



Utah Long-Term Services and Supports Research Study Final Report

Plain Language Summary

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Prepared for:

Utah Department of Health and Human Services (DHHS)

Prepared by:

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Introduction

About 1 out of 5 people living in Utah have a disability. These disabilities include intellectual and developmental disabilities like cerebral palsy and Down syndrome. They also include visual disabilities, hearing disabilities, physical disabilities, and brain injury. There are also a lot of older adults living in Utah. Some people need support so they can keep living well in their homes and communities. Many people get support from families and friends. Some people also get support from Utah’s Department of Health and Human Services (DHHS). That support is called long-term services and supports (LTSS). People get LTSS in institutions or through home and community-based services (HCBS). For people who qualify, DHHS supports people with HCBS. HCBS are provided through “waivers.”

DHHS hired Human Services Research Institute (HSRI) to do a research study about LTSS. DHHS wanted to know what works well and what doesn’t work well in Utah’s system. HSRI did a study from 2023 to 2025. HSRI talked to a lot of people during the study. The people HSRI talked to included: people who receive services, family members, service providers, advocacy organizations, and community members.

After learning about Utah’s system, HSRI developed recommendations for DHHS. This report lists the recommendations. A full final report is also available.

HSRI’s recommendations include information about:

- Changes DHHS could make.
- How DHHS can start making changes.
- How much changes could cost.
- When DHHS can make changes and how long the changes could take.
- Things that DHHS will need to think about when it begins to make changes.

There are 4 categories of recommendations:

1 Community First Support people to live in and be part of their community.	2 Improving Quality Update quality improvement systems. Meet new requirements.	3 HCBS Waivers Simplify the waiver structure. Make it easier for people to access services.	4 Addressing the Waiting List Make waiting for services predictable. Connect people to supports while they wait.
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1. Recommendations About Community First

Many states, like Utah, have used institutions to support people with disabilities. Institutions are places where many people with disabilities or older adults live together. People in institutions can get services 24 hours a day. Across the country, institutions have been closing. When they close, people can go live with their families and in their communities. People can also get services in the community that they used to get in an institution. People also get some services away from the community, like employment services. Today, most people get the support they need in the community. HSRI recommends that Utah focuses on services in the community. We recommend Utah takes the following actions:

Planning for community

- **Develop a Community First Plan** – States sometimes use a plan to make sure that their services, policies, and practices are community-focused. DHHS can work with community members to develop this plan.
- **Create a shared person-centered planning process** – There are differences in the person-centered plans used across divisions. DHHS can build on the work already done to improve the planning process and make sure that all people in services can use the process. Along with this updated plan, DHHS can provide training on how to use the plan and to make informed choices about services and supports.

Help people transition from institutional and segregated services

DHHS can help people to transition from the Utah State Developmental Center (USDC) and Intermediate Care Facilities for Individuals with Intellectual Disability (ICF-IID). DHHS can help people avoid going to nursing facilities. It can help by making sure there are supports to keep people at home as they age. DHHS can also help people who participate in sheltered work get competitive, integrated employment instead. Sheltered work is not in the community. It is sometimes paid below minimum wage. Competitive, integrated employment is in the community. It usually pays more than sheltered work. DHHS can help by making sure there are good employment services. Those services will help people explore, find, and keep jobs.

Some people get institutional services because they can't get services they need in the community. DHHS can try to make sure that people who have behavior or medical needs can get services they need in their own homes. DHHS should make sure that people who need nursing, nursing oversight, home health aide, and behavior services



can get those services. Families are often the main support for people with disabilities and older adults. DHHS should also make sure that families can get the help they need. This will help families to continue to support the person. DHHS can take these steps to put community first.

2. Recommendations About Improving Quality

DHHS wants to measure the quality of services and supports because that is important to people. To measure quality, DHHS may look into the services they offer to learn how well people are being cared for. DHHS also has to report to the federal government about DHHS service quality. There is a new rule about this. It is called the Access Rule. To meet new requirements in the Access Rule, Utah will need to improve how it measures service quality.

Access Rule Requirement

Utah should make sure it meets all requirements of the Access Rule. This includes:

- **Creating a better “grievance system”** – a way for people to tell DHHS when services don’t work well.
- **Creating a set of checks to measure how well services are working** – DHHS can use surveys, like National Core Indicators, and other data.

Performance Measures

Performance measures tell how well DHHS meets certain requirements and serves people. Performance measures are reported to the federal government. HSRI recommends that Utah use the same performance measures for different waivers. Right now, many waivers track similar measures. Making them the same could make reporting easier. This way, DHHS could measure one time instead of many times. It would make measuring simpler without losing quality or oversight. Making the measures the same would also prepare DHHS to create future waivers that cover many disabilities. It could help make a more integrated and person-centered system.

National Core Indicators (NCI)

If DHHS keeps using National Core Indicators surveys, Utah will need work to get more completed each year. It will also need to include more groups of people. This will help meet the Access Rule requirements.



Develop Continuous Quality Improvement Plan

Utah could use a continuous quality improvement plan. This plan will help make sure new changes keep people safe and healthy. DHHS should share the plan with the community. DHHS should also tell the community what it learns from the plan.

3. Recommendations About Restructuring HCBS Waivers

HCBS waivers serve people who have disabilities and older adults. There are 9 different HCBS waivers in Utah. DHHS wants to know if it should keep or change them. HSRI recommends changing the waivers in two phases. This will make it easier for people who use services.

Phase 1: Improve Existing Waivers

- **Update services to better support people with complex needs:** People with the most complex needs often have medical and behavioral support needs. DHHS should make sure that all waivers offer certain things. They should all offer nursing, nursing oversight, home health aide, and behavior services.
- **Update performance measures:** DHHS should make the performance measures for the 9 waivers the same. This will make it easier to measure and compare.
- **Get ready to give people a supports budget based on their needs:** A supports budget is money that a person can use to pay for services. DHHS should choose a support needs assessment. Then, DHHS should use it for people who get services. This will help DHHS make sure people have an amount of money that matches their support needs. When possible, DHHS should make service rates the same across waivers.

Phase 2: Change HCBS Waivers

- **Change waivers in each division:** DHHS should change the waivers to make the 3 DHHS Divisions have 2 waivers each.
- **Update waiver services:** DHHS should decide if some services need to be renamed to be clearer. They should think about grouping similar services together. This could help people find services easier. DHHS should add employment support services and peer support services to all new waivers. DHHS should also work to align payments and policies to be consistent.
- **Use supports budgets based on needs:** DHHS should develop support levels. The levels should show how much support people need. They should also show



supports budgets that match the needs. Supports budgets are a fair way to help people get the services they need and want. They also help DHHS learn how much it will cost to support people.

4. Recommendations About Addressing/Eliminating the Waiting List

Sometimes, people who apply for HCBS can't get services right away because there isn't enough money. The Division of Services for People with Disabilities (DSPD) currently has a large waiting list. There are more than 5,000 people on it. The waiting list makes it hard for people to get the help they need in time.

DSPD has two ways of fixing the waiting list:

1. **Get more money approved by state lawmakers** – the money should pay for most or all the people on the waiting list to get services.
2. **Give better or more support to people while they wait for services** – people could be connected to more basic help and services.

Each year, DSPD asks state lawmakers to approve money to get people off the waiting list. It is up to lawmakers to decide whether to approve more money or not. Because of this, HSRI's recommendations focus on what DSPD can do.

Planning for future service needs and sharing information about the waiting list

Families and advocates say it's hard to find basic information about the waiting list. DSPD should share estimates of how many people will need help in the future. They should include this information in reports and on the waiting list webpage. DSPD should make sure that people can easily find information about the waiting list online and in MySteps.

Checking whether programs that help people while they wait are working well

This means making sure that programs like the Supported Work Independence and the new Family Peer Support Program provide quality support. DSPD may also want to create a "Community Care Hub" to be a one-stop place to find support.



Making sure money is shared fairly between the Limited Supports Waiver (LSW) and the Community Supports Waiver (CSW)

People with lower support needs should be able to get services before problems get too big. DSPD should help lawmakers understand this and why the LSW is important.

Using Medicaid to help people get basic help and services

DSPD should think about allowing more people waiting for HCBS to qualify for Medicaid. They could also help people connect to state plan services.

How the Recommendations Meet Priorities for the Utah Service System

This research study had a steering committee to help guide the work. The committee had more than 40 people with professional and lived experience of the Utah service system. The committee and DHHS decided what is most important for the study. These are called “priorities.” The priorities for the study are:

- Inclusion
- Person-Centered Support
- Service Quality
- Effective Service System

Here’s how HSRI’s recommendations meet the priorities:

Inclusion means supporting people’s choices for where they live and who they live with. This includes giving people options for receiving community services and participating in competitive integrated employment.

- **How Community First Recommendations Meet This Priority:** Promoting community first through a Community First Plan. Modified services and supports can help people to live and work in their communities with families that are supported.
- **How Quality Recommendations Meet This Priority:** Listening to people and their families when improving services helps make sure people with lived experience have a say in shaping the system. Measuring quality can help people know about whether people are included.
- **How Restructuring HCBS Waiver Recommendations Meet This Priority:** Modifying service arrays will give people more options for getting community services. This includes services for people with complex needs. It also includes people who want to work in competitive integrated employment.



- **How Recommendations for Addressing/Eliminating the DSPD Waiting List Meet This Priority:** Giving people timely access to services is important. It can prevent people from feeling like their only option is institutional services when what they want is to be in the community.

Person-Centered Support is about empowering people to maintain control over their own life and services (self-direction) by offering holistic support.

- **How Community First Recommendations Meet This Priority:** Strengthening person-centered planning and informed choice puts the needs and wants of people first. Offering services to people in their homes and communities for as long as possible is another way to empower people and give them choices.
- **How Quality Recommendations Meet This Priority:** Following the Access Rule and setting up a grievance system will help make sure people get the right services in the best way. It will also make sure people’s concerns get addressed.
- **How Restructuring HCBS Waiver Recommendations Meet This Priority:** Creating cross-disability waivers will offer holistic support to people. It will empower people to have control over their life and services.
- **How Recommendations for Addressing/Eliminating the DSPD Waiting List Meet This Priority:** Providing services as soon as possible can prevent a crisis. If a person has to wait too long for services, there are negative impacts on the person.

Service Quality ensures that people in Utah equitably receive the services that they need. This includes promoting high quality services and highly qualified providers and direct support professionals.

- **How Community First Recommendations Meet This Priority:** High quality training for support coordinators can improve the services and supports people receive. Creating new services and incentives for service providers can also improve quality.
- **How Quality Recommendations Meet This Priority:** Continuous Quality Improvement will make sure people get high-quality services offered by well-trained providers and support staff.
- **How Restructuring HCBS Waiver Recommendations Meet This Priority:** Using the same performance measures for all waivers will help the state learn about HCBS trends. It will also help to make improvements for everyone.
- **How Recommendations for Addressing/Eliminating the DSPD Waiting List Meet This Priority:** Services run more smoothly when people get services they need before a crisis happens. Service quality is lower when the system can’t handle people’s urgent needs.



An **Effective Service System** improves coordination between agencies, funding, and reimbursement of services to help more people.

- **How Community First Recommendations Meet This Priority:** A service system can be more effective if divisions coordinate with each other. Divisions should work together to plan and pilot new programs. The system can also be more effective if the number of people who get services in institutions goes down.
- **How Quality Recommendations Meet This Priority:** Using consistent performance measures will make reporting easier. It will also reduce paperwork. Overall, it will improve how DHHS measures service quality.
- **How Restructuring HCBS Waiver Recommendations Meet This Priority:** It will be easier for people and families to navigate HCBS if the number of waivers goes down. Also, DHHS staff can better manage waivers if there are fewer of them.
- **How Recommendations for Addressing/Eliminating the DSPD Waiting List Meet This Priority:** When state agencies and community partners work together, it can help people get connected to extra support.

Moving Forward

DHHS has been working to make LTSS better for a long time. DHHS has been trying to help people get quality services in the community. DHHS is also working to help people get services faster, live at home longer, and find and keep jobs. DHHS has been trying to help families support people with disabilities and older adults. DHHS can build on the work it's already been doing to keep improving by following our recommendations. These changes can make things better now and in the future.

