



# Utah Long-Term Services and Supports (LTSS) Research Project

## Plain Language Summary

### **What are Long-Term Services and Supports (LTSS)?**

About 1 out of 5 people living in Utah has a disability. These disabilities include intellectual and developmental disabilities like cerebral palsy and Down syndrome, visual disabilities, hearing disabilities, physical disabilities, and brain injury. There are also a lot of older adults living in Utah.

Some people with disabilities and older adults need support so they can keep living well in their homes and communities. Many people get support from their families and friends. Some people also get support from Utah's [Department of Health and Human Services \(DHHS\)](#). These supports are called long-term services and supports (LTSS). LTSS are provided in institutions and as home and community-based services (HCBS).

For people who qualify, DHHS has LTSS to help people in their homes, communities, and jobs. Some of these services include:

- **Day Services** to help people develop work and community living skills
- **Supported Living** to help people to take care of their daily needs in their homes
- **Transportation** to community services, activities, and resources

- **Homemaker Services** to help people with household activities
- **Personal Attendant Services** to help people with their daily needs
- **Supplemental Meals** to make sure people have enough to eat

DHHS has different divisions that help people with different needs. The [Division for Services for People with Disabilities \(DSPD\)](#) pays for services to people with intellectual and developmental disabilities. The [Division of Aging and Adult Services \(DAAS\)](#) pays for services for older adults. The [Division of Integrated Health \(DIH\)](#) pays for services for people with exceptional medical needs. DHHS also pays for services in institutions. Institutions are places where many people with disabilities or older adults live together. People in institutions can receive service 24 hours a day.

Over time, the rules for LTSS have changed. States—like Utah—occasionally review their LTSS to understand what is working well and what can be improved.

## **What is this project?**

DHHS wants feedback from people who receive services, people waiting for services, family members, providers, Support Coordinators, advocacy organizations, and other community members. DHHS wants to learn about what is going well and what is not going well in the disability and aging service system.

We will use this feedback to make recommendations to DHHS on how to:

- Meet people's wants and needs in a person-centered way
- Structure services
- Make sure DHHS can serve as many people as possible
- Expand people's choices

To learn about the disability and aging service system we are:

1. Engaging with people
2. Doing research and giving recommendations
3. Doing an analysis of future needs
4. Writing a final report

We describe each of these activities more below.

## **1. Engagement**

We are working with a study steering committee made up of people who know about the disability and aging service system. This includes professionals and people with lived experience. The steering committee will hear about the project and give feedback. We will talk to many different people to learn about the disability and aging service system. We will talk to:

- People receiving services and their families
- People waiting for services
- Support coordinators
- Providers
- Advocates
- DHHS staff, and other professionals

We will interview people for some research topics. We will also have focus groups. Focus groups are interviews with a group of up to 10 people.

## **2. Research/Recommendations**

We are researching many different topics. We describe these topics below. For this research we will explore:

- What is happening in Utah
- What other states are doing
- What experts on disabilities and aging say

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After we finish the research, we will suggest possible changes for Utah’s disability and aging service system. We will discuss these options with our steering committee. We will write a report with a plain language summary for each research topic.

### **3. Analysis of Future Needs**

We are coming up with a strategy to learn how many people will need services in the future. This will also help DHHS figure out what services people need and how much they will cost.

### **4. Final Report**

When we finish all our research, we will write a final report. This report will include:

- Changes that DHHS and the steering committee want to happen
- How DHHS can start the changes they want to make
- How much the changes will cost DHHS
- Timelines for when DHHS can make the changes
- Things that DHHS will need to think about as it begins to make changes

We will include a plain language summary of this final report.

## **What are the research topics?**

Our project will cover many research topics, including:

***Recruitment and Retention of Quality DSPs*** – Direct Support Professionals (DSPs) help people with disabilities and older adults in their communities. They are also called Direct Care Workers or Direct Support Staff. All over the United States, it is hard to find and keep good DSPs. DHHS wants to figure out how to *recruit*, or find, DSPs and how to *retain*, or keep, good DSPs.

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***Strengthening Natural Supports*** – Natural supports are people who help people with disabilities and older adults often without being paid. Natural supports can include a person’s family, friends, neighbors, or other community members. DHHS wants to make sure that natural supports are a strong part of the disability and aging service system.

***Addressing/Eliminating the Waitlist*** – People who are eligible for services may not always be able to get services right away. Sometimes, they have to wait for services until funding becomes available. In Utah there are about 4,000 people waiting for DSPD services. DHHS wants to learn how to serve more people so that everyone can get services when they need them.

***HCBS Payment Models*** – HCBS cost money to deliver. About one-third of this money is provided by the Utah government and the other two-thirds comes from the federal government. Utah's DHHS wants to look at different ways to pay for services and to pay for better services.

***LTSS Trends for Complex Medical/ Behavioral Needs*** – Some people who have disabilities and older adults also have medical needs or behavioral needs. Having medical or behavioral needs might mean that a person needs more or different services. It can be hard to make sure that all of a person’s services and supports work together well. DHHS wants to make sure that people with medical and behavioral needs get support that helps them stay healthy and safe.

***Supports for Co-Occurring DD/MH*** – Some people who have developmental disabilities (DD) also have mental health needs. Having mental health needs might mean that a person needs more or different services. It might mean that DSPs need

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different training. DHHS wants to make sure that people with DD and mental health needs get support that helps to address all of their needs.

***Institutional Settings vs HCBS Settings*** – Institutions are places where many people with disabilities or older adults live together. People in institutions can receive services 24 hours a day. Across the United States, institutions are closing so that people can live with their families and in their communities. DHHS wants to understand what the difference is between getting services in an institution or getting HCBS.

***Medicaid Training and Technical Assistance Center*** – Because the disability and aging service system is so big, it can be difficult for everyone to know what to do. DHHS wants to explore whether a Medicaid Training and Technical Assistance Center could help to inform people receiving services, service providers, and others.

***Quality of Care in LTSS*** – DHHS has to make sure that the services it pays for are good. DHHS has to tell the federal government how well DHHS serves people with disabilities and older adults. DHHS wants to make sure that it measures what is important to people.

***Long-Term Services and Supports Array*** – People with disabilities and older adults have lots of options for LTSS. People might not want all of the services. People might want different services. DHHS wants to figure out what services people need and want. DHHS also wants to know which services people do not need or want.

***LTSS Structure and Funding Options*** – Services are paid for by Medicaid. People who are eligible for services get on a waiver. Waivers serve people who have disabilities and older adults. There are 9 different waivers in Utah. DHHS wants to know if it should keep these 9 waivers, or if it should change them. DHHS wants to make it as easy as possible for people to get what they need.

## What are the priorities of this project?

Our steering committee and DHHS decided what is most important in this project, or the priorities. These are the project priorities:

### ***Inclusion***

Support and honor people's choices for where they live and who they live with. Give people options for receiving community services and participating in competitive integrated employment.

### ***Person-Centered Support***

Empower people to maintain control over their own life and services (self-direction) by offering holistic support.

### ***Service Quality***

Ensure that people in Utah equitably receive the services that they need. Promote high quality services and highly qualified providers and direct support professionals.

### ***Effective Service System***

Improve coordination between agencies, funding, and reimbursement of services to help more people.

## Who is doing this project?

[Human Services Research Institute \(HSRI\)](#), along with our partners at the [Utah State University's \(USU\) Institute for Disability Research, Policy, and Practice](#) and [Burns & Associates \(B&A\)](#), were hired by Utah's DHHS to work on this project.

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HSRI is a national nonprofit that was started in 1976 to improve the availability and quality of supports for children and adults with disabilities and other vulnerable populations.

This is our belief: *All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.*

## **How can I be involved in this project?**

Your voice is important! We want to hear from you if you are involved in the disability and aging service system!

Learn more and find ways to get involved at the DHHS's website: <https://dhhs.utah.gov/>

If you want to share ideas with us or feedback about our project, use the QR code below or follow this link: <https://forms.office.com/r/9FGKrbrced>

We look forward to hearing from you!

