Utah Department of Health & Human Services Services for People with Disabilities

Guide to eligibility & services



Thank you to everyone who contributed to the Guide.



The Division of Services for People with Disabilities (DSPD) is part of the Utah Department of Health and Human Services (DHHS). DSPD promotes opportunities, and provides supports by overseeing home and community-based services for people with disabilities in order to lead self-determined lives. Services help people live, learn, and work in their communities while ensuring their health and safety. DSPD also promotes both public awareness and acceptance of people with disabilities.

Please visit our website at dspd.utah.gov



The Utah Parent Center is an award-winning, nonprofit organization founded in 1983 by the parents of children and youth with disabilities. They help other parents facing similar challenges throughout Utah. The mission of the Utah Parent Center (UPC or Center) is to help parents help their children with disabilities to live included, productive lives as members of the community. We accomplish our mission by providing accurate information, empathetic peer support, valuable training, and effective advocacy based on the concept of parents helping parents.

The caring and competent staff of the UPC has utilized a parent-to-parent model to help many

thousands of parents and to represent families in many systems-level activities. Staff of the Center have built collaborative networks that include education, health and human service professionals, agencies, and organizations. The UPC promotes change within the community through various projects and activities.

Visit the Utah Parent Center's website at www.utahparentcenter.org.



The Family to Family Network (FtoFN) is a statewide parent support network run by volunteers. It is designed to educate, strengthen, and support families of persons with disabilities, especially those who are on the waiting list or are in services with the Division of Services for People with Disabilities (DSPD). Network leaders are parents of individuals with special needs. They link families to local resources, services, and disabilityfriendly events. The FtoFN is a project of the Utah Parent Center.

They can help you by providing:

- support through local meetings, either inperson or online;
- information and referral;
- family to family support;
- tips on how to advocate for your family;
- assistance for families who qualify or may be eligible for services from DSPD. They can guide you in understanding programs and services, and how to work with service providers and support coordinators

Visit the Network's website at

https://utahparentcenter.org/projects/family-tofamily/

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ACRONYMS & DEFINITIONS

What does eligibility for services mean?

DSPD needs to determine if you are eligible to receive services. People of all ages can be eligibile for services. You may be eligible if you have a qualifying disability in one of the three areas listed:

- intellectual disability and related conditions
- acquired brain injuries
- physical disabilities

Intellectual Disability & RelatedConditions

A qualifying disability meets the definition of either intellectual disability or a related condition. Common related conditions include cerebral palsy, epilepsy, and autism.

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and adaptive behavior with evidence of onset during the developmental period. In the United States, the developmental period means before the age of 18. Intellectual functioning refers to general mental capacity, such as learning, reasoning, and problem solving. Generally, an IQ test score around 70 indicates a limitation in intellectual functioning. Adaptive behavior is the collection of conceptual,

social, and practical skills that are learned and performed by people in their everyday lives.

A **related condition** is a severe, chronic disability that:

- results in impairment of general intellectual function or adaptive behavior similar to that of intellectual disability;
- manifests before the age of 22;
- is likely to continue indefinitely; and
- results in substantial functional limitations in three or more areas of major life activity.

Functional Limitations

DSPD evaluates a person's functional limitations in seven areas of major life activity for eligibility purposes. To be eligible, the person must have three or more functional limitations. The areas evaluated for eligibility depend on the person's age at the time of application.

- Self-care
- Expressive and Receptive Language
- Learning
- Mobility
- Capacity for Independent Living
- Self-direction
- Economic Self-sufficiency

Acquired Brain Injuries

Acquired brain injury is defined as injury related and neurological in nature. It may include cerebral vascular accidents and brain injuries that have occurred after birth. Acquired brain injury does not include individuals whose functional limitations are due solely to mental illness, substance abuse, personality disorder, hearing impairment, visual impairment, learning disabilities, behavior disorders, aging process, or individuals with deteriorating diseases such as multiple sclerosis, muscular dystrophy, Huntington's chorea, ataxia, or cancer.

The Acquired Brain Injury results in at least three functional limitations. DSPD uses the International <u>Classification of Diseases diagnosis codes</u> to identify eligible brain injuries.

Functional Limitations

DSPD evaluates seven areas of functional limitations for eligibility purposes.

• Memory or Cognition

- Activities of Daily Life
- Judgment and Self-protection
- Control of Emotion
- Communication
- Physical Health
- Employment

Physical Disabilities

A qualifying physical disability is expected to last for a continuous period of not less than 12 months and results in the functional loss of two or more limbs. Functional loss means that the assistance of a trained person is required in order to accomplish activities of daily living.

To receive services the person must

- be age 18 years or older;
- be medically stable;
- have a qualifying physical disability;
- require at least 14 hours per week of personal assistance services in order to live in their community;
- be able to manage their own personal assistant;
- be able to manage their own financial and legal affairs;
- at least one personal attendant available to provide the authorized waiver services; and
- live in a residence that can accommodate the assistance and equipment needed to adequately and safely care for the person.

Conditions Not Eligible For Services

DSPD is **not** the agency for people whose disability or primary need for assistance is due to:

Mental health condition or behavioral health condition

Contact your local mental health authority (LMHA)

• Learning disabilities

Contact your school district or charter school

- Blindness or severe hearing impairment, contact your local school district, charter school, or:
 - o Division of Rehabilitation Services,
 - o Division for the Blind and Visually Impaired,
 - o <u>Division for the Deaf and Hard of Hearing</u>
- Conditions due to aging:
 - o Division for Adult and Aging Services
- Any disorder arising after the age of 22 except an acquired brain injury or a physical disability
- Deteriorating diseases such as multiple sclerosis, muscular dystrophy, Huntington's chorea, ataxia, and cancer



Apply Online

Start intake through MySTEPS

Apply By Phone

Call 1-844-275-3773

Choose the "Apply for Services" option.

How do I APPLY for services?

Start as soon as possible.

An eligibility determination requires a lot of information. DSPD intake workers will help you navigate intake and eligibility. During the intake process, you will be asked to provide information that demonstrates your qualifying disability in one of the areas that DSPD serves. That information may include:

- A copy of basic identifying information such as name, phone number, address, social security number;
- Psychological evaluations, or a developmental assessment for children younger than six years of age;
- School evaluations;
- Medical health summaries;
- Other documentation unique to your disability.

DSPD has 90 days to complete the intake process. Intake includes reviewing all of your supporting documentation and then making an eligibility determination. If DSPD does not receive enough information to make an eligibility decision within those 90 days, the application becomes inactive. You may continue your application at any time by contacting your intake worker.

Visit <u>dspd.utah.gov</u> for more information and to start online intake.

Determined eligible, now what?

Needs Assessment

DSPD determines how critical each person's need for services is by using a standardized evaluation called the Needs Assessment Questionnaire (NAQ) An intake worker completes the NAQ to establish a "needs" score for each person eligible for DSPD services. The NAQ assesses a variety of factors, including:

- urgency of the need;
- severity of applicant's disability;
- caregiver's ability; and
- length of time spent on the waiting list.

People with the highest scores generally have the first priority for services. The NAQ score determines a person's rank order on the waiting list. The needs assessment can be re-scored at any time. Consider updating the NAQ when a person's circumstances change, or when a change in one or more of the factors is likely to occur. Call your intake worker to request another assessment. Explain what circumstances have changed or will change.

Waiting List

DSPD is usually not able to offer services immediately after a person is determined eligible. Disability services are dependent on funding allocations from the Utah State Legislature each year. Currently, thousands of eligible Utahns are waiting for services. As funds become available, individuals on the waiting list are notified by a DSPD intake worker and brought into services. Services are provided to those with the most critical needs through our comprehensive waivers. Services are provided to those with low support needs on our limited supports waiver. Priority rank is determined by the NAQ score. Priority is given to those who have been waiting the longest. Call your intake worker to update the NAQ anytime that your needs change.

Are other resources available?

Other state and community programs offer support for people with disabilities. Service eligibility and availability will vary by program.

Utah Department of Health:

- Baby Watch early intervention
- Bureau of Children with Special Health Care Needs
- <u>Children's Health Care and Evaluation (CHEC)</u>
- Children's Health Insurance Program (CHIP)
- Intermediate Care Facility (ICF/ID) 24-hour residential programs
- HCBS waivers

The public education system provides educational and related services for eligible children and youth with disabilities.

The <u>Utah State Office of Rehabilitation</u> provides short-term services related to employment for eligible young adults and adults with disabilities.

Disability Law Center Alternatives to Guardianship Factsheet.

Information on guardianship can be found on the Utah Courts website on Resources on Guardianship and Conservatorship.

Information about assistive technology:

- <u>Utah Center for Assistive Technology</u> online or at (801) 887-9380
- Institute for Disability Research, Policy, and Practice, <u>Utah Assistive Technology Program</u> online, or at: (435) 797-3824 or toll free at (800) 524-5152

The <u>Utah Parent Center's disability resource book</u> is a list of agencies, programs, service providers, and other resources.



How do SERVICES work?

DSPD services are funded with state and federal money. When possible, DSPD provides services through a Medicaid home and community-based services waiver. You can access services through two different service models: Provider Agency Services and Self-Administered Services. One or both service models may be used depending on your support needs.

If you have questions or concerns about DSPD services, contact your intake worker, support coordinator, or DSPD Constituent Services. Constituent Services can be reached at 801-538-4091 or online at <u>About DPSD</u>.

Support Coordination

As you transition into services, you may choose a support coordinator to help manage your services. Your support coordinator knows how to navigate the service system and complete person-centered planning. Person-centered planning determines which services will best support your goals and needs. A person may change their support coordinator at any time. Use the **DSPD Find A Support Coordinator Tool** to access a list of contracted support coordinators, the companies

they are associated with, and their contact information.

Additional resources to help you select a private support coordinator are:

- A short guide entitled <u>Time to Choose A</u> <u>Support Coordinator – A Guide for</u> <u>Individuals and Families Using DSPD</u> <u>Services</u>.
- A <u>short video from the Family to Family</u> <u>Network</u> will talk you through the information in the Guide. (Click on "What you Need to Know about DSPD: DSPD 101").

Assessment and Planning

DSPD has implemented two approaches to assessing the Person's needs and their desire to achieve a "best life." The first approach is implemented through the Utah Comprehensive Assessment of Needs and Strengths (UCANS). UCANS is a multi-purpose tool that assesses needs and strengths across the person's lifespan. This assessment is a living document that helps to guide person-centered planning by identifying both the individual's assets and interests.

The second approach is implemented through Person Centered Planning, applying both tools and philosophy. This approach is based on the Charting the LifeCourse (CtLC) framework. The CtLC framework was created to help individuals and families of all abilities and ages to develop a vision for a good life. It is designed to help families think about what they need to know and do; to identify how to find or develop supports; and to discover what it takes to live the lives they want to live. The framework is the keystone for supporting a community learning champions of that transformational change through knowledge exchange, capacity building, and collaborative engagement. (Charting the Lifecourse Nexus, 2020)

Provider Agency Model

The disability support services that you receive through DSPD may be provided by a contracted provider agency. Providers contract to provide one or more services. These different services can then be combined to provide a group of services that meets the individual's needs for a best life. If you are receiving DSPD services, your support coordinator will help answer questions and explore your options. After you choose a provider, your support coordinator will help set-up services and allocate your budget.

People waiting for DSPD services may privately pay a provider agency. Contact the provider agency directly to arrange for privately paid services. Your intake worker will talk with you about service options that may be available.

For more information about provider agencies go to the DSPD website at <u>www.dspd.utah.gov</u> or check with the Utah Association of Community Services.

Self-Administered Services (SAS) Model

Self-Administered Services is a term used to describe services that are managed by the person with a disability, or by their family.

The person with a disability or a family member becomes the employer, and hires other people to provide services. This option gives the person or their family more control over who provides services and how they do it. SAS also brings an added responsibility for hiring, firing, training employees. The person or family member must be willing to put forth the necessary time and effort to monitor and report on the services delivered to the person with a disability.

Employers must keep required records and tax forms. The person directing services will choose a fiscal agent to help with payroll and associated taxes. The SAS model is typically limited to respite and personal care services. Other services are available through the SAS model for intellectual disability, related conditions, and brain injury. All physical disability services are self-administered.

If you are interested in Self-Administered Services, talk with your Support Coordinator.

Fiscal Agents

A fiscal agent is a company contracted with DSPD to handle the employer's payroll requirements, which include state and federal tax deductions. The fiscal agent will issue paychecks to the employees who are delivering the services based on timesheets that you approve.

You have a choice on which fiscal agent you use. For more information on fiscal agents, work with your support coordinator or contact DSPD.

Medicaid Waivers

Medicaid is a partnership between the states and the federal government to provide health insurance and long-term care services to certain groups of people who are low income and have few assets. States are not required to offer Medicaid. If a Medicaid program is offered in a state, it is an **entitlement** for those found eligible. The state must provide Medicaid state plan services to every person determined eligible.

At this time, all states offer a Medicaid program, but not all state Medicaid programs are alike. States may offer a wide range of health care services under the state plan. Each state is required to pay a portion of their program costs. The federal government provides an incentive for states to take part in Medicaid by matching the money the state pays.

The federal matching money is important for the Medicaid program to operate. Utah Medicaid offers additional Medicaid services for special populations. These special services are available through a home and community-based services **waiver**. A waiver allows the state to set aside some of the federal rules that apply to the Medicaid state plan program. Waivers differ from state plan Medicaid in that the state is able to design a program that meets the needs of a particular group of people. The state defines the group of people who are eligible for benefits, the geographic area that the waiver will cover, the services to be offered, the amount of services provided, and the total number of people who can receive the services. The state must receive approval from the Centers for Medicare and Medicaid Services (CMS) for any waiver.

Unlike state plan Medicaid, **waivered services are not considered an entitlement**. The number of people served under a waiver depends upon the amount of money received from the Legislature each year. This means that a person may be eligible for the services, but is not able to receive services until there is funding available to give them services. When a person receives waiver funding, they have access to all services within that waiver, and state plan Medicaid services.



DSPD offers a variety of services to individuals with qualifying disabilities based on their assessed needs. Service offerings vary between waivers and age groups.

Respite Care

Respite is care provided by a trained person that temporarily relieves parents or caregivers from the day-to-day care they provide to the individual with disabilities. Respite can be provided in a variety of locations depending on the needs and preferences of the family or individual.

Behavior Supports

Behavior Services include supports to help influence socially important behaviors and to develop independence skills.

Family Assistance and Support

Family Assistance is a means of supporting and maintaining a family's capacity to keep a child with a disability at home. These services are flexible and might include developing interventions to help the family cope using techniques of behavioral supports, or activities that promote inclusion in the community such as recreation or social skill building.

Family Training and Preparation

Family Training and Preparation Services help families participate in the Self-Administered Services Model. The fiscal agent offers learning opportunities for the person and family to become effective employers. Services may also include family training in areas such as parenting, skill training for daily living and other areas that are identified as a need for the family.

Partial Day Supports (After School Program)

Partial Day Supports provides a safe, non-residential, structured program during the day *after normally occurring school has ended* for the day or week. The person may receive one-on-one or group hourly support, supervision and skill building.

Supported Employment

Supported Employment includes job development, placement, intensive on-the-job training, and supervision by a job coach.

Day Services

Day Services include daytime supervision and support. The person may engage in activities that develop and maintain self-help, community living, social, and communication skills.

Senior Supports

Senior Supports are similar to Day Services. Services are designed for the needs of, and paced for, older adults with disabilities.

Residential Habilitation Supports

Residential Supports help a person gain and maintain skills for independent living. Support assists the person with full participation in a community setting of their choosing. It provides up to 24 hours of support, supervision, training, and assistance to maintain the person's health and safety.

Host Home

Host Homes are out-of-home placements for a short or extended period of time within the private home of a trained family. This alternative to an institution or group home setting is available for adults. Other DSPD services may be available depending on individual needs.

Professional Parent Home

Professional Parent Homes are out-of-home placements for a short or extended period of time within the private home of a trained family. This alternative to an institution or group home setting is available for children. Other DSPD services may be available depending on individual needs.

Supported Living

Supported Living is a residential service provided in the person's home to help support the person's independence.

Supervised Living

Supervised Living is a residential service offered in a group home or supervised apartment. The level of supervision is determined by the person's needs and can vary from intensive 24-hour to intermittent supervision.

Advocate/Advocacy: To actively promote the fundamental principles of self-determination for all individuals with disabilities.

Assistive Technology: Any type of device or service that can be used to increase, maintain or improve the capabilities of persons with disabilities.

Acquired Brain Injury Waiver (ABIW): A home and community-based services waiver that assists people age 18 and older who have an acquired brain injury (ABI) with services outside of a nursing home.

CHEC (Child Health Evaluation and Care): A preventative care program for children up to 21 years of age that tries to identify and treat health problems before they become disabling.

CHIP (Children's Health Insurance Program): An insurance program for children 19 years of age and younger whose family does not qualify for Medicaid and cannot afford health insurance.

Community Supports Waiver (CSW): A home and community-based services waiver that assists people of all ages who have an intellectual disability or related condition with services outside of an intermediate care facility (ICF/ID).

Division of Services for People with Disabilities (DSPD): A state agency within the Department of Human Services responsible for the administration of state and federal funding to provide services for people with eligible disabilities.

Early Intervention: Programs and services for children with disabilities from birth to age 3.

Eligible Disability: Intellectual disability or related conditions, brain injury, and physical disability as defined in Administrative Rule R539-1.

Eligibility: Determining whether a person qualifies for DSPD services based on specific criteria outlined in Administrative Rule R539-1.

Family to Family Network: A statewide parent support network run by volunteers, designed to educate, strengthen, and support families of persons with disabilities, especially those who are on the waiting list or are in services with DSPD. A program of the Utah Parent Center.

Family Training and Preparation: Training provided to families to assist them to self-administer their services.

Fiscal Agent/Intermediary: A company that is hired to handle payroll duties for those who use the self-administered services model.

Guardian: The person who makes decisions on behalf of another person who is considered incapacitated.

Guardianship: The legal process parents/families go through to become legally appointed to make decisions of behalf of a person with disabilities who is eighteen years of age or older and considered incapacitated.

Home and Community-Based Services (HCBS) Waiver: An approval to waive certain requirements in order to use Medicaid funds for an array of home and community-based medical assistance services as an alternative to institutional care.

Host Home: Specially trained individuals or families who care for an adult who may need out-of-home placement for a short or extended period of time.

Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/ID): A 24-hour residential facility for persons with intellectual disabilities and related conditions.

Individuals with Disabilities Education Act (IDEA): A federal law requiring all children with disabilities to have a free and appropriate public education.

IEP: Individual Education Plan that directs the services for a child with a disability in a school district or charter school.

Inclusion: The process of enabling persons with disabilities to be educated, live, work and participate socially in the same environment as others who are not labeled disabled. Inclusion is also used by educators to refer to the integration of children with disabilities into regular classes for part or all of the school day.

Independent Living: A community living situation in which a person with disabilities lives alone or with others with the necessary supports from paid staff and natural supports.

Informed Consent: A decision based on knowledge of advantages, disadvantages, and implications of choosing a particular course of action.

Least Restrictive Environment: The most integrated, appropriate setting for an individual with disabilities, so they can interact as much as possible with peers who do not have disabilities.

Local Interagency Council: Local agencies that work together to improve service delivery to children and youth at risk who are experiencing multiple problems and who receive services from more than one state agency.

Medicaid: A federal program that pays for health care and long-term support expenses for people who meet eligibility requirements. Benefits are paid with federal and matching state dollars.

Monthly Summary: A summary of daily notes required at the end of each month to be given to the Support Coordinator.

Natural Supports: The family and people in the community who support a person with a disability without payment.

Needs Assessment: An assessment used by DSPD to rank order individuals on the waiting list based on their needs.

PASS Plan: Plan to Achieve Self-Sufficiency, allows a person receiving Social Security benefits to set aside money received to help achieve self-sufficiency without losing benefits.

Person-Centered Planning Process: A process that describes the strengths, preferences, needs, and dreams of the individual along with the services required to maintain health and safety.

Physical Disabilities Waiver (PDW): An approval to waive certain requirements in order to use Medicaid funds for people age 18 and older with physical disabilities to help them maximize their independence in their choice of home, work, school, community and daily activities.

Progress Notes: See "Monthly Summary"

Provider Companies/Provider Agencies: Independent companies that contract with DSPD to deliver supports and services to people with disabilities.

Rates: The amount that DSPD pays to a provider, company or individual for each service/support for an individual.

Respite: Temporary relief from the day-to-day care of a family member with a disability.

Self-Advocate: A person with disabilities who advocates for their own supports, rights, and self-determination.

Self-Determination: The philosophy of developing and making your own choices, plans, and directing some or all aspects of your life.

Self-Administered Services (SAS): Services directed by the person/family receiving the service.

Support Coordinator: The person who works with individuals with disabilities and their families to develop a person-centered support plan based on the individual's needs and wishes; and coordinates and monitors the services and supports provided.

Support Strategies: The detailed steps for accomplishing the goals of an Action Plan.

Supplemental Security Income (SSI): A federal government assistance program based on the income and disability of the person.

Transition: The process of moving from one environment or stage of life to another. This often refers to a person with a disability leaving the school system and entering the adult world.

Utah Parent Center: The mission of the Utah Parent Center (UPC or Center) is to help parents help their children, youth and young adults with **all** disabilities to live included, productive lives as members of the community.

Waiting List: A list of eligible individuals who have completed the application process for services and are not yet funded. The list is prioritized according to critical need.



DSPD.UTAH.GOV

Contact DSPD, the Utah Parent Center, and the Family to Family Network for help with accessing resources.