BRIEF #5

Utah LTSS Project

Trends for Supporting People with
Complex Medical and Behavioral Needs

November 2024

Contents

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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 HCBS 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 Brief #5, we will explore strategies for strengthening LTSS for people with complex medical and behavioral needs. 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 we have identified the following key opportunities for DHHS to strengthen LTSS for people with complex medical and behavioral needs:

- Establish Complex Care Advisory Team
- Enhance Provider Qualifications
- Update Service Array to Better Accommodate Complex Needs

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 take all research topics into consideration holistically to develop the right plan for Utah and will be outlined in our final report.

Background

Please note that the topic covered in this brief is closely tied to the topic covered in Brief #6 Supports for People with Developmental Disabilities and Mental Health Needs and each of the key opportunities outlined within this brief are also applicable to that topic as well. The research teams responsible for each of these briefs collaborated throughout the research and writing process to ensure these briefs cumulatively cover the broader topic most effectively. An underlying mental health condition is often one of the root causes of significant behaviors and, particularly for individuals with intellectual or developmental disabilities, obtaining quality mental health services and supports is often a challenge. In this brief, greater focus is placed on discussion of the needs of people with complex medical and behavioral needs; in Brief #6, we focus on discussing the needs of those with intellectual and developmental disabilities (IDD) and mental health considerations. Both topics will be further addressed as part of the final report and final recommendations will be targeted at addressing the broadest intersection of need identified through our research.

Defining Complex Needs

The definition of "complex medical needs" and "complex behavioral needs" is not standardized from state to state. The existence of a medical or behavioral support needs does not in and of itself constitute a "complex need." Everyone needs medical and behavioral support from time to time. When we say "complex needs," we are referring to needs that have a substantial impact on person's ability to complete activities of daily living (either on their own or when considered in combination with other aspects of the person's underlying disability) and which are of a seriousness or intensity that can imminently impact the health or safety of that person or others (Oliver, et al. 2022, 1141). In other words, complex needs have an identifiable impact on the day-to-day activities of a person receiving LTSS, including those with IDD, a physical disability, and older adults. It is important to note that individuals with the most complex needs often have both medical and behavioral support needs.

Utah Landscape

Under the Utah Medicaid state plan, eligible individuals can receive medical, dental, and behavioral health services through a managed care plan (in select counties only) or the fee-for-service network of providers (Utah DHHS 2024). Among services such as primary care physician services and hospital services, individuals receiving Medicaid state plan are also offered the following services up to specified limits: personal care, home health, specialized medical equipment and supplies, physical therapy, occupational therapy, speech/language therapy, audiology services, private duty nursing, non-emergency medical transportation, skilled nursing facility services and intermediate care facility services (Utah DHHS 2024).

In addition to state plan services, individuals who require the level of care provided in institutions (such as nursing facilities or intermediate care facilities for individuals with intellectual disabilities (ICF/IID)) may also receive certain LTSS through home and community-based service (HCBS) waivers. Utah currently operates nine HCBS waivers across three divisions—DIH, DAAS, and DSPD. Each HCBS waiver is targeted to serve selected individuals and offers unique services to these targeted individuals. The mechanisms and supports available for addressing complex needs vary in

Utah depending on whether the person has primarily complex medical needs or primarily complex behavioral support needs.

The *New Choices Waiver*, *Medically Complex Children's Waiver*, *Waiver for Technology Dependent, Medically Fragile Individuals*, *Waiver for Individuals Age 65 or Older* and the *Physical Disabilities Waiver* appear to be primarily designed to address individuals' medical needs and generally do not offer behavioral supports. The *Community Transitions Waiver*, *Community Supports Waiver*, *Acquired Brain Injury Waiver*, and the *Limited Supports Waiver* appear to be primarily designed to address individuals' behavioral needs with limited supports for complex medical needs.

However, it is important to note that often people with the most complex needs do, in fact, have both medical and behavioral support needs. Across the entire LTSS system in Utah there is a wide variety of services, but the availability of services within individual waivers do not adequately address the full range of needs of these individuals. For example:

- While everyone has access to state plan nursing services, only two of Utah's nine HCBS waivers offer access to skilled nursing services on an extended basis (one paired with home health and the other paired with medication monitoring). Two other waivers offer a combination of home health and medication monitoring, while two others offer only medication monitoring. More extensive coordination and support from a nursing professional is essential to ensuring good health outcomes for individuals with complex needs.
- Residential supports are limited to one medical-focused waiver and three behavioral-focused waivers. Residential Habilitation does not include medical/health care services. It is our understanding that that individuals with the most complex medical needs in Utah have no community-based residential support options other than living with family and only two facilities in the state can support their level of medical need—South Davis Hospital and NeuroRestorative Utah.
- Remote support monitoring services are only offered through one IDD waiver.
- Only four waivers offer behavioral consultation or supports—three IDD waivers and one traumatic brain injury waiver. However, behavior is a key form of communication for many people with all types of disabilities and understanding that communication is essential to providing quality support.

Finally, individuals receiving Utah Medicaid services have access to certain case management services through both the state plan (dependent upon diagnosis) and HCBS waivers (dependent upon level of care). Case management services are typically intended to assist participants in gaining access to needed waiver services and other Medicaid State Plan services, as well as needed medical, social, educational, and other services, regardless of the funding source. However, such case managers are not typically equipped to handled coordination of services and supports for complex needs.

Research Findings

To inform our understanding, we gathered information through community engagement activities, focus groups, and key informant interviews with people in the state to understand the most pressing issues facing those with complex medical and behavioral support needs in Utah today. We also sought peer-reviewed research related to supporting those with complex needs and reviewed promising practices being operationalized to address these identified needs. An overview of these research findings is provided below.

Engagement Themes

Throughout our engagement with people receiving LTSS, families, and providers we received feedback about a number of challenges faced by people with complex needs and their families and supports. Primary themes shared included:

- Services within and outside of DHHS (e.g., mental health care system) are often fragmented and siloed with numerous barriers to information sharing.
- There is a lack of community-based residential support options (outside of living with family) for individuals with complex medical and/or behavioral needs.
- Behavior support is needed by many individuals but is often inaccessible. Further, behavior support services are not offered to those who also present with complex medical needs.
- There is a desire for increased quality in the HCBS services being provided. The current standards and expectations for new and existing HCBS providers appear insufficient.

Individuals receiving LTSS with complex needs in Utah report that they often find themselves embedded in multiple service sectors. This demands effective coordination across behavioral health, disability, and health care sectors but such coordination is consistently challenging and sometimes lacking. A Utah listening session participant shared, "We need case workers to help coordinate care through multiple areas of care—medical, behavioral, financial, social, pharmacy."

In addition to coordination and collaboration across DHHS and other sectors, it is essential that all providers serving people with complex needs have knowledge and skills to provide quality care. As one individual, speaking about people with complex needs, reported, "Finding qualified staff and retaining qualified staff is extremely difficult."

People with complex needs generally use more health services and require care from more and different professionals. A more intensive multidisciplinary approach to care that integrates medical/health, social, and behavioral health across various sectors remains a current challenge in Utah. As one listening participant commented, "You can find a provider that can do behavioral or medical needs, not both." Another participant noted, "When you have complex needs, you are refused by most programs." Often people with complex needs must present to an emergency department to receive essential care which are also ill-equipped to effectively address their needs.

Finally, it should be noted that people with complex needs living in rural areas face all of the above mentioned challenges, but often to a greater degree due to geographic isolation.

Other States' Strategies for Supporting People with Complex Needs

Comprehensive Care Coordination

Because people with complex needs generally receive more services as compared to those with lower support needs and their services are often provided by multiple health professionals and social service agencies, it can be particularly challenging to ensure that all of a person's supports work well together (Rich, et al. 2012). When their supports are not appropriate and/or well-coordinated it results in fractured care and increases the likelihood an acute need will arise that requires reliance on broader public resources. This may look like accessing emergency room services due to a medical need (Chase, Bilinski and Kanzaria 2020) or calling the police or other type of response team during a behavioral health crisis. Emergency room personnel and law enforcement are rarely well equipped to address the confluence of these complex needs; reliance on these public resources can result in costly medical expenses, ongoing involvement with the criminal justice system, or worse (Tuzzio, et al. 2021). Even though individuals with complex needs comprise a small portion of all HCBS recipients, the costs associated with meeting their needs make them a particularly important population to understand and effectively support (Dinora, Bogenschutz and Broda 2020).

Effective care coordination across the health care and social service sectors is a critical systems-level response to effectively meeting complex needs and reducing fragmented care (Albertson, et al. 2022). This requires collaboration, communication, and advocacy across provider systems (Albertson, et al. 2022). Different states and organizations have addressed this need for complex care coordination in different ways.

In Georgia, nearly 2,000 people with complex needs have been enrolled in Intensive Support Coordination (ISC) and receive specialized coordination of waiver services and medical and behavioral support services (Georgia DBHDD 2024). In addition to the traditional support coordination service, intensive support coordinators assist ISC participants in overcoming access barriers to care, securing needed resources through the waiver and the larger health care system, and developing important relationships and supports (Georgia DBHDD 2024). ISC coordinators have small caseloads (<20 people), conduct monthly in-person visits, receive clinical supervision from a registered nurse or licensed behavioral professional, and have at least a bachelor's degree in the human services field (Georgia DBHDD 2024). In San Francisco, a local hospital recognized that "the percentage of patients experiencing complex social and medical needs [had] risen significantly in recent years because they have no place else to go for the variety of complex needs they face" (San Francisco General Hospital Foundation 2021). To improve care delivery, the hospital established an emergency department social medicine (EDSM) team that included a patient navigator, social workers, care coordination nurses, a pharmacist, physician consultants, and specialists in transitional care, substance use, and quality improvement experts (Chase, Bilinski and Kanzaria 2020). The EDSM team members developed interdisciplinary workflows to integrate care by reviewing electronic health records of individuals with complex needs and rounding in the emergency department to elicit necessary referrals from clinicians and to connect individuals to appropriate social services (Chase, Bilinski and Kanzaria 2020). In New Hampshire, the University of New Hampshire's Disability and Health Program created a Responsive Practice Training series that includes two free, online, self-paced modules for health professionals to develop the skills and knowledge needed to provide

disability-competent care (NH Institute on Disability 2024). While open to all health professionals, the course specifically offers free continuing education credits to physicians, nurses, and pharmacists who complete it (NH Institute on Disability 2024). The modules focus on providing health care and screenings to persons with disabilities and engaging in effective, adaptive communication (NH Institute on Disability 2024).

Provider Qualifications and Competency

While the Centers for Medicare & Medicaid Services (CMS) give states significant flexibility regarding the expectations and qualifications of those providing services, states are required to specifically outline the qualifications they have established and how they ensure those expectations are being met. Through its HCBS settings rule and recent access rule, CMS has demonstrated increased expectations regarding the quality of long-term services and supports. Further, research indicates that professionals providing direct supports to people with complex needs must be equipped with enhanced skills and knowledge to deliver effective care (Kuluski, et al. 2017).

States have taken different approaches to ensure DSPs have the requisite skills and knowledge to support individuals with complex needs, including requiring DSP's to have a college degree (e.g., bachelor's, master's, or Ph.D.), requiring extensive on-the-job experience supporting individuals with complex needs, and/or requiring additional/ongoing training. Pennsylvania offers a separate DSP credential for people who are able to support people with IDD and behavioral health needs. Raised provider expectations are an important component of ensuring quality supports but must be accompanied by the necessary tools to meet those expectations. Such tools might look like higher rates to offset the overhead costs of additional general training or hands-on individual-specific training but can also look like state technical assistance to providers or trainings offered or developed directly by the state (or its proxies) to ensure the expectations of providers are being clearly and consistently communicated.

Iowa Medicaid provides training and support to LTSS providers and case managers. Various LTSS service providers, including, but not limited to home-based programs, habilitation services, nursing/personal care, elderly care, and case management can access this free competency-based training and technical assistance (TA) to enhance positive outcomes (Iowa HHS 2024). This support helps providers understand compliance with state and federal regulations, details expectations of direct support roles, and enhances statewide access to information (Iowa HHS 2024). LTSS providers can submit TA requests "which may include tailored education and support based on their specific needs" (Iowa HHS 2024).

Service Offerings that Support Individuals with Complex Needs

Nursing and Nursing Oversight

As stated in the background information above, more extensive coordination and support from a nursing professional can be essential to ensuring good health outcomes for individuals with a combination of support needs. Research has shown that "nurse-led care coordination interventions proved effective in improving access to appropriate treatment; reducing costs; [and] improving clinical outcomes and quality of care" (Karam, et al. 2021).

More than 18 states (including California, Georgia, Idaho, Montana, Oklahoma, and Virginia) offer skilled nursing services across waivers targeting both IDD and Aged/Disabled populations. Additionally, Indiana offers a service titled "Integrated Healthcare Coordination," which promotes

improved health status and quality of life, delay/prevent deterioration of health status, manage chronic conditions in collaboration with physicians, and integrate medical and social services. More specifically, this service provides for the development and oversight of a health care support plan which includes coordination of medical care and proactive care management of both chronic diseases and complex conditions such as falls, depression and dementia.

Residential Supports

Increasingly, new residential models are being considered for people with complex needs, especially considering the HCBS Settings Rule that requires that people receiving LTSS live in the home of their choice and have access to the benefits of community living. Research shows that smaller living arrangements integrated in the community contribute to better outcomes for people with and without complex needs as opposed to institutional care or larger congregate settings (Kozma, Mansell and Beadle-Brown 2009).

The Green House model is one such residential model of long-term care for older adults. Green House homes are small (10-12 residents) residential-style houses located in community neighborhood that emphasize a day-to-day organizational structure that places residents at the center of all decision-making (Cohen, et al. 2016). Additionally, staff are cross-trained to assist with personal, clinical, and home care activities with an emphasis on empowerment and relationship building (Cohen, et al. 2016). While there has been limited formal research conducted on Green House homes, studies reveal some positive effects, including improved resident quality of life in specific domains (e.g., privacy, dignity, autonomy), increased resident and family satisfaction, and less decline in activities of daily living (Kane, et al. 2007).

Remote Supports

Technological supports (e.g., smart-home technologies, remote support services) offer innovative opportunities for states to advance their commitment to supporting the autonomy and well-being of persons with complex needs. Consistent with the philosophy of person-centered practice, the use of technologies can contribute to increased independence, self-direction, privacy, and personal sense of security and safety for people with complex needs. Increasingly, people with disabilities are indicating the benefits of these types of support. (Tassé, Wagner and Kim 2020).

As a secondary benefit, technology supports can supplement and even enhance the role of direct support professionals (DSPs) (Tanis, et al. 2023). The addition of technology allows for individuals to maximize opportunities for support and allows DSPs to apply their skills and expertise where most needed (Tanis and ANCOR 2021). This is particularly valuable given the current DSP workforce crisis (Tanis, et al. 2023). "The primary goal of remote support services is not to replace DSP workers. Rather, it is intended as an element of the services/supports options to promote independent living and leading a self-determined life for adults with IDD. Being able to reduce the need for DSP worker hours in one area allows more flexibility to shift these resources to support individuals for whom have a DSP worker may be more critical to their health and safety" (Tassé, Wagner and Kim 2020). In many circumstances, persons with complex needs can benefit from a combination of remote and in-home supports to maximize their opportunities across environments (Tanis and ANCOR 2021).

Remote support services are not limited to a single device or tool or type of technology, but rather represent a variety of services tailored to the individual's needs and preferences (Tanis, et al. 2023). They can include specialized use of monitors, sensors, cameras, and computers to aid individuals

from a distance in living more independently (Tanis, et al. 2023). Wide ranging they can include more basic tools like personal assistants (e.g., Alexa), digital door locks, and video doorbells to more advanced sensor-based tools to detect risks to safety, such as fall risk prevention, appliances unintentionally being left on, or to alert remote staff to possible health concerns (Tanis, et al. 2023).

Ohio was one of the first states to successfully implement the use of remote supports into its HCBS waivers (ODDD 2024). In their 1915(c) HCBS waiver, Ohio defines remote supports as follows:

> *Remote support is the provision of supports by staff at a remote location who are engaged with the individual through technology/devices with the capability for live two-way communication. ... Individual interaction with the staff person may be scheduled, on-demand, or in response to an alert from a device in the remote support equipment system. Remote supports allow for an individual to choose the method of supportive caregiving which best suits their needs. In this way, remote supports help ensure an individual's rights of privacy, dignity, and respect, as well as freedom from coercion in that individuals now have a different method of receiving care.*

Under the state's Technology First Initiative, remote supports are considered as the first option for support before considering in-person staff support (ODDD 2024). Additionally, this initiative aims to help people with disabilities and their families learn more about how to use technology to improve their quality of life and experience increased freedom and self-sufficiency (ODDD 2024). Since implementation, Ohio has seen a significant increase in the number of people receiving LTSS using supportive technology (ODDD 2024). Additional information on how Ohio has implemented remote supports can be found at: Remote Support | Department of Developmental Disabilities (ohio.gov).

Positive Behavior Support Across the Lifespan

People with and without disabilities of all ages can benefit from receiving positive behavior support (PBS). Complex behavioral needs can occur as a result of many factors, some internal and others external. For example, behaviors can be an expression of medical needs (e.g., physical pain), mental health conditions (e.g., anxiety), or a response to one's environment (e.g., abuse, neglect, isolation, trauma) (Poppes, van der Putten and Vlaskamp 2010). For many people with significant disabilities, behavior is commonly used to communicate unmet needs, feelings, or preferences. Additionally, research suggests that people with IDD are at a higher risk than people without disabilities for developing complex behaviors, such as aggression, self-injury, and property destruction (Dunlap and Carr 2007, 469), as well as co-occurring chronic illnesses (Morin, et al. 2012, 455).

Positive behavior support helps people with complex needs to develop new behaviors and skills that are more socially effective, so that they can better learn, reach their goals, and participate in their communities. This approach is individualized and flexible, allowing it to benefit persons with varying diagnoses, needs, and challenges and can be provided across environments (e.g., work, community).

In Virginia, the state is seeing the value of providing PBS via alternate modalities such as telehealth in order to support individuals with complex needs and those who would otherwise be unable to access such support. The use of behavior support via telehealth can include a variety of interventions from teaching communication skills to addressing challenging behavior (Simacek, Dimian and McComas 2017). It is important to stress, however, that the telehealth modality is not meant to replace in-person support, but rather compliment it or decrease access barriers to those who experience challenges in accessing a provider or who may struggle with in-person support.

Opportunities for Change and Further Considerations

Based on the above research findings that emphasize best practices, we have identified three potential opportunities for change to strengthen LTSS in Utah for people with complex needs. Opportunities that we believe may be well-suited for implementation in Utah include (1) increasing collaboration and competency building across providers and systems (2) facilitating innovative residential and remote supports, and (3) increasing access to positive behavioral supports across the lifespan. 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.

Establish a Complex Care Advisory Team

The state should consider establishing a complex care advisory group to make recommendations for effectively meeting individuals' complex needs and reducing fragmented care. This group could meet quarterly, as well as on an ad-hoc basis as needed, and its membership should represent (1) HCBS subject matter experts from each DIH, DAAS, and DSPD, (2) Medicaid medical/pharmacy/mental health services experts from DIH, (3) social services experts from Division of Family Health, Division of Child and Family Services, and Juvenile Justice and Youth Services, (4) individuals with complex needs and their families from Utah, (5) Utah providers of complex care in Utah (including (i) at least one emergency department physician/nurse and (ii) a representative from the Utah State Developmental Center (USDC) or a private ICF/IID, and (6) training officials for law enforcement officers.

This advisory group could be tasked with:

- Being a resource for and consulting with person-centered planning teams regarding the best ways to support individuals who present with a high degree of clinical complexity
- Developing procedures for efficiently coordinating complex care across divisions
- Reviewing policies and program designs at the DHHS divisional level to identify gaps and inefficiencies in responding to individuals with complex needs
- Making recommendations for policy and program design changes, including establishing competency expectations for service providers who support individuals with complex needs
- Developing informational briefs and training opportunities for external entities (such as law enforcement and ED health care providers) on effectively responding to individuals with complex needs.

Benefits of Opportunity

A multidisciplinary team approach to care coordination has been shown to both improve outcomes for individuals with complex needs (Chase, Bilinski and Kanzaria 2020) and reduce health care expenditures over time for this same group of people (Unützer, et al. 2008). Through direct

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consultation with individuals and their planning teams, the advisory team would be well-positioned to make recommendations for future policy changes within the state regarding complex needs services and supports. Further, such a team provides opportunity for DHHS staff, other professionals, and individuals with lived experience to collaborate to improve care coordination and services for individuals with complex needs.

Potential Barriers to Implementation

Implementation of this opportunity would require dedicated time from state staff to coordinate and administer this advisory team. Coordination and alignment of policies across DHHS divisions may be difficult due to siloed funding streams, data-sharing challenges, inconsistencies with outcome measures, and varied goals and priorities. Additionally, prior establishing this group, the state would likely need to (i) conduct a comprehensive review of statutes and administrative rules to identify necessary changes (if any), and (ii) seek legal advice whether such a group would be subject to the state's Open and Public Meetings Act (OPMA).

Impact on Utah LTSS Priorities and System

Establishing a complex care advisory group would support Utah's efforts to increase case management options for people with complex medical or behavior support needs and greater coordination of care among sectors.

Enhance Qualifications for Providers Supporting Individuals with Complex Needs

The state should consider enhancing current provider qualifications, with a particular focus on providers supporting individuals with complex needs. The state could conduct a thorough review of the existing Medicaid provider qualifications in place in the state and comparing and contrasting these expectations with those in place in states that have been identified as serving individuals with complex needs most effectively. Provider qualifications are specifically outlined in each Medicaid waiver and may be updated through an amendment or during a required renewal period. It may also be necessary to update Utah administrative code if the broad landscape of Medicaid provider qualifications is going to be revised.

Utah could also consider pairing use of a 1915(b)(4) with existing 1915(c) waivers to engage in selective contracting for services that are specifically designed to accommodate the needs of those with the most complex needs. This would allow the state to put out a request for proposal from providers with specific requirements identified as being needed to meet the unique and specialized needs of this population that go above and beyond the general Medicaid provider qualifications. Multiple contracts could then be awarded to ensure an adequate network of providers and that individuals have choice while better ensuring the health and safety of these individuals. This would allow the state to ensure that only those providers who have demonstrated the necessary skillsets were engaged and would allow the state to provide additional oversight of these providers through the specified contract.

Benefits of Opportunity

Enhancing the qualifications for providers would have the benefit of improving service quality broadly, not just for those with complex needs. Use of a 1915(b)(4) selective contracting waiver would allow the state to ensure that only those providers who have demonstrated the necessary skillsets to meet the additional needs of those with complex needs were engaged and would allow the state to provide additional oversight of these providers through the specified contract. Such a targeted approach would also open up the opportunity to ensure that any enhanced funding or rates meant to accommodate these complex needs were truly met with enhanced skills.

Potential Barriers to Implementation

Enhancing the qualifications for providers supporting individuals with complex needs may be opposed by the provider community, especially increased expectations not supported through enhanced reimbursement rates. For this reason, the state may also want to consider enhancing reimbursement rates (as needed) to accommodate these newly increased qualifications. Using a 1915(b)(4) brings additional administrative effort including developing an RFP, going through the selection process, and additional contractor oversight. Finally, there may not be ready provider pool to meet the enhanced qualifications, and such training and knowledge/skill acquisition takes time.

Impact on Utah LTSS Priorities and System

Enhancing the qualifications for providers supporting individuals with complex needs would support Utah's efforts to improve the quality of HCBS provided to individuals with complex needs.

Update Home and Community-Based Service Offerings

The state should consider modifying and updating its service offerings to better accommodate individuals with complex needs. Such modifications could include:

- Improving Access to Nursing and Nursing Oversight. While everyone has access to state plan nursing services and some waivers offer additional nursing services, other waivers such as the Community Supports Waiver, only provide Professional Medication Management. Improving access to nursing and nursing oversight could include modifying the way nursing services are made available to individuals in all waivers, ensuring that the relationship between state plan nursing services and waiver services is seamless (e.g., nursing services as extended state plan services), or adding integrated health care coordination as part of the state's waiver service offerings.
- Expanding Community Residential Options. Institutional settings should not be the only option for individuals who require residential supports and have complex needs. Expanding community residential support options could include expanding access to existing residential supports across waivers or adding new residential support models as part of the state's waiver service offerings.
- Expanding Access to Remote Supports. Remote supports can be maximized to offer those with the most complex needs greater independence by using technology. Expanding access could include offering line of sight supervision while still offering space to those with significant behavior needs or adding remote support services across the state's waivers. Implementation would require Utah to determine the specific service definition and full scope of remote supports. Notably, Utah Administrative Code R539-3 on Rights and Protections

states that remote supports can be used as part of the person-centered support plan and therefore do not constitute a privacy restriction. Similarly, R539-3 indicates that with proper consent and safeguarding providers "may use electronic surveillance in the least intrusive manner possible to meet a health or safety concern" (e.g., signed informed consent, human rights committee approval, signage in the home that indicates remote support use).

- <u>Improving Access to Positive Behavior Supports</u>. Behavior consultation as a service is currently limited to three of Utah's HCBS waivers. Improving access to behavioral supports could include adding positive behavior supports across the state's waivers or allowing behavioral supports to be provided via telehealth.

Benefits of Opportunity

Updating its service offerings, would help the state to better accommodate individuals with complex needs. First, more extensive coordination and support from a nursing professional can be essential to ensuring good health outcomes for individuals with a combination of support needs. Second, expanding residential support options can increase individual autonomy and reduce utilization of institutional services. Additionally, remote supports have been shown to enhance self-determination, personal safety, privacy, and autonomy, particularly for those with intellectual and developmental disabilities. For older adults, the use of remote supports can decrease isolation, enhance social connectedness, improve wellness, and prevent health crises (Brent and Tanis 2020). Finally, the addition of behavior supports across all waivers could improve communication (and ultimately health outcomes) for many people with all types of disabilities, as well as reduced use of physical restraints to manage behavior (Singh, et al. 2016). Additionally, the provision of behavioral supports via telehealth could be particularly useful for those with complex needs living in Utah's rural and frontier areas. Specifically, positive behavior support provided via telehealth is being shown to reducing challenging behaviors and increasing access to care for those residing in rural areas who lack access to trained providers (Ferguson, Craig and Dounavi 2019).

Potential Barriers to Implementation

Updating the state's home and community-based service offerings could increase the cost of providing such services. However, introducing individual budget limits to services (as discussed in Brief #4: Payment Models) could be one way of mitigating the increased costs while ensuring that individuals have equitable access the services they need. Additionally, these updates would likely require an expanded network of providers or risk compounding existing provider shortages. Finally, the utilization of telehealth for behavior supports bring challenges related to "provider and enrollee training, internet connectivity, privacy of personal information, and technology costs" (OIG 2021).

Impact on Utah LTSS Priorities and System

Updating the state's home and community-based service offerings would support Utah's efforts to improve the quality of HCBS provided to individuals with complex needs, increase residential service options for individuals with complex needs, decrease reliance on institutions, and increase access to services for people living in rural areas.

Further Considerations

In addition to the barriers discussed above, HSRI recommends DHHS consider whether any opportunity may have the impact of imposing stricter eligibility standards, reducing the amount duration or scope of services, or devising lower provider rates. Changes with such impacts may be interpreted as a violation of the Section 9817 maintenance of effort requirements under the American Rescue Plan Act of 2021 (ARPA) that would require the state to return ARPA funds to the federal government. This risk can be mitigated by ensuring proposed changes are not implemented prior to the state of Utah expending all funds attributed to the increased federal medical assistance percentage made available through that legislation. DHHS should also consider the amount of time needed to complete Legislative and Regulatory Changes to effectuate proposed changes.

Finally, HSRI acknowledges that this research topic overlaps several other topics, such as, Supports for People with Developmental Disabilities and Mental Health Needs, Recruitment and Retention of Quality DSPs, Long-Term Services and Supports Array, and Medicaid LTSS: Structure and Funding. Recommendations in the final report will consider these topics holistically.

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Appendix A: Plain Language Summary

Brief 5: Trends for Supporting Individuals with Complex Medical and Behavioral Needs

Who is this brief for?

This brief is for anyone interested in learning about ways to support people with complex medical or behavioral needs in Utah.

What is this brief about?

Often individuals with the most complex needs have both medical and behavioral support needs. This brief explores ways that Utah can better support these people in the community.

What did researchers find out?

Many states have made progress in supporting people complex medical and behavioral needs. Improving care coordination, enhancing qualifications for providers, and updating the HCBS waiver service offerings are ways that Utah can begin to provide better supports.

What is most important to know?

Utah can take actionable steps to better support people with complex medical and behavioral needs to improve their outcomes while receiving services in the community.

Where can I learn more about this?

To learn more, reach out to our Project Coordinator Jasmine Hepburn at jhepburn@hsri.org or visit the project webpage.

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