

# #CareCantWait:

## Why Congress Must Make a Historic Investment in Home and Community-Based Services for People with Disabilities

**Right now, people with disabilities must sometimes wait years to get Medicaid services. We must improve access to Medicaid funded disability services so people can get help when they need it.**

### What is Medicaid?

Medicaid pays for health care and other supports and services for people with disabilities and other groups.



Medicaid is run by each state — but they must follow federal rules. Medicaid pays for many services that people with disabilities get in their community.

These are called home and community-based services (HCBS).

### HCBS include many things, like:

- Working at a job in the community
- Making food and eating
- Managing money and medications
- Shopping and community activities
- Bathing and dressing

### How does the United States pay for HCBS right now?

We rely on Medicaid and families to provide HCBS to people with disabilities.

Private health insurance and Medicare do not provide HCBS. And, private long-term disability insurance is rare.

HCBS are currently paid for by state and federal funds.

It is very difficult for people with disabilities to get Medicaid to pay for HCBS.

### Each state has different rules about:

- Who can get Medicaid health coverage and HCBS
- What types of HCBS people can get

Even when people can get Medicaid, they may end up on a waiting list to use HCBS.

It can take years or even a decade to move to the top of a waiting list and get services.

So, families often must pay for HCBS using their own money while they wait.

People with disabilities must often rely on family members, friends, and neighbors to provide HCBS because the only other option is an institution. Many of these people are not paid; they give their own time to help.



### **Why are there waiting lists?**

Most people want to live at home and in their community and use HCBS.

But, Medicaid HCBS are not always paid for.

The federal government **requires** that Medicaid pay for services for people in nursing homes and institutions.

Institutions are often far away from people's homes, families, and communities.

People with disabilities who live in institutions don't get to choose the lives they live.

Many people think institutions are closed; but they still exist in 36 states.

The federal government **does not require** that Medicaid pay for HCBS; they are optional.

So, many states have very long waiting lists for people to get HCBS at home in the community.

### **What can happen now to help end waiting lists?**

We need a historic investment in HCBS so everyone can access services in their community.

President Biden and Congress have proposed a plan to fund \$400 billion for the Medicaid HCBS system, to increase access, and to increase wages for the direct care workforce, and create more of these jobs.

HCBS is one of many important issues that must be part of the COVID-19 recovery.

We need Congress to pass the Better Care Better Jobs Act to expand access to HCBS!

**Learn more and act now to help make this change at [TheArc.org/COVID19recovery](https://www.TheArc.org/COVID19recovery).**