

# What Are HCBS Waivers?

- HCBS waivers are Medicaid programs for nonmedical, community-based services.
- Services you get at home instead of living in an institution.
- Services like personal care, employment support, residential support, assistive technology.
- For example: Waivers like Section 1915(c) or 1115.





[https://www.youtube.com/watch?v=B-Ho9rsQ\\_gY&t=2s](https://www.youtube.com/watch?v=B-Ho9rsQ_gY&t=2s)

# Why Waitlists Exist

## HCBS services are not entitlements.

- An entitlement is like an IEP in school.
- It means the government must make sure everyone who qualifies and needs help gets the services they are promised.

## HCBS waiver programs are different.

- They have a limit on how many people can get services, because there is only so much money.
- When the limit is reached, new people have to wait.
- When the program is full, people go on a waitlist.

## Each state has its own rules:

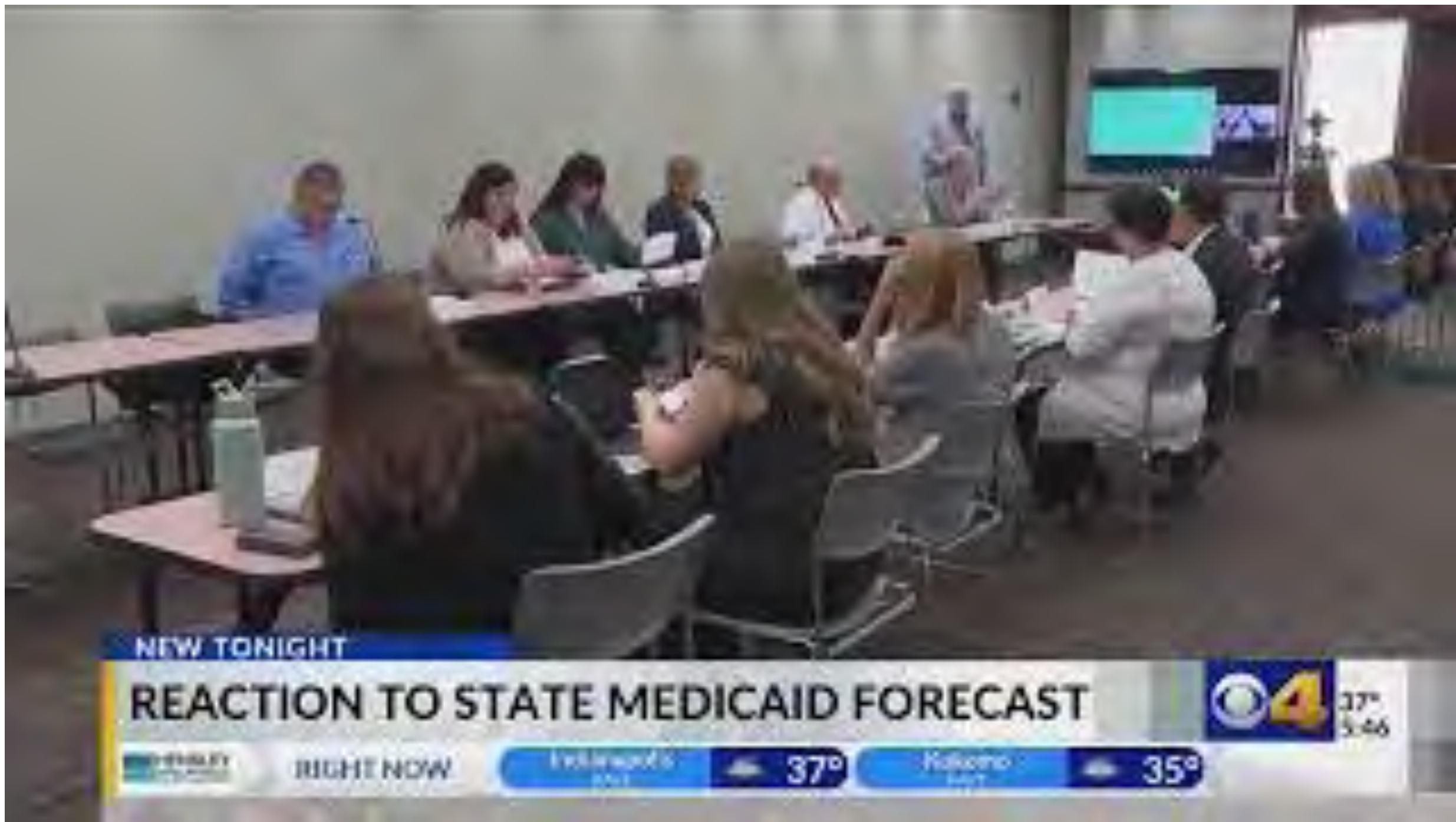
- Some states check if you qualify before putting you on the list.
- Other states add you to the list without checking first.



# How Big are the Waitlists

- 690,000–700,000 people were on waitlists in 38 states from 2023–2024
- 73% are people with intellectual or developmental disabilities (I/DD).
- Others include seniors, physically disabled or people with mental illness.





<https://www.youtube.com/watch?v=xROWP10-03Q&t=3s>

Green Mountain Self-Advocates and SARTAC [www.selfadvocacyinfo.org](http://www.selfadvocacyinfo.org)

# How Long Are the Waits?

The time people wait HCBS is very different depending on the state and the type of disability.

- In 2024, the average wait for all people was about **40 months**. This is a little better than 2021, when the wait was about **45 months**.
- People with intellectual or developmental disabilities often wait the **longest**. In 2017, the average wait was **66 months** (more than 5 years).
- Older adults usually wait **much less**. In 2023, their average wait was only about **5 months**.



# How Long Are the Waits?



Starting in **July 2027**, states must publicly share waitlist information. Until then, it is important to contact your state's Medicaid office or waiver agency to check your wait time and make sure your application is complete and up to date.

**"Screening" means that a state asks questions to see if a person is eligible to get services.**

- In states that do screening, people wait about 43–45 months to get services.
- In states that do NOT do screening people wait 61-70 months



<https://www.youtube.com/watch?v=5-bZH76wzew&t=3s>

# Access to Other Services While Waiting

- Most people can still get **some limited HCBS services** while they are on the waitlist, through their state's Medicaid plan.
- These services usually cover fewer hours and may not include all the help people need, such as bathing, preparing meals, or taking medicine.



# Waitlists—An Imperfect Measure

- Waitlists show how many people are asking for services, but they do not show the exact number of people who need help.
- Each state defines waitlists differently and serves different groups of people.
- Some people sign up early “just in case,” and some may find out they do not qualify when their name comes up.



# What is the Impact?

- Families face emotional, financial, and care burdens.
- Delayed care reduces independence and quality of life.
- Increases strain on families and communities.



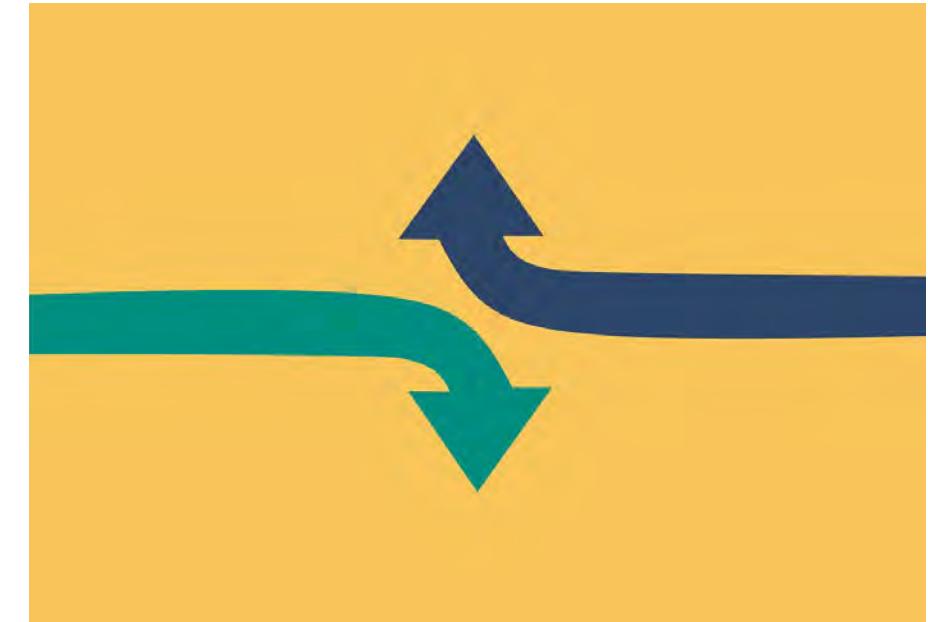
# State Differences and Policy Choices

In 32 states they make sure you are eligible for services before they put you on the waitlist.

In 8 states do not screen or make sure you are eligible to get services before they add your name to the waitlist.

Examples:

- Texas: 170,000+ people are waiting up to 16 years.
- Indiana: Uses a Managed dashboard. Because the system is more organized and monitored, people are moved through the waitlist faster. In other words, the dashboard helps the state manage requests more efficiently, which results in shorter waiting times for people who need services.
- Kansas: 7,500 people are waiting up to 10 years.



# Looking Forward—Policy & Solutions

- By July 2027, CMS will require each state to report their waitlist to the public.
- During COVID when the government expanded Medicaid it made it easier for people to get services. And so fewer people were on the waitlist.
- Program success story: Wisconsin cut waitlists by 92% by using a managed care system.



# Conclusions & Call to Action



- HCBS waitlists are long, often years.
- Those with I/DD most affected.
- Solutions: more funding, screening, transparency, Medicaid expansion.

**NEW  
UPDATE!**

# New HCBS Waiver Program in the One Big Beautiful Bill Act

- A new program will give Home and Community-Based Services (HCBS) to people **who do not need nursing home-level care**.
- States can apply, but **only if** joining does **not** make wait times longer for people who do need higher levels of care.
- The federal government will give **\$50 million in 2026** and **\$100 million in 2027** to support this program.
- In 2020, the average cost of HCBS was **\$36,275 per person**. This means in the first year, the funding would cover about **27 people per state**, before figuring in inflation or other costs.
- The bill also makes big cuts to Medicaid, which could lead to **longer wait times**. Because of this, many states may **not qualify** for the new program.

NEW  
UPDATE!

# Kansas's New Community Support Waiver

Kansas is launching a \*\*state-run\*\* waiver called the \*Community Support Waiver (CSW)\* — not part of the federal budget bill.

- Designed for people with intellectual or developmental disabilities (I/DD) who \*\*don't need 24/7 care\*\*.
- Aims to reduce the long I/DD waiver waitlist.
- Services may include:
  - \* Transportation to and from work
  - \* Employment support
  - \* Personalized budgets to choose your services
  - \* Personal care and respite
  - \* Therapy, technology aids, and caregiver supports
- - Lower-cost support option; ~500 slots expected by FY 2026.
- - Waiver application to CMS planned for \*\*late fall 2025\*\*.
- - Services could start around \*\*spring 2026\*\*, if approved.

NEW  
UPDATE!

# How Other States Handle HCBS Waitlists

- Kansas is special\*\* because it is making a new program (the CSW) only for people on the I/DD waitlist.
- Other states don't have a brand-new program just for waitlisted people\*\*. They use other ways to manage their lists:
- Regular Waivers With Waitlists
- Many states already have waiver programs, but the number of spots is limited.
- When all spots are full, they make a waitlist.
- Example: Indiana calls people from the list every month when a spot opens.

# Tracking Tools for Waitlists

- **Nebraska:** Keeps a list (called a registry) to track how many people are waiting for services.
- **North Carolina:** Has a public website that shows the waitlist for a program called the Innovations Waiver.

<b>State</b>	<b>New Program?</b>	<b>How They Track the Waitlist</b>
<b>Kansas (CSW)</b>	Yes	Starting in 2025–2026, offers a new program for people on the waitlist
<b>Indiana</b>	No	Calls people on the list each month when a spot opens
<b>Nebraska</b>	No	Uses a registry to count and track people waiting
<b>North Carolina</b>	No	Posts the waitlist for the Innovations Waiver on a public website