

**BRIEF #3** 

# **Utah LTSS Project**

Addressing/Eliminating the DSPD Waitlist **July 2024** 

# Contents

Introduction	1
Background	2
Research Findings	
Opportunities for Change and Further Considerations	
References	12
Appendix A: Plain Language Summary	14

#### Prepared for:

Utah Department of Health and Human Services (DHHS)

#### Prepared by:

Saska Rajcevic, Team Lead - Human Services Research Institute Jami Petner-Arrey - Human Services Research Institute Jasmine Hepburn - Human Services Research Institute Jodi Franck - Human Services Research Institute John Agosta - Human Services Research Institute

#### About the Human Services Research Institute

The Human Services Research Institute is a nonprofit, mission-driven organization that works with government agencies and others to improve health and human services and systems, enhance the quality of data to guide policy, and engage stakeholders to effect meaningful systems change.



# Introduction

The Utah Department of Health and Human Services (DHHS) strives to ensure all Utahns have fair and equitable opportunities to live safe and healthy lives. Through its Division of Integrated Healthcare (DIH), Division of Aging and Adult Services (DAAS), and Division of Services for People with Disabilities (DSPD), DHHS has established a comprehensive long-term service and Support (LTSS) system. In recent years DHHS and its divisions have engaged in multiple initiatives to improve services and supports.

DHHS contracted Human Services Research Institute (HSRI) to build on current initiatives to strengthen LTSS and make recommendations to DHHS on how to further these efforts. DHHS and our Steering Committee requested that we prioritize opportunities that focus on:

- 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.
- 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.
- Person-Centered Support Empower people to maintain control over their own life and services (self-direction) by offering holistic support.
- Effective Service System Improve coordination between agencies, funding, and reimbursement of services to help more people.

In this Research Brief (#3), we explore strategies for addressing or eliminating the DSPD waitlist.

To inform our understanding of this topic, we (1) reviewed relevant Utah policy and program documents, DHHS and divisional websites, and relevant data (as applicable); (2) conducted focus groups and informational interviews to learn from people receiving services, family members, providers, advocacy organizations, and field experts (as applicable), (3) reviewed Utah's waivers and HCBS programs in other states; and (4) researched and a wide variety of literature.

Based on this research and as discussed in more detail in the sections that follow, we identified the following key opportunities for DHHS to address or eliminate the DSPD waitlist:

- Waitlist Needs Analysis and Strategic Plan
- Waitlist Management
- Waitlist Funding Sources

Our initial research findings were presented to the Project Steering Committee and the committee's feedback is incorporated in this research brief. The opportunities outlined in this research brief are not final recommendations. Our final recommendations may change as we collect more information on this and other research topics and explore their feasibility. Some opportunities may not be possible for DHHS now or in the future. Our final recommendations will consider all research topics holistically, creating the right plan for Utah. These will be outlined in our final report.

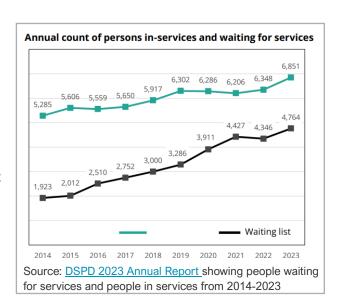


# Background

The primary funding source for community services for people with disabilities and older adults is Medicaid and, more specifically, the Home and Community-Based Services (HCBS) authority through which states can opt to receive a waiver of Medicaid rules governing institutional care (see Section 1915(c) of the Social Security Act). Each state develops and has one or more HCBS waivers for targeted populations approved by the Centers for Medicare and Medicaid Services (CMS). This includes setting the maximum number of people that may be enrolled in each waiver. Once a waiver cap is reached, new applicants are placed on a waitlist until additional funding is available or the cap is raised. As of 2023, the Kaiser Family Foundation (KFF), reports 38 states have waitlists with nearly 700,000 people waiting for services nationally with an average wait time of three years. Most people on waitlists have intellectual or developmental disabilities.

# **Utah Landscape**

In its 2023 Annual Report, the Utah DSPD reports that there are 6,851 people receiving HCBS services while 4,764 people wait for services with an average wait time of 5.4 years. As of 2024, Utah's Aging Waiver operated by DAAS and Utah's Tech Dependent Waiver operated by the DIH both have waitlists of a little over 100 people each. Therefore, when discussing the "waitlist" for services throughout this research brief, we are referring to the DSPD waitlist due to its significant size. While addressing and/or eliminating the DSPD waitlist was not identified as an initial research topic, we learned from community members and the study Steering Committee that resolving the waitlist is a top priority.



#### Between 2010-2023:

- People receiving DSPD services increased by 40% from 4,893 to 6,851 people.
- People waiting for DSPD services increased by 169% from 2,819 to 4,764 people, steadily closing the gap between those served and those waiting for services.
- Utah's population increased by nearly 25% to 3.4 million, a trend that will likely continue.

In addition, given a state population of 3.4 million, the 6,851 people currently served amounts to 201 people per 100,000 of state population. Nationally, Larson et al. (2022) reports that in 2019 the national average of people served per 100k population was 283, meaning that DSPD must serve 82 more per 100k population (2,796 more people) to match the 2019 national average. This result would still yield a wait list of 1,968 (4,764 - 2,796). If DSPD eliminated the waitlist entirely by serving all 4,764 people waiting for services, it would likely rank among the highest serving states at 342 per 100,000 people.



# Research Findings

To inform our understanding, we reviewed promising practices related to waitlist management in other states. We also synthesized information gathered through community engagement activities, focus groups, and key informant interviews with people in the state to identify present issues associated with waitlist management unique to Utah. This follows research that has already been completed on the waitlist, including a 2023 report by the Utah Developmental Disabilities Council (UDDC 2023) and a report prepared for the Social Services Appropriations Subcommittee on waitlist strategies (DSPD, Department of Health Medicaid 2023). Our findings on strategies used in other state programs to address waitlist issues are outlined below.

# **Engagement Themes**

Since the beginning of this project, we have consistently received feedback about the need to reduce the number of people waiting for services, or preferably to eliminate the DSPD waitlist altogether. In response to this feedback and at the request of the Steering Committee, we added research activities focused on the waitlist.

In much of our outreach, concerns expressed about the waitlist largely centered on the need to reduce the waitlist to help those in need of immediate supports and services. People acknowledged that funding is a major limitation and described confusion over available services and access to those services. They also talked about the overwhelming process of accessing services, even when they intend to pay for services independently.

"[I] don't know what to do to get services—even out-of-pocket—while on the waiting list," one parent said during a listening session. "[My] daughter needs social activities and speech therapy; I need respite. [I] don't know how find services."

Some parents expressed that the shortage of services limited children's and families' potential.

"We were on the waitlist for 33 years," another parent said. "The funding my daughter is receiving now would have been very helpful then."

Families also expressed worries about what would happen to their children when families are no longer able to provide support.

"[We have] stress over the future," a parent said. "There is no safety net, we don't know what will happen to him when we die."

Families also spoke about burnout and experiencing "too many years living in emergency mode." And—as one parent said—all family members can experience burnout: "[We need to focus on] not overburdening the natural supports available, like siblings. They need to be able to be kids, not caregivers all the time."

People expressed that even a little bit of support would be helpful. Though the Limited Supports Waiver offered them hope, its eligibility criteria means that people with limited needs must wait.



"My son has mid-level support needs," one parent said. "His score is too high for the Limited Supports Waiver, but he does not have acute support needs. I feel like he will wait forever for the comprehensive waiver."

"[I say], 'When I die, DSPD will take care of her,' but that is not true. A huge gap will open when we are gone or can't take care of her anymore."- Listening session participant

In addition to the above themes, previous waitlist reports have focused on engagement with the community and contain themes that may still be relevant. The 2023 report submitted to the Social Services Appropriations Subcommittee (DSPD, Department of Health Medicaid 2023) described four overarching themes that prevented families from joining the waitlist:

- 1. Information and application process may be overwhelming.
- 2. Families who support people with lower-level needs don't want to take a spot on the waiver from someone with greater need.
- 3. Families may be discouraged by the very existence of a waitlist.
- 4. General lack of awareness about DSPD and services available

Another report completed by the UDDC identified additional needs of families, including information about available resources, and navigating the system, support coordination while on the waitlist, higher rates for respite, and the ability for family caregivers to be paid to provide support. Families also wanted to know if they could use Support Coordinator funds for alternative needs and reported that parents remained unemployed to provide care for their children.

# **State Programs Research**

To explore how DSPD can eliminate the waitlist, we researched states that have had success and interviewed representatives from those states. We identified three promising practices:

- Develop and enact a strong plan in collaboration with state leadership and other partners to build capacity
- Collect and use data on service need and the available provider network
- Provide frequent education to policy makers about the benefits and fiscal implications of addressing the waitlist

Several states we examined are still in the process of researching and developing strategies to reduce waitlist populations. States that have successfully implemented measures to reduce or eliminate their waitlists are detailed below.

#### Oklahoma

Since cost is often the primary factor in limiting or delaying access to waiver services, understanding the needs of people waiting for services—including what services they need, when, and how much—is a key step in determining cost. Oklahoma's approach to eliminating its waitlist involves comprehensive and strategic data collection and fiscal estimation. Through this approach, Oklahoma accurately determined its budgetary needs to eliminate the waitlist.



Oklahoma eliminated its 13-year waitlist for 4,993 people seeking developmental disability services in 2023 with \$32.5 million in legislative funding. Oklahoma's multifaceted approach centered on closely estimating what it would cost to bring those on the waitlist into services. The state hired third-party assessors who reviewed the needs of each person on the waitlist to determine a valid cost estimate for services (Oklahoma DDS 2024). People on the waitlist in Oklahoma had not previously been assessed for service eligibility. The assessors spoke with everyone on the waitlist to determine eligibility, services needed, and when people were likely to need those services. With this information, the state developed a valid cost estimate for services. Through the assessment process, the state learned that not everyone who was on the waitlist needed or was eligible for services, with 50% of people determining that they did not want services when offered.

Another aspect of estimating costs included comparing what was authorized in service plans, versus actual spending. Oklahoma state staff previously budgeted the full amount for plans of care, however, only 80%-90% of the budgets were being spent, freeing up significant funding. Those funds were then reallocated to fund services for people on the waitlist. Oklahoma recognized the need to both offer more people services and ensure an adequate provider network. Therefore, as part of its comprehensive approach, Oklahoma also funded a 25% increase in provider rates with funds provided by the American Rescue Plan Act (ARPA). This increase was implemented in parallel with bringing people into services to promote provider capacity. Additionally, Oklahoma enacted a "Call to Care" campaign to recruit Direct Support Professionals (DSP) and address workforce shortages.

Combined, this effort resulted in 4,992 requests for services resolved with 1,672 people being moved from the waitlist into services, as of 2024 (Oklahoma Human Services 2024). While this effort has undoubtedly provided much needed supports to thousands of people, it is unclear how the waitlist will be managed in the future.

### Virginia

In Virginia, state and agency leadership, legislators, advocates, and families combined efforts to enact an initiative designed to eliminate the waitlist for services and supports. The state's three-year "Right Help, Right Now" behavioral health initiative was introduced by Gov. Glenn Youngkin in 2022 and commits \$307 million to fund 3,440 slots on the Priority One waitlist, effectively eliminating the waitlist for those with the most urgent need for services (Youngkin 2024). In Virginia, waivers are assigned based on the urgency of need. Virginia manages a three-level priority categorization for its waitlist to ensure that people with the most urgent needs are prioritized for services. The levels are as follows (The Arc of Virginia 2021):

- Priority One waitlist houses people in need of services within one year
- Priority Two waitlist houses people in need of services in one to five years
- Priority Three waitlist houses people in need of services in five years or longer

"Right Help, Right Now" centers around pre-crisis prevention and aims to create greater upstream capacity by reducing strain on individuals, families, law enforcement, and the behavioral health system (Youngkin 2023). In addition to the \$307 million to fund a slot for every person on the Priority One waitlist, "Right Help, Right Now" allocates money to improve provider capacity and the DSP workforce. To improve provider capacity, the initiative grants a one-time \$5.2 million allocation to the Arc of Virginia with \$2 million going to a recruitment campaign, \$2.9 million going to business startups and expansion incubators, and \$330,000 going to educate people on underused inclusive



services for people with disabilities (Schabacker 2024). The initiative also allocates funding for a 5% increase to provider rates (Ress 2023). While just getting underway, Virginia's careful tracking of who has the most immediate need for services allows for quick targeting of available service dollars where they are most needed.

#### **New Mexico**

New Mexico addressed its waitlist through grassroots efforts, legislative support, and the state's use of one-time funding through ARPA. Through interviews with representatives from the state (New Mexico DOH 2024), HSRI learned that legislative support and frequent public education were critical pieces of New Mexico's approach to eliminating their waitlist. In 2019, New Mexico Gov. Michelle Lujan Grisham, (a former cabinet secretary for both Aging and Long-Term Services and the Department of Health) ordered the Department of Health and the Department of Human Services to develop a plan to end the waitlist, including the development of a new waiver (McKay 2019). "A waiting list of this size is completely unacceptable and indicative of a lack of care and attention by state leadership in recent years," Grisham said in a statement (McKay 2019). To eliminate the waitlist, education was geared toward legislators and policymakers and focused on the cost implications of the waitlist and the benefits of addressing it. At the time New Mexico's waitlist was created, there was no funding to bring people into services.

Prior to addressing the waitlist, the average wait time for services was 13 years. Annually, New Mexico brought 100 waitlisted people into services but added 300 more people to the waitlist. In 2022, when funding became available through ARPA, New Mexico used the funds to decrease their waitlist for people with intellectual and developmental disabilities. Over a period of 18 months, New Mexico decreased their waitlist from 3,500 people in 2022 to fewer than 300 people in 2023 (Burns 2023). Framing the waitlist as an ongoing commitment to the person, rather than a one-time situation, was key. When ARPA funding became available, the waitlist was earmarked to address with windfall funds.

Initially, it was unclear how future funding to maintain people formerly on the waitlist in services would be secured; however, New Mexico has been able to continue to secure legislative funding.



# Opportunities for Change and Further Considerations

Based on this research and as discussed in more detail in the sections that follow, we have identified the following key opportunities for DHHS to consider regarding the waitlist including: 1) conducting a needs analysis which would ultimately feed into a strategic plan, 2) better managing the waitlist, and 3) identifying sustainable funding sources. We plan to work with the Steering Committee and DHHS to help prioritize and select which opportunities to include for further exploration in our final report. Our recommendations may change as we collect more information on this and other research topics and explore their feasibility.

# Waitlist Needs Analysis and Strategic Plan

Understanding the characteristics of people waiting for services such as their demographics, support needs, interests, and service goals can help states understand requirements to serve those who are waiting. Before requesting legislative funding, some states have conducted "needs analyses" to gain a clearer picture of costs to fund the waitlist, the types of services wanted and needed by people waiting for services, and the capacity of providers to take on new service recipients. Using information obtained through the needs analysis, DSPD can work in collaboration with community partners to develop a strategic plan to address the waitlist. The plan should account for increasing access to services for people living independently and with families throughout the state, ensuring people have access to the services they need and prefer, sustaining funding from year to year, and ensuring a sufficient provider network is in place. DSPD can build on the learnings of other states that have taken such a path.

## **Benefits of Opportunity**

Conducting a needs analysis of people currently waiting for services would allow for DSPD and advocates to have a greater sense of what it would take to move people into services. In conversations with advocates seeking funding for the waitlist, many highlighted ongoing confusion about how much funding is needed to move people into services. They also questioned whether the current system can handle an influx of people moving into services and to what extent (Informants 2024). The development of a strategic plan based on the results of the needs analysis would help establish a shared vision and action steps for addressing and/or eliminating the waitlist. In 2021, the Kansas InterHab provided recommendations to the Kansas Legislature Special Committee on the HCBS IDD waiver in the form of a Strategic Roadmap for Eliminating the IDD Waiting List and Addressing IDD Capacity Erosion (InterHab 2021). The roadmap outlined demographic information about people waiting for services and identified service needs and how immediate those needs were, along with additional needed services. Subsequently, the Kansas InterHab outlined a five-step multiyear effort overseen by a modernization taskforce of state representatives, legislators, and providers to ensure provider capacity and establish ongoing funding adjustments to address the waitlist. Establishing a roadmap in collaboration with partners and community members can help ensure a coordinated and well-informed approach to addressing the current waitlist.



#### Potential Barriers to Implementation

The needs analysis and strategic plan development process would need to be led by state staff or an independent contractor, requiring dedicated time and resources. Community partners would also need to build capacity within their own organizations to participate in the creation of the strategic plan and provide meaningful input. Additionally, getting people off the waitlist depends almost primarily on securing additional funding and support from the legislature, which have been significant barriers in the past. Regardless, specific estimates of need and cost can help to facilitate more manageable conversations about how to move forward and help to garner universal support.

### Impact on Utah LTSS Priorities and System

The process of conducting the needs analysis and creating the strategic plan alongside community partners would support Utah's efforts to improve coordination between internal and external partners. A completed needs analysis could mitigate confusion among interested parties regarding what is needed to bring people into services. A comprehensive strategic plan could also support alignment among partners and clarify roles and action steps for addressing the waitlist. Further, identifying tangible steps could help alleviate the stresses families face while waiting for support.

# **Waitlist Management**

States use a variety of methods to manage and prioritize their waitlists. Currently, people who apply for DSPD services complete a Needs Assessment Questionnaire (NAQ) to determine their current needs and calculate a numeric score that reflects those needs. Per DSPD Directive 1.16, "NAQ scores determine a person's waiting list ranking in relation to each other person on the waiting list" (Utah Division of Services for People with Disabilities 2021). Areas measured include the person's severity of need (50% of the overall score), caregiver support (30% of the overall score), time on waiting list (20% of the overall score), and urgency of need. These waitlist rankings are dynamic and fluctuate as people apply for services. In their respective waitlist questionnaires, states may choose to prioritize certain factors or characteristics over others when calculating the waitlist score. For example, some states choose to weigh a person's level of need more heavily than their time spent waiting for services and vice versa. While there is no ideal methodology for calculating waitlist scores, it is important to note that states who prioritize level of need most heavily can establish a culture of crisis, since the only people who are moved from the waitlist are people who have extremely severe support needs.

States also choose whether waitlist rankings remain dynamic like Utah's, or whether people receive a static, unmoving waitlist score. There are pros and cons in these approaches but, in general, fluctuating waitlist scores can lead to greater frustration for people and families waiting for services; this was readily expressed during community engagement with people on the DSPD waitlist in Utah. Therefore, HSRI has identified a two-pronged approach to moving people into services and establishing a priority tier system for the waitlist, or a combination of the two, as potential waitlist management strategies for DSPD to pursue.

The two-pronged approach is designed to address equally important factors for people waiting for services: (1) duration of time on the waitlist and (2) the level of need. To ensure that both factors are considered, some other states "reserve" some, rather than all, funding for people that are in crisis to enter services. This approach would use time on the waitlist as the main factor in determining where an individual is on the waitlist for part of the available funding. This would help people and families



know their place on the waitlist is being held for them and take some of the frustration of fluctuating on the waitlist away. However, due to the length of the waitlist, there will always be people that have increased needs and possibly even crisis-level needs, and those people will need to be able to access services. Therefore, the other prong would allow for some budgeted waiver slots to be set aside for people most in need.

Another strategy is establishing a priority tier system for the waitlist like what is used in the Virginia "Right Help, Right Now" behavioral health initiative (as discussed in the previous section). This three-level priority categorization for the waitlist ensures that people with the highest needs are prioritized for services. To ensure that this strategy is effective, a waitlist needs analysis would be critical to identify how many people may fall into each category and ensure funding is allotted correctly.

#### **Benefits of Opportunity**

Both the two-pronged approach and the priority levels can offer the benefit of a person's place within the waitlist remaining more static. We heard from multiple sources that in the current system, a person's place on the waitlist is relative to the need of others. This means that a person's place on the waitlist can move up and down as new people apply for services. Since there are always people with significant needs, people with lower needs for services are being moved down the list, thus delaying supports that could help them to be more independent, and in some cases leading people and families into crisis. Alleviating some of the movement within a list through priority levels may help in offering timely support, preventing crisis, and reducing frustration for people and families.

Both waitlist management strategies presented would address this. In the two-pronged approach people would be on the waitlist based on when they got on the waitlist. As crisis or high needs occur, however, people could be entered into the system through the emergency waiver funding available. In the priority tier system, people would be placed in a priority tier based on their needs and would be static within that priority list based on time on the list, allowing Utah to meet both urgent and less urgent needs.

Both strategies require that there be periodic check-ins with people on the waitlist to ensure that their needs have not changed. Waitlist management will also work better in combination with the needs analysis and strategic plan noted in the first opportunity.

## Potential Barriers to Implementation

There are potential barriers for both waitlist management strategies to consider. The approaches require that a needs analysis of people waiting for services is conducted. The most important factor for these opportunities is that there is funding available in parallel with the increase in demand for services. The waitlist has been steadily increasing throughout the years and the funding must be able to meet these demands.

For the two-pronged approach, the state would need to set aside a specific number of budgets per year to address crisis or emergency needs. This can help to ensure that people can access services when they need them without their needs becoming so extensive that they require higher services, which are more costly. However, this may mean that some people in crisis do not get supports when they need them. Therefore, crisis funding must be carefully estimated. The priority list would also require consideration of funding amounts per year for the Priority One tier to ensure an adequate number of people can come off the waitlist to meet priority in order of when people will need



services. The model would allow people to enter services when their needs dictate. Again, planning funding carefully for bringing people off the waitlist will continue to be important for either management strategy to be effective. Managing multiple waitlists without a plan for funding them may create additional burden on DSPD and increase frustration and fear on the part of people and families. Even so, thoughtful management of the waitlist will allow DSPD to act quickly and address the most urgent needs when and if funding becomes available.

#### Impact on Utah LTSS Priorities and System

The most tangible impact of either of these strategies on people waiting for services in Utah is more transparency and understanding of their place on the waitlist which was a concern we heard during engagement with people on the waitlist. Both strategies allow for those in the immediate need categories to access services without impacting those waiting for long periods of time directly.

# **Sustainable Waitlist Funding Sources**

While there are opportunities for the state to better manage the list of people waiting for services, understand individual needs, and review system infrastructure and capacity; ongoing and sustainable funding is critical to ultimately addressing and/or eliminating the waitlist. Continued legislative advocacy by community members and people waiting for services will be key to securing additional legislative funding. While DSPD does not have control over legislative funding decisions, the division can explore additional funding or revenue mechanisms. One option suggested during the 2024 Utah General Session was the creation of a permanent trust fund with earnings on the deposit or investment of assets being used bring people on the waitlist into services (Dailey-Provost 2024). Additional suggestions include establishing a license plate to raise funds and community awareness of the importance of addressing the waitlist. Minor fees of \$1 to \$2 could be incorporated into citations such as parking tickets or violations to generate a passive but ongoing revenue stream.

## Benefits of Opportunity

To date, additional funding for the DSPD waitlist has been appropriated by the legislature in the form of one-time funding from year to year in contrast to states who receive ongoing appropriations to bring an established number of people into services each year. Having consistent and sustainable funding streams to address waitlists can support states in better managing their waitlists and ensuring that action is taken each year to mitigate the number of people waiting for services. In recognition that resources are limited, and the legislature may not always appropriate funds, establishing ongoing funding sources for the waitlist is critical. This funding should align clearly to the supports that people want and need, including which waiver will best meet their needs.

## Potential Barriers to Implementation

When identifying potential revenue streams, it is important that long-term stability and feasibility is considered so that DSPD does not come to rely on funding that may disappear in the future. Additionally, DSPD should consider whether the cost of implementing or coordinating additional funding streams will present enough of a return on investment to be meaningful.

## Impact on Utah LTSS Priorities and System

Securing additional funding for the waitlist would have an immediate impact by getting people the services and supports they need. Many people currently waiting for services from DSPD have applied due to a presumed future need as they have heard that it can take years to get into services.



As noted in our interview with New Mexico, decreasing the waitlist can lead to people applying only if they have an actual need, thereby, mitigating the number of people applying based on perceived wait times.

## **Further Considerations**

It is important to note that if the waitlist continues its current growth trajectory, Utah may reach a tipping point within the next decade with the number of people waiting for services surpassing the number of people in services. Without decisive action, planning, and partnership among the disability and aging services community, Utah's long-term services and supports system will reach such a point.

As with all states that have successfully eliminated or significantly lowered their waitlists for services, external champions and strong legislative advocacy will be the key to making progress. The state should continue to provide transparent data and information to policymakers and the public on the impact of the waitlist.

HSRI will continue to explore additional waitlist strategies not referenced directly in this research brief to determine what is most feasible and impactful for the state to implement. This includes reviewing the Limited Supports Waiver (LSW) and its effect on mitigating the waitlist in a future research cycle, along with the types of waivers and funding structures that may provide the most benefit to the state.



# References

- Burns, Alice, Maiss Mohamed, Molly O'Malley Watts. 2023. "A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023." Kaiser Family Foundation, November 29. https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023/.
- Dailey-Provost, Jennifer. 2024. "HB0393S03 compared with HB0393S01." *Utah Legislature*. https://le.utah.gov/~2024/bills/hbillint/HB0393S03\_ComparedWith\_HB0393S01.pdf.
- InterHab. 2021. "Strategic Roadmap: Eliminating the IDD Waiting List/Addressing IDD Capacity Erosion." *Kansas Legislature*. https://kslegislature.org/li\_2022/b2021\_22/committees/ctte\_spc\_2021\_hcbs\_idd\_waiver\_1/documents/testimony/20211021\_05.pdf.
- McKay, Dan. 2019. "New Mexico to redesign major disability program." *Las Cruces Sun News*, July 10. https://www.lcsun-news.com/story/news/local/new-mexico/2019/07/10/new-mexico-disability-program-gov-lujan-grisham-healthcare-insurance/1693271001/.
- New Mexico Department of Health Key Informants. 2024. "Interview with Key Informants; New Mexico Department of Health." Interview by Saska Rajcevic and Jami Petner-Arrey. February 5.
- Oklahoma Developmental Disabilities Services. 2024. *Oklahoma Developmental Disabilities Services, DDS Waitlist.* March 13. https://oklahoma.gov/okdhs/services/dds/ddswaitlist.html.
- Oklahoma Developmental Disability Services Key Informants. 2024. "Interview with Key Informants; Oklahoma Developmental Disability Services." Interview by Jami Petner-Arrey and Saska Rajcevic. Feburary 16.
- Ress, Dave. 2023. "Youngkin: We'll end a waiting list for help with developmental disabilities." *Richmond Times-Dispatch*, December 13. https://richmond.com/news/state-regional/government-politics/youngkin-well-end-a-waiting-list-for-help-with-developmental-disabilities/article\_ac763ed2-99fb-11ee-901e-b343ccbc5447.html.
- Schabacker, Emily. 2024. "Youngkin's plan would fund thousands of people with disabilities. Even more are waiting." *Cardinal News*, February 7. https://cardinalnews.org/2024/02/07/youngkins-plan-funds-care-for-people-with-the-most-serious-developmental-disabilities-the-rest-will-be-left-waiting/.
- The Arc of Virginia. 2021. "What Happens When You are on the DD Waiver Wait List." www.thearcofva.org. March 11. Accessed February 1, 2024. https://d3n8a8pro7vhmx.cloudfront.net/thearcofva/pages/57/attachments/original/162466691 1/DD\_Waivers\_Priority\_Needs\_Checklist\_3.11.21\_%284%29.pdf?1624666911.
- Utah Developmental Disabilities Council. 2024. "Interview with Utah Developmental Disabilities Council." February 28, 2024. Interview by Saska Rajcevic, John Agosta, Jasmine Hepburn, Jodi Franck and Jami Petner-Arrey.



- Utah Division of Services for People with Disabilities. 2021. "Needs Assessment Questionnaire." *Utah Division of Services for People with Disabilities.* https://dspd.utah.gov/wp-content/uploads/2021/05/D\_1.16\_NAQ\_2021\_Final.pdf.
- Youngkin, Glenn. 2023. "Right Help. Right Now. Transforming Behavioral Health Care for Virginians." https://www.hhr.virginia.gov/media/governorvirginiagov/secretary-of-health-and-human-resources/pdf/behavioral-health/Right-Help-Right-Now 01-11-23.pdf.
- Youngkin, Glenn. 2024. "Right Help. Right Now. Transforming Behavioral Health Care for Virginians, Year 1 Report, December 2022 December 2023." Richmond: Commonwealth of Virginia Office of the Governor. https://www.hhr.virginia.gov/media/governorvirginiagov/secretary-of-health-and-human-resources/pdf/behavioral-health/1-Year-Update-RHRN-FINAL-complete-Feb2024.pdf.



# Appendix A: Plain Language Summary

# Brief #3: Addressing/Eliminating the DSPD Waitlist

#### Who is this brief for?

This brief is for anyone interested in learning about ideas for decreasing or getting rid of the Utah Division of Services for People with Disabilities (DSPD) waitlist for Home and Community-Based Services (HCBS).

#### What is this brief about?

Sometimes, people who apply for HCBS can't get services right away because there isn't enough money. DSPD currently has a large waitlist of over 4,000 people. The waitlist makes it hard for people waiting for services and their families since they can't get the help they need.

#### What did researchers find out?

Some states have been able to get rid of large waitlists by doing a few things. First, they have worked to understand what people waiting for services need and created an action plan to help them. Second, states have prioritized both a person's level of need and how long they have been waiting. Third, states have created ways to get money for the waitlist.

## What is most important to know?

DSPD needs to act now with the support of legislators, advocates, and community partners to resolve the different waitlist issues.

### Where can I learn more about this?

You can learn more about this research by reaching out to our Project Coordinator, Jasmine Hepburn, at jhepburn@hsri.org.

