**BRIEF #2**

# Utah LTSS Project

Strengthening Natural Supports

**July 2024**

# Contents

# 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 (#2), we explore strategies for strengthening the natural supports.

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 strengthen natural supports.

- Build Infrastructure for Collaboration and Engagement
- Enhance Networking & Connecting
- Review Services that Support People and Families

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

People with disabilities and older adults compose a significant portion of our families and communities. Often, they benefit from a variety of supports to live the life they want and to participate in community life. Aside from the publicly financed services, strengthening and expanding natural support networks of people with LTSS needs provides access and inclusion to the community. Historically, the term "natural supports" referred to unpaid supports provided by family members. According to the Wingspread report, the goal of supporting families "…with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members" (Hecht, et al. 2011). For this research brief, we recognize the critical role that family members play in the lives of people with disabilities and older adults, but also seek to broaden the concept of a natural support network to include friends, neighbors, coworkers, and other community assets such as transportation and public resources. Studies show that social networks in the lives of older adults and people with disabilities can: act as a protective factor to prevent abuse and exploitation (Friedman 2023), reduce poor outcomes associated with loneliness and isolation (McVilley, et al. 2006), and help people with disabilities find jobs (Petner-Arrey, Howell-Moneta and Lysaght 2016)

Family caregivers have significant, and potentially growing, responsibilities to provide support to their family members who have long-term support needs. This is in part due to an aging American population and multigenerational caregiving duties. According to the report, Caregiving in the U.S., one in five Americans (21.3%) are providing caregiving to an adult or child with support needs (AARP, 2020). Very often these individuals live in their own homes or with family members and have specialized needs, as do their family caregivers (Young and Crankshaw 2023). As a result, individuals may receive publicly funded assistance, such as Medicaid-financed home and community-based services (HCBS), to complete everyday activities. Services offered through Medicaid are targeted to the Medicaid beneficiary, thereby limiting the services offered directly to family members.

When considering how to best strengthen natural support networks for older adults and people with disabilities we leveraged concepts offered in the Charting the LifeCourse (CtLC) framework (Reynolds, Palmer, and Gotto 2018). CtLC advances policies and practices that focus on supporting people with long-term support needs and their families. One component of the framework includes a categorization of the following three primary areas where individuals and families require support:

1. **Discovery and Navigation** where people have the information and tools needed to navigate life and seek out the necessary support.

2. **Connecting and Networking** where people make connections with peers to receive and give support and network other community serving resources.

3. **Goods and Services**: where people have access to day-to-day tangible items and/or services (publicly funded or not) that are needed.

In this context, the challenge to policy makers is to establish policy and practice that blends these sources of support together to yield an effective service response to people and families.

# Utah Landscape

Utah, the 11th largest state, is home to about 3.4 million people. Given its size and emphasis on in-home support, Utah requires efficient and effective means to deliver services to a widely dispersed population. This includes delivering HCBS to supplement the natural supports available in the community or other generic supports or social services. Below we provide an overview of the types of support that are currently available in Utah to strengthen natural support networks for older adults and people with disabilities organized by the three buckets of support.

## *Discovery and Navigation*

Discovery and Navigation relates to meeting people's need for information and/or training, and help navigating supports that meet their needs. This can include information about disability, advocacy, support groups, and self-care, as well as how to navigate systems of support (e.g., early intervention, education, medical and mental health care, nutrition supports, housing, transportation, and HCBS). People with disabilities and older adults, along with their caregivers, might also need information about how and when to enroll in certain benefits such as Medicare, Medicaid, or other state or county programs. Often, people in natural support networks remark that they just need someone to call who can help them navigate these complex systems. There are several community resources in Utah intended for these needs, including:

- **Utah Parent Center.** The Utah Parent Center (UPC) is nonprofit, that assists parents to help their children, youth, and young adults with all disabilities to live included, productive lives as members of the community. UPC provides information, peer support, training, and advocacy that are based on the concept of parents helping parents. UPC was founded on the belief that parents are full-time partners in the decision-making process that directs their child's care and programs, and as such, can provide significant support to other parents in similar circumstances. UPC is one of the main resource and training centers for disability-related information across the state of Utah. UPC developed a Guide to HCBS Waivers and other training materials. The UPC website's "Transition Planning" page also provides resources for caregivers to support family members from birth through adulthood. The Transition University page gives information about adult services, too.
- **Eldercare Locator.** Elder Locator is a national web-based tool that helps people find community resources for older adults and their families based on location (e.g., ZIP code, city/state). It has an option to speak with an information specialist as well as information targeted for caregivers/care partners. Other areas of the website are organized by topic such as support services, housing, elder rights, insurance benefits, health, and transportation.
- **Utah Commission on Aging (UCOA).** UCOA hosts UtahAging.org, which is a virtual resource center for older adults. Navigation links to several topics of interest for older adults are available on the website and help people find needed services and supports.

## *Connecting and Networking*

Connecting and Networking offer ways for older adults and people with disabilities to connect with peers and to give and receive support. Resources that offer peer support-type services in Utah include:

- **Utah Family-to-Family Network (F2F).** This is a project of the Utah Parent Center and is made up of local volunteer leaders and groups that provide education and support to families

who have a member with a disability. F2F provides a range of activities that support opportunities for connection among peers. Related to informational needs, F2F hosts events such as *DSPD 101, New Dx, Now What?, and All About Caregiver Compensation.* The funding allocation provided by DSPD is largely based on the previous year's amount and may be increased from year to year. The F2F submits a bi-annual report with an update on the number and type of activities provided, numbers of attendees, and major successes and challenges encountered.

- **The Alzheimer's Association.** The national [Alzheimer's Association](#) offers peer-or professionally led support groups for people living with Alzheimer's and their caregivers. In addition, many of the support groups cater to children, people with early onset and early-stage Alzheimer's, caregivers, and others.
- **Utah's Multicultural Disability Network.** Utah State University's Multicultural Disability Network is a community of practice whose primary goal is to balance disability services and cultural diversity. Service providers in Utah can join the network for free, which includes quarterly webinars, community of practice meetings, and networking opportunities for other Utah professionals to share knowledge.

## *Goods and Services*

Goods and Services meet the day-to-day support needs of older adults and people with disabilities. These services include those that might be offered through local community serving organizations or county or state governments. Similar to other states, a review of the HCBS waivers in Utah reveals a variety of supports available that could be leveraged to strengthen natural support networks and keep people living as independently as possible in their communities. Some of the waivers include services specifically geared toward families, including Family Training and Preparation Services (Community Supports, Community Transitions) and Respite (Acquired Brain Injury, Community Supports, Community Transition, Limited Supports, Medically Complex Children, New Choices, 65 & Older, Technology Dependent/Medically Fragile).

The scope of work for this research brief included a specific request to review the Caregiver Compensation program that has provided payments to family caregivers of people with disabilities. This option started as one-time funds authorized to certain qualifying groups each year; however, as of the writing of this brief, plans are underway to include it as an ongoing program across four waivers operated by DSPD in the next set of amendments slated for summer 2024 (Utah DHHS 2024). The waivers that will add this option are:

1. Community Supports Waiver (CSW)
2. Community Transitions Waiver (CTW)
3. Acquired Brain Injury Waiver (ABI)
4. Limited Supports Waiver (LSW)

As this program gets codified into the waivers, there are new programmatic design elements that are being added including:

- Defining who is eligible to be a paid caregiver under this program
- Defining what constitutes "extraordinary care"
- Developing tiered payment structures based on assessed need
- Incorporating an upper limit to caregiver compensation of 40 hours per week

Many of these aspects of the program are intended to create a sustainable model that can be administered uniformly across paid family caregivers. These design aspects become even more important as Utah, along with the rest of the nation, seeks to address the direct support professional (DSP) workforce crisis in ways that assure that people with disabilities can get the support they need while also maintaining autonomy, choice, and control over their service delivery.

The Utah Caregiver Support Program funded by the Older Americans Act (OAA) and state general funds generally provides a relatively small amount of funding (e.g., $1,500 for respite care) to family members providing care to older adults, people with dementia or physical disabilities, or older adults caring for minor children. There is no income requirements for this program. Funding is available for approximately one year and according to DAAS many people use this program for environmental modifications that help older adults age in place.

# Research Findings

To inform our understanding of natural supports we reviewed literature and promising practices in other states aimed at strengthening natural support networks. To better understand the Utah's unique issues associated with strengthening natural support networks, we synthesized data gathered through community engagement activities, focus groups, and key informant interviews. Below, we detail a range of activities aimed at strengthening natural supports; these activities include those implemented in Utah, in other states, or through community organizations.

## Engagement Themes

Many focus group and interview participants reported similar experiences with connecting to the support they and their families needed. Family members of people with disabilities said that while they try to help their loved one access unpaid natural supports to engage in activities in the community, they rely on formal services to meet day-to-day needs and maintain a routine schedule. One focus group participant said that they were part of a close-knit community network, but that it was still difficult to find people who were comfortable providing the type and level of care their daughter needed; therefore, a family member or a paid staff member had to accompany the daughter while in the community with her network. Some had experience with their family member transitioning from the waitlist to waiver services and spoke about the positive difference that it made in their family's lives. Many of the focus group participants talked about the importance of having meaningful activities to do during the day. A few families expressed concern that if certain types of services were not available that their family member would have to spend a lot of time at home.

> *"I was surprised at how real the 'cliff' is after high school. I am a pretty connected parent and I know the resources, and still found that we were floundering and my son was left at home with nothing to do."* — Focus group participant

Family members also talked about the importance of finding connections and support from others with similar experiences. One focus group member said she felt she had more peer support connections when her child was young but hasn't found the same level of support available now that her son is an adult.

Comments collected through community engagement activities revealed that the most pressing concerns related to natural support networks include:

- Waitlist and getting access to pro-active supports to prevent crisis
- Challenges finding services that meet the level of need
- Staffing shortages
- Difficulty assessing the quality of service providers
- Confusing policies
- Desire for peer connections and support
- Hesitancy to acknowledge need for supports as people age

- Caregiver fatigue and burnout

Many of those who received the caregiver compensation expressed satisfaction with the program and a desire for it to continue, though also expressed concern with forthcoming changes.

# State Program Research

Here we present a review of the relevant findings from our national review of state programs organized by each of the three buckets of support.

## *Discovery and Navigation*

Access to information is a critical component to supporting older adults, people with disabilities, and their natural support networks particularly because many may not meet the eligibility criteria, currently or in the future, for LTSS. Related to information sharing activities, our research pointed to ways that service systems can provide avenues for engagement and access to information. For example, some states have dedicated staff roles within state agencies who have primary responsibilities for engaging with the community. People in this role are often a central point of contact and coordinate outreach and training activities within and outside of the service system. People in this role may serve as a liaison with the formal and/or informal family support networks across the state and help them craft information sessions and trainings to meet the community's informational needs. One example of this type of role is from the Connecticut Department of Developmental Service's Director of Family Support Strategies and Advocacy position within the executive team (Thaler 2012). This role was designed to focus on supporting families while shifting away from legacy systems.

To enhance navigation of community resources, a few state agencies serving older adults and people with disabilities have worked to make connections with 211 call lines that are intended to serve as a local resource hub for information and referrals. Several years ago, the DC Department on Disability Services (DDS) partnered with their local 211 to map existing resources available to all families across the lifespan (Kardell and Agosta 2017). It helped to build relationships with community resources as well as recognize the array of supports available in the community beyond disability services. Similarly, San Diego 211 and the Community Information Exchange created a network that relies on data sharing and interoperability between many community partners including health and social services to develop a singular plan for each person needing supports. This plan collects eligibility information for a range of available services and supports and actively refers the person to those for which the qualify, while also connecting the organizations delivering the supports and services.

There is a growing recognition of the benefits of state agencies working together to address common issues faced by people with LTSS needs. A scoping review of caregiver interventions being done in both aging and developmental disability research revealed that increased partnership between the fields of aging and developmental disabilities is critical for both populations (Heller, Gibbons, and Fisher 2015). Some states have developed models for routine cross-agency committees or workgroups that foster communication and coordination across supports and identify shared priorities. For example, the Indiana Family and Social Services Administration (FSSA) has formed a structure of Key Results (KRs) workgroups that includes staff members across divisions under FSSA that are working toward shared objectives.

## *Connecting and Networking*

Our literature review points to the benefits of peer support (Carter, et al. 2017) (Chakraborti, et al. 2012) . Peer support is offered among people with similar lived experiences. Scott and Doughty 2012 characterize peer support as "caring about" rather than "caring for." There are many forms of support that fall under this category such as peer support among family members, caregivers, or care partners as well as peer support among people who are aging and those with disabilities.

State agencies are often interested in finding ways to support and/or fund structures that can provide organized peer support activities. It is often organizations in the community that are best positioned to offer this type of support. We found a range of peer support opportunities that exist among the community from informal Facebook groups to organized Dementia support groups, to more formalized self-advocacy or family-to-family network organizations that may receive a combination of funding sources including federal, state, and local grants, as well as fundraising and donations.

There is a growing recognition that these organizations must be equipped to meet the needs of diverse families. One example is the Virginia Family-to-Family Network is an initiative of the Center for Family Involvement at the Virginia Commonwealth University's Partnership for People with Disabilities. The Virginia F2F employs a regional strategy to serve as a place, "where family members of culturally and linguistically diverse children and adults with disabilities (of all ages) have people in their own communities to call upon in their efforts to identify and obtain needed information, services, and community supports." (Center for Family Involvement 2023). To help them fulfill their mission, the F2F in Virginia employs regional Cultural Brokers/Liaisons to assist with outreach to various communities.

The New Jersey Office of Education on Self-Directed Services, intended to supplement support coordination, provides education and training to people receiving services, their families, advocates and support coordinators, as well as community partners. One key role they fulfill is hosting sessions on peer and family networking. These sessions are intended to help to foster opportunities for those who are self-directing to meet each other and share resources. The office also provides technical assistance which includes education on self-direction, direct assistance with self-direction, and provides one-to-one connections with people receiving services, families, and providers.

## *Goods and Services*

A robust service array can assist people to remain living in the most independent environment possible. Services that proactively balance independence and dignity of risk with the support before a person or family reaches a crisis point, may prevent more restrictive living settings (i.e., nursing homes, group homes). A review of services offered in HCBS waivers revealed that services such as community navigator, peer support, self-direction, and remote supports are gaining in popularity to help people leverage and build natural support networks that help them maintain independence.

Another trend in HCBS waivers is the recognition of the dual benefit of respite services – a break for both the caregiver and the person receiving services. There has been a shift in the way that respite services are named and defined. For example, Alabama offers a service on the Community Waiver Program called Breaks and Opportunities to signal that it is a break for the caregiver and an opportunity for the person to participate in an activity outside the home (AL.1746.R00.01 2022). Louisiana offers an Individual and Family Support Service that aims to help the person "achieve and

maintain increased independence, productivity, enhanced family functioning and inclusion in the community or for the relief of the primary caregiver" (LA.0401.R04.04 2023)

In terms of helping people live more independently in the community, many states are revisiting the types of living settings that are supported. They are seeking to expand options that offer a middle ground between a family home and a more restrictive option like a group home or a nursing home. These services tend to be an expansion of supported living, shared living, or remote supported living models.

The subject of paying family caregivers has long been a complex policy issue; however, it has recently been brought into focus due to the impacts of the pandemic. Many state agencies chose to enact policies that allowed legally responsible individuals (e.g., parents of minor children and spouses) to deliver services during the Public Health Emergency (PHE) as one way to make sure that people could continue to get the supports they needed (Edwards 2023). Beyond the PHE, some states decided to create pathways to continue this practice by codifying it into waiver programs (National Association of State Directors of Developmental Disabilities Services 2023). In these cases, states had to clearly define what constituted "extraordinary care," meaning care that is above what would be normally expected of a person in that role, as well as craft safeguards to ensure that services were delivered according to the best interest of the individual and promote choice and control (National Association of State Directors of Developmental Disabilities Services 2023).

# 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 including: 1) build infrastructure for collaboration and engagement, 2) enhance networking and connecting, and 3) review services that support people and families. 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.

## Build Infrastructure for Collaboration and Engagement

One opportunity for the DHHS to consider is to build or leverage existing infrastructure to support cross-agency collaboration. This would allow the state to streamline efforts to address common issues that relate to strengthening natural supports that would be beneficial for all people with LTSS needs and those who will not be eligible for LTSS. Undergirding the effort to strengthen the natural support network, DHHS might convene a group of people with LTSS needs, families, and community to define the vision for supporting families in Utah that will result in a guiding policy statement and strategic actions to build infrastructure and collaboration to strengthen the natural support network.

To ensure that DHHS is focused on supporting people to access all of the supports that meet their needs DHHS might develop a cross-agency family and caregiver engagement staff position within DHHS leadership. Adding a position like this will ensure that a staff member is fully tasked with coordinating engagement with families and natural supports to provide needed information and education. DHHS may also consider developing interagency agreements or work groups among agencies or entities that have a role in supporting families and caregivers so that supports are as seamless as possible. This ensures that people have adequate access to whichever supports will benefit them, regardless of which state agency or community serving organization provides them. UCOA serves as an example of how such a partnership might exist to develop a shared vision, ensure that all partners are actively working toward such a vision, and creating a venue for thoughtful and collaborative action. UCOA developed A Master Plan for Aging in Utah called Utah for the Ages that outlines specific priorities, action items, and a timeline for completion (Utah Commission on Aging 2023). DHHS could potentially build on this structure between agencies and public partners to support people and families most effectively.

### *Benefits of Opportunity*

Creating an engagement director position would allow that staff member to remain focused on activities to engage with and strengthen natural support networks. Without a dedicated position, engagement activities may be one of many activities assigned to a staff role that can be stalled due to other priorities. An engagement director could have responsibilities for organizing and managing the other processes suggested under this opportunity. They could play an important role in facilitating

coordination between agencies and working with the community for creating a vision for strengthening natural support networks.

There may be models of interagency coordination that currently exist in Utah related to time-limited projects or initiatives that can be leveraged to build a more permanent structure. For example, the process and recommendations provided in the The Utah Family Caregiver Report 2022 appear to be consistent with the focus on engagement and approach provided in this opportunity (The Utah Family Caregiver Report 2022). Any work that has been done in furtherance of those recommendations in the aging sector could be leveraged and expanded to include the broader disability community.

### *Potential Barriers to Implementation*

Creating a new staff position could be a cumbersome process that relies on approval from entities within or outside DHHS. It might also be difficult to add a staff position within DHHS that would have ability to support multiple agencies depending on how FTEs are funded and distributed across agencies. Establishing cross-agency collaborative models would rely on effective facilitation to maintain focus on shared priorities. While agencies may agree with the intent of a cross-agency collaborative, discussion topics and action items should remain relevant, and members would need to see positive impacts to maintain forward momentum. Additionally, people engaged in cross agency collaboration should have ownership over specific tasks and actions so that all members are actively working toward greater continuity among programs. Infrastructure costs for developing technological means to further collaboration (e.g., 211 determining eligibility for some programs) could be costly and time intensive to develop.

### *Impact on Utah LTSS Priorities and System*

Having centralized staff support and organizing structures for cross-collaboration among agencies supporting people with similar needs will ultimately benefit the communities they serve. End-users of services are often in favor of reducing barriers caused by siloes across agencies and systems. Building this type of infrastructure and consistency in supports, will allow for sustained efforts to focus on growing natural support networks for older adults and people with disabilities and help them lead healthy lives in their communities.

# Enhance Networking & Connecting

This opportunity focuses on strengthening avenues for peer support, connection to community resources, and training for natural support networks regardless of the age of the person with LTSS needs or where they live. It was clear from the focus groups that having access to peer support opportunities across the lifespan would be beneficial.

In response, we offer the following options for consideration:

- Expand existing structures such as the Family-to-Family Network to serve as connector role.
- Expand the community mapping exercise started by DSPD that includes both eligibility-specific and generic community resources.
- Continue to fund the Waitlist Liaison program.
- Move forward on efforts to combat social isolation.

Existing structures in Utah might be well-positioned to expand their scope and reach in order to serve as a connector to the community. A first step would be to identify those entities that currently exist, such as the Family-to-Family network, to review their current scope, and add or alter functions that are more closely aligned with developing networking and connections.

DSPD previously conducted an asset-mapping exercise to identify applicable resources in the community. Hosted on DHHSs' website [Find a Community Resource](#) enables people to search for resources within their community, including advocacy oriented, peer and family supports, service providers, and other community supports. Expanding this resource to others with LTSS needs including older adults and people with mental health care needs would help all to identify peer and family supports, thus strengthening the natural support network.

While the issues surrounding the waitlist are covered in another research brief in this series (Research Brief #3: *Addressing/Eliminating the DSPD Waitlist*), we understand that there is a need for people and their families to have access to information and other resources while they wait for services. The Waitlist Liaison program was a two-year pilot conducted in collaboration with the Utah Parent Center and the Utah Developmental Disabilities Council in which a case manager helped more than 35 families figure out informal and formal supports to help stabilize families. With promising outcomes from this pilot, there is interest in expanding the program. The Utah Development Disabilities Council has requested funding this legislative session for three case managers across three different ZIP codes to continue the program.

UCOA's Master Plan for Aging identifies efforts to combat social isolation for older adults (Utah Commission on Aging 2023). While we understand that this work is in progress, combating social isolation and combatting lifelong learning opportunities will deepen connections for people with LTSS needs, strengthening the natural support network overall.

## *Benefits of Opportunity*

This opportunity will help to connect people with other people with lived experience. Having established mechanisms to help people find others who are experiencing similar circumstances can offer support that often cannot be provided within service systems, since these natural supports provide invaluable insight into not only what may available, but how to access it, and also cope with any challenging circumstances that the person or caregiver may be experiencing. They may also help to alleviate concerns and informational gaps, as well as provide information in a culturally appropriate way.

## *Potential Barriers to Implementation*

Initiatives that focus on peer support and connection can be difficult to sustain. State agencies are not always the best entities to be in a position to support connection among people that may or may not be receiving formal services. Several states, however, are actively trying to nurture these connections through the provision of information about such networks, specific staff charged with making connections amongst people and families, encouraging or paying community organizations to support connection, and actively planning to combat isolation. A formal review may be needed to determine the best methods for fostering connections.

## *Impact on Utah LTSS Priorities and System*

In order to strengthen the natural support network, DHHS cannot simply ensure that everyone who needs services gets them, DHHS must also ensure that people have a broad range of supports across the three buckets, that enable them to live healthy and full lives. Peer and family connections are a critical part of the service system that DHHS can foster and grow overtime.

# Review Services that Support People and Families

While a more in-depth review of the LTSS service array will be offered in a subsequent research brief, it is a worthwhile exercise to map the current continuum of services available to support people to live as independently as possible in the community. An important aspect here is to note that older adults and people with disabilities may experience different trajectories related to community living. For older adults, the emphasis may be on offering progressively more intense supports to help them age in place; for people with disabilities, emphasis may be placed on early intervention to acquire skills that support independent living options.

Related to this opportunity, we suggest that DHHS consider completing a review of the continuum of services available to support independent living options for LTSS populations in Utah and define clear policies and procedures for the Caregiver Compensation Program. DHHS will further the capacity of people and families by offering a broad range of supports that meet people where they are. These supports may include community navigator, peer support, self-direction, and remote supports that are matched to each person's needs. The goal is to allow the person to live as independently as possible while maximizing choice and control over supports and who provides them. The Caregiver Compensation Program was specifically cited through multiple engagements as a boon to caregivers. Going forward ensuring that the policies and procedures that are being developed to stabilize the program over-time are offered at a level that meets the needs of people receiving services and paid caregivers.

## *Benefits of Opportunity*

Examining the current service array including supported living options will help inform the direction DHHS may want to pursue to make sure that people can age in place or live as independently as possible. This review can include the types of services that might also bolster natural support network.

## *Potential Barriers to Implementation*

Adding services to HCBS waivers requires significant effort. Beyond creating service definitions and provider qualifications and standards, any additional services will require a review for fiscal impacts. In addition, steps would need to be taken to prepare the provider community to offer any new services. Changes to the Caregiver Compensation Program will likely impact families who have factored such supports into their lives (e.g., reducing work hours outside of the home in favor of providing support to a loved one).

## *Impact on Utah LTSS Priorities and System*

Ensuring that a broad range of services are available to meet people's needs and that caregivers have options to be compensated will no doubt allow people options for how the access formal and informal supports. Coupled with other opportunities, services may supplement rather than supplant natural support networks.

# Further Considerations

The opportunities presented above may work alone or in combination to strengthen natural supports within the state. With each of the opportunities suggested above, DHHS will need to carefully consider how to prioritize and make decisions about what might be the best to pursue and then identify short and long-term objectives. Some may also have a fiscal impact that will need to be accounted for in the decision-making process. In addition, it will be important to find a variety of ways to engage with the community to make sure that priorities are informed by community needs. DHHS should also ensure that any opportunities that are pursued are culturally competent and provide a range of options for people from diverse communities.

# References

AARP and National Alliance for Caregiving. 2020. *Caregiving in the United States.* Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001. 2020.

Alabama. 2022. "Community Waiver Program." AL.1746.R00.01.

Carter, Sanders, Blake, and Keegan. 2017. "Parent-to-Parent Peer Support for Parents of Children with a Disability: A Mixed Method Study." *Patient Education and Training* 1537-1543.

Chakraborti, Gitimoghaddam, McKellin, Miller, and Collet. 2012. "Understanding the Implications of Peer Support for Families of Children with Neurodevelopmental and Intellectual Disabilities: A Scoping Review." *Public Health.*

Edwards, Elizabeth. 2023. *Paying Family Caregivers: State Options, Limitations, and Policy Considerations.* National Health Law Program.

Friedman, Carli. 2023. "Natural Supports and Quality of Life of People with Disabilities." *Journal of Developmental and Physical Disabilities.*

Hecht, Elizabeth, Michelle Reynolds, John Agosta, and Kathy McGinley. 2011. *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities.* Racine, Wisc.: Report of the Wingspread Conference on Building a Family Support National Agenda.

Heller, Gibbons, and Fisher. 2015. "Caregiving and Family Support Interventions: Crossing Networks of Aging and Disabilities." *Intellectual and Developmental Disabilities* 329-345.

Kardell, Yoshiko, and John Agosta. 2017. *Setting a Fresh Course: Assessing the Impact of the National Community of Practice for Supporting Families of Indivdiuals with IDD.* National Association of State Directors of Developmental Disability Services.

Louisiana. 2023. "New Opportunities Waiver." LA.0401.R04.04.

McVilley, Keith R. , Roger J. Stancliffe, Trevor R. Parmenter, and Rosanne M. Burton-Smith. 2006. "'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness." *Journal of Applied Research in Intellectual Disabilities* 191-203.

National Association of State Directors of Developmental Disabilities Services. 2023. "Caring Families: Paying Family Caregivers Topic Brief."

Partnership for People with Disabilities, Virginia Commonwealth University. 2023. *Center for Family Involvement.* August 23. https://cfi.partnership.vcu.edu/programs/family-to-family-network/.

Petner-Arrey, Jami, Angela Howell-Moneta, and Rosemary Lysaght. 2016. *Facilitating Employment Opportunities for Adults with Intellectual and Developmental Disability through Parents and Social Networks.* Disability and Rehabilitation.

Reynolds, Michelle, Susan Palmer, and George Gotto. 2018. *Reconceptualizing Natural Supports for People with Disabilities and Their Families.* International Review of Research in Developmental Disabilities, 177-209.

Scott, A, and C. Doughty. 2012. *Care, Empowerment, and Self-determination in the Practice of Peer Support.* Disability & Society.

Thaler, Nancy. 2012. *Two States' Efforts to Strengthen their Support of Families: Supporting Individuals Living with Families is the Foundation of a Sustainable Future.* National Association of State Directors of Developmental Disabilities Services .

Utah Commission on Aging. 2023. "Utah for the Ages: A Master Plan for Aging in Utah."

Utah Commission on Aging, Special Committee on Family Caregiving (SCFC). 2022. *The Utah Family Caregiver Report.*

Utah DHHS. 2024. *Draft Implementation Plan for Caregiver Compensation as an Ongoing Service.* Utah Department of Health and Human Services, Division of Services for People with Disabilities.

Young, Natalie A.E., and Katrina Crankshaw. 2023. *The Demographics of Disability in the Family: Prevalence, Characteristics, and Implications for Financial Well-Being.* Working Paper Number SEHSD WP-2023-22, United States Census. https://www.census.gov/library/working-papers/2023/demo/SEHSD-WP2023-22.html.

# Appendix A: Plain Language Summary

## Brief 02: Strengthening Natural Supports

**Who is this brief for?**

This brief is for anyone who wants to learn about ways to increase natural support networks for older adults and people with disabilities.

**What is this brief about?**

This brief is about what is sometimes called "natural support networks". A natural support network means family members, friends, neighbors, coworkers. It can also mean supports that are meant for all members of a community.

**What did researchers find out?**

We found that there are three main areas that can help strengthen natural support networks.

1. Information
2. Peer support and networking
3. Goods and services

**What is most important to know?**

Strong natural support networks, along with services, can help older adults and people with disability live the life they want in the community.

**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.

HSRI