WAITING LIST MANAGEMENT STRATEGIES

Report for Social Services Appropriations Subcommittee

utah department of human services
SERVICES FOR PEOPLE WITH DISABILITIES

UTAH DEPARTMENT OF HEALTH
MEDICAID
A Bridge to Wellness for Utah's Vulnerable

Abstract

As a result of legislative intent language during the 2018 general session, the Division of Services for People with Disabilities (DSPD) conducted a study on effective waiting list management. This study found that 27,206 additional Utahns with disabilities (79.3% children) would need DSPD services by the year 2030. In an effort to provide the right scope of services for each individual, DSPD developed an optional management strategy that would implement two additional 1915(c) Medicaid waivers. Expenditure projections predict that enrolling 27,206 new Utahns with disabilities into the system, as currently designed, would cost $628,820,000 General Fund. In contrast, the cost to support all 27,206 new enrollees under the draft option is $314,940,000 General Fund. The draft option cost outlined in this report includes: the state portion of waiver services, a 17.6-22.2% increase to services targeted for improved accessibility, a 2% cost of living adjustment, new people accessing Medicaid State Plan services, and administrative costs. Stakeholder input was obtained through initial focus groups, final public webinar presentation, and survey follow-up. Prior to implementation of any new waivers, the Department of Human Services (DHS)/DSPD would work closely with people with disabilities, their families, Department of Health, providers, support coordinators, the legislature, and other stakeholders to ensure that the elements of service design match the will of its constituents.

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Background

The 2018 General Session HB2 intent language requested research on effective waiting list management strategies. Eleven areas were identified for data analysis:

1. identification of barriers to access for needed services;
2. identification of needs to better understand the demand for those services and how the need can be met by private contract providers and state agencies;
3. a description of how to maximize federal matching funds and other funding sources that may be available;
4. a report on the number of people needing various types of services including an estimate of the number of people who need services but are not currently on the waiting list;
5. an estimate of the number of people who would become eligible to be on the waiting list each year for the next ten years;
6. a proposal for ways to target available funds to the most beneficial services and how providing limited benefits to some people could allow more people to be served;
7. limitations that need to be considered, such as federal requirements, noting areas where waiver authority could be reasonably requested and granted;
8. steps that could be taken to make sure that only those who truly need government support are determined to be eligible;
9. a projection of costs associated with providing services to individuals identified in the study;
10. a discussion of innovative and creative ways that private partners and charities could work with the program to meet those needs; and
11. any other considerations related to effective management strategies for the DSPD waiting list.

The report includes reporting requirements received during the 2017 Interim Session, in a Legislative Fiscal Analyst *Budget Deep-Dive Into Disability Service Provider Rates* that examined payment rates available to community disability service providers, as well as, recommended four legislative actions regarding the Utah public disability services system. Legislative Action #4 tasked the Division of Services for People with Disabilities to examine cost-containment strategies implemented by other states - including cost limits, service or hourly limits, geographical limits, and transitioning to managed care - and report during the 2018 Interim on the potential for long-term savings, improved care, and ability to serve more people within the same budget.

Medicaid Long-term Service and Support Authorities

Medicaid acts as the primary funding source for long-term services and supports (LTSS), which are predominately accessed by seniors and people with disabilities. States have some flexibility in the design of their Medicaid programs. Federal regulation requires state Medicaid programs to cover some services as mandatory benefits, while other services are considered optional. Under its "Medicaid State Plan," each state must provide services such as inpatient hospitalization, physician services, home health services and institutional care as mandatory benefits.

As optional Medicaid benefits, states can choose to provide LTSS as home and community-based services (HCBS) through a variety of regulatory authorities, each proffering a unique set of elements to customize a state's LTSS delivery system. The most commonly used authority to deliver HCBS as an alternative to institutional care is found in section 1915(c) of the Social Security Act. Programs delivered through 1915(c) authority are commonly known as "HCBS waivers." Through HCBS waiver authority, states have flexibility to target the population to be served, place a cap on the number of individuals served, restrict services to a geographical location, and allow different income and asset rules to determine eligibility for the waiver population. Other regulatory authorities will be discussed later in the report. *See* Description of Funding.

HCBS Waivers Operated by DSPD

The Utah Department of Health (UDOH) is designated as the Single State Agency for the Utah Medicaid program. In its coverage of HCBS waivers, UDOH must maintain final administrative oversight of all HCBS waivers, but has discretion to designate a separate state agency, known as an "Operating Agency," to perform day-to-day waiver administration and operations. UDOH has designated the Division of Services for People with Disabilities (DSPD) as the Operating Agency for four of Utah's eight HCBS waivers: Community Supports Waiver (CSW), Acquired Brain Injury Waiver (ABIW), Physical Disability Waiver (PDW) and Medicaid Autism Waiver (MAW).

The mission of DSPD is to promote opportunities and provide supports for persons with disabilities to lead self-determined lives. To that end, DSPD provides support to 5,917 individuals in home and community based settings, and maintains a waiting list of 3,000 individuals. Each person receiving services participates in person-centered planning which offers them choice of setting, services, and support coordinator.

The CSW serves the majority of individuals receiving Medicaid HCBS waiver services in Utah. It provides a comprehensive array of supports across the lifespan. The CSW serves individuals with a qualifying intellectual disability or related condition diagnosis. While individuals served in the CSW and ABIW have the option to use provider based and self-administered services, individuals served in the PDW only have the option to receive self-administered services.

CSW eligibility criteria consists of two components: evidence of intellectual disability or a related condition during the developmental years that results in the individual meeting ICF/ID level of care, and, at least, three functional limitations in a major life activity (i.e., self-care, receptive/ expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency). R539-1-4. An intellectual disability diagnosis captures the individual's overall intellectual functioning based on severity of limitation in social, conceptual, and practical skills expected of peers. Generally, an intelligence quotient (IQ) of 70 or less significantly correlates with intellectual disability. Related conditions consist of various genetic syndromes,

seizure disorders, brain injuries, autism spectrum conditions (ASC)[1], neural tube defects, cerebral palsy, etc. Disability onset must be within the developmental years, typically before age twenty-two.

The Acquired Brain Injury Waiver serves persons, eighteen years of age and older, with acquired brain injuries. Injuries must cause substantial limitations in, at least, three cognitive abilities or physical functions, and result in the individual meeting nursing facility level of care. Individuals have the option to use the same comprehensive provider based and self-administered service array as the CSW, as well as, a diagnosis specific, cognitive retraining service.

The Physical Disability Waiver provides self-administered services designed to assist people to remain in their own home, and financial management services to perform payroll administration. Persons must be eighteen years of age or older, and capable of managing their own attendant services, finances, and legal matters. Eligible physical disabilities must result in a permanent functional loss of two or more limbs and result in the individual meeting nursing facility level of care.

The Medicaid Autism Waiver provides services to children, up to seven years old, with ASC. With recent CMS guidance requiring state Medicaid programs to cover ASC-related services to individuals under 21 as an Early Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, the waiver will be discontinued at the end of state fiscal year 2019, when the last of the children originally enrolled in the program turn seven years old. Accordingly, individuals served in this waiver are not the focus of this report.

Barriers to Service Delivery

(1) identification of barriers to access for needed services;

The disabilities targeted by HCBS waivers operated by DSPD are persistent, not static. Individual assistance needs fluctuate across the lifespan, as a reflection of the complex relationships between biological, psychological, social, and physical environments.[2] Eligible persons seek assistance to lead multidimensional lives readily experienced by their non-disabled peers, which consist of autonomy, self-determination, inclusion, and dignity of risk. For many people, achieving that goal requires assistance beyond what their natural support system can provide. A self-determined, interdependent life prioritizes the person's autonomy and choice, which can be achieved regardless of intellectual ability. IQ does not predict ability for self-determination, rather, choice-making opportunity and mindset does.[3] The more opportunity afforded a person to make life choices, the more likely the person will participate in making life choices.

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[1] Simon Baron Cohen et al, *Prevalence of autism-spectrum conditions: UK school-based population study*, 194 British J. Psychiatry 500 (2009). (We favour use of the term 'autism-spectrum condition' rather than 'autism-spectrum disorder' as it is less stigmatising, and it reflects that these individuals have not only disabilities which require a medical diagnosis, but also areas of cognitive strength.); *See generally*, Simon Baron Cohen, *Editorial Perspective: Neurodiversity - a revolutionary concept for autism and psychiatry.*, 58 J. Child Psychol Psychiatry 744 (2017); Morton Ann Gernsbacher, *Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma*, 58 J. Child Psychol Psychiatry 859 (2017); Lorcan Kenny et al., *Which terms should be used to describe autism? Perspectives from the UK autism community*, 20 Autism 442 (2016).

[2] Fla. Developmental Disabilities Council, Guidelines for Understanding and Serving People with Intellectual Disabilities and Mental, Emotional, and Behavioral Disorders (2009), *available at* http://www.nasddds.org/uploads/documents/Florida_DD_Council_Guidelines_for_Dual_Diagnosis.pdf.

[3] Cynthia R. Chambers et al, *Self-Determination: What Do We Know? Where Do We Go?*, Exceptionality (2007) *available at* https://www.tandfonline.com/doi/abs/10.1080/09362830709336922. Michael Wehmeyer affiliates with the Kansas University Center on Developmental Disabilities (UCEDD). The Kansas UCEDD is one of a five member leadership consortium for the National Training Initiative that created the National Gateway to Self-Determination. A copy of slides describing the research findings are *available at* http://www.aucd.org/docs/SD-WhatDoWeKnow.pdf; Travis Bradberry, *Why Attitude Is More Important Than IQ*, Forbes (2016).

Housing

Affordable housing matters to people with disabilities.[4] Residence type influences access to employment and type of employment gained. People living in their own private home or apartment have the best chance of securing paid community work[5]; but "[n]owhere in Utah can the median person with a disability afford the median gross rent."[6] Nationally, 20.9 percent of people with disabilities live in poverty.[7] The intersection of housing security and competitive employment influences long-term individual financial outcomes. It is difficult for people with disabilities to obtain affordable housing when Social Security Income (SSI) is their sole source of income and local housing authorities have no or limited funding assistance available.

Until recently, little data tracked the relationship between ID/DD and homelessness. In 2011, research identified below-average intellectual functioning as a risk factor for homelessness.[8] Researchers in the United Kingdom (UK) published the first peer-reviewed study investigating a link between autism spectrum conditions and homelessness in April 2018. Results indicate 12.3 percent of the UK homeless population screened positive for a "range of autistic traits consistent with meeting DSM-5 diagnostic criteria."[9] The research team anticipates the results to underestimate prevalence and noted that the sample did not include persons without stable accommodation, also known as the "hidden homeless." Preliminary data from an on-going research study in Canada shows a ten percent prevalence rate of intellectual, developmental, and learning disabilities among homeless youth.[10]

Self-advocates ask for affordable housing to bolster their access to integrated support.[11] Affordable, non-congregate housing can reduce overall program expenditures and capitalize on service provision through technologies that increase self-determination.[12] Assistive technology, *e.g.* communication devices and remote monitoring, and mechanical adaptations, *e.g.* lifts and ramps, tick the boxes for health and safety assurances without restricting rights or diminishing autonomy.[13] Portable technologies also improve independent navigation of the community and employment opportunities.

System Barriers and Needs Identified by Focus Groups

People with disabilities, families, self-advocates, support coordinators, providers, and advocates each have a unique and valuable perspective on the barriers and obstacles faced, every day, by people with disabilities and their families. Each of these groups are crucial to ensuring that people with disabilities have the support they

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[4] Autistic Self Advocacy Network (ASAN), ASAN's Invitational Summit on Supported Decision-Making and Transition to the Community: Conclusions and Recommendations (2018); Athena Mandros, Open Minds Executive Briefing, *The Future of I/DD Is In The Home* (2017), https://www.openminds.com/market-intelligence/executive-briefings/future-idd-home/.

[5] Dorothy Hiersteiner et al, National Core Indicators (NCI), WORKING IN THE COMMUNITY: THE STATUS AND OUTCOMES OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN INTEGRATED EMPLOYMENT –UPDATE 2 (2016).

[6] Workforce Services Housing & Community Development, STATE OF UTAH AFFORDABLE HOUSING ASSESSMENT 34 (2017).

[7] Rehabilitation Research and Training Center on Disability Statistics and Demographics, DISABILITY STATISTICS ANNUAL REPORT (2017), *available at* https://disabilitycompendium.org/sites/default/files/user-uploads/AnnualReport_2017_FINAL.pdf.

[8] C. Mercier & S. Picard, *Intellectual Disability and Homelessness*, 55 J. of Intellect Disabil Research 441-449 (2011).

[9] Alasdair Churchard et al, *The Prevalence of Autistic Traits in a Homeless Population*, Autism (2018) *available at* http://journals.sagepub.com/doi/10.1177/1362361318768484.

[10] S. Baker Collins et al, The invisibility of disability for homeless youth (2017) *available at* http://conference.caeh.ca/wp-content/uploads/COH10_The-invisibility-of-disability-for-homeless-youth_Steph-Baker-Collins.pdf.

[11] ASAN 2018, *supra* at 13. Throughout the document, ASAN refers to group homes as segregated housing due, in large part, to the inability to determine one's own schedule, activities, roommates, and staff.

[12] Monica E. Oss, Open Minds Executive Briefing, *For I/DD, The Question Isn't Managed Care Or Not - It's Residential Care Or Not* (2017), https://www.openminds.com/market-intelligence/executive-briefings/idd-question-isnt-managed-care-not-residential-care-not/.

[13] Ohio Dept. Developmental Disabilities, Individuals & Families, Technology First, http://dodd.ohio.gov/IndividualFamilies/Pages/TechnologyFirst.aspx; OAC 5123: 2-9-35.

need to live as independent and fulfilled lives as possible. Given their invaluable perspectives, DSPD conducted focus groups with individuals representing each of these points of view in hopes of gaining a better understanding of the challenges people with disabilities face; as well as, why families do and do not choose to join the waiting list.

Throughout these groups, four main themes were consistently communicated as the biggest barriers for families considering joining the waiting list. The first being that, both, the eligibility process and the amount of paperwork required to join the waiting list is overwhelming. Families, with at least one member eligible for DSPD services, have an abundance of unique responsibilities, and adding one more task to their list can often be very discouraging. There are so many components to the eligibility process that families do not have the time or energy to fulfill the requirements. Additionally, the complexity of the process can be very confusing, and frustrating for individuals and families trying to apply for services. Each of the groups mentioned that widespread confusion about how to start the application process often discourages people from trying.

The second theme pertained to why an individual/family would not apply for DSPD services: individuals brought into services are typically those who are in crisis or have very high needs. People with disabilities with relatively low needs often feel that there are other people who could use services more than them, and do not want to take a slot that someone else could use. The current system is set up in such a way, that does not encourage early intervention or preventative care. By not getting preventative services when the person's need is low, they are forced into crisis later; and, only then, do they receive supports and services. Several of the focus groups discussed increasing the amount of early intervention services in an effort to decrease the number of people going into crisis each year.

Four Waiting List Themes
• Eligibility/application paperwork is overwhelming
• Lack of preventative services leads to crisis
• The waiting list discourages applicants
• Lack of awareness about DSPD services

The third theme noted that the mere existence of a waiting list discourages people from applying for services. Commonly known throughout the disability community, is that individuals with low or moderate needs can remain on the waiting list for years. Many individuals and families do not see the point of applying if their circumstances will not change in the foreseeable future. These can be the same people who end up going into crisis, because their needs were not addressed at an earlier stage.

The fourth, and final theme identified by each of the focus groups, was a lack of awareness about DSPD services across the state. Many individuals, who could greatly benefit from DSPD services, do not know that state assistance is available to them. Some other challenges mentioned in the groups include a sense of responsibility that the family can take care of the individual with disabilities, and the assumption that a person is not eligible for services. Several groups also commented that many individuals in rural areas would like to take advantage of DSPD services, but there tends to be very few provider options for people that live outside of cities.

In addition to reasons that people do not apply for services, focus groups also discussed several justifications for why individuals and families do apply. Burnout was listed, by many of the groups, as one of the top reasons that a family applies for services. A family is often able to care for the individual for many years before requiring assistance. As parents age, needs become more complex and more strain is put on relationships, causing natural caretakers to experience burnout. Young adults leaving school was also mentioned as a frequent reason families apply for services. Other reasons families/individuals apply for services include: mental health issues, unstable employment of the caretakers, increasing medical bills and economic hardship,

socialization for the individual, safety of the individual, increasing behavioral needs, and a lack of other outside help.

Outside of DSPD, families turn to other groups and services to gain the support that they need to help their family member with a disability. Some of these groups include: other natural supports, such as family, friends, and neighbors; faith based organizations; support groups; organizations that provide supplies and equipment for people with disabilities; and private providers. Parents of children and young adults with disabilities often heavily rely on schools to help manage and support their child. Unfortunately, many families do not, or are unable to, seek out these supports and end up using coping strategies which typically do not work in the long run and potentially have unintended, negative impacts. Families have been known to live in fear, give up and isolate themselves, self medicate, and over medicate.

In order to curb some of these harmful coping mechanisms, and maximize DSPD support, each focus group brainstormed several services which would be beneficial for individuals and families waiting for ongoing services. Respite services, parent and family training, and peer to peer/family to family support were mentioned by each of the groups as three of the most helpful, time limited services for families. Additionally, implementing training for parents while their child is on the waiting list for ongoing DSPD services is one recommendation seen across multiple groups. Other suggestions include employment, behavior supports, and connection to outside resources.

(2) identification of needs to better understand the demand for those services and how the need can be met by private contract providers and state agencies;

Infrastructure Capacity

Supported Living and Respite services are difficult for large providers to sustain. Agencies cannot bill time spent providing coordination type activities with families, and changeable scheduling makes staffing a challenge. Six of seven supported living providers, serving 15 or more clients, decreased the number of persons that they served during FY18. Families report difficulty finding agencies that will provide respite, even if the agency's contract with DSPD includes respite. Providers suggest that smaller owner/operator agencies may be better positioned to provide these services, because the model does not easily scale under the current rate structure.

Behavior consultation and transportation services were also discussed as having inadequate and unsustainable rates. Providers report that current rates for behavior consultation are unprofitable, resulting in few providers willing to deliver that service. Transportation is a crucial element to many services that individuals receive. With current rates, some providers have a difficult time delivering the service to all individuals who require transportation.

Residential providers, also, report concerns with rising housing costs. Increasing costs make buying and renting property, necessary for residential support, difficult. Note that federal regulations prohibit DSPD from reimbursing room and board using Medicaid waiver dollars. People using residential support typically pay for room and board through their monthly Social Security Insurance (SSI) award. Providers, presumably, consider the limits of SSI awards and increasing overhead expenses when scaling a residential program.

Support Coordinator Capacity

Feedback received from the Independent Support Coordinator Association (ISCA) indicated that the support coordination system would have difficulty handling a large influx of new service recipients. Support coordination companies identify two areas of concern: training and caseloads.

The issue related to training is the administrative time investment that companies must make in the initial year of a new support coordinator hire. So far, companies have not had problems finding applicants with a bachelor degree and one year of experience to fill new support coordination positions. ISCA, however, has concerns about inundating the DSPD system with a large number of support coordinators who lack DSPD-specific system knowledge.

The issue related to caseloads is the amount of time that it takes to build a new support coordinator caseload to capacity. Customarily, new support coordinators only carry a partial caseload. Some companies decide to limit their new hire to part-time employee status. Other companies might maintain the employee with full-time status and operate at an initial loss. Receiving a dependable constant stream of new participants into the DSPD service system could help support coordinators make predictable hiring plans.

DSPD tracks the number of external support coordinators (SCE) leaving and entering the system during a fiscal year, shown in the table below. Historically, as new service recipients have entered the system, companies have been able to respond to growth with additional support coordinators. Whether support coordination can easily scale to meet an annual demand increase is unclear at this time.

Fiscal Year	Number of SCEs Leaving	Number of New SCEs
2018	6	17
2017	14	11
2016	7	21

Description of Funding

(3) a description of how to maximize federal matching funds and other funding sources that may be available;

As optional Medicaid benefits, states can choose to provide LTSS as home and community-based services (HCBS) through a variety of regulatory authorities. Each authority offers a unique set of elements for states to consider in the design of their LTSS delivery system. Following are some examples of options available to states.

1915(c) HCBS Waiver

The 1915(c) HCBS waiver is the most commonly used authority to deliver HCBS as an alternative to institutional care. Because 1915(c) waiver authority permits states to impose limits on the amount and type of services and cap enrollment, states are able to maintain maximum control of state budgets using this authority. Once an individual is enrolled in a HCBS waiver, they must have access to all services offered within that waiver. This does not guarantee that all people receive all available services at any time, only that a person cannot be denied a waiver service, on their enrolled waiver, for which they meet eligibility and demonstrate need. If the state operates multiple waivers with different available service options, persons can move between waivers as needs change and space becomes available. Utah offers eight HCBS waivers.

1915(i) HCBS State Plan Services

Originally authorized by the Deficit Reduction Act of 2005 and modified under the Affordable Care Act, Section 1915(i) of the Social Security Act gives states the option to offer a variety of HCBS under the Medicaid State

Plan rather than through an HCBS waiver program. In addition to serving those who meet institutional level of care, specific program eligibility requirements must be established to assure states serve individuals who have care needs that meet institutional level of care. Services must be provided statewide and states cannot impose limits on the number of individuals served. However, states can define a target group of individuals who may receive the services. If a state chooses to select a target population, it is required to renew the State Plan benefit, similar to an HCBS waiver, every five years. If a state does not select a target population, plan renewal is not required. The program will allow states to serve individuals who have incomes up to 300% of Supplemental Security Income and create a new Medicaid eligibility category to provide full Medicaid benefits to individuals who receive services under a 1915(i) program. At this time, UDOH and DSPD do not recommend pursuing a 1915(i).

1915(k) Community First Choice (CFC) Option

Section 1915(k) was authorized under the Affordable Care Act of 2010. The Community First Choice Option (CFC) allows states to provide HCBS attendant services and related supports to eligible Medicaid clients under their Medicaid State Plan. Under CFC, states are eligible to receive a six percent enhanced Federal Medical Assistance Percentage (FMAP) rate for these services. However, this enhanced FMAP does not apply to other services individuals may receive through the Medicaid program. CFC is only available to individuals who meet institutional level of care and who are otherwise eligible for Medicaid under the existing eligibility standards. Services must be provided statewide, states cannot impose limits on the number of individuals served and cannot identify a target population to be served.

Because CFC is available as a State Plan benefit, the State would have limited tools available to limit the growth of the program, creating an open-ended budget obligation for the state. While the availability of enhanced funding is attractive, the Departments' analysis shows that the savings achieved by the enhanced FMAP would be expended on increased service utilization (through use of additional hours of Personal Care Services and utilization of new services required under CFC, such as Personal Emergency Response Services) for individuals already receiving services. If more individuals enrolled in the program than those who are currently receiving similar services, CFC would result in additional costs.

In December 2015, the Office of the Secretary of Health and Human Services submitted a final report to Congress on the implementation of the CFC option. The report identifies the following with regard to financial considerations of CFC:

> *"Some states note that the 6 percentage point increase in FMAP is insufficient to cover populations that move from waivers or the State Plan Personal Care Benefit into CFC, because of the additional hours individuals receive. In addition, new enrollees have enrolled under CFC. In states experiencing an upsurge in enrollment, CFC implementation has led to increased costs, well beyond the additional 6 percentage points in federal service match."*

And

> *"...when considering CFC, states expressed concerns about the financial impact on already-constrained state budgets. This was true of states that ultimately pursued CFC and those that did not. Even in states with existing HCBS infrastructure, states anticipated there would be new costs associated with CFC and the additional 6 percentage point in FMAP would not cover the costs of implementing, providing and evaluating the CFC benefit. This concern was amplified by the statutory requirement that for the first 12-month period of CFC implementation, the state must maintain or exceed the level of state expenditures for HCBS attributable to the preceding 12-month period. In a time of uncertainty for state budgets, ambiguous or indeterminate costs prevented states from choosing CFC. In some states there was uncertainty about future HCBS costs due to increasing population of adults with intellectual disabilities or developmental disabilities (I/DD), of which, a large proportion reside in community-based settings….According to state officials, costs for this population are growing more than any other HCBS population because individuals with disabilities are living longer. At least two states that adopted CFC, and at least one state that did not, expresses a preference for covering the developmental disabilities population under*

> *1915(c) waiver services due to cost/utilization controls already discussed. These states expressed fear that the growing costs of providing services to this population under CFC would have a major impact on their already-strained state budgets. The states who have adopted CFC despite this concern are still evaluating the ways to control costs within the program restrictions."*[14]

With potential increased costs to the overall Medicaid budget in mind, CFC was not considered to be a viable option for the State's LTSS service delivery system.

Department of Health, as the State Medicaid Agency, is largely responsible for the implementation of any changes to the State Plan service delivery system. Neither DSPD nor UDOH recommend pursuing a 1915(k) at this time.

1115 Demonstration Waiver

Section 1115 of the Social Security Act offers states the opportunity to apply for experimental, pilot, or demonstration projects that promote the objectives of the Medicaid and CHIP programs; and for the purpose of expanding eligibility, including new services, and implementing innovative service delivery systems. Demonstration breadth of scope spans implementation of comprehensive system changes, smaller targeted changes, and emergency services.[15] At the Secretary's discretion, certain federal rules may be waived to allow for budget neutral reforms that would:[16]

- Improve access to high-quality, person-centered services that produce positive health outcomes for individuals;
- Promote efficiencies that ensure Medicaid's sustainability for beneficiaries over the long term;
- Support coordinated strategies to address certain health determinants that promote upward mobility, greater independence, and improved quality of life among individuals;
- Strengthen beneficiary engagement in their personal healthcare plan, including incentive structures that promote responsible decision-making;
- Enhance alignment between Medicaid policies and commercial health insurance products to facilitate smoother beneficiary transition; and
- Advance innovative delivery system and payment models to strengthen provider network capacity and drive greater value for Medicaid.

As of January 2017, eleven states are utilizing 1115 waiver authority in their LTSS delivery system[17]. The 1115 waiver authority can be used in either a fee-for-service or managed care payment model. UDOH and DSPD do not recommend pursuing an 1115 Demonstration Waiver at this time.

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[14] https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/cfc-final-report-to-congress.pdf

[15] Mary Sowers et al, The Henry J. Kaiser Family Foundation, Streamlining Medicaid Home and Community-Based Services: Key Policy Questions (2016).

[16] MaryBeth Musumeci et al, The Henry J. Kaiser Family Foundation, Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers (2018); Medicaid.gov, Section 1115 Demonstrations, About 1115 Demonstrations, https://www.medicaid.gov/medicaid/section-1115-demo/about-1115/index.html (last visited 8/1/2018); National Conference of State Legislators (NCSL), Understanding Medicaid Section 1115 Waivers: A Primer for State Legislators (2017).

[17] https://www.kff.org/medicaid/report/medicaid-section-1115-managed-long-term-services-and-supports-waivers-a-survey-of-enrollment-spending-and-program-policies/

Combining Waiver Authorities - Managed Long Term Services and Supports (MLTSS)

Deep-Dive: transitioning to managed care

By using 1115 waiver authority or the waiver authority authorized in Section 1915(b) of the Social Security Act, in combination with 1915(c) waiver authority, states can implement a managed long term services and supports (MLTSS) delivery system.

In MLTSS, State Medicaid programs provide capitated payments to managed care organizations for the provision of LTSS. States have implemented a variety of MLTSS models of care, including those that focus primarily on LTSS, or other models that provide integration of most or all Medicaid services.

A report issued by Truven Health Systems, *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update*[18], describes that older adults and those with physical disabilities are populations most commonly served in MLTSS. However, there are nine states that have MLTSS programs that specifically target individuals with ID/DD.

In its 2012 report to the President, the President's Committee for People with Intellectual Disabilities stated the following with regard to providing LTSS to individuals with ID/DD under a managed care model.

> *"Compared with the traditional fee-for-service system, movement towards managed care can provide excellent tools to improve coordination, quality, and access to acute care for individuals with ID/DD. However, there are also legitimate concerns among advocates about limiting access to care. There are concerns about sudden disruptions of care and services. Managed care will limit choice of providers to those in approved networks. Some individuals with ID/DD and their families have established trusted relationships with health care providers over many years. They could lose access to the only local provider with adequate training and competence serving individuals with ID/DD. There are particular concerns about access to specialists to meet unique complex medical needs and circumstances of some individuals with ID/DD. In addition, there are concerns of denials and reductions in necessary services, which could occur due to motives of health plans to maximize profits and/or inadequate payments to health plans from states seeking to fill immediate budget shortfalls.*
>
> *There are legitimate reasons for caution. The fact is that research on the outcomes of Medicaid managed care for individuals with disabilities, particularly individuals with ID/DD, is scarce and inconclusive. Recent analyses of the literature have indicated 21 mixed findings on access and quality (Connolly & Paradise, 2012). Moreover, it is virtually impossible to draw any general, overarching conclusions from the research due to the tremendous diversity across states in program design, populations served, and quality measures.*
>
> *While many states are driven by immediate budget pressures, research on cost savings is also inconclusive. Compared with other populations, the potential for short-term costs savings in the ID/DD population is likely less. Medicaid fee-for-service rates are so low in many states that there is very little room for savings by merely squeezing provider payments (Connolly & Paradise, 2012). If savings are to be achieved they will likely come from long-term improvements in care coordination, promoting health and wellness, and avoiding unnecessary hospitalizations and institutional placements (Lewin Group, 2004). The potential for savings from preventing unnecessary hospitalizations may be less for the ID/DD population in comparison with other populations, such as older individuals (Konetzka, Karon, & Potter, 2012). However, research exploring preventable hospitalizations has often not considered major reasons for emergency room and hospitalizations for individuals with ID/DD –such as behavioral issues, seizures, and infections. There are clear opportunities to better understand this area and improve care for individuals with ID/DD. To maximize long-range outcomes, additional investments in the system, addressing unmet needs for long-term services and supports, and targeting efforts to certain subpopulations of individuals with ID/DD may be needed (Brown & Mann, 2012)"*[19]

[18] https://www.medicaid.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf
[19] https://www.acl.gov/sites/default/files/news%202017-03/PCPID_FullReport2012.pdf

DSPD and UDOH do not recommend pursuing MLTSS at this time.

State Case Studies

Deep-Dive: cost-containment strategies used by other states

Washington State.[20] In 2017, Washington transformed their Medicaid delivery system through an 1115 Demonstration.[21] The demonstration draws on statutory elements across the Social Security Act. Primarily providing state plan services through managed care systems, the demonstration prioritizes integration of behavioral and physical health and value-based payment. It reserves administration of disability services in five 1915(c) waivers serving more than 20,000 people.

Accountable Communities of Health (ACH) and MCOs work together to attain value-based payment goals through targeted programming and health homes.[22] All waivers include nursing services. Washington expanded the State Plan to include 1915(i) and (k) for persons at-risk of needing LTSS or institutional care. Using 1915(k) for personal assistance services increased available funding for the Developmental Disabilities Administration (DDA) to immediately open a waiver with 4,000 slots.

Individuals and Family Services Waiver	Savings realized from implementation of a 1915(k) amendment initially funded the waiver. Serves ages 3 and up, in their home, with four budget tiers: $1,200, $1,800, $2,400, or $3,600 annually. Current enrollment at 6,500 people.
Basic Plus Waiver	Serves all ages with a capitated budget of $6,192 and the option of $6,000 in emergency funds annually for in-home support. Can combine with 1915(k). Current enrollment at 8,870 people.
Core Waiver	Includes residential services for all ages and maintains cost neutrality with the $550 average ICF/ID daily rate. The majority of the 4,570 enrollees use supported living, and 500 people, with significant nursing needs, live at home.
Community Protection Waiver	Serves adults at moderate or high risk for sexually predatory behavior and assault. Most of the 407 enrollees are adjudicated. Includes residential services and maintains cost neutrality with the $550 average ICF/ID daily rate.
Children's Intensive In-Home Behavioral Support Waiver	Serves children, ages 8-21, living at home, at immediate risk of separation from their family. Child must enroll prior to age 18. Capitated budget of $4,000 per month. Enrollees typically transition to the Basic Plus and Core waivers.

Waivers continuously enroll due to active attrition. A state employed case management staff of 450 people conduct a Supports Intensity Scale (SIS) assessment at the time of service request. Then a committee reviews the SIS and waiver request to determine unmet needs, current supports, services requested, and available alternatives; if the person meets eligibility, a determination of most appropriate waiver is also made. Those determined to lack a current unmet need can re-request services at any time.

In moving the state's health care philosophy toward that of medical homes, Washington developed programming to address transitions between home, acute, and long-term care. System wide targeted case

[20] Information obtained during a phone call, on July 25, 2018, with five administrators from the DDA and state Medicaid agency.

[21] Wash. State 1115 Demonstration Medicaid Waiver language (Oct. 2017) *available at* https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/wa/medicaid-transformation/wa-medicaid-transformation-appvd-eval-dsgn-10262017.pdf.

[22] Healthier Washington, Medicaid Transformation Project Toolkit (2017), *available at* https://www.hca.wa.gov/assets/program/project-toolkit-approved.pdf.

management assists persons move between levels of care with person-centered care plans and follow-up. Through a State Plan amendment, Washington altered their PASRR program to arrange for specialized services through HCBS providers.[23] Nursing facilities now access disability specific, 1915(c) waiver service providers through PASRR Specialized "Add-on" Services eligible for federal financial participation. This HCB and institutional partnership increases successful transitions between the different settings through continuity of care and robust person-centered planning.

Washington's Nurse Delegation Program[24] compliments PASRR changes and helps people remain in the community, reflected in the state's ICF/ID population of less than 700 people. Nurses train, delegate, and oversee skilled nursing tasks delivered by HCB service providers.[25] The program served approximately 8,300 persons during 2017, at an average annual cost of $680 per person versus skilled nursing facility average annual cost of $72,000 per person.[26] Populations served include long term care, developmental disability, and private pay.

Connecticut.[27] Three 1915(c) waivers serve approximately 10,000 people with intellectual and developmental disability. All three waivers cap annual individual budgets. Comprehensive Support Waiver includes residential services and funds an annual individual budget at 150 percent of state institutional costs. Individual and Family Support Waiver, also, includes residential services and funds an annual individual budget at a similar percentage of state institutional costs. Employment and Day Support Waiver offers a capitated individual budget, currently being amended to slightly over $58,000 annually in order to support transition age youth into employment. Most of the state's ten waivers carry a waiting list.

Due to budget constraints, Connecticut made changes to their Medicaid State Plan by including 1915(i) and (k). The 1915(i) amendment targeted the benefit to persons 65 and older at-risk of skilled nursing facility care. So far, the 1915(k) benefit only serves 1,000 people. It provides assistive technology/ adaptations, personal assistance services, transition costs, home delivered meals, occupational therapy, physical therapy, speech therapy, and an emergency response system. A State Plan amendment to provide PASRR specialized services through HCBS providers is also underway. Connecticut will gain a 50 percent FMAP for day services, behavior consultation, nutrition/ dining support, and support coordination provided in nursing facilities.

Delaware.[28] Recently, Delaware used an 1115 demonstration waiver to transition the Medicaid system into managed care, including disability services. A managed care organization, focused on physical health, now oversees disability related services, except residential services. Provider capacity and rate development issues warranted keeping the service under fee for service (FFS).

The Division of Developmental Disabilities Services (DDDS) serves 4,900 people statewide, of which 1,100 receive waiver services and will increase to 2,200 people. One 1915(c) waiver previously offered only residential services, even though DDDS provided all other services through state general funds alone. After learning that most residents prefer to remain home, the waiver now offers a comprehensive service menu

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[23] PASRR Technical Assistance Center (PTAC), Washington State Plan Amendment (SPA) Adding DD Services to Specialized Services (2015).

[24] Oregon, Maryland, and Alabama also devised delegation programs: OAR 851-047, Md. Dept. of Health Dev. Disabil. Admin., Nursing, https://dda.health.maryland.gov/Pages/health_and_nursing.aspx; State of Alabama, Acts 1993, No. 93-183, § 2: Code of Alabama, Chapter 610-X-6.

[25] RCW 18.79.260.

[26] Wash. State Dept. of Social and Health Services, Understanding Community Based Nurse Delegation (2017), https://www.dshs.wa.gov/sites/default/files/ALTSA/rcs/documents/ND%20Orientation.pdf; National Council of State Boards of Nursing, *National Guidelines for Nursing Delegation*, 7 J. Nursing Regulation 5 (2016); World Health Organization, Task Shifting Global Recommendations and Guidelines (2008).

[27] Information obtained during a phone call with the state Medicaid agency on June 27, 2018.

[28] Information obtained during a phone call with the state developmental disability authority on July 9, 2018.

excluding day habilitation. Day Community Participation replaced the traditional service with a part-time program intended to compliment other community activities, like employment. Their State Plan includes 1915(i) to provide day habilitation and supported employment, and 1915(j) to gain matching funds for respite. Services include private duty nursing and doctors-at-home, due to a state nursing shortage.

Delaware made decreasing crisis through trauma-informed and preventative care integral to the new delivery system design. Previously a pilot program with SAMHSA, the Assist Program, will become a health home. Program data demonstrated decreasing crisis and hospital placements for persons with co-occurring ID/DD and mental illness. Regional data indicates that, in contrast to Mandt, Ukeru works better for significant behavioral challenges, and may require certification in both methods. Overall, State Plan expenditures related to crisis care decreased.

Louisiana.[29] Stakeholder requests to address the 1915(c) waiting list and simplify access to services motivated Louisiana to redesign their ID/DD waiver system. Previously, persons requesting assistance enrolled in ID/DD services on a first-come-first-served basis limited by available funding. Four 1915(c) waivers serve over 11,000 people, and had two registries equaling 16,000 people with a wait time of ten years.

The four available waivers all use budget and service caps; only one, the New Opportunities Waiver, offers comprehensive services. New Opportunities Waiver manages service utilization and budget through a resource allocation model based on the SIS. Residential Options Waiver categorizes enrollees into four budget capped service levels ranging from $48,000 to $61,000 annually. Supports Waiver focuses on vocational assistance and limits the maximum support hours. Children's Choice Waiver offers a maximum annual budget of $16,410 that includes support coordination, family support, environmental/vehicle modifications as well as other therapy services not covered under the State Plan. Children's Choice individuals can also access EPSDT (Early Periodic Screening Diagnostic and Treatment) services under the State Plan.

When one requested services they went onto a registry until funding opened a slot on the appropriate waiver. To immediately address the needs of persons waiting, Louisiana implemented a plan for prioritization of the waiting list and tiered waiver services. Now a screening tool, the SUN, captures urgency of need which determines whether one moves from the registry to the waiting list. SUN scores of 4, needing services within ninety days, or 3, needing services within one year, qualify for the waiting list. Fifteen percent of registered persons obtained a score of 3 or 4, which amounted to approximately 1,100 people.

Due to persuasive self-advocates and the developmental disabilities council, Louisiana offered the entire waiting list (those with SUN score of 3 or 4) into Home and Community Based waiver services through three funding streams: appropriation, attrition, and surplus fund. Legislative appropriation opened 627 slots and surplus funding allowed 650 slots beginning in fiscal year 18/19.

Pennsylvania.[30] Four FFS waivers serve 37,000 people: two waivers use capped budgets and two waivers limit the amount of services. Both capitated budgets exclude support coordination from the maximum. The Person/Family Directed Support waiver caps the annual budget at $33,000 and sees an average budget of approximately $24,000 annually. A consolidated waiver with access to residential services see an average budget of approximately $160,000 annually. Those using supported employment, on a capitated waiver, can request an additional $15,000 annually.

County centers directly administrate intake and eligibility. Assessment prioritizes unmet need(s) by category: emergency, critical (need services within two years), and planning (needs services within five years). The

[29] Information obtained during a phone call with the state Medicaid agency on July 13, 2018.

[30] Information obtained during a phone call with the state developmental disability authority on July 16, 2018.

emergency category enrolls first with available funding. Eligible persons without an identified unmet need may re-apply at any time, and as often as desired; but are not considered waiting for services.

Pennsylvania underwent multiple changes over the last fiscal year. Addition of an enhanced rate schedule to three services related to medical and behavioral needs requires more time and education to help enrollees effectively use the service with capitated budgets. The enhanced rate schedule created 50 procedure codes that the agency hopes to simplify by 2020. Residential services predominantly use the SIS to place enrollees into needs groups with a cost-based payment schedule. Managed LTSS may be considered in the future.

(4) a report on the number of people needing various types of services including an estimate of the number of people who need services but are not currently on the waiting list;

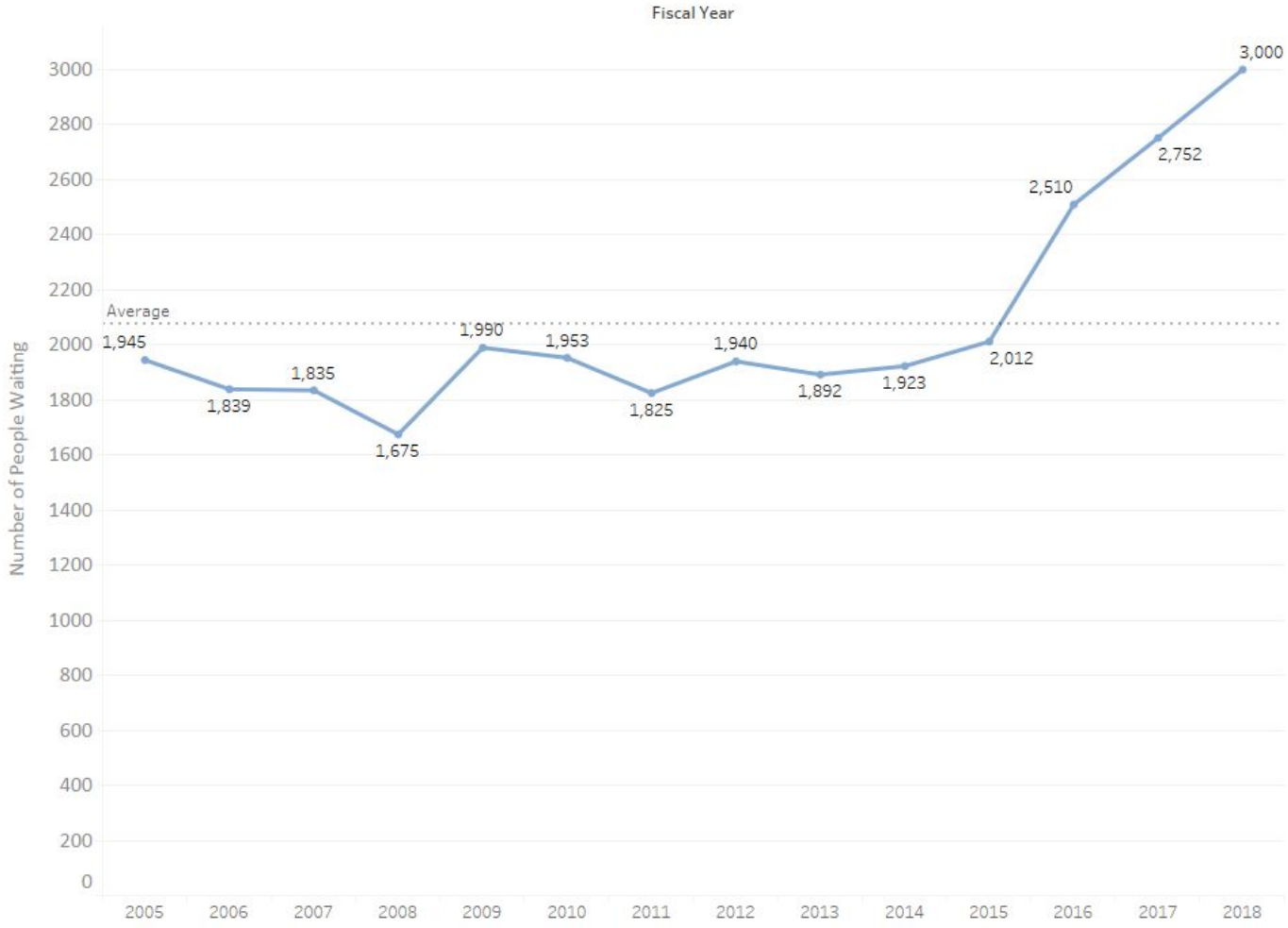
Utahns in Need of Support

Current DSPD Waiting List

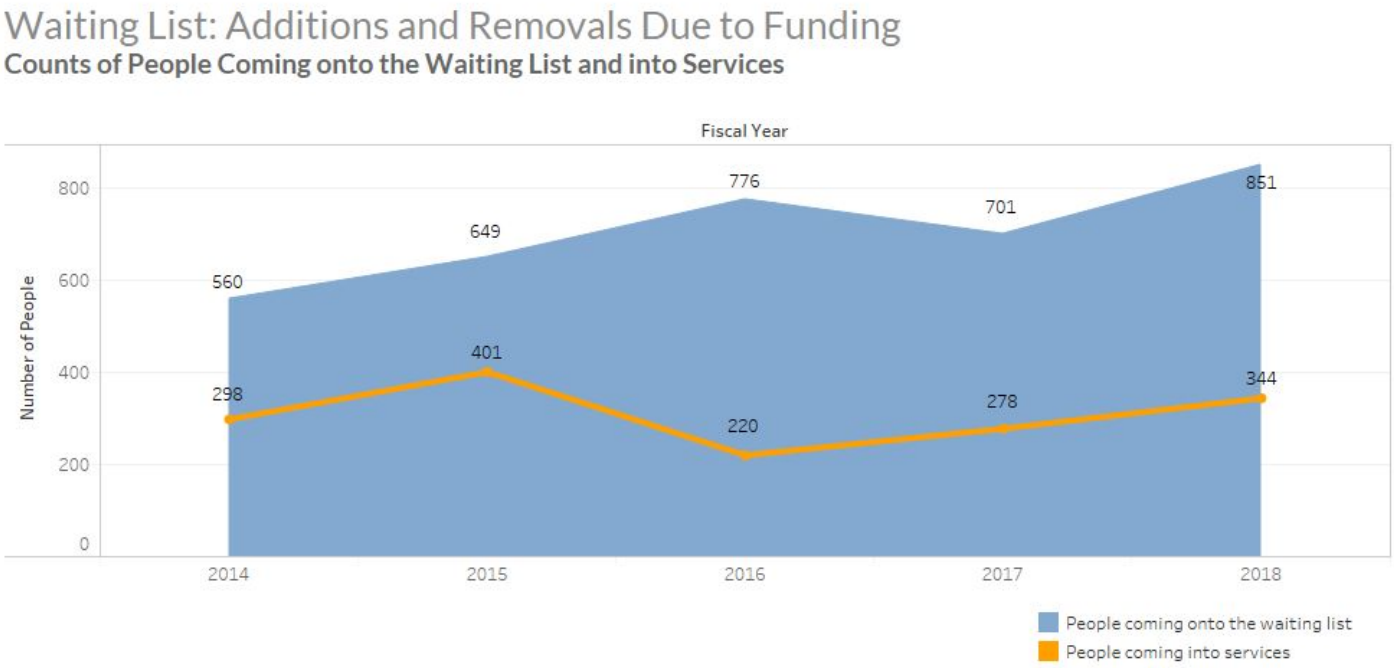
As of June 30, 2018, three thousand people were on the waiting list for ongoing DSPD services. Utah saw no measurable growth between 2005 and 2015; a sharp contrast to the 16.3 percent average annual growth between 2015 and 2018.

Historic DSPD Waiting List Counts

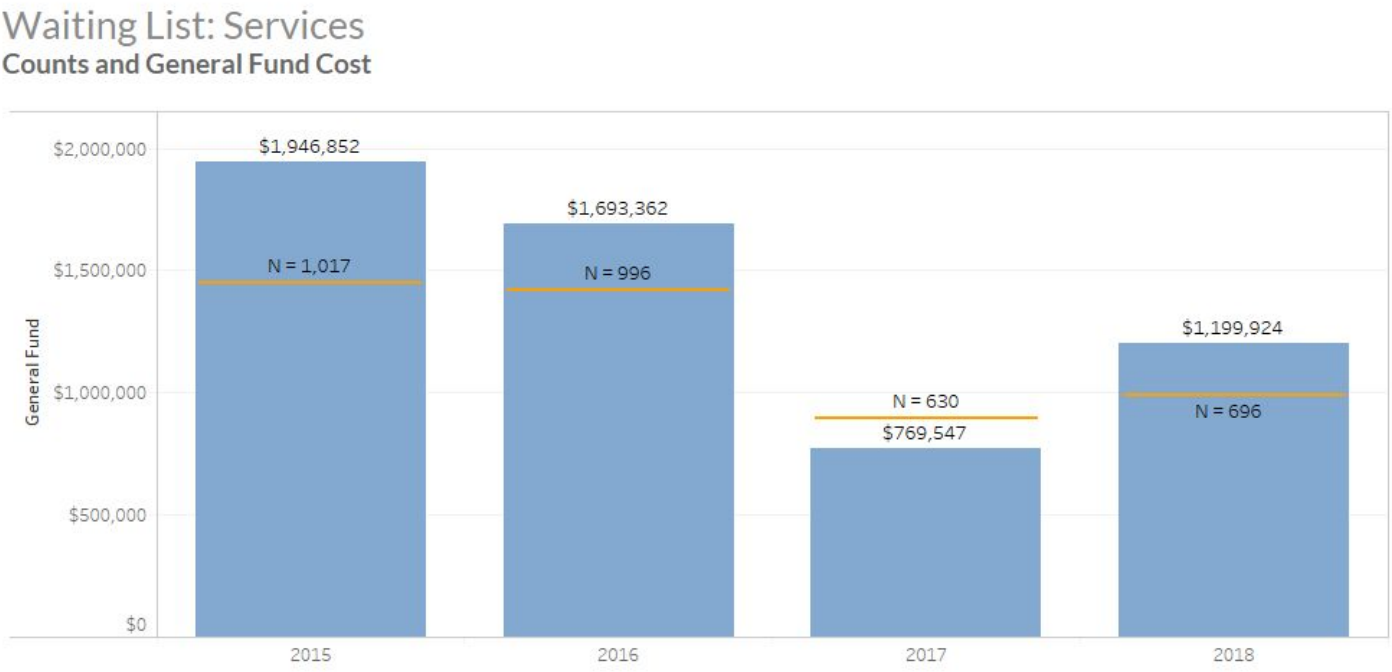
FY2005 to FY2018



Focus groups identified the waiting list, itself, as a barrier to application. Many families refrain from application when faced with lengthy wait times and cumbersome paperwork. Funding has been unable to match the pace of individuals with disabilities entering the waiting list, causing growth in the number of individuals waiting for services. In spite of these obstacles, 851 people were added to the DSPD waiting list in FY18. In contrast, 344 people were brought into ongoing DSPD services from the waiting list. The chart below shows the historic trend of people found eligible and placed on the DSPD waiting list, contrasted with the number of people funded from the waiting list and brought into services each year. Note that people are additionally removed from the waiting list each year because they have moved out of state, passed away, do not respond to repeated attempts at contact, or are otherwise no longer interested in DSPD supports.

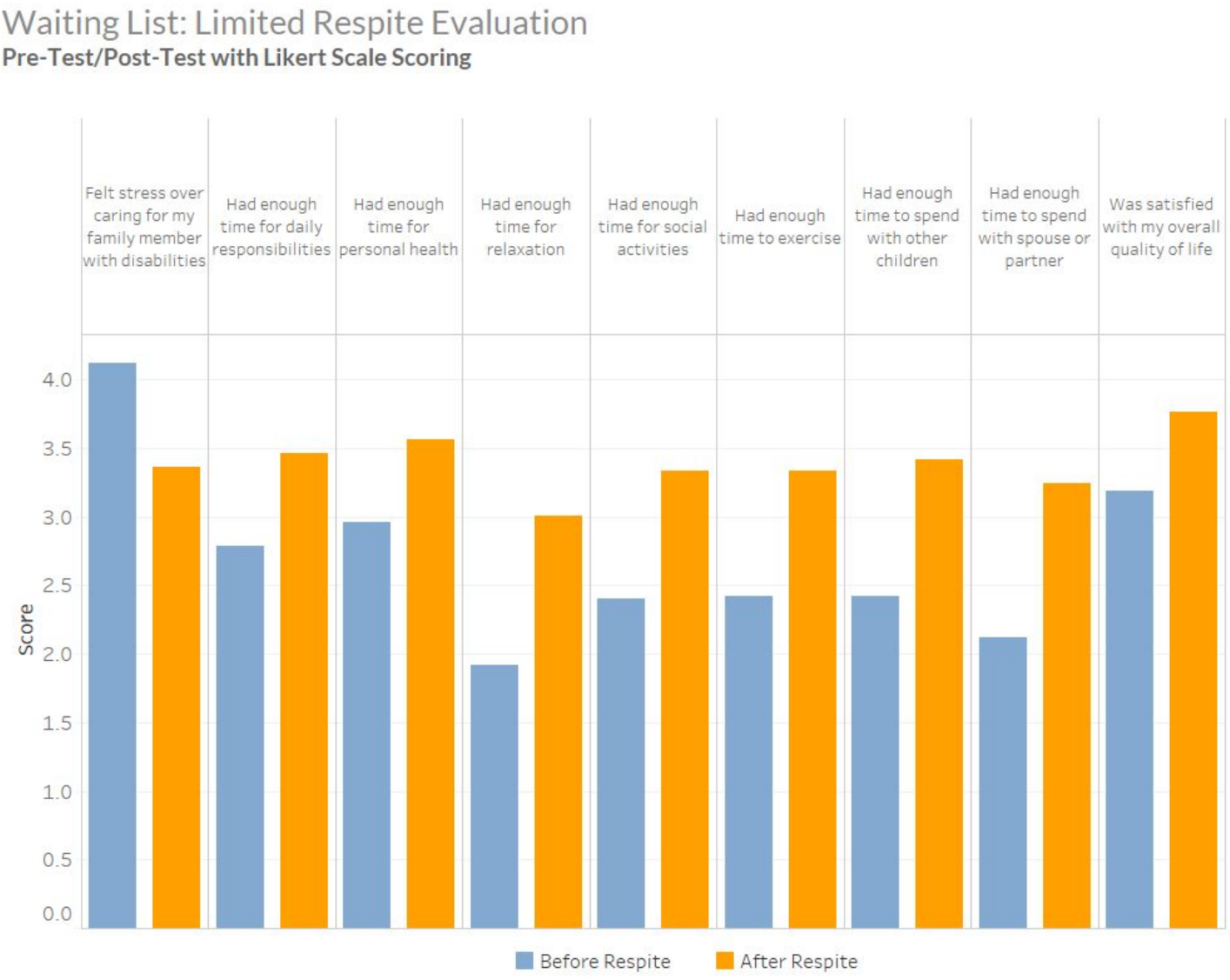


In FY18, 696 people accessed one-time respite, community service brokering, and employment support while waiting. Each of these services are funded by state funds only, and do not receive matching federal Medicaid funds. The chart below shows the number of people receiving services while on the waiting list, as well as, the state General Fund costs associated with those supports.

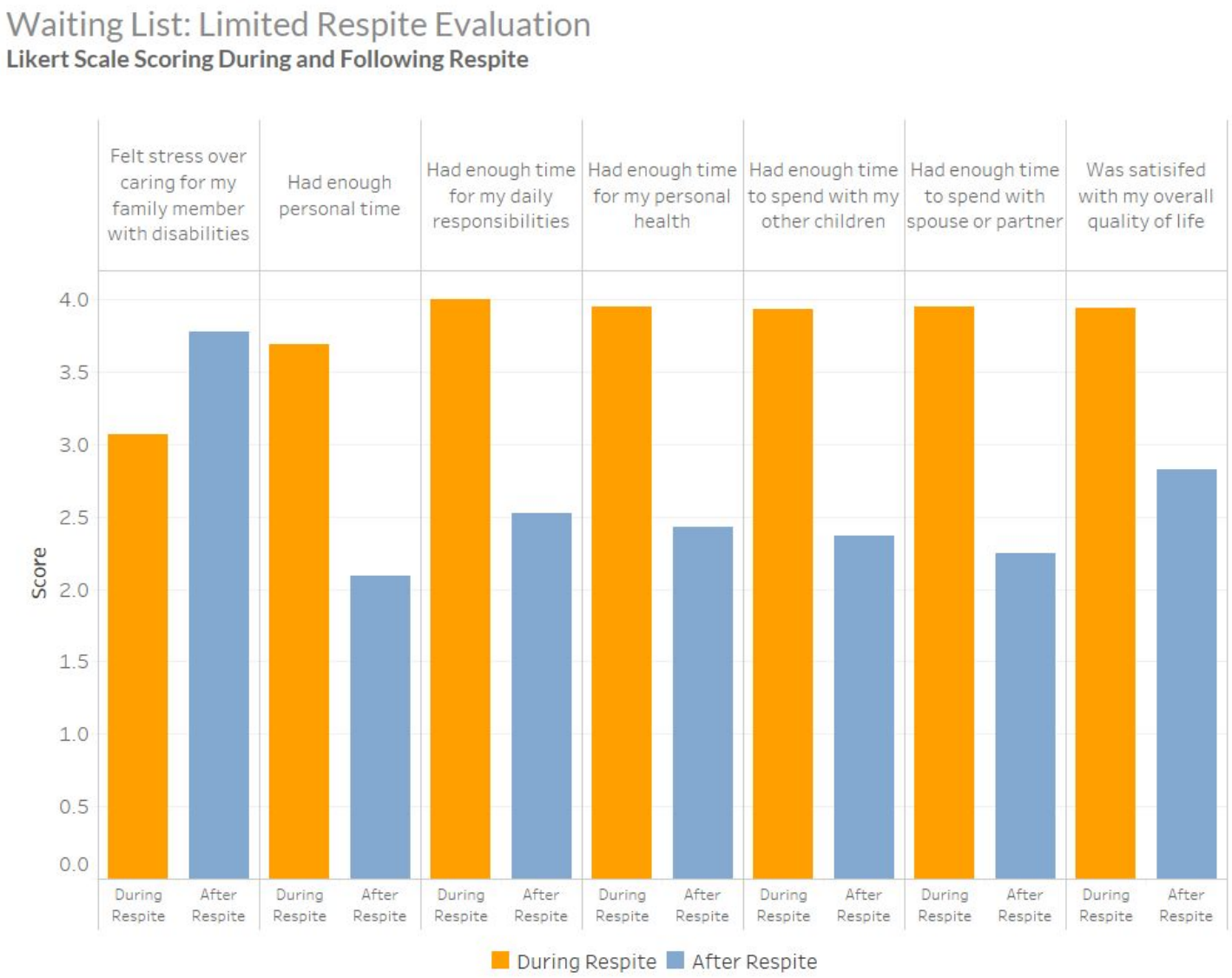

Waiting List: Services
Counts and General Fund Cost
General Fund
$2,000,000
$1,500,000
$1,000,000
$500,000
$0
$1,946,852
N = 1,017
$1,693,362
N = 996
N = 630
$769,547
$1,199,924
N = 696
2015
2016
2017
2018

WAITING LIST MANAGEMENT STRATEGIES

Respite services are one of the most commonly requested services among families. Additionally, focus groups specifically identified respite as one of the most needed services to enhance the family's quality of life and reduce the chance of caregiver burnout. Caregiver burnout increases the likelihood of an out of home placement for their family member with a disability. In 2014 and 2016, surveys were sent out to recipients of one-time respite. The 2014 study asked a series of quality of life questions and found that each indicator had a statistically significant increase after receiving respite, as compared to before. The survey also found that the level of stress a caregiver feels showed a statistically significant decrease, which was the desired trend, shown below.



Similar to the 2014 survey, the 2016 survey also asked quality of life questions. The only difference is the 2016 survey asked the family questions during the time they were receiving respite, and not before. This study found that the caregiver's quality of life was significantly better while receiving respite services than after those services had concluded.



Prevalence

Prevalence statistics are used to determine the proportion of the population that would be eligible for DSPD services. Based on current projections[31], Utah's population will reach 3,896,678 people in 2030. One study[32] weighs intellectual/developmental disability prevalence more heavily among children (69.9 per

2030 Population:	3,896,678
Prevalence:	2.71%
Participation:	32.1%

[31] http://gardner.utah.edu/wp-content/uploads/Projections-Brief-Final.pdf

[32] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

1,000)[33] than adults (7.9 per 1,000)[34]. The study reports that this is due to rising awareness of ASC and higher prevalence rates in children. Utah has a higher proportion of children than other states with 30% of the population comprised of children under the age of 18 in 2017[35]. This weighting by age yields a prevalence statistic for Utah of 2.71%. Based on this prevalence, 105,600 people would qualify for DSPD services by the year 2030.

Participation

The participation rate is the percent of individuals who qualify for DSPD supports and who would utilize services. In reviewing various social service programs in Utah, the percent of eligible people participating varies from 68%-83%. The participation rates in Utah are typically much lower than other states. In 2015, Utah ranked 41st in the nation for adult participation in Medicaid, and 50th for children participating in Children's Health Insurance Program (CHIP)[36]. In the same year, Utah was ranked 49th for the participation rate in the Supplemental Nutrition Assistance Program (SNAP)[37].

Program	Participation Rate	State Ranking Including DC
SNAP	69%	49th
Medicaid Participation Among Parents 19 to 64 Years, 2015	68%	41st
CHIP Participation Among Children 18 and Younger, 2015	83%	50th

These social service programs typically offer some tangible financial benefit that would yield higher participation rates than expected for DSPD programs. DSPD services typically require immersion of direct care staff into the lives of families. Based on focus group feedback, many families are able to support their family member independently, or by leveraging their formal and informal networks, without relying on government support.Based on utilization in other states, a participation rate of 32.1%[38] is the ceiling of people who would likely choose to receive home and community based services. This participation rate results in an estimated 33,898 Utahns with disabilities who could use DSPD services. The remaining 67.9% of eligible individuals would likely be able to leverage their formal and informal networks, such as family, faith, and community supports.

The Unmet Need

By the year 2030, 33,898 people could potentially utilize DSPD services; however, 6,692 people already receive supports. Most recent figures of people receiving supports include 775 people who (as of 6/30/2017) reside in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/ID). Additionally, 5,917 people received home and community based services from DSPD (FY18). Another 3,000 people (as of 6/30/2018) were on the DSPD waiting

(5) an estimate of the number of people who would become eligible to be on the waiting list each year for the next ten years;

[33] Zablotsky, B., Black, L.I., Maenner, M.J., & Blumberg, S.J. (November 2017). Estimated Prevalence of Children with Diagnosed Developmental Disabilities in the United States 2014-2016. National Center for Health Statistics Data Brief, No. 291. Washington DC: U.S. Department of Health and Human Services. Retrieved from: https:// www.cdc.gov/nchs/data/databriefs/db291.pdf

[34] Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106, 231-252.

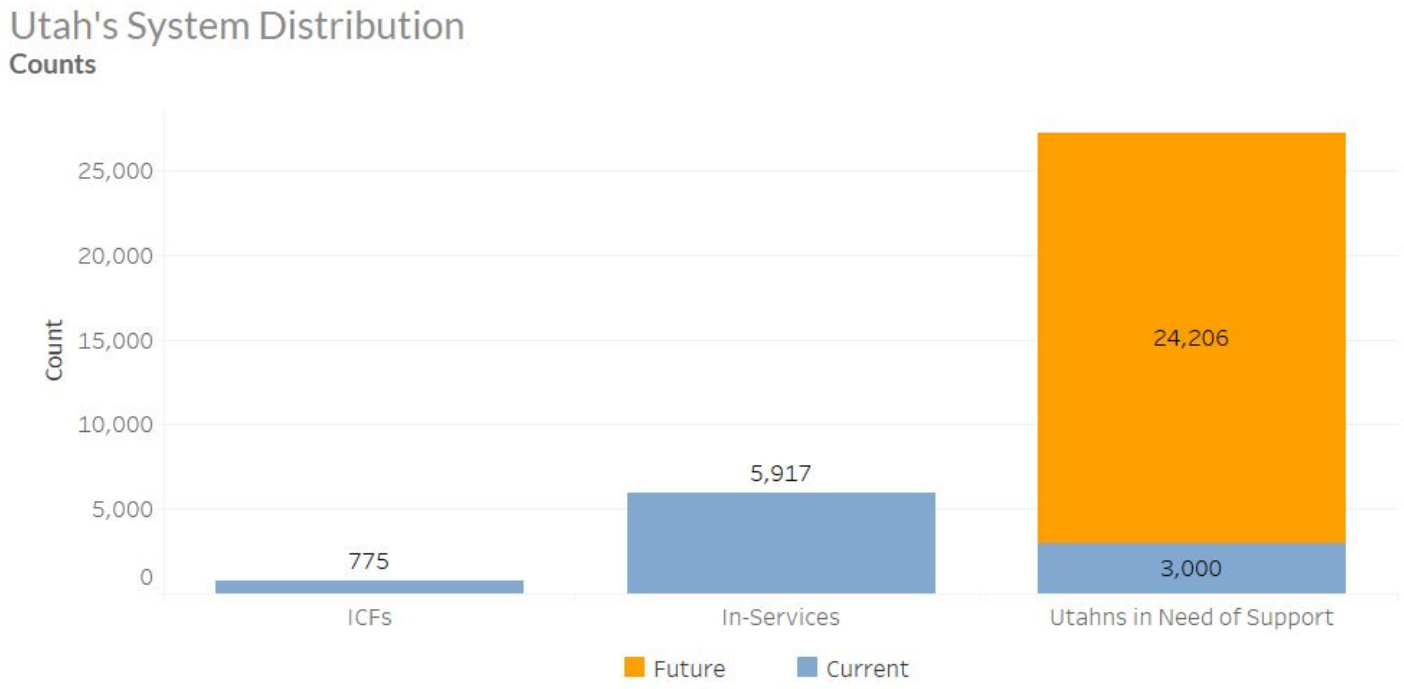
[35] https://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult#detailed/2/2-53/false/871/39/417

[36]https://www.urban.org/sites/default/files/publication/90346/2001264-medicaid-chip-pariticipation-rates-rose-among-children-and-parents-in-2015_1.pdf

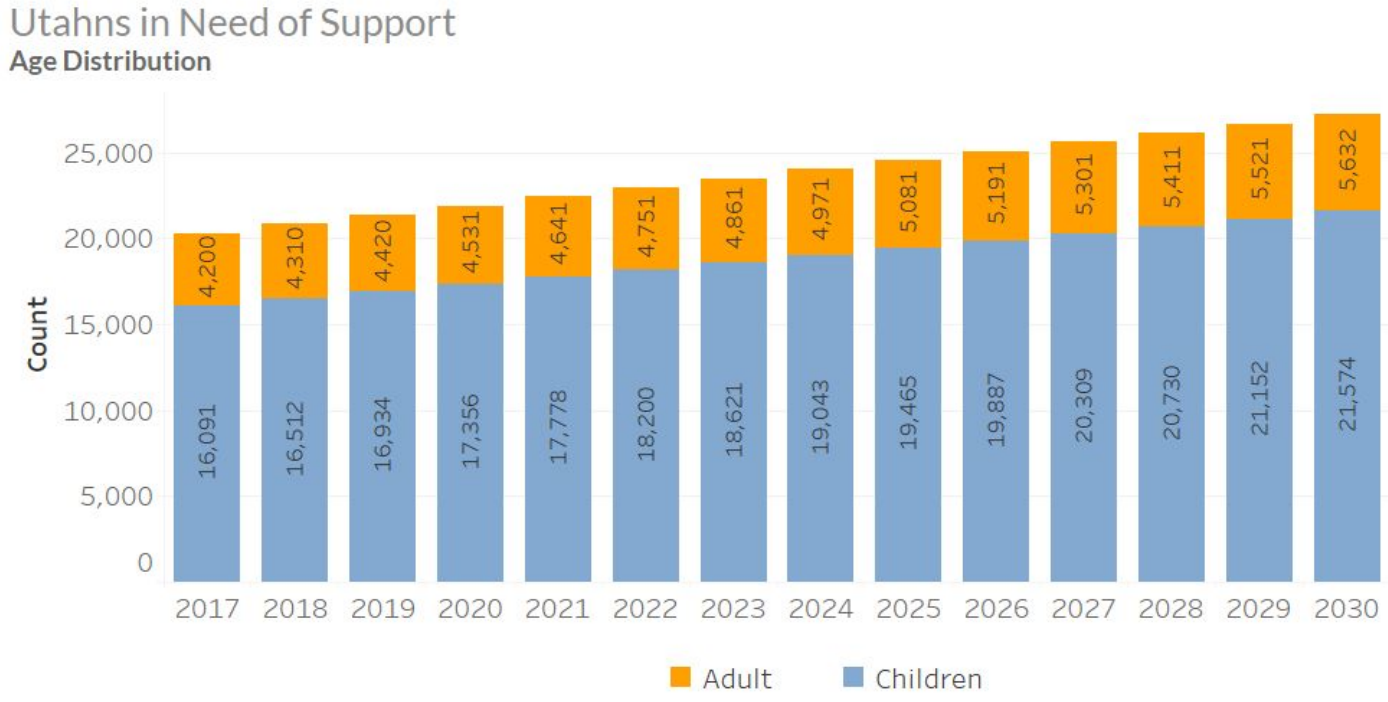
[37] Reaching Those in Need: Estimates of State Supplemental Nutrition Assistance Program Participation Rates in 2015. USDA. January 2018.

[38] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

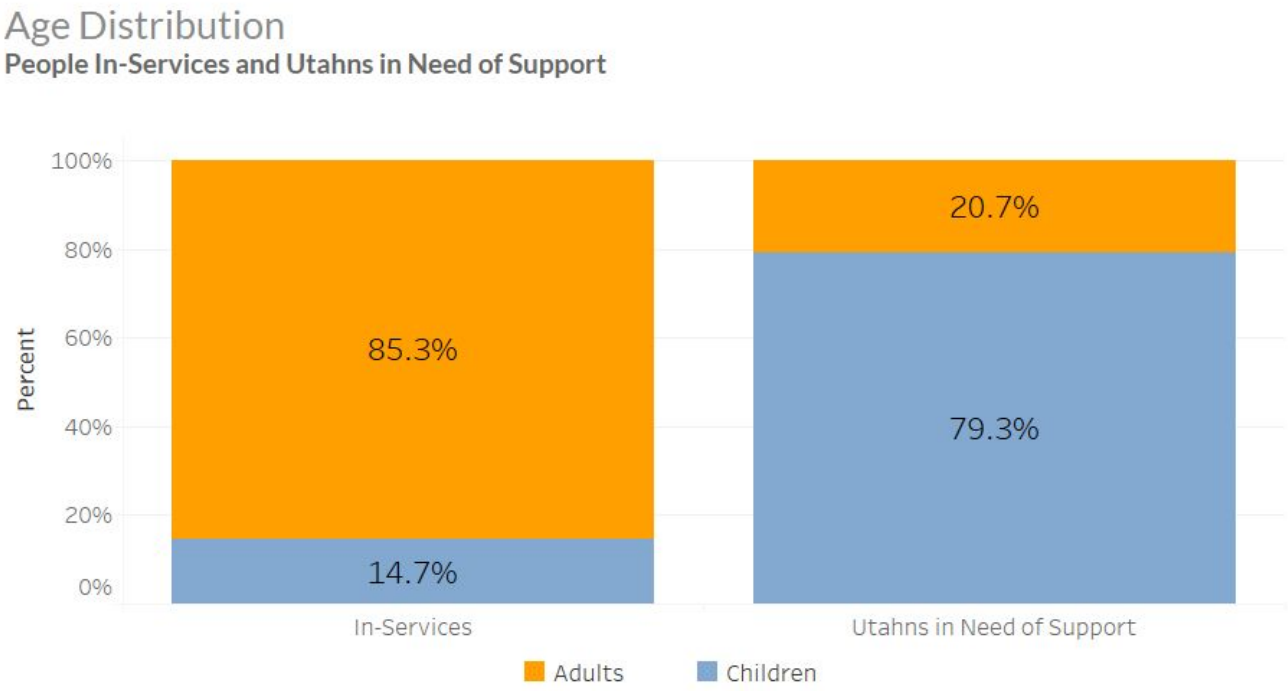
list in need of ongoing services. Therefore, the total number of individuals already known to the disability service system is 9,692. The total estimated number of people in need of DSPD services is 27,206. This includes 3,000 people already on the DSPD waiting list and 24,206 people who are not currently waiting for, or receiving, DSPD services.



As shown in the chart below, DSPD estimates that an increasing number of children and adults who are eligible could potentially join the waiting list through 2030.



Based on the prevalence calculation, and shown in the graph below, DSPD anticipates that 79.3% of people in need of support will be children under the age of 18 years, and the remaining 20.7% will be adults. Currently, 85.3% of individuals receiving DSPD services are adults, and 14.7% are children. Recognizing the needs of the younger age demographic will be a crucial element to building infrastructure capacity for the 27,206 people in need of DSPD supports.



Various Ways 1915(c) Can Be Used

Cost Controls

A 2016 Kaiser Family Foundation (KFF) report compared use of the three cost control measures allowed under a 1915(c) waiver across all states: fixed expenditure caps, service provision and hourly caps, and geographic limits.[39] DSPD operated waivers do not include the listed cost controls in the waiver language. DSPD does, however, apply a fixed expenditure cap to one-time and emergency state-funded respite services.

Deep-Dive: cost limits, service or hourly limits, geographical limits

Geographic limits used by states changed between 2015 and 2016. KFF data from 2015 lists nine states as using geographic limits on 1915(c) waivers: California, Colorado, Michigan, Montana, North Carolina, Nevada, Texas, Washington, and Wisconsin. KFF data from 2016 lists six states as using geographic limits: California, Colorado, Minnesota, Montana, New York, and Washington.[40] A review of all fifty 1915(c) waivers in all six states yielded the following information: Minnesota no longer waives statewideness in their waivers, and no state waives statewideness in waivers targeted to people with Intellectual Disabilities/Developmental Disabilities (ID/DD).

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[39] Terence Ng et al, The Henry J. Kaiser Family Foundation, MEDICAID HOME AND COMMUNITY-BASED SERVICES PROGRAMS: 2013 DATA UPDATE (2016).

[40] Molly O'Malley Watts & MaryBeth Musumeci, The Henry J. Kaiser Family Foundation, MEDICAID HOME AND COMMUNITY-BASED SERVICES: RESULTS FROM A 50-STATE SURVEY OF ENROLLMENT, SPENDING, AND PROGRAM POLICIES (2018).

Current System

DSPD's largest HCBS waiver (the Community Supports Waiver (CSW)) provides comprehensive support to people through a wide array of services. Services range from provider based to self-administered, from full residential support to respite for caregivers. Additionally, DSPD contracts with support coordinators to assist with access to and use of available waiver services. The CSW serves all ages and does not impose individual cost limits, which results in annual requests for mandated additional needs.

A single waiver can include capitated budget tiers. States using this funding scheme develop resource allocation formulas in conjunction with the Supports Intensity Scale (SIS). DSPD providers do not advocate for using the SIS for resource allocation. DSPD has, therefore, drafted an option for the development of new waivers rather than implement funding caps within a single waiver.

(6) a proposal for ways to target available funds to the most beneficial services and how providing limited benefits to some people could allow more people to be served;

Draft Option

A limited support waiver (LSW) capitalizes on the unique features and flexibility of 1915(c) waivers, which make it an ideal waiting list management tool. The draft option recommends two new 1915(c) waivers, with limits on individual budgets and available services. DSPD estimates that absorbing 27,206 people into the CSW by 2030 as it is currently structured will cost an additional $628,820,000 General Fund ongoing. Strictly controlling resource ceilings on the most requested in-home services will meet the majority of needs and reserve money for more complex cases. Well-executed services should habilitate, thus, diffusing and preventing crises. Addressing the waiting list through a combination of LSWs adjusts the estimated annual cost down to $314,940,000 General Fund ongoing.

Current funding methods primarily address the most critical needs on the waiting list. In FY14, the Legislature enacted section 62A-5-102 in an effort to address this preventative care need. This statute mandates that 85% of appropriations given to bring individuals off the waiting list are applied to those with the most critical needs. The remaining 15% of funds are used to bring individuals into services whose only need is respite. This statute combats crises from developing and provides preventative care to individuals with relatively low needs. DSPD recognizes the value of addressing needs as early as possible, and has drafted this option in an effort to address these needs in the most efficient way possible. Providing appropriate preventative assistance could serve more people within anticipated future expenditures.

Design of the new waivers would be subject to the feedback of the legislature, individuals waiting for DSPD services, those currently receiving DSPD services, HCBS providers, and other stakeholders. Implementation of the new waivers would require new legislative appropriation and CMS approval. These two new waivers could be implemented as soon as July 1, 2020.

Limited Support Waivers

The Level I Waiver (L1) is designed to serve individuals who need minimal support to maintain independence in their own home or their family's home. Foundational services include case management and family training ($1,800 total dollars), which would not contribute toward the individual's budget cap. In addition to these foundational services, $16,400 (total dollars) could potentially go towards purchasing: respite, behavior consultation, employment services, day programs, transportation, environmental adaptations, and community integrated programs (after school/summer/senior programs). The L1, as currently contemplated, does not include personal assistance, supported living, or residential habilitation. If the Draft Option was authorized by the Legislature, the specific array of services included on the L1 would be determined through stakeholder

workgroups during the waiver design phase. The design would allow individuals who demonstrate a need for additional support beyond the initial budget cap to request an additional $10,600 (total dollars) for one-time enhanced services. Therefore, the maximum amount that could be spent is $28,800 (total dollars). These figures include an initial targeted rate increase for transportation, respite, behavior consultation, and supported living services. *See* Targeted Provider Rate Increase.

The Level II Waiver (L2) targets adults, 18 years and older, who live independently in their own home or their family's home. The services in this waiver would mirror those offered in the Level I Waiver, and adds personal assistance and supported living services to help the person with activities of daily living. When possible, technology assistance would be used in place of direct support professionals (DSP) to encourage independence. Following the L1 structure, foundational services would not contribute to the budget maximum. A higher individual budget cap ensures that services like day habilitation, supported employment, and transportation could be used along with other supportive assistance. Maximum spending for capped services would be $48,200, with an additional $10,600 available for those requiring one-time enhanced support. Including the $1,800 for foundational services (support coordination and family training), the total that could be spent is $60,600. These figures include an initial targeted rate increase for transportation, respite, behavior consultation, and supported living services. Residential habilitation would not be included on the L2.

Service	Description	L1	L2
Foundational Services			
Family Training/ Peer Support	Training includes instruction about treatment regimens and use of equipment specified in the plan of care, and shall include updates as necessary to safely maintain the person at home and to maintain the integrity of the family unit. Training may also include instructions on how to access services, how to participate in the self-direction of care, how to hire, fire and evaluate service providers, consumer choices and rights, consumer's personal responsibilities and liabilities when participating in person-directed programs (e.g., billing, reviewing and approving timesheets), instruction to the family, and skills development training to the person relating to interventions to cope with problems or unique situations occurring within the family, techniques of behavioral support, social skills development, and accessing community cultural and recreational activities. Ideally, training techniques will be developed and provided by people with disabilities.	X	X
Support Coordination	Assists Waiver eligible Persons in selecting and obtaining HCBS Waiver and other non-Medicaid based services and supports. SCE services include monitoring the health and safety of Persons, performing monitoring visits in various locations where the Person is active in community, reviewing and approving Department of Human Services, Division of Services for People with Disabilities (DHS/DSPD) service provider activities with/for the Person and billings relating to each Person's services and supports, and maintaining all documentation required in the Person's Person Centered Support Plan (PCSP) and recorded in Utah System for Tracking Eligibility, Planning, and Services (USTEPS) including the USTEPS Provider Interface (UPI).	X	X
Capitated Services			
Respite	One-to-one or group care to give relief to, or during the absence of, the normal caregiver.	X	X
Behavior Consultation	Individually designed one-to-one interventions intending to replace the person's targeted behaviors with socially acceptable appropriate behaviors, address serious behavior problems, and address or prevent crisis behavior problems, in an effort to, increase the person's access to community integration.	X	X

Environmental Adaptations	Mechanical adaptations and technology devices used to support autonomy and reduce hours of human assistance.	X	X
After School/ Summer/Senior Programs	Partnering with county recreation centers and private programs offering after school, summer, and other social programming to build integrated activities.	X	X
Community Integrated Employment	Person driven assistance with developing skills related to gaining and maintaining competitive employment, including ongoing support with job duties.	X	X
Day Habilitation	Provides one-to-one or group support, supervision and training for a child, adult or elder; may be provided on a daily or hourly basis. Service provides a safe, non-residential, community habilitation program in a structured programmatic setting, other naturally occurring environment or community setting where a person can receive supports during the day to avoid becoming isolated and to participate in and contribute to his or her community. Service maintains or improves a person's job-readiness skills, work abilities, dexterity, stamina, memory, personal safety, interpersonal relations, self-help, communication, mobility and other functional abilities and life skills.	X	X
Transportation	Service that enables person to gain access to waiver and other community services, activities and resources, specified by the individual support plan (ISP), including community habilitation programs or facilities that provide day supports.	X	X
Personal Assistance Services	Activities of daily living (ADLs), instrumental activities of daily living (IADLs) and health related tasks, through hands-on assistance, supervision, and/or cueing; Acquisition, maintenance, and enhancement of skills necessary for the individual to accomplish ADLs and IADLs and health-related tasks.		X

Federal Limitations

(7) limitations that need to be considered, such as federal requirements, noting areas where waiver authority could be reasonably requested and granted;

This report has discussed in-depth the various CMS authorities available to the State Medicaid Agency (SMA). *See* Description of Funding. This includes home and community based waiver services 1915(c), state plan services 1915(i), community first choice state plan services 1915(k), and 1115 demonstration waivers. Note, also, that all new waivers must meet Settings Rule requirements to be approved by CMS.[41]

(8) steps that could be taken to make sure that only those who truly need government support are determined to be eligible;

Assessing Support Eligibility

By implementing multiple waivers, DSPD is able to offer service options that provide the most beneficial supports to individuals and families. Persons with disabilities and their families are able to choose the most appropriate services to fit their individualized needs. Because these waivers are set up to be self/family-directed budgets, people are able to engage in the amount of supports that is deemed necessary, within their budget caps. *See*

[41] CMS, Fact Sheet: Summary of Key Provisions of the Home and Community-Based Services (HCBS) Settings Final Rule (2014).

Self-Directed/Family-Directed Budgeting. As needs change, there will be a process to assess individuals to place them in a more appropriate waiver. *See* Service Design.

Projection of Costs

(9) a projection of costs associated with providing services to individuals identified in the study;

Estimated Cost Under the Current System

Without any changes to the current system, the cost to support the estimated 27,206 Utahns in need of services between now and 2030 would total $628,820,000 General Fund. This calculation is based on the average General Fund cost of $13,781 per person, derived from FY17 service recipient budgets, plus a 2% compounding of Cost of Living Adjustment, State Plan Costs, and Administrative Costs for DHS, UDOH, and DWS.

Comprehensive waiver participants tend to experience increased health and safety support needs over time. To maintain federal funding, DSPD must provide increased supports, which is associated with increased costs of 3% annually on average, or 38% compounded over ten years. Using existing waiver recipient expenditures as a basis of cost means the inclusion of this 3% growth factor represents the effect of additional service needs. If the 3,000 people currently on the DSPD waiting list enrolled on the LSWs, the estimated average cost for the first year of service is $8,953 General Fund per person. Applying a 10-year growth factor of 38% yields an expected cost of $12,355, which is similar to the current average per person cost of $13,781 (FY17). Therefore, it should be considered that costs being reported represent both new waiting list allocations and ten years of costs associated with mandated additional needs.

Estimated Costs under the Draft Option

Estimating waiver placement and the estimated costs associated with each waiver are used to determine the projected cost to serve all 27,206 people in need of support.

Estimating Waiver Placement

Based on historic data, DSPD estimated the percent of adults in need of L1 versus L2 waiver services. The proportion of non-residential adults (2,920) currently receiving personal assistance is 58%. It is, therefore, assumed that 58% of 4,132 adults in need of supports would utilize the Level II Waiver and the remaining 42% would utilize services from the Level I Waiver. Future analysis may reveal a different proportion of adults actually needing the Level II Waiver.

In FY18, 270 people entered residential services. Of these 270 people, 150 were newly enrolled from the waiting list. The remaining 120 people were already participating in the Comprehensive Waiver. Children, up to age 21, constituted 19% of residential placement, and 12% of those entered services in a residential placement due to Division of Child and Family Services (DCFS) custody. Individuals typically enter residential services following loss of a caregiver, significant behavioral challenges, or safety concerns. Over ten years, DSPD expects that 2,010 new people could require residential supports on the comprehensive waiver.

Estimated Cost

Calculating the average cost of the capitated waiver options includes multiple factors:

1. What percent of the budget cap will be spent? Based on a review of states utilizing budget caps, it is believed that those with a relatively low budget cap will see 80% of funding spent, while those with a relatively high budget cap will see 50% of funding spent[42].

2. Assumes highest cost placement. Recognition that a person's circumstances change over time influenced cost projections. In order to account for waiver changes and anticipate residential service need, estimates assumed placement of persons in their highest cost placement.

3. What percent will require enhanced services? It is difficult to predict what proportion of service recipients will require a one-time enhanced budget to $28,800 on the L1 or $60,600 on the L2. Enhanced funding levels are designed to meet the needs of only a small minority of the population. Estimated costs assume only 10% of people require this level of support.

Persons entering the comprehensive waiver need residential support, which increases the assumed average cost. An average cost (FY18) of existing residential service recipients ($89,185 total dollars) was used to determine the cost associated with the comprehensive waiver.

Targeting Services for Improved Accessibility

Ensuring accessibility and sustainability of in-home service structures is critical to the success of waiver design. The provider industry reports reimbursement level deficiencies in the following service rates: respite, behavior consultation, transportation, and supported living. The provider industry also reports a need to redevelop respite and supported living service descriptions and requirements. Rate correction is necessary to build an adequate service delivery system. Based on the recent study performed by a contracted CPA firm, the service delivery system on aggregate showed a 17.6% loss in the delivery of DSPD transportation services. In the surveys received, a total of $4,195,196 was paid to providers with Medicaid allowable costs of $4,931,276 reported. Transportation rates would therefore need to increase by 17.6%. Additionally, current behavior consultation rates for DSPD should be increased to levels similar to behavior consultation services available through the Medicaid State Plan. This would require a 22.2% rate increase to existing DSPD behavior consultation services. Supported living and respite services are similarly identified by providers as lacking adequate reimbursement rates. Based on the need for a rate increase quantified for transportation services (17.6%) and behavior consultation services (22.2%), reimbursement rates would need to be increased by similar levels (19.8%) for supported living and respite services. The table below shows the rate increase required and the General Fund cost to support 27,206 new enrollees in the DSPD service system.

Service	Rate Increase	GF cost to implement for 27,206 new enrollees
Transportation	17.6%	$956,000
Respite	19.8%	$1,085,000
Behavior Consultation	22.2%	$2,756,000
Supported Living	19.8%	$462,000
		$5,259,000

[42] http://www.nasuad.org/sites/nasuad/files/hcbs/files/127/6301/gaugingfr.pdf

Cost of Living Adjustments (COLA)

To prevent wage disparities that increase job vacancies and turnover, rates need to more closely match the job market, which includes regular inflation- related rate increases. Regular rate increases protect the integrity of programming and improve staff retention. An analysis of the most recent twenty years of legislative appropriations for DSPD provider rate increases revealed an average growth rate of 2% annually. The Utah State Legislature has appropriated $13,500,000 during the past four legislative sessions. Direct care staff turnover has decreased from 86% and is now fluctuating from 49-62%. An annual General Fund appropriation ranging from $1,498,000 (year 2) to $42,879,000 (year 10) with an average of $16,426,000 (over years 1-10) would be necessary to maintain market rates for direct care staff necessary to provide services for the 27,206 individuals phasing into the current system. In contrast, under the draft option, additional costs from $631,300 (year 2) to $18,069,000 (year 10) with an average of $6,922,000 (over years 1-10) would be expected annually to maintain the status quo, with understanding that additional appropriations could be required depending on the job market and direct care staff turnover.

State Plan Services

Additional costs will be experienced due to extending Medicaid state plan benefits to new enrollees. Costs were determined by reviewing the fiscal year 2018 Medicaid expenditures for individuals enrolled in the CSW. Newly enrolled children up to the age of 21 are eligible for Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefits including diagnosis, screening, and treatment for autism spectrum disorder. These state plan benefits for children were $3,674 General Fund per member per year (PMPY) in 2018. An additional $1,676 PMPY was expended through local fund sources for school based services and behavioral health for children. Adults on the CSW in 2018 were eligible under disability Medicaid. These state plan benefits for adults were $2,669 General Fund PMPY in 2018 with an additional $515 expended through local fund sources for behavioral health. These costs are projected to increase with medical inflation at an estimated rate of 2% annually.

Age Group	Fund	FY18 PMPY	FY21 PMPY	FY30 PMPY
Children (0-21)	**Total Funds**	**$17,353**	**$18,415**	**$22,007**
	Federal	$12,003	$12,737	$15,222
	Local	$1,676	$1,778	$2,125
	General	$3,674	$3,899	$4,660
Adults	**Total Funds**	**$10,290**	**$10,919**	**$13,050**
	Federal	$7,105	$7,540	$9,011
	Local	$515	$546	$653
	General	$2,669	$2,833	$3,386

A September 2017 analysis of the waitlist of individuals seeking enrollment in the CSW determined that approximately 48% of children and 66% of adults on the waitlist were currently Medicaid eligible. This percentage of individuals already Medicaid eligible is estimated to be consistent with the future projected enrollment. Applying these estimates, the state plan costs for 10,299 children and 3,744 adults is excluded from the cost projection. The ongoing cost for the newly eligible 11,275 children and 1,888 adults is $58,940,000 General Fund ongoing. An additional $25,190,000 ongoing expenses will be funded from local entities. The total of non-Federal funds is $84,130,000.

DHS Administrative Costs

Additional DHS staff are necessary to perform functions related to: intake/eligibility, contract development/monitoring, transition services, quality management, contract compliance monitoring, and incident reporting. Increasing the volume of DSPD clients would have a corresponding impact on workload across three agencies within the Department of Human Services: DSPD, Office of Quality and Design, and Office of Licensing. The number of staff needed is based on calculations of current caseloads in these areas. Some efficiencies could be realized by implementing the new waivers outlined in the draft option. By implementing spending caps, people with disabilities, their families and support coordinators would be empowered by the work of initial person-centered planning, assessment, and service allocation. The total estimated DHS staff needed under the draft option is 78.2 FTEs with a cost of $3,040,000 General Fund. Maintaining waivers as currently designed under the existing system would require 127.7 FTEs costing $4,950,000 General Fund.

UDOH Administrative Costs

The Department of Health will experience increased administrative costs with additional Medicaid enrollment. In the first year of operation, one Health Program Representative FTE will be needed in order to assist individuals with plan selection and assistance with accessing Medicaid benefits. Two waiver specialist FTEs will be needed to comply with additional administration responsibilities inherent with the 1915(c) waivers, including post-payment review and cost neutrality reporting. One Claims Examiners will be required for the processing of additional state plan claims. These four FTEs in year one will need to increase to 11.5 FTEs in year 10 with caseload growth. With an estimated two percent cost of living adjustment annually, the year 10 personnel expense will be $400,000 GF. These personnel expenses will be supported with local entity fee collections related to existing state match contracts. As local entities provide additional non-Federal match for behavioral health and school based services, fees for those seeding contracts will provide $820,000 ongoing funds. The resulting net impact to the Department of Health personnel line item will be a reduction of $420,000 ongoing. Software development will be necessary in order to add additional waiver benefit plans, modify claim editing logic, and process increased claim volume. This will require $25,000 and $225,000 General Fund one-time in 2021 and 2022 respectively.

DWS Administrative Costs

There would also be administrative costs associated with Medicaid eligibility determination for the Department of Workforce Services (DWS). These costs include software development, eligibility determination staff, and associated support staff. DWS estimates the one-time cost of software development to be $50,000 General Fund with a 90% Federal Medical Assistance Percentage (FMAP). Additionally, 55 FTE for eligibility determination staff, and 6.7 FTE for associated support staff, are estimated to be needed as an addition to the workforce for 27,000 people to brought into services from the waiting list. Based on the FMAP of 75% (Federal portion), new ongoing costs of $1,140,000 General Fund would be required to cover the cost associated with 61.7 new staff added over ten years.

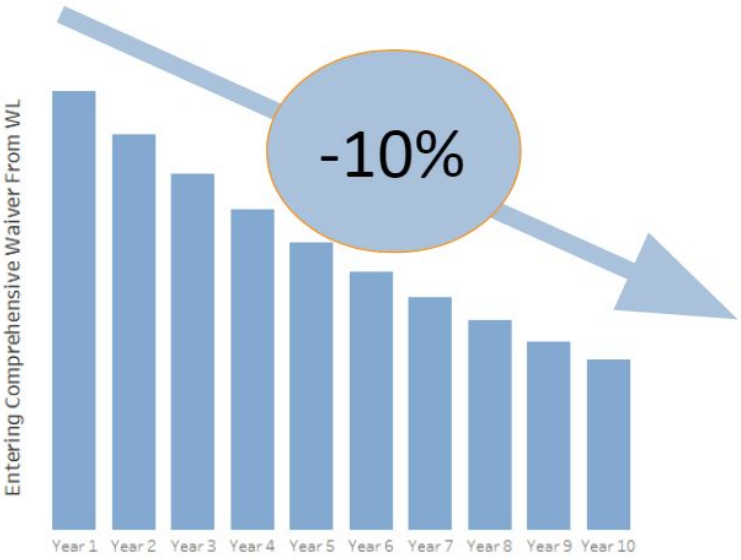
Cost to support 27,206 new HCBS enrollees by 2030

	Total GF Cost	Avg GF Cost	Avg Total Cost	Max Total Cost	New Youth Supported (0-17)	New Adults Supported (18+)	New People Supported
Ongoing Waiver Costs							
Draft Option:							
Add new enrollees to new waivers							
Level I Waiver (All Ages)	$73,310,000	$3,212	$10,700	$27,200	21,112	1,715	22,827
Services include: Respite, Behavior Consultation, Environmental Adaptations (Emphasis on Technology), After School/Summer Senior Programs (Community Integrated), Community Integrated Employment/Day Programs & Transportation Services Exclude: Residential, Supported Living, Personal Assistance							
Level II Waiver (Ages 18+)	$25,450,000	$10,745	$35,800	$57,200	0	2,369	2,369
Services include: Respite, Behavior Consultation, Environmental Adaptations (Emphasis on Technology), After School/Summer Senior Programs (Community Integrated), Community Integrated Employment/Day Programs & Transportation, Supported Living, Personal Assistance Services Exclude: Residential							
Running sub-total	$98,760,000						
Targeted Services for Improved Accessibility 17.6-22.2%	$5,260,000						
Services Include: Transportation, Respite, Supported Living, Behavior Consultation							
Adjusted spending for Level I Waiver		$3,392	$11,300	$28,800			
Adjusted spending for Level II Waiver		$11,316	$37,700	$60,600			
Running sub-total	$104,020,000						
Add new enrollees to existing waiver							
Comprehensive Waiver (Residential for all ages)	$53,810,000	$26,769	$89,185	N/A	462	1,548	2,010
Draft Option Sub-total	$157,830,000		**Total**		21,574	5,632	27,206
Current System Option							
Add new enrollees to existing waiver							
Comprehensive Waiver (All ages)	$374,930,000	$13,781			21,574	5,632	27,206
Services include: All Services Exclude: None							
Current System Option Sub-total	$374,930,000		**Total**		21,574	5,632	27,206

	Draft Option	Current System Option
Ongoing Waiver Costs Sub-total	$157,830,000	$374,930,000
2% COLA compounded	$69,220,000	$164,260,000
Running sub-total	$227,050,000	$539,190,000
Ongoing State Plan Costs		
State Plan Costs (Includes 2% COLA)	$84,130,000	$84,130,000
Running sub-total	$311,180,000	$623,320,000
Ongoing Administrative Costs		
Administrative Costs DHS	$3,040,000	$4,950,000
Administrative Costs DOH	-$420,000	-$590,000
Administrative Costs DWS	$1,140,000	$1,140,000
Administrative Costs Sub-total	**$3,760,000**	**$5,500,000**
Ongoing Grand Total	**$314,940,000**	**$628,820,000**
Additional One-time Costs		
Software Development		
DOH	$250,000	$0
DWS	$50,000	$0
One-Time Grand Total	**$300,000**	**$0**

Additional Potential Cost Savings

The savings ($313,880,00000) comes from comparing the draft option ($314,940,000) to the current system ($628,820,000). In addition to this cost-effective approach, potential offsets to funding requests are also important to note. Currently, DSPD has been given direction to use attrition funding to enroll additional individuals from the waiting list. Between fiscal years 2015-2018, an average of $1.7M in General Fund became available annually due to individuals leaving services. Attrition will continue to offset costs, however, an estimated amount is difficult to derive. DSPD anticipates that, over time, prevention services would help decrease the number of people requiring residential supports. A 10% annual decrease in the number of people needing residential services could yield savings of $1,602,000 annually over ten years. A 10% reduction goal was modeled after a Healthy People 2020 initiative[43]. It is a goal of DSPD to continue work to find lower cost, integrated



[43] https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health/objectives

residential support alternatives. These savings may help offset appropriation funding needed to serve all Utahns with disabilities in need of support, but good data is not yet available to estimate the effect on funding requests.

Ongoing Review and Analysis

The calculations described in this section are based on anticipated results using a combination of historic DSPD data and experiences seen in other states. Waiver delivery systems vary greatly across states. It is not possible to know with certainty what actual utilization patterns will be seen in Utah. After adopting new waivers, DSPD would engage in a process of ongoing review and analysis to improve forecasted costs using actual experience data post-implementation.

Private/Public Partnerships

(10) a discussion of innovative and creative ways that private partners and charities could work with the program to meet those needs;

Innovative alternatives to the existing provider infrastructure are needed. New business models will need to be developed by providers to meet the needs of a younger population. The Self-Administered Services (SAS) model allows individuals and families to act as the employer of record, in order to hire, fire, and train their own staff. This model offers a fiscal management service to help individuals and guardians learn employer requirements, complete payroll, and file taxes. Additionally, DHS will look at what other resources are available, considering, in particular, how to access and strengthen services that already exist in local communities.

Outside of DSPD, families turn to other groups and services to gain the support that they need to help their family member with a disability. Some of these groups include: other natural supports, such as family, friends, and neighbors; faith based organizations; support groups; organizations that provide supplies and equipment for people with disabilities; and private providers. Parents of children and young adults with disabilities often heavily rely on schools to help manage and support their child.

Other Considerations

(11) any other considerations related to effective management strategies for the DSPD waiting list.

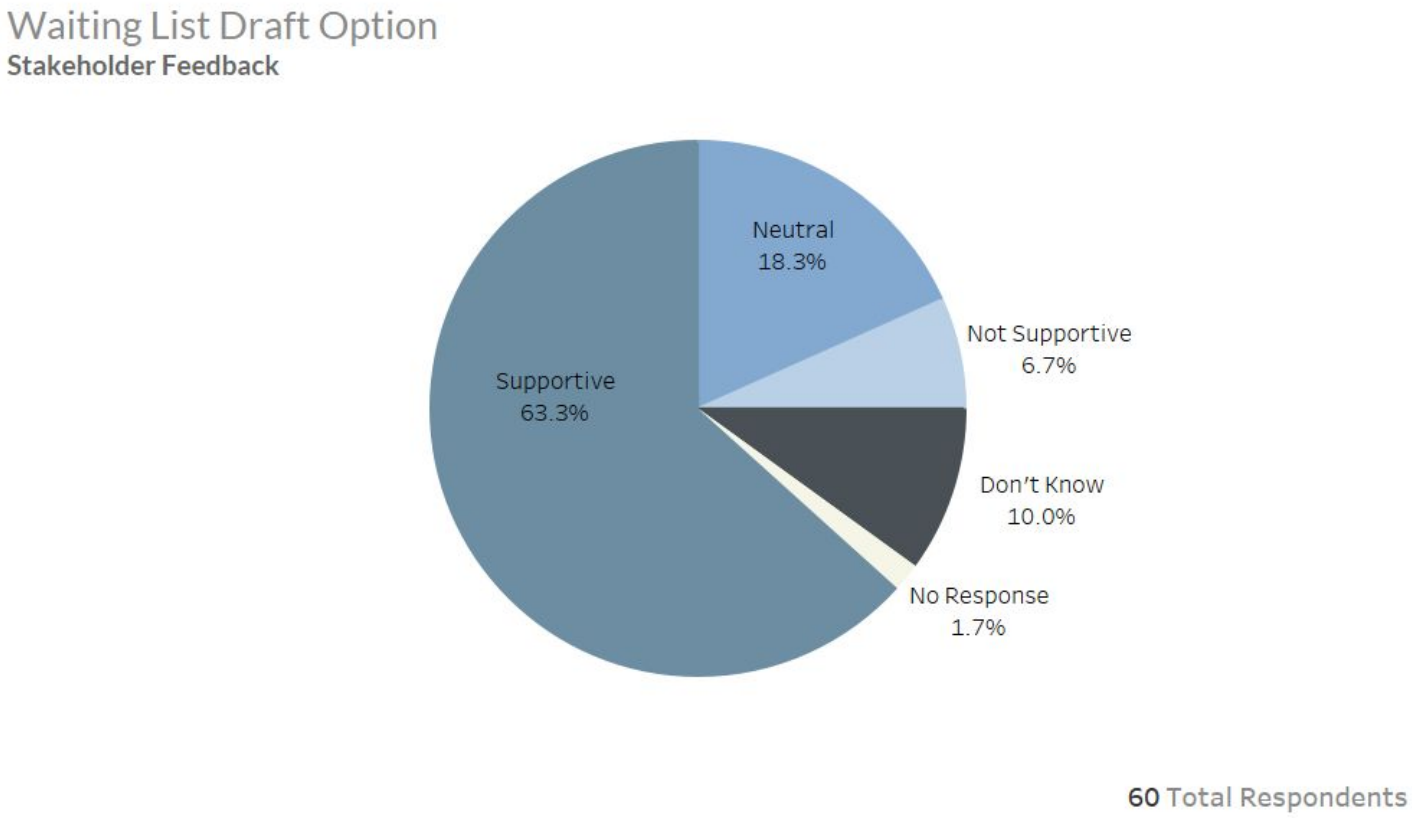
Ongoing Feedback

Throughout the waiver design process, DHS will engage people with disabilities and stakeholders to inform key decisions. New waivers and services implemented as early as July 1, 2020, will incorporate the thoughtful considerations of DSPD constituents. After implementation, continuous improvements will be made to the design process as DHS optimizes its service delivery system.

Stakeholder Feedback on Draft Option

A public information webinar was held on August 29 to discuss the draft option. A follow-up survey was implemented to gather data on individual's level of support, and perceived benefits and drawbacks of the draft option. Shown in the graph below, the survey received 60 responses, and found that 63.3% of individuals are supportive of this draft option, 18.3% are neutral, 6.7% are not supportive, 10.0% did not know, and 1.7% did not respond to this question. Of those who are supportive of this draft option, 71.1% are family members

of a person with a disability, 5.3% are people with a disability, and 23.6% of respondents are other stakeholders.



Some of the benefits individuals reported include:

- Meeting the needs of individuals prior to crisis, and emphasizing preventative care
- Serving more individuals
- Giving all individuals with disabilities services, even while waiting for residential care
- Providing respite to families

Some of the concerns individuals reported include:

- Support coordinators and providers not being able to scale to capacity with such a large influx
- Current provider rates are too low
- Competing funding for the waivers
- Discouraging amounts of paperwork and difficulty using SAS for some families

In addition to the pros and cons listed above, several people commented on their confusion for how people can move between waivers, how rates will be structured, and how people will be pulled into services. As explained under the Draft Roadmap below, each of these concerns, and several others, could be addressed prior to implementation with specific workgroups geared toward making the new system seamless for individuals, families, and other stakeholders.

In addition to soliciting feedback from all stakeholders after the 8/29/2018 presentation, DSPD held discussions with the Utah Association of Community Services (UACS) and the Independent Support Coordinator Association (ISCA). As a result of this feedback, DSPD modified the draft option outlined above to explicitly include day programs and transportation services in the array of services on the two limited support

waivers. Additionally, DSPD incorporated a funding adjustment for targeted services needing improved accessibility (transportation, behavior consultation, respite, and supported living).

Potential Disadvantages to Implementing Draft Option

Increased Complexity. Confusion surrounding application for assistance already exists within the current system. Adding new waivers will add to stakeholder confusion. Families compare available services, rates, and budgets with one another; identified variations in access raise questions. Shifting expectation to the new ideas of limited support and most appropriate waiver takes time and engagement. Washington State acknowledged constituent difficulty navigating multiple waivers. Louisiana will consolidate multiple waivers into a single waiver to address stakeholder feedback requesting a simplified system. DSPD anticipates that outreach and education, along with a simplified intake process, will sufficiently manage confusion. Entry into the L2 waiver requires meeting age criteria (18 years) as well as a need for supported independence in the form of personal assistance/supported living. Since the majority (79.3%) of the 27,206 Utahns in need of support are children, relatively few will need to recognize the distinction between the two new draft option waivers.

Administrative Burden. Serving large quantities of people requires administrative overhead. Adding waivers increases administrative needs across three agencies: DHS, UDOH, and DWS, that include software development and full time employees. Providing services through separate waivers could affect billing. Agency collaboration and careful process alignment should mitigate problems drawing-down federal financial participation for services rendered.

Cost Neutrality. Section 1915(c) waivers must be cost neutral; meaning that the cost of the waiver program must not exceed the cost of the institutional program for the same population, based on average annual per capita estimates.[44] The calculation assumes that the unduplicated number of people using HCB supports would have accessed institutional services but for the choice to remain in the community. Aggregating cost across a waiver allows lower dollar individual budgets to balance higher dollar budgets. Monitoring the impact of limited waivers on the comprehensive waiver cost neutrality will be needed in order to correct any problems. The cost neutrality concern is mitigated in part by retaining low cost individuals on the existing comprehensive waiver.

Should new 1915(c) waiver(s) be added?

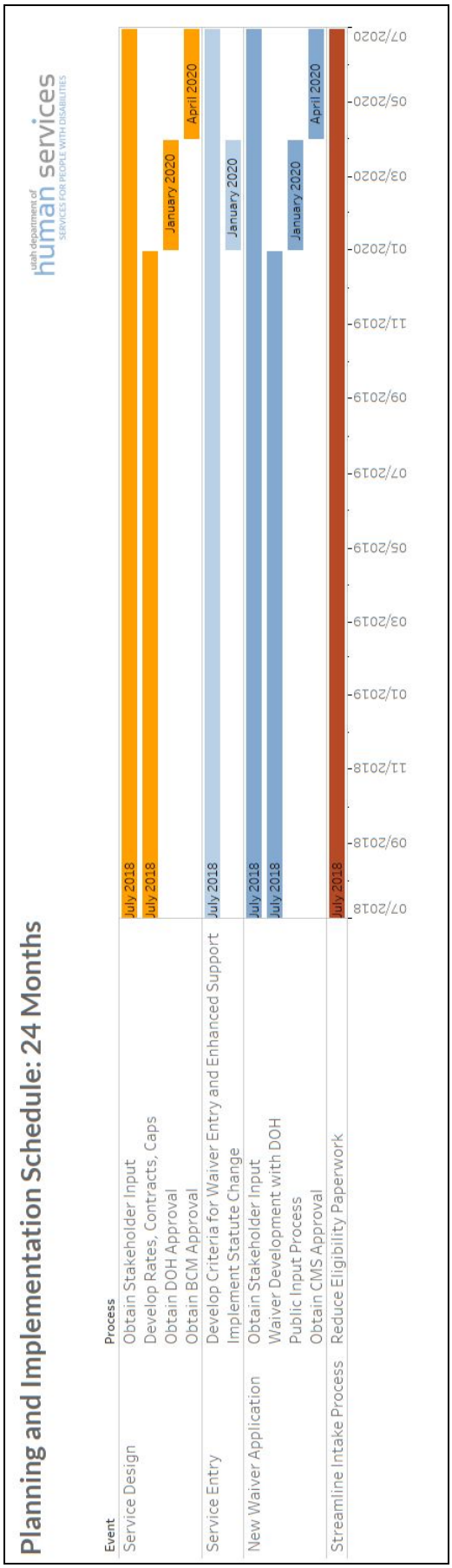
Waiver Applications

If the Legislature mandates creation of additional 1915(c) waivers, DHS will work collaboratively with UDOH to apply for and implement new waivers. The process includes development of the waiver application, public input period, submission of application to CMS by UDOH, and CMS decision. Following CMS approval, DHS and UDOH would begin implementation as outlined in the Two and Ten- Year Roadmaps.

Two-Year Roadmap

The draft option includes ongoing study of CMS authorities and continuing stakeholder input. Workgroups will be formed to determine the details of bringing 27,206 individuals into services. There are four main system components which need to be developed to ensure smooth intake and transition, including: service design, service entry, new waiver applications, and streamlining the intake process. The chart below shows the schedule of planning over the next 24 months, up to implementation of the new waivers in July, 2020.

[44] 42 U.S.C. § 1396n(c)(2)(D) (under such waiver the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individuals does not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for such individuals if the waiver had not been granted;).


Planning and Implementation Schedule: 24 Months
utah department of human services
SERVICES FOR PEOPLE WITH DISABILITIES
Event
Process
Service Design
Obtain Stakeholder Input
Develop Rates, Contracts, Caps
Obtain DOH Approval
Obtain BCM Approval
Service Entry
Develop Criteria for Waiver Entry and Enhanced Support
Implement Statute Change
New Waiver Application
Obtain Stakeholder Input
Waiver Development with DOH
Public Input Process
Obtain CMS Approval
Streamline Intake Process
Reduce Eligibility Paperwork
July 2018
January 2020
April 2020
07/2018
09/2018
11/2018
01/2019
03/2019
05/2019
07/2019
09/2019
11/2019
01/2020
03/2020
05/2020
07/2020

Which services should be offered?

Which age groups should be targeted?

Which target population(s) disability types?

Service Design

Service design comprises details such as the services, budget caps, and rates for each of the LSWs. This also includes obtaining approval of the waivers from UDOH and the Bureau of Contract Management (BCM).

Services. To determine the Foundational services, DSPD drew from strategies used in other states. DSPD chose the two Foundational services, because the nature of the services are such that one need not choose between it and another needed service. Focus groups identified Family Training as an invaluable service that waiting list families need. Support Coordination, used by all persons in-service, improves access to services and quality of care.

Should DSPD implement individual budget caps?

What spending cap should be implemented?

Budget Cap. For the draft option, budget caps were determined based on data analysis of various populations currently in DSPD services and the population assumed to need DSPD services by 2030. Cap levels of $16,400 and $48,200, for the L1 and L2 respectively, should adequately finance the intended populations receipt of support commensurate with anticipated needs. Providing limited support to more people means that services must be provided within the cap. These budget caps will be thoroughly discussed in workgroups during the planning phase to ensure they are set to appropriate levels.

Rates. The rates at which services are set dramatically impact the number of providers willing to deliver a given service. DSPD will continually assess the adequacy of existing rate reimbursement levels. New service and rate development are critical to the health of the provider system.

Service Entry

Service entry includes the development of criteria for both waiver entry and enhanced supports.

Which service entry method should be used?

Determining Method for Service Entry. There are three options for how DSPD could prioritize entry into services, should additional waivers be adopted. The first method is needs- based entry. This would be similar to the current method of service entry and would require DSPD staff to administer the Needs Assessment Questionnaire. The second method is to use random selection. This would disregard the length of time that an individual has been waiting; instead, individuals would be randomly pulled into services from the waiting list each year. The third option is to utilize a first come, first served method. This method would first enroll persons on the waiting list, and then enroll persons in the order in which they are deemed eligible. Advantages and disadvantages to each method may be influenced by the availability of ongoing annual appropriations.

Determining Most Appropriate Waiver. When an individual is brought into DSPD services, there will need to be an assessment process to determine which waiver is the most appropriate waiver to meet their needs. The same process could be used to assess significant changes in circumstances, like aging, that require movement between waivers. Since there is currently only one waiver for individuals with intellectual disabilities and related conditions, DSPD does not currently have a process to determine the most appropriate waiver. This criteria will be determined through ongoing workgroups with stakeholders during the planning phase.

Enhanced Support Criteria. DSPD recognizes that there are unique situations in which a person requires a one-time increase in their budget. This could include events such as temporary loss of a caregiver (due to surgery, sickness, etc), one time environmental adaptation (such as a lift), or enhanced behavior supports. During the planning phase, DSPD, in conjunction with stakeholder workgroups, will be determining how an individual can apply for, and receive, enhanced supports.

Ten-Year Roadmap

DSPD also created a general ten year timeline to implement each phase of the potential waiting list management strategy. A legislative statute change in the 2020 General Legislative Session would be necessary to begin implementation of any waiver changes. The chart below shows an overview of the planning and implementation phases from 2018 through 2030. If implemented in July 2020, there would be ten subsequent phases of implementation of the Level I and II Waivers. Obtaining input from individuals with disabilities and other stakeholders will be a crucial element to revise the process and ensure needs are being met to the fullest extent.

Planning and Implementation Schedule

utah department of human services
SERVICES FOR PEOPLE WITH DISABILITIES

Event	Process	
Level I & II Waivers	Planning	7/1/2018
Level I & II Waivers Phase I	Implementation	7/1/2020
Level I & II Waivers Phase II	Implementation	7/1/2021
Level I & II Waivers Phase III	Implementation	7/1/2022
Level I & II Waivers Phase IV	Implementation	7/1/2023
Level I & II Waivers Phase V	Implementation	7/1/2024
Level I & II Waivers Phase VI	Implementation	7/1/2025
Level I & II Waivers Phase VII	Implementation	7/1/2026
Level I & II Waivers Phase VIII	Implementation	7/1/2027
Level I & II Waivers Phase IX	Implementation	7/1/2028
Level I & II Waivers Phase X	Implementation	7/1/2029
Funding Statute Change	Planning	7/1/2018
	Implementation	7/1/2020
Streamline Intake Process	Planning	7/1/2018
	Implementation	7/1/2020
Study of CMS Authorities	Implementation	7/1/2018
Stakeholder Input	Implementation	7/1/2018

2018 2019 2020 2021 2022 2023 2024 2025 2026 2027 2028 2029 2030

Internal Efficiencies

Some efficiencies could be gained by improving system processes in a manner that allows DSPD to effectively transition a larger number of individuals from the waiting list into services.

Streamlining Intake

As part of the planning phase, DSPD will facilitate workgroups to improve the intake, waiting list, and service entry processes. The workgroups will focus on streamlining processes, reducing paperwork requirements, and developing a logical business flow to ensure speedy entry into the DSPD service system. Process efficiency gains intend to improve constituent experiences and increase satisfaction.

Reduced Needs Assessment Questionnaire

Before implementing system changes on July 1, 2020, stakeholder input will be used to determine the best method for service entry. If it is determined that first-come first-served or random selection is the best method for service entry, DSPD could achieve some efficiencies by only administering its assessment of need to those who are requesting comprehensive services.

Self-Directed/Family-Directed Budgeting

DSPD, currently, exercises two budget allocation and service review mechanisms to monitor service usage and person-centeredness. The Division developed a system to rigorously vet requests that add new services to and increase use of services in individual budgets. Support coordinators submit a standardized, electronic form to the Utah System for Tracking Eligibility, Planning, and Services (USTEPS) for review by a request-for-services (RFS) specialist. A completed form specifies the service(s) to be increased and/or added with attached relevant documentation of need. Specialists work with support coordinators to fix errors in the request, discuss evidence of need, and reallocate available funding to achieve the person-centered goals. Requests that cannot be approved or denied by the specialist move to the RFS committee for review and decision. A notice of agency action conferring appeal rights follows all denied requests.

Yearly utilization reviews, conducted by finance specialists, remove excess funds from individual budgets. A review considers use of a service over a two year period before defining unused funds as excess. DSPD gives the person and their support coordinator notice of review and notice of agency action if review results in removal of funds. Support coordinators have the option to justify unused funds to the finance specialist during the review, and problem-solve any barriers to service use.

Capitated individual budgets, however, allow persons in-service, and their families, to make service decisions within the predetermined annual budget. Support Coordinators can make adjustments, as part of person-centered planning, to the service prescription without prior authorization from an RFS specialist. Yearly utilization reviews would not be necessary, because annual caps renew each year regardless of usage. Three benefits emerge from LSW capitated budgets: reduced response time to situation changes, reduced paperwork for support coordinators, and dampened administrative increases needed to serve an additional 27,206 people.