Illinois Medicaid State Advocacy Guide

# Introduction

The American Association of People with Disabilities (AAPD) has created this State Advocacy Guide to empower people with disabilities, their families, friends, and allies to effectively advocate against harmful budget cuts proposed in federal budget reconciliation legislation. Specifically, this guide is designed to help you engage with your U.S. Representatives and Senators and urge them to **REJECT harmful cuts to Medicaid.**

# Why This Matters

Medicaid is a vital resource for people with disabilities. It provides essential services such as healthcare, Home- and Community-Based Services (HCBS), employment supports, and school-based care, including preventive health screenings and physical, occupational, and speech therapies.

Right now, the system is already strained:

* There is a **severe shortage of care workers**.
* Over **700,000 people with disabilities** are on waiting lists for HCBS, most of which are delivered through Medicaid I/DD waivers.
* Proposed cuts of **$880 billion** would further endanger access to critical services and deepen our current healthcare crisis.

# We Need Your Voice

AAPD **NEEDS YOU** to contact your Representatives and Senators, request a virtual meeting online via Zoom or at their DC or local district offices, and **share your personal story** about how Medicaid cuts would affect your life or the lives of those you care about.  
  
If setting up an in-person meeting and transportation is a barrier, **AAPD offers financial assistance** to help you get to and from these meetings. Please email Rachita Singh at [rsingh@aapd.com](mailto:rsingh@aapd.com) if you need help paying for transportation.

# How to Use This Guide

This State Advocacy Guide provides everything you need to take action, including:

* Medicaid FAQs – Understand the basics and importance of Medicaid.
* State-Specific Medicaid Information – Learn how Medicaid impacts your state with Medicaid data and talking points for congressional meetings for each of the 50 states.
* [AAPD Advocacy Guide](https://www.aapd.com/advocacy-guide/) – A general guide for all advocates, including tips and step-by-step instructions for setting up and having a productive meeting.
* [Medicaid One-Pager](https://www.aapd.com/medicaid-one-pager-reject-harmful-cuts-to-medicaid/) – A handout you can leave with your elected officials.

# Medicaid FAQs

**What is Medicaid?**

Medicaid is a government-funded healthcare program for millions of Americans with low income, including people with disabilities and older adults. It is jointly funded by federal and state governments, with states managing the program. Medicaid is vital for disabled Americans, covering essential medical expenses like long-term care, medical services, and rehabilitation therapy.

**Why Is Medicaid Important for Disabled Americans?**

For many disabled individuals, Medicaid is the primary source of their health coverage. More than [35%](https://www.kff.org/medicaid/issue-brief/5-key-facts-about-medicaid-coverage-for-people-with-disabilities/#:~:text=Medicaid%20is%20a%20major%20source,have%20Medicaid%20(Figure%201).) of disabled people have Medicaid. It helps pay for vital services that allow disabled people to live independently, such as:

* Personal care services
* Prescription medications
* Physical and occupational therapy
* Mental health services
* Long-term care in nursing homes or at home

Without Medicaid, many disabled individuals would face insurmountable medical bills, limited access to necessary treatments, or could be forced into institutions. Medicaid helps ensure disabled Americans have access to the healthcare and support they need to maintain a good quality of life.

**What Harmful Changes to Medicaid Are Proposed?**

1. Reducing Medicaid Funding

Reducing federal funding for Medicaid could lead to states cutting services, cutting the number of eligible recipients, or limiting benefits, which would disproportionately harm people with disabilities who rely on Medicaid for critical healthcare needs.

1. Medicaid Block Grants or Per-Person Caps

There has been a push to replace the Medicaid program’s open-ended funding structure with block grants or per-person caps. This would give states a fixed amount of money for Medicaid, limiting their ability to provide services in times of increased need. Block grants or per-person caps can lead to cuts in healthcare services, which would harm people with disabilities who rely on Medicaid for essential services like home and community-based services.

1. Work Requirements for Medicaid

Many in Congress support the idea of imposing work requirements on Medicaid recipients. These requirements would force low-income individuals, including disabled people, to complete burdensome paperwork proving that they meet specific employment criteria to maintain their Medicaid benefits. The concept of work requirements is unnecessarily strict, hard to meet, and likely to exacerbate health disparities.

**How Will These Actions Affect Disabled People?**

Efforts to cut Medicaid funding, implement work requirements, and promote block grants will significantly affect disabled Americans, particularly those who rely on Medicaid for long-term care, healthcare services, and daily living support. The imposition of work requirements may cause disabled people who are unable to work, or who work unconventional schedules because of their disability or other health needs, to lose access to Medicaid coverage. Additionally, reductions in funding or the implementation of block grants may lead to reduced services, longer wait times for care, and potentially force individuals into more institutionalized settings, limiting their independence.

Moreover, Medicaid is critical in helping disabled individuals remain in the workforce by covering necessary healthcare services that allow them to work. If Medicaid is cut or restricted, it may make it even more difficult for disabled individuals to remain employed or engage in activities that support their independence.

Read on to see how this will play out on a state-by-state level.

## Illinois

**Senators:** Dick Durbin (D), Tammy Duckworth (D)

**Representatives can be found here:** [https://www.house.gov/representatives](https://www.house.gov/representatives#state-california)

**Talking Points:**

* More than [35%](https://www.kff.org/medicaid/issue-brief/5-key-facts-about-medicaid-coverage-for-people-with-disabilities/#:~:text=Medicaid%20is%20a%20major%20source,have%20Medicaid%20(Figure%201).) of people with disabilities across the country rely on Medicaid
* [3,438,447 constituents enrolled in Medicaid in Illinois](https://files.kff.org/attachment/fact-sheet-medicaid-state-IL)
  + 1 in 3 working-age adults with disabilities or over 234,000 constituents
  + 3 out of 8 children
  + 2 out of 3 nursing home residents
  + 654,000 adults ages 50 and older
  + Look up district-specific data using this [site](https://www.kff.org/medicaid/issue-brief/congressional-district-interactive-map-medicaid-enrollment-by-eligibility-group/) for meetings with representatives
* 39% of births in IL are covered by Medicaid
* Family caregivers benefit from Medicaid both as enrollees themselves and from the Medicaid-covered services for their care recipient. [Close to one in ten family caregivers nationally receive Medicaid coverage for their own health care](https://www.aarp.org/pri/topics/ltss/family-caregiving/caregiving-in-the-united-states/)
* Illinois is a trigger law state, meaning that state Medicaid funding gets cut if federal funding falls below a certain level - around [700,000 will lose Medicaid coverage](https://hfs.illinois.gov/medicalclients/faqsendofcontinuouscoverage.html#faq-item-faq-3-3) if benefits are rolled back
* Cutting funding or using block grants may result in fewer services and longer wait times for care, and could push people into more institutional settings, which would limit their independence
  + It would mean fewer people within the state can access healthcare, fewer benefits would be provided, and/or payments to providers would be cut
* It will also increase the burden on the state to provide funds and put other parts of the state budget at risk, like funding for K-12 education or veterans
* Medicaid is necessary for stability in the health care system, especially when it comes to supporting rural hospitals
* All of us are already struggling with higher costs of living, but cuts to Medicaid will lead to cuts in services and harm your constituents’ health, also putting more strain on both the health systems and the economic systems of the state
  + [The state GDP could shrink by over $3 billion and over 27,000 jobs could be lost](https://www.commonwealthfund.org/publications/issue-briefs/2025/mar/how-cuts-medicaid-snap-could-trigger-job-loss-state-revenue)
    - If you impose work requirements the state GDP could shrink by up to [$2.5 billion](https://www.commonwealthfund.org/publications/issue-briefs/2025/may/medicaid-work-requirements-job-losses-harm-states?utm_campaign=Achieving%20Universal%20Coverage&utm_medium=email&_hsenc=p2ANqtz-9d29p1mprNp9mUj6CQke5GFc4lNy7GaTvWY0gb5-mGkKm6ihWyyDUlIA9R6lbqoDAU_mgxA4wIvSrs9dw6uf17OO7p_g&_hsmi=359462813&utm_source=alert)
* Mandatory work requirements for Medicaid have no real positive impact - most adult beneficiaries are already working or are exempt because they are unable to work
  + The harm is very real if mandated though - [up to 5.2 million Medicaid beneficiaries could lose their coverage in 2026](https://www.commonwealthfund.org/publications/issue-briefs/2025/may/medicaid-work-requirements-job-losses-harm-states?utm_campaign=Achieving%20Universal%20Coverage&utm_medium=email&_hsenc=p2ANqtz--sxwkOlDxSEL1H567a5Xd_JVolS2J1NBmcv7TvWnLwCPdmPgWp4p77rwgz7jF5ird2suUdRzFIiQJEAvw251qoYVYuWA&_hsmi=359462813&utm_source=alert)
* There is strong support for Medicaid nationally - a majority of voters in states across the country, especially in battleground congressional districts, support the Medicaid program
  + In every congressional district in the U.S., less than 15% of voters support cuts to Medicaid
    - Use this [link](https://www.dataforprogress.org/blog/2025/4/23/voters-in-every-congressional-district-oppose-cuts-to-medicaid) to find the specific percentage for your district when meeting with Representatives
* Senator Durbin has been a strong supporter of the ACA and improving access to healthcare in Illinois - we hope he can maintain that stance when it comes to protecting Medicaid and objecting to cuts during the reconciliation process
* Senator Duckworth has also been a supporter of the ACA and has been a great champion for people with disabilities and veterans
  + Nearly 2 million — or 1 in 10 — veterans rely on Medicaid
  + And over half of the veterans on Medicaid have a disability
  + <https://modernmedicaid.org/medicaidspotlight/strengthening-medicaid-to-support-our-veterans/>
* Research Representatives and the issues important to them to make connections during meetings
* Millions of people could be cut off from health coverage or lose their health care benefits if state policymakers responded with deep cuts to Medicaid. Losing health coverage could push people to take on medical debt or force them to avoid or delay care, harming their health.
  + This is about saving lives - [shrinking the federal medical assistance percentage (FMAP) could lead to over 427,000 more uninsured people in Illinois and almost 1,300 more lives lost per year](https://www.americanprogress.org/article/congressional-republicans-proposals-to-slash-medicaid-could-cost-tens-of-thousands-of-lives/)
* **Include personal stories!**