

# ADVANCING THE RIGHTS OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

June 11, 2025



# In This Session

- Overview of The Arc history, structure and public policy agenda
- Review of related disability policy milestones
- Highlights of advocacy strategies
- Update on current federal policy debate

# The Arc of the US and Its Priorities

1. The Arc of the US is an advocacy organization for individuals with disabilities and their families
2. The Arc is a network of nearly 600 state chapters, local chapters, advocates and The Arc of the United States
3. Protect Medicaid funding, services, and structure.
4. Protect the right of children with disabilities to a free, appropriate public education

# Public Policy Agenda

1. [Comprehensive public policy agenda](#) revised in 2025
2. Partnership with
  - American Association on Intellectual and Developmental Disabilities (AAIDD)
  - America Network of Community Options and Resources (ANCHOR)
  - Association of University Centers on Disabilities (AUCD)
  - Autism Society of America (ASA)
  - Autistic Self Advocacy Network (ASAN)
  - TASH
  - The Arc of the United States
  - United Cerebral Palsy

# Priority Areas

Civil Rights

Community-Based Long Term Supports and Services

Criminal Legal System

Developmental Disabilities

Direct Support Professionals

Education

Employment Training and Wages

Health Care

Medicaid

Social Security/Income Maintenance

# Other Critical Areas

Child Welfare, Foster Care, Adoption  
Emergency Management  
Family Support  
Housing  
Immigration and Naturalization  
Liability Insurance Protections  
Non-Profit Organizations  
Quality of Services  
Research and Data Collection  
Tax  
Technology  
TANF  
Transportation



# **History of Accomplishment**

# Disability Advocates Make the Country Better

- Legal Advocacy that expanded education rights
  - *Parc vs the Commonwealth of Pennsylvania*
- Closure of Pennhurst and Willowbrook institutions
- Establishing discrimination protections in housing for people with disabilities and families with children
- Enacting the Americans with Disabilities Act
- Advancing high expectations for the academic achievement of students with disabilities
- Creating supported employment opportunities for adults with disabilities
- Ended discrimination in private health insurance based on pre-existing conditions





# **The Arc's Immediate Priorities**



# Education

# US Department of Education

- Administers funding to states for the Individuals with Disabilities Education Act
- Provides technical assistance to states
- Funds teacher training
- Investigates violations of civil rights for students with disabilities
- Provides accurate information to the public about federal education laws

# Key Dates

- March 11, 2025
  - 50% of US Department of Ed staff are subject to a reduction in force
- March 20, 2025
  - The Trump Administration issues an executive order to dismantle the US Department of Education
- March 31, 2025
  - The Arc of the US files legal declaration to provide factual information about the crucial work that the Department does to support students with disabilities
- May 22, 2025
  - Federal court rules Department of Education employees must be reinstated

# What has not changed

- The statute and regulations of the Individuals with Disabilities Education Act
  - State general supervision requirements
- The statute and regulations regarding students with disabilities under Section 504 of the Rehabilitation Act of 1973
- The law that established the Department of Education

# What is all means

- Delays in investigations of discrimination
- Delays in stakeholder responses to technical questions
- Uncertainty on existing and new guidance to assist states understand their roles and responsibilities
- Uncertainty in the continued flow of federal funding for formula and discretionary grants
- Profound brain drain as staff with decades of technical experience were terminated
- Legal actions to stop the dismantling of the Department

# School Choice advances

- The House of Representatives budget bill includes the Educational Choice for Children Act (ECCA), a \$20 billion federal school voucher proposal
- The Arc opposes this policy because:
  - Not all private schools will enroll all students with disabilities
  - Parents may not understand fully the loss of due process protections if they place their child in a private school
  - Parents may not understand fully the loss of FREE in a free, appropriate, public education (FAPE)
  - **States still have to deliver FAPE regardless of funding**

The background is a gradient of orange and yellow. On the left, there is a large, light orange chevron pointing right. On the right, there is a large, light yellow chevron pointing left. The word "Medicaid" is centered in a bold, white, sans-serif font.

**Medicaid**



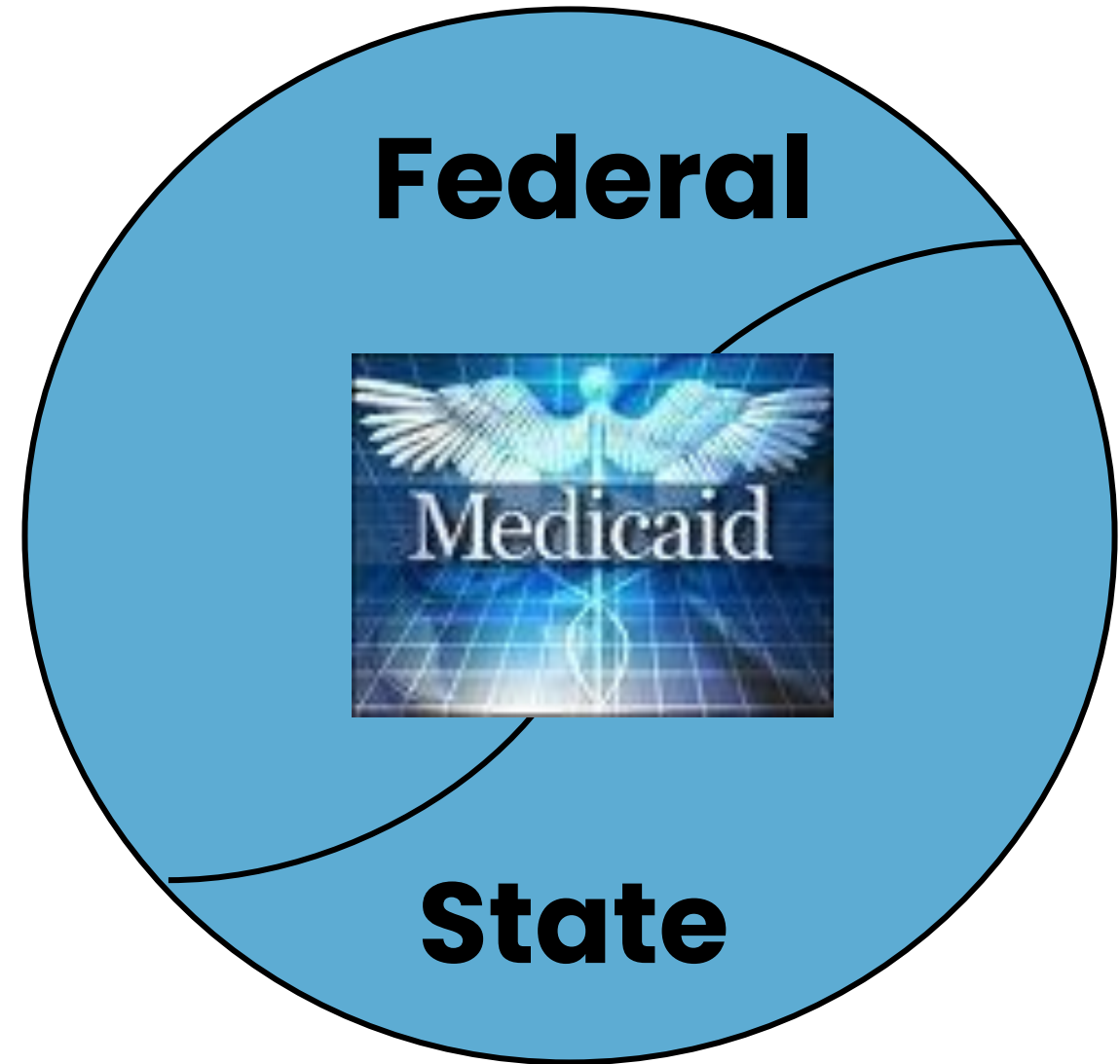
# The Arc's Position Statement on Health

*"All people, including people with intellectual and/or developmental disabilities<sup>1</sup> (IDD), should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs; maximizes their health, well-being, and function; and increases their independence and community participation."*

Revised 2024

# Medicaid: A Federal-State Program

- Provides comprehensive health care and long term supports & services for certain populations.
- Congress sets baseline eligibility, financing structure, and rules states must follow to get federal funding.
- States can add to what Congress does



# The House Bill

- Congress debating legislation and strategy with two primary goals: extend 2017 tax cuts and reduce the size of the federal government
- Adopted 215–214 on May 22, 2025
  - New administrative burdens on states for work requirements
  - New administrative burdens on states for adult renewals
  - \$715 billion in cuts over 10 years

# Current Make up of Congress

## House of Representatives

- Total members: 435
- Republicans: 220
- Democrats: 212
- Vacancies 3

## Senate

- Total members: 100
- Republicans: 53
- Democrats 45
- Independents 2

# Our strategy -- Congress

1. Getting the necessary votes, one at a time
2. Targeting Republicans who have personal connections to disability or to The Arc
3. Providing accurate and timely information to our stakeholders, including the media
4. Focusing on the outcomes of policy
5. Reminding ourselves that its not over until its over



# **What State Policy Makers Need to Know**

# People with IDD Will Be Impacted

- Cuts to Medicaid in one area affect all others—cascading effect
- People with IDD are found in all parts of the Medicaid program
- Overall cut in federal funding and more uninsured will challenge hospitals and other medical providers.
- While the bill does not directly target HCBS spending --history shows that a loss of Medicaid funding hurts HCBS – see [study](#)



# People with IDD Will Be Impacted By Work Requirements

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Exemptions for IDD and others are vague and will vary by state

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Many people with IDD are not on SSI

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People who are exempt lose coverage because they cannot navigate or are unaware of the rules

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People who are working part-time, seasonal jobs, or other work schedules will lose coverage because they do not fit into the rules or cannot navigate the changes



# What We Are Hearing

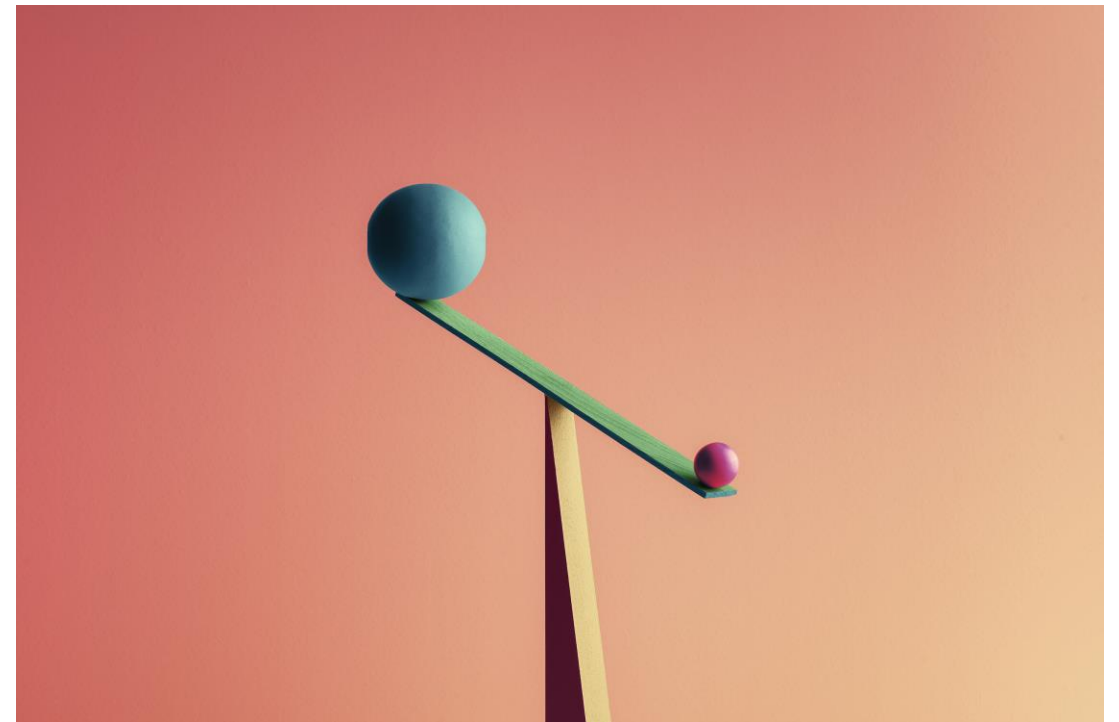
- Just eliminating Fraud Waste and Abuse
  - Few provisions that enhance existing fraud detection programs
  - Bill labels the highly regulated, legal, provider tax provisions "abuse"
  - Bill labels frequent eligibility checks as fraud provisions

# Also Hearing

- Doing this to protect the most vulnerable people and sustain Medicaid
  - Bill does **not** reinvest savings into the Medicaid program
    - Savings used for other federal priorities
  - Cuts will hurt the Medicaid program
    - Hospitals and other providers rely on Medicaid to keep health care system intact and cuts to coverage or general Medicaid mean more uncompensated care and threaten closures of health care facilities and fewer providers accepting Medicaid
    - Changes will likely require more cuts in Medicaid
  - Cuts will hurt vulnerable people
    - People will lose health coverage which means the doctor visits, medications, therapies, and other health care costs must be absorbed by individuals and families

# What's Does It Mean For State Budgets?

- Shifts **significant** financial and administrative responsibilities from the federal government to the states
- Implementing the mandatory work requirements and increased eligibility checks will be costly to states
- SNAP changes create a hole in state budgets
- State options to close the funding gap
  - Increased taxes, cuts in other Medicaid spending such as provider reimbursement, eligibility cuts, cuts to optional services or cuts to other state spending.





# **Advocacy Actions**

# Comprehensive Medicaid Advocacy

## 1. Lobbyists on Capitol Hill

more than 100 visits with Republican members

## 2. Grassroots advocacy

More than 330,000 actions to Congress

Rallies at state capitals

## 3. Robust storytelling

800 stories for 24 hour rally

## 4. Getting the word out through the media



# TOGETHER, WE CAN PROTECT MEDICAID.





# Chapter Advocacy:

## The Arc Minnesota



The Arc Minnesota

May 3 · ⚙️



Thank you, thank you, thank you, to our speakers, attendees, virtual supporters, partner organizations, and staff for making today's rally possible! We are stronger together!!

We're not done yet, we are committed to continuing the fight to protect disability rights!!! 🧡



# Chapter Advocacy:

## The Arc of Nebraska

Video credit: [The Arc of Nebraska](#)





# Chapter Advocacy!

## Across the country

- ABC Green Bay, WI: [The Arc Fond du Lac raises concerns on funding through President Trump's bill](#): **The Arc Fond du Lac interviewed.**
- Rochester Business Journal: [Don't abandon people with disabilities: Protect Medicaid funding](#): **Op-ed from The Arc of Monroe**
- CBS Des Moines, IA: ['Think about the children': Central Iowa family concerned about potential cuts to Medicaid](#): **Family connected to The Arc of Iowa featured.**
- Minnesota Public Radio: [Minnesotans, lawmakers in St. Paul protest federal cuts to disability funding](#): **The Arc of Minnesota featured.**
- Macomb Daily: [Local health advocates assess weight of possible Medicaid cuts](#): **The Arc of Macomb County interviewed.**
- AL.com: [Plan to cut Medicaid threatens a 'critical lifeline' for Alabamians with disabilities](#): **The Arc of Dekalb County featured.**
- Orleans Hub: [Arc GLOW joins other advocates in DC to 'Save Medicaid'](#): **Arc GLOW featured.**
- Capital & Main: [A Mother's Battle to Protect Her Son's Care](#): **The Arc of California interviewed.**




# **Tools and Resources**

# 2025 Medicaid Toolkit

This toolkit includes resources you can use to educate people with disabilities, family members, and lawmakers about the importance of and need for continued investment in Medicaid home and community-based services.


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**READ FIRST**  
Advocacy Toolkit  
Medicaid

Medicaid - How You Ca...


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**What Medicaid Cuts  
Would Mean**

What Medicaid Cuts Me...


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**Key Talking Points  
About Medicaid**

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**Medicaid  
Links & Resources**

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**Medicaid Overview  
Leave Behind**

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**Medicaid Work  
Requirements  
Issue Brief**

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**Medicaid  
Words to Know**

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**Medicaid Funding  
Explainer**

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**Medicaid State Data  
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**Medicaid Stories  
You Can Share**

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Welcome Letter**

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**SAMPLE  
Meeting Agenda  
Worksheet**  
For Meetings With Lawmakers & Staff

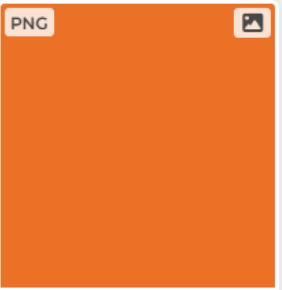
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## Chapter Medicaid Toolkit

[thearc.org/advocacytoolkits](https://thearc.org/advocacytoolkits)

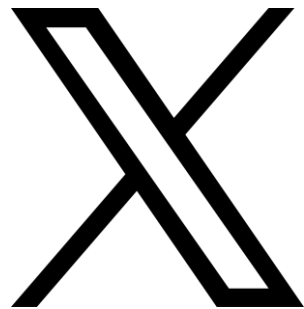
# New Resources: In toolkit, or Coming Soon to toolkit

- House Bill overview
- Updated state fact sheets.
- New SNAP fact sheet.
- New graphics
- Updated action alert
  - – noting House votes + including SNAP
- Signs and buttons
  - sent to chapters in May.
- Coming week of June 16: short 101 video for advocates



# The Arc's Action Center & Social Media

- We have updated petitions & ways to write members of Congress at [thearc.org/action](https://thearc.org/action)
- #WeActWednesday on social media
- Follow, share, uplift, subscribe, and tag us on



# Process & Timeline



# What are the steps?

The House of Representatives passed their version on May 22.

The House & Senate must pass the same bill.

The Senate must pass their version – they could make changes or keep it the same.

The President signs the bill, and it becomes law.

**WE ARE HERE**

# Senate Tensions

- Some members are nervous about the cuts to Medicaid
- Some are nervous about increasing the deficit
- Many unknowns about how Senate will move forward
- July 4th goal to finish



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**Its not over  
until its over**



**Thank you!!!**