Utah Parent Center

# WHAT HELP IS AVAILABLE?

## AGENCIES PROVIDING SERVICES FOR ADULTS WITH DISABILITIES

This handbook was developed to help you identify your youth's strengths and preferences as well as their needs. As you plan for their transition from school to adult services which have eligibility requirements you will look for programs and services that will meet those needs. This section is meant to help you with that search.

There are many agencies that provide services for transition-aged youth with disabilities. You may have problems finding an agency that provides the specific services your youth needs or that serve people with their disability. You may also encounter a long waiting list of eligible people. Even if an agency does not have exactly what you are looking for, ask what services they do provide and if your youth is eligible. Add the information you receive to the appropriate section of your records. Ask school personnel and other parents, agencies, and organizations about possible services or resources. It may be necessary to make many calls in search of suitable and desirable services, but it will be time well spent to locate what your youth needs.

If you find a gap in the types of services your youth needs, there may be other young adults with disabilities and families needing these services. This is an excellent opportunity to meet with your Community Transition Council (CTC) or other groups and ask for their assistance in filling this particular gap. Contact your local school district office to reach their Transition Coordinator who can tell you if and when a CTC meets.

Access Utah Network provides information and referral about a broad range of agencies as well as product and service providers for people with disabilities. They also maintain a database of used equipment which is for sale or donation. They are able to provide detailed information and presentations about the American with Disabilities Act. Call: (801)533-4636 or (800)333-8824.

**The Disability Law Center** is a private, non-profit organization which is federally mandated to provide advocacy services to eligible clients with disabilities. They protect and advocate for the rights of individuals with disabilities and mental illness, and those seeking assistive technology devices or services under the Rehabilitation Act. Services are free of charge and available to all eligible individuals in Utah. Call: (801)363-1347 or (800)662-9080 – voice or (800)550-4182 – TTY.

**Independent Living Centers** assist Utahans with disabilities to live independently in their communities. Services may include assistance in obtaining modifications to a home or vehicle, adaptive equipment, personal care providers, advocacy, peer counseling, and skills training for independent living. There are four centers in Utah with some satellite locations as well. Call: (801)466-5565 or (800)355-2195.

**Medicaid** provides financial assistance with medically related costs to those who qualify. Applications are handled through the Family Support/Workforce Services Office of Utah's Human Services Department. Those who qualify for SSI may be eligible for Medicaid but still need to apply.

If your child has special needs, so do you! We can help!230 West 200 South, Suite 1101Salt Lake City, UT 84101-1337801-272-1051 or 800-468-1160www.utahparentcenter.org

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**WorkAbility** helps prepare people with disabilities to work. The program was designed for people who receive public benefits like Medicaid and Social Security due to a disability. Work Ability connects people with supports to help them find and maintain work. Call: (801) 887-9529.

**Social Security Administration (SSA)** administers Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) and work incentives (PASS and IRWE). Call: 1-800-772-1213 between 7:00 a.m. and 7:00 p.m. Monday through Friday for information, applications, and to schedule appointments.

**Utah Center for Assistive Technology (UCAT)** provides accurate and up-to-date information on all aspects of assistive technology to people with disabilities and their families. They have a large display of a full range of assistive devices including computers, with staff members available for demonstrations, equipment try-outs, and customization. They also have information about possible funding sources. Call: (801)887-9500.

**Utah Division of Services for People with Disabilities (DSPD)** can provide information about service throughout Utah for people with disabilities. Family Support, Supported Employment, Personal Assistance, Day Training and Residential Programs are available for those who meet eligibility requirements. Services go to those with the most immediate and critical needs first, and others are placed on waiting lists. Request their booklet "A Guide to Services for People with Disabilities" from the state or regional office. It contains a general resource guide which includes locations of their offices, listings of service providers, agencies and organizations in Utah as well as national toll-free numbers. Call: (801)538-4200 or (800)837-6811.

**Utah Parent Center** is a private, non-profit organization which serves parents of children and youth with disabilities statewide. It provides training, support, and information that equips parents to function as equal partners in planning and accessing needed services for their children. It offers parents individual consultations; workshops and conference presentations; printed materials, resources, and information on a variety of disability issues; and information and referral to programs, services, agencies, and organizations. It also promotes collaboration by professionals of all agencies and organizations along with parents. Call: (801)272-1051 or (800)468-1160.

**Utah Schools and the Schools for the Deaf and Blind** have designated Transition Coordinators. The name and phone number is available by calling the local school district office. Call (801)629-4700 - voice, (801)466-9910 – TTY or (800)990-9328.

**Utah State Office of Rehabilitation** administers Vocational Rehabilitation programs which assist **eligible** individuals with disabilities in making career decisions, preparing for and finding suitable employment. They may provide training to develop specific vocational skills, to gain self-confidence, and to help adjust to the work setting. When appropriate, they provide medical treatment and services or assistive technology to reduce or stabilize the effects of a disability and improve abilities to participate in training or work. Call: (801)538-7530 or (800)473-7530.

# PARENT SUPPORT GROUPS

For families living with people with disabilities, the problems that arise in getting through one day can be overwhelming. Families with a person with a disability have all the problems and obligations of ordinary families plus the added burden of the extra needs of that person. These families' lives are different than the lives of most families. Talking to people who have had to get through days much like their own provides an outlet that can't be found anywhere else.

Parents of young adults with disabilities feel that there are a lot of things they 'should' be doing. There are also a lot of things they think others, including teachers, doctors, relatives, and counselors, expect of them. Our 'to do lists' can get so overwhelming that finding time to attend a parent support group itself

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seems impossible. If parents look at their list of things to do they may notice that some of the things listed could be done more easily (or might have already been done) by a group of parents who share some of the same experiences.

Support groups are invaluable to many parents of youth with disabilities. Parents gain the following benefits from attending support groups:

- Support groups provide a place where you can go and talk about your feelings without being misunderstood. When parents of students with disabilities meet with other parents in the same situation it eases their sense of isolation.
- Support groups provide a place for the beginnings of organized advocacy groups.
- Support groups give parents a chance to share information, ideas, and solutions.
- A group lets it members access professionals and services that they might not have access to on an individual basis. Professionals will often speak (frequently free of charge!) to a group of parents for a couple of hours. An opportunity that, if scheduled clinically, would be half as long and very expensive.

#### How can you find out if a support group already exists in your area?

- Call your Parent Training and Information Center: Utah Parent Center at (801) 272-1051 or tollfree in Utah at 1-800-468-1160.
- Call Access Utah Network at (801) 325-5822 or 1-800-333-8824.
- Talk to your son or daughter's doctor, special educator, or VR counselor.
- Contact the county health nurse.
- Look in the yellow pages under "psychology" or the name of the disability.
- Look in the local newspaper in the upcoming events section for group meetings.
- Call the Department of Human Services, Division of Services for People with Disabilities.
- 211

The Utah Family to Family Network has groups in many areas of the state and provides support in the community to parents of children with all disabilities.

If no support group exists, create your own! Find other parents facing a situation similar to yours, and meet! (See "Organizing Parent Groups" in the supplemental material in the back of this manual.) There are several clearinghouses for information that have lists of groups in each state.

The following is a list of things that have worked well in the day-to-day functioning of one support group:

• Making personal contacts with other parents is the best way to get them to come to meetings. Call and talk to prospective parents. Provide transportation for the first meeting and look at carpooling for following meetings.

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- Welcome children, provide on-site childcare, or develop a pool of caregivers and pay them if possible.
- Be open to differences. Fathers and mothers, all family structures, and different types of disabilities, should all be included.
- Have parents and advocates continue to run the group. Professionals are great resources and speakers, but sometimes they intimidate families.
- Meet in a neutral place. Civic centers, public libraries, and most public buildings have meeting rooms available. Meeting in private homes may be uncomfortable for some people.
- Structure the meetings so that "something" happens. Have an agenda and accomplish it. Include a social time before or after, or on a different day. Make the meeting time work for parents' schedules."

"...What you can do is often simply a matter of what you will do... so many things are possible just as long as you don't know they're impossible." The Phantom Tollbooth, Norton Juster, 1989

> This content is taken from the Utah Parent Center handbook: From NO Where to KNOW Where: A Parent Handbook for the Transition to Adult Life.