

# SHARING YOUR STORY: A GUIDE TO MEDICAID ADVOCACY



Medicaid provides funding for services that help millions of people with disabilities and their families across the country. This guide has information to help you share your lived experience with policymakers so they understand the importance of Medicaid and the services it provides to people with disabilities.



**RUTGERS HEALTH**

**The Boggs Center  
on Disability and Human Development**

Robert Wood Johnson Medical School

# INTRODUCTION

**Advocacy** involves expressing your views and wishes about issues that are important to you. People with developmental disabilities and their families can share their experiences to advocate for the long-term services and supports they need to live, learn, and work in their communities.

These vital services, funded through **Medicaid**, include home and community-based services like:

- Personal care and community support provided by Direct Support Professionals and Self-Directed Employees
- Related services in schools and the community like occupational therapy, physical therapy, and speech therapy
- Assistive technology
- Behavior supports
- Supported employment services

When policymakers understand the difference these services make in your life, they are more likely to protect them. You can share your story to help protect Medicaid!



## What you will find in this guide:

### HOW MEDICAID WORKS

On **page 3**, you will find information about how Medicaid works.

### UNDERSTANDING THREATS TO MEDICAID

**Page 3** also has information to help you understand commonly proposed threats to Medicaid funding and how they impact people with disabilities. These include block grants, per capita caps, reducing the match rate, and work requirements.

### SHARING YOUR STORY STEP-BY-STEP

Beginning on **page 4**, you will find step-by-step tips for sharing your story, including how to **learn about the issues, find your legislators, and plan your advocacy message.**

### PLANNING YOUR MESSAGE WORKSHEET

You can use the **Planning Your Message Worksheet** on **page 6** to take notes on what you will say or write when you contact your legislator(s).

### REFERENCES

Learn more about how Medicaid works and how proposed changes could impact people with disabilities by checking out the resources listed on **page 7.**

# HOW MEDICAID WORKS

First, let's explain how Medicaid works. Medicaid funding is a partnership. The cost is shared between the federal government and the states. In New Jersey, the federal government typically pays 50 cents for every dollar the state spends on its Medicaid program. By **matching** what the state spends, the Medicaid program can reach more people in need. Sometimes, the federal government has an **enhanced matching rate**, which means it will pay even more to encourage states to expand certain programs.



# UNDERSTANDING THREATS TO MEDICAID

Some policymakers believe the government should pay less for programs like Medicaid. They propose to save money by cutting how much the federal government pays.

Commonly proposed changes to the Medicaid program include **block grants**, **per capita caps**, **reducing the match rate**, and **work requirements**. These changes would have a big impact on people who rely on Medicaid, including people with disabilities.

Below you'll find information about the common threats to Medicaid. It's important to understand how these proposals could affect people who rely on Medicaid.

## BLOCK GRANTS



Instead of sharing the costs, some policymakers propose that the federal government give states money for Medicaid in one lump sum, or **block grant**. The state would then decide how to spend it. Block grants erase the funding partnership, so the federal government wouldn't have to pay extra if a state's Medicaid costs go up. States would either have to pay the extra cost on their own or cut back on who gets Medicaid or what services it offers. Home and community-based services for people with disabilities could be reduced or eliminated since they are optional for states to provide.

## WORK REQUIREMENTS



Some policymakers think Medicaid should have **work requirements**. These are rules that mean people need to work a certain number of hours, volunteer, or go to school or job training to receive Medicaid services. If they don't meet these requirements, they would lose their Medicaid coverage.

## PER CAPITA CAPS



**Per capita caps** are limits that the federal government could set on the amount it spends per person using Medicaid. If the care that person needs goes over the limit, the state would have to pay for the extra costs.

## REDUCING THE MATCH RATE



By **reducing the match rate**, the federal government would pay states less for every dollar they spend on their Medicaid program. States would need to pay a bigger share to provide care to people in need. If they can't afford to pay a bigger share, states might choose to cut back on who gets Medicaid or get rid of services they aren't required to provide, like long-term care for people with disabilities.

# SHARING YOUR STORY STEP-BY-STEP

## LEARN ABOUT THE ISSUES

1

Stay informed about proposed changes to Medicaid by following the news and getting involved with policy and advocacy organizations. You can subscribe electronically to receive policy updates and action alerts from organizations that monitor issues important to people with disabilities closely.

Some of these organizations include:

- Association for University Centers on Disabilities (AUCD) - [aucd.org](http://aucd.org)
- The Arc of the United States - [thearc.org](http://thearc.org)
- Center for Public Representation - [centerforpublicrep.org](http://centerforpublicrep.org)
- National Councils on Developmental Disabilities - [nacdd.org](http://nacdd.org)
- National Disability Rights Network - [ndrn.org](http://ndrn.org)
- National Health Law Program - [healthlaw.org](http://healthlaw.org)



You don't need to be a policy expert to advocate! The best thing you can do is share your experience and voice your concerns.

## FIND YOUR LEGISLATORS

2



You can write, email, or call your legislator's office to share your story. Make sure you share that you are a constituent.

There are many policymakers, also called **legislators**, who represent you. Federal legislators, like members of the House of Representatives and Senators, make decisions that impact the entire country. State legislators, called Senators or Assembly members in New Jersey, make decisions that impact those within the state.

Your message is most important to the policymakers who represent your district or state. This is because they have a better chance at re-election when **constituents**, or those they represent, are happy with their decisions.

You should contact federal legislators to advocate around national policies, and state legislators for policies that only affect people in New Jersey.

Find your legislators and information about how to contact them using the "Find Your Members" search tool:

<https://www.congress.gov/members/find-your-member>

# SHARING YOUR STORY STEP-BY-STEP

## PLAN YOUR MESSAGE

3

It can be helpful to plan out what you are going to say before you contact your legislators. This page offers tips on what to include in your message when you write to or speak with your legislators. On **page 6**, you will find a worksheet to help you plan your message.



**Keep it personal!**  
Form letters are not as effective at influencing policymakers as personal written messages.



Introduce yourself, including where you live.



Identify the issue you are writing or calling about. Share the bill number if you know it.



Briefly state your position on the issue you are writing or calling about.



Share your experience with receiving services funded by Medicaid and the difference they make in your life.

You may want to include:

- What services you receive through Medicaid funding
- What the services you receive help you to do
- What the impact of not having those services means for your life



Be specific in asking for action. For example, “Please vote against this proposed change.”



Always say thank you!



Share your full name, address, phone number, and email address for follow-up.

# PLANNING YOUR MESSAGE WORKSHEET

You can plan your message using the spaces provided to take notes on what you will say or write when you contact your legislator(s). You may want to include your family, friends, or others that know you well to help you think about and record your responses.

## THE BASICS

**What issue are you calling about? Identify the issue or bill number and your position.**

**Who are you contacting about the issue? List the legislator(s) you plan to get in touch with here.**

**Do you plan to call, write a letter, or send an email? Check all that apply.**

- Call
- Write a letter
- Email

## YOUR STORY

**What services do you receive through Medicaid funding?**

**What difference do the Medicaid services you receive make in your life? What do they help you do?**

**What would your life look like if you didn't have those services?**

## THE ASK

**What do you want your legislator(s) to do? Be specific and let them know how to take action!**

# REFERENCES

Want to learn more about how Medicaid works and how proposed changes could impact people with disabilities? Check out the resources we used to put this guide together:

- “Protect Medicaid Funding Issue # 6: Older Adults and People with Disabilities” by the National Health Law Program: <https://healthlaw.org/wp-content/uploads/2024/09/06-Older-Adults-and-PWD.pdf>
- “Medicaid Threats in the Upcoming Congress” by Allison Orris and Gideon Lukens at the Center on Budget and Policy Priorities: <https://www.cbpp.org/sites/default/files/12-3-24health.pdf>
- “Medicaid: What to Watch in 2025” by the Kaiser Family Foundation: <https://www.kff.org/medicaid/issue-brief/medicaid-what-to-watch-in-2025/>
- “Follow the Money: How Medicaid Financing Works and What That Means for Proposals to Change it” by the Kaiser Family Foundation: <https://www.kff.org/policy-watch/follow-the-money-how-medicaid-financing-works-and-what-that-means-for-proposals-to-change-it/>
- “Work Requirements for Medicaid Enrollees” by The Commonwealth Fund: <https://www.commonwealthfund.org/publications/explainer/2025/jan/work-requirements-for-medicaid-enrollees>
- “Writing Your Elected Representatives” by the American Civil Liberties Union: <https://www.aclu.org/writing-your-elected-representatives>
- “Communicating With Your Representative” by the American Organization for Nursing Leadership: <https://www.aonl.org/advocacy/engaged/communicating>
- “Advocating for Change Advocacy Toolkit” by the Iowa DD Council: <https://www.iowaddcouncil.org/advocacy-toolkit>

# SHARING YOUR STORY:



## A GUIDE TO MEDICAID ADVOCACY

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