orphan drug exclusion from Medicare negotiation • May approve new 1915 waivers for HCBS • Cost sharing of up to $35

What does this mean for people with AS?

Provisions of the new law will be phased in over time, between now and 2028. The law sets forth new requirements for states, but each state will implement the new requirements differently depending on their current program structure and political and policy environment. Below is a summary of some of the major changes, followed by a timeline of when the changes go into effect.

Impact on state budgets

The OBBBA's nearly $1 trillion in Medicaid cuts are likely to significantly strain both state and federal resources available for Medicaid programs – states will need to determine whether the loss of federal and nonfederal funding can be made up with general fund revenue (taking away from other state priorities) or other financing mechanisms. If not, they will be forced to make tough decisions about where to cut their own Medicaid program spending. States options for cutting Medicaid generally fall into one or some combination of the following:

- Cutting eligibility (for example, implementing stricter financial or functional criteria for HCBS programs that individuals with AS may wish to enroll in)
- Cutting services (for example, reducing the number of slots in an HCBS waiver program, reducing the scope or amount of services beneficiaries are eligible to receive)
- Cutting provider payments (which could in turn reduce access to covered benefits that have not been cut in other ways).

Impact on the health care system

The OBBBA's impacts go beyond Medicaid. The OBBBA includes numerous provisions that are expected to increase costs for people in the ACA Marketplace (including, but not limited to, the absence of a provision to extend enhanced premium tax credits). Combined with other actions by the Trump Administration, the Medicaid and ACA Marketplace provisions are expected to increase the number of uninsured people by 16 million by 2034[1]. Coverage loss is expected to significantly change the risk pool in both the Medicaid and Marketplace populations, driving up health care costs for those that remain. The increase in the uninsured rate is expected to put additional pressure on hospitals and health systems, who are already facing cuts to Medicare and Medicaid payment. This could result in hospitals and other providers shifting additional costs to privately insured patients, driving up health care costs for everyone.

Impact on AS

In a survey conducted by the community, associated medical and daily living costs of Angelman syndrome (AS) are estimated to be around $80,000 per year[2]. Medicaid helps people with AS throughout their lifetime to get the care they need to protect their health and well-being. Medicaid is essential in supporting the care of most individuals with Angelman syndrome, providing critical assistance to families nationwide by:

- Covering essential health services for children with disabilities or other special health care needs.
- Often covering needs that private insurance does not adequately cover, such as complex wheelchairs, prosthetics, treatments, and technologies that help people communicate and live in the community.
- For many people with Angelman syndrome, Medicaid is their only source of funding for LTSS to enable them to live at home with their families and community.[3]

Many of the changes in the OBBBA such as work requirements, should not impact people with AS. However, overall reduced federal funding for Medicaid could lead to changes in benefits or increased wait times, depending on your state.

[1] Congressional Budget Office (CBO). June 4, 2025. Estimated Effects on the Number of Uninsured People in 2034 Resulting From Policies Incorporated Within CBO's Baseline Projections and H.R. 1, the One Big Beautiful Bill Act | Congressional Budget Office

[2] Jarvis, et al. The economic impact of caregiving for individuals with Angelman syndrome in the United States: results from a caregiver survey. Orphanet Journal of Rare Diseases. 2025. https://ojrd.biomedcentral.com/articles/10.1186/s13023-025-03551-4

[3] The Katie Beckett waiver provides Medicaid coverage for home-based care for children with serious conditions who would otherwise qualify for institutional care. In 2024, KFF ported 43 states included a Katie Beckett State Plan or comparable option. Medicaid Eligibility for Katie Beckett Children with Significant Disabilities and Special Income Rule | KFF

What can we do?

The Angelman Syndrome Foundation (ASF) and the Foundation for Angelman Syndrome Therapeutics (FAST) are committed to supporting the Angelman syndrome community in its advocacy to protect access to care. We will be monitoring changes to Medicaid programs state by state. As you learn more about changes that may impact you in your state, please keep us informed. We look forward to continuing to partner with you to advocate on behalf of our community.