

An Introductory Guide to the Division of Services for People with Disabilities



Utah Department of Human Services

*Prepared by the Family to Family Network
and the Utah Parent Center*

Approved by DSPD

August 2013



The **Division of Services for People with Disabilities** promotes opportunities and provides support for persons with disabilities to lead self-determined lives. The Division oversees home and community-based services for more than 5,000 people who have disabilities. Support includes community living, day services, supported employment services. The Division also provides services to just over 200 people at the Utah State Developmental Center (USDC), a state operated Intermediate Care Facility for people with Intellectual Disabilities (ICF/ID).



Visit the Division's website at www.dspd.utah.gov

Utah's **Family to Family Network** is a grassroots volunteer network composed of family leaders in various communities across Utah who have a relative with a disability that is supported by the Division of Services for People with Disabilities. The mission of the Family to Family Networks is to educate, strengthen and support families of persons with disabilities. They help by providing:

- Support through local meetings, either in-person or online.
- Information and referral.
- Family to family support.
- Advocacy for families.
- Help to families who qualify or may be eligible for services from the Utah Division of Services for People with Disabilities (DSPD) to help them understand programs and services and how to work with service providers and support coordinators.



Visit the Network's website at www.utahfamilytofamilynetwork.org

The **Utah Parent Center** is an award-winning, non-profit organization founded in 1983 by parents of children and youth with disabilities to 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. The UPC accomplishes its 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 has built collaborative networks with education, health and human service professionals, agencies, organizations, and the UPC promotes change within the community through various projects and activities.

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

The most recent version of this guide can be found online by visiting the website of one of these organizations.

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A Guide to Services for the Division of Services for People with Disabilities

Utah Department of Human Services

WHAT DOES DSPD DO?

The Division of Services for People with Disabilities (Division or DSPD) is part of the Utah Department of Human Services. The Division offers services that assist people to live, learn, and work as part of their communities. The services that the Division provides are based on eligibility and designed to ensure a person's health and safety and help an individual to live a more self-determined and fulfilling life. The Division also promotes public awareness and acceptance of people with disabilities.

WHO IS ELIGIBLE FOR SERVICES?

When you first contact the Division, they will need to determine if you are eligible to receive services. An individual may be eligible if they have qualifying disabilities in one of the three areas listed below:

- Intellectual Disabilities or Related Conditions
- Acquired Brain Injury (ABI)
- Physical Disabilities

Children and adults **may** be eligible for services if they have the following qualifying disabilities:

- **Intellectual Disability:** a disorder in which a person's overall intellectual functioning is well below average – an intelligence quotient (IQ) of 70 or less. Individuals with intellectual disability have a significantly impaired ability to cope with common life demands and lack some daily living skills expected of people in their age group and culture. The impairment must result in a substantial functional limitation of three or more areas of major life activity. (See Areas of Major Life Activity descriptions in the box below).
- **Cerebral palsy:** a medical condition caused by a permanent brain injury that occurs before, during, or shortly after birth. It is characterized by a lack of muscle control and body movement.
- **Autism:** a disorder of brain function that appears early in life, usually before the age of 3. Children with autism have problems with social interaction, communication, imagination, and behavior.
- **Severe epilepsy:** a chronic brain disorder that causes seizures, characterized by a variety of symptoms including uncontrolled body movements, disorientation or confusion, or loss of consciousness. Epilepsy may result from a head injury, stroke, brain tumor, lead poisoning, genetic conditions, or severe infections.
- **Acquired Brain Injury:** an acquired brain injury is the result of a traumatic injury to the brain that occurred after birth.



An acquired brain injury may be the result of physical trauma to the brain or non-traumatic injury resulting from an external source such as a stroke, brain tumor, infection, hypoxia, toxic exposure, or substance abuse. The injury can have occurred at any age, but the applicant must be over 18 years of age to receive services, and the injury must result in a substantial functional limitation in three or more of the following areas:

- Memory or Cognition;
 - Activities of Daily Life;
 - Judgment and Self-Protection;
 - Control of Emotion;
 - Communication;
 - Physical Health; and
 - Employment.
- **Physical Disabilities:** for eligibility purposes, a physical disability is characterized by a person who cannot use 2 or more limbs. The illness or injury could have occurred at any age but the applicant must be over age 18 to receive services and the applicant's disability must result in a substantial functional limitation in in three or more areas of major life activity. (See Areas of Major Life Activity descriptions in the box below).

Areas of Major Life Activity:

- Self-care: a person who requires assistance, training, or supervision with eating, dressing, grooming, bathing, or toileting.
- Receptive and expressive language: a person who lacks functional communication skills, requires the use of assistive devices to communicate, or does not demonstrate an understanding of requests or is unable to follow two-step instructions.
- Learning: a person who has a valid diagnosis of intellectual disability based on the criteria found in the current edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM).
- Mobility: a person who requires assistive devices to be mobile and who cannot evacuate themselves in an emergency.
- Self-direction: a person who is significantly below average in making appropriate decisions relating to safety, legal, financial, or residential issues or someone who has been legally declared incompetent.
- Capacity to live independently: a person who does not have the basic survival skills necessary to live in the community or someone who is a significant danger to themselves or others.
- Capacity to become economically self-sufficient: an adult who receives disability benefits or who is unable to work 20 hours a week or is paid less than minimum wage without employment support.

HOW DO I APPLY FOR SERVICES?

Anyone seeking to apply for services from the Division should call the toll-free number 1-877-568-0084 and ask for an Intake Worker. The Intake Worker will gather information to begin the process of determining eligibility.

TIP: A great deal of information is necessary to determine eligibility and to identify needed services, so start the process as early as possible.

WHAT HAPPENS WHEN PEOPLE MEET ELIGIBILITY REQUIREMENTS?

NEEDS ASSESSMENT: The Division determines how critical the need for services is by using a standardized evaluation called the Needs Assessment. A local Intake Worker assesses the individual's needs based on a variety of factors including:

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

The Needs Assessment Tool establishes a "needs" score which indicates the level of need for DSPD service and determines a person's ranking on the waiting list. The needs assessment can be re-scored if a person's circumstances change or there is suspected change in one or more of the factors. To initiate this process, a request is made for another assessment from the Intake Worker to explain what changes have occurred and why the needs should be reevaluated. DSPD encourages persons and families to report any changes that may affect a person's needs score.

WAITING LIST: The Division is not usually able to offer immediate services to eligible individuals so they are placed on a waiting list. Currently, there are just less than 1,900 people waiting for services for which funding is not available. Funding for services is determined by allocations from the Utah State Legislature each year. As funds become available, individuals on the waiting list are notified by a DSPD Intake Worker and brought into services. The Utah State Legislature recently made changes to the way the Division uses funds designated to bring people off the waiting list. Eighty-five percent (85%) of those funds will go to those identified as having the most critical needs, while fifteen percent (15%) will now go to those persons who are waiting for only respite services. Additionally, if a person, who was receiving services, ceases to receive those services, the Division will now use those newly available funds to bring those with the most critical needs off the waiting list.

SUPPORT COORDINATOR: When an individual receives funding for services, they are asked to select a Support Coordinator. Support Coordinators help individuals and families evaluate their needs and determine which services would best support them.

A person may choose to have their Support Coordination provided by DSPD or from a list of companies under contract with the Division. For more information on contracted Support Coordination providers, check the list of Support Coordination Contractors online at:

http://www.dspd.utah.gov/docs/sce_contact_info_PUBLIC.pdf or contact the Division.

Resources: Additional resources to help you select a private Support Coordinator are:

- A short guide entitled *Time to Choose A Support Coordinator – A Guide for Individuals and Families Using DSPD Services*. It can be found at: http://www.dspd.utah.gov/docs/Time%20to%20Choose%20a%20Support%20Coordinator_1.pdf or on the Utah Family to Family Network website at: <http://www.utahparentcenter.org/services/family-to-family/supportcorddspd/>

WHO IS *NOT* ELIGIBLE FOR SERVICES?

The Division of Services for People with Disabilities is **not** the agency for people whose disability or primary need for treatment is due primarily to:

- Mental illness or behavior disorder (depending on how the behavioral disorder is defined and diagnosed).
 - Contact your local mental health agency.
- Learning Disabilities.
 - Contact your local school district or charter school or the Learning Disabilities Association of Utah.
- Blindness or severe hearing impairment.
 - Contact your local school district, charter school, the Division of Rehabilitation Services, Division for the Blind and Visually Impaired, or Division for the Deaf and Hard of Hearing.
- Conditions due to aging.
 - Contact the Division of Aging and Adult Services.
- Any disorder arising after the age of 22 except acquired brain injury or physical disability.

Services from DSPD may only be provided to U.S. citizens or legal permanent residents, who are residents of the State of Utah.

WHO PROVIDES SERVICES?

PRIVATE PROVIDER AGENCIES

The Intellectual Disability or Brain Injury Waiver services you receive through the Division may be provided by a provider agency (a company that works under contract with the Division). These provider agencies may specialize in specific types of services, so work with your Support Coordinator or Intake Worker to obtain more information. If you are receiving services from the Division, your Support Coordinator will arrange for funds to be allocated to the provider agency of your choice. Your Support Coordinator will help answer questions and explore your options. Provider agency services may also be paid for privately and you may contact providers directly.

For more information on Provider Agencies you may contact the Division or go to the DSPD website at www.dspd.utah.gov, work with your Support Coordinator, or check with the Utah Association of Community Services at www.UACS.org.

SELF-ADMINISTERED SERVICES (SAS)

Self-Administered Services is a term used to describe services that are managed by the person with a disability and/or their family. All services provided under the Physical Disabilities Waiver are self-administered under the SAS model. Services provided under the Intellectual Disabilities and Acquired Brain Injury Waivers, may be provided using either the SAS model or through a provider agency, and sometimes a combination of the two.

Under the Self-Administered Services option, a person or a family member of a person who has disabilities becomes the employer of the individuals providing direct services. This option gives the person or family more direct control over the person's budget, but it also brings the added responsibility for hiring, firing, training and keeping required records and tax forms. A 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. The person directing services will choose a fiscal agent to help with payroll and associated taxes. If you are interested in Self-Administered Services, talk with your Support Coordinator.

Fiscal Agents

A fiscal agent is a company contracted with the Division to handle the employee's payroll, including 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 the Division.



WHAT SERVICES ARE PROVIDED?

SERVICES FOR CHILDREN AND ADOLESCENTS

The following are descriptions of some of the services that may be available to individuals with qualifying disabilities (under the age of 22) through the Division based on individual needs.

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. It can be provided in the family's home, in the home of the respite provider or in a specialized facility, depending on the needs and preferences of the family or individual.

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 are intended primarily to help families participating in the Self-Administered Services method with the acquisition of skills necessary to function effectively as 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 hourly support, supervision and skill building for individuals and groups of up to twenty children. This service provides a safe, non-residential, structured program during the day *after normally occurring school has ended* for the day or week.

Professional Parent Home

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

SERVICES FOR ADULTS

The following are descriptions of some of the services that may be available to adults (over the age of 22) through the Division based on individual needs.

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 to develop and maintain self-help skills, community living skills, social skills, and communication skills.

Senior Supports

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

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 individuals with disabilities. It can be provided in the family's home, in the home of the respite provider or in a specialized facility, depending on the needs and preferences of the family or individual.

Residential Habilitation Supports

Residential Supports are designed to help a person to gain and/or maintain skills to live as independently as possible and fully participate 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 (for adults) are out-of-home placements for a short or extended period of time within the private home of a trained family. This is an alternative to an institutional or group home setting. Other Division 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.

Utah State Developmental Center (USDC)

The USDC is Utah's only state-operated intermediate care facility for people with intellectual disabilities, which is a 24-hour institutional setting. The Center offers intensive medical, behavioral, psychological and dental services to those over age 18. Admissions are limited and require an intensive screening process.

HOW ARE SERVICES FUNDED?

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, but states can choose to participate in the program. 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 programs under Medicaid. If a Medicaid

program is offered in a state, it is an **entitlement** for those found eligible, which means that it must be provided by law to the eligible party.



If a state chooses to partner with the federal government and offer Medicaid, the state is required to pay a portion of the 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 **waivers**. A waiver allows a state to set aside some of the federal rules that apply to the regular Medicaid program.

Waivers differ from regular 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 regular Medicaid, **waivered services are not considered an entitlement**. The number of people served under a waiver is dependent upon money received from the State legislature. This means that a person may qualify for the services, but is not made eligible to receive services until there is funding available to give him/her services. Once the person is given funding under the waiver, all services within that waiver are available if they are determined to be a need, and all regular Medicaid services (see above) are available if medically necessary.

WHAT IF I HAVE CONCERNS OR QUESTIONS?

If you or your family member is receiving DSPD services and you have a concern or problem, the first contact is your Support Coordinator. He or she can help you with questions you may have about Division services. Your Support Coordinator can also help you determine the appropriate person you should talk to if the problem lies outside the Division but involves your services such as Medicaid, provider agencies, etc.

If your Support Coordinator is unable to help you, contact the Division Constituent Services representative at 801-538-4137.

The Division has also prepared a list of Common Questions with helpful answers that is posted on their website at www.dspd.utah.gov/faq.asp.

The DSPD A-Z Index found at www.dspd.utah.gov/a-zindex.shtml on the website is another way to easily access helpful information and resources that for individuals with disabilities, their families, and the professionals who serve them.

HOW DO I CONTACT THE DIVISION?

Administration Mailing and Street Address:

195 North 1950 West
Salt Lake City, UT 84116
801-538-4200 State Office Phone
1-877-568-0084 Statewide Intake Number

LOCAL OFFICES STATEWIDE

Administration (Salt Lake)	195 North 1950 West	(801) 538-4200
Clearfield	1290 East 1450 South	(801) 779-6741
Provo	150 E. Center Street	(801) 374-7005
Price	475 W. Price River Dr. #262	(435) 636-2390
Salt Lake City	1385 S. State St.	(801) 468-0084
St. George	377 E. Riverside Dr. Bldg. B Ste. A	(435) 674-3961
Vernal	980 W. Market Dr.	(435) 789-9336

WHAT ARE OTHER RESOURCES TO MEET OUR NEEDS?

The Division of Services for People with Disabilities is **not** the only source of services and supports for people with disabilities. Other resources include:

- The State Department of Health
 - Early intervention services through Baby Watch (birth -2),
 - Bureau of Children with Special Health Care Needs
 - Children's Health Care and Evaluation (CHEC)
 - Children's Health Insurance Program (CHIP)

- A variety of services including private intermediate care facilities (24 hour residential programs in a larger congregate living or institutional setting) for eligible individuals with intellectual disabilities (ICF/ID).
- The public education system provides educational and related services for eligible children and youth with disabilities.
- The State Division of Rehabilitation Services provides short-term services related to employment for eligible young adults and adults with disabilities.
- Information on guardianship can be obtained by contacting Guardianship Associates of Utah, Inc. at (801) 533-0203 (www.guardianshiputah.org).
- Information about assistive technology is available the Utah Center for Assistive Technology at (801) 887-9539 (www.usor.ut.gov:81/ucat) or the Utah Assistive Technology Program at the Center for Persons with Disabilities at (435) 797-3824 or Toll-free: (800) 524-5152 (www.uatpat.org).
- A list of agencies, programs, service providers, and other resources online on the Utah Parent Center's website at <http://www.utahparentcenter.org/publications/disability-resource-book/>

WHAT DOES IT MEAN? ACRONYMS AND DEFINITIONS

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

All: "All" means "everybody", not just people without disabilities.

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

Brain Injury Waiver: An approval to waive certain requirements in order to use Medicaid funds to assist people with acquired brain injury (ABI) and traumatic brain injury (TBI) to receive 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 but cannot afford health insurance.

Division of Services for People with Disabilities (Division): 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 disabilities as defined in Administrative Rule R539-1 for the Division found at <http://www.rules.utah.gov/publicat/code/r539/r539-001.htm>.

Eligibility: Determination of whether or not a person qualifies for Division services based on specific criteria outlined in Administrative Rule R539-1 for the Division and type of disability found at <http://www.rules.utah.gov/publicat/code/r539/r539-001.htm>.

Family to Family Network: A group of parents who work together to improve the quality of life for people with disabilities and to advise local Division offices.

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 supports 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 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 and 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 tool used by the Division to rank individuals on the waiting list according to most critical 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 the dreams of the individual and the services required to maintain health and safety.

Physical Disabilities Waiver: An approval to waive certain requirements in order to use Medicaid funds for people 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 the Division to deliver supports and services to people with disabilities.

Rates: The amount that the Division 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/self-determination.

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

Self-/Family-Administered Services: Services directed by the person/family receiving the service.

Support Coordinator: The person who works with individuals with disabilities and their families to develop service and Support Plans, based on the individual’s needs and wishes, and to coordinate and monitor the services and supports provided.

Support Strategies: The detailed steps for accomplishing the goals of an Action Plan which is part of the person-centered planning process.

Supplemental Security Income (SSI): A federal government assistance program based on the income and/or 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.

Waiting List: A list of individuals who have completed the application process for services but are not yet funded. The list is prioritized according to the Critical Needs Assessment.



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