

Other Transition Concerns for Parents



Utah Parent Center
Special needs, extraordinary potential

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AGE OF MAJORITY

All special education rights transfer to the student at age 18 unless guardianship has been previously awarded.

At age 18 the student reaches the age of majority and is considered an adult. Parents are no longer required to be informed or to give their consent for programs or services. The law requires schools to notify students about the rights that transfer to them when they reach the age of majority by at least one year before their eighteenth birthday. As an adult, your student could decide to exclude you from participating in meetings and making decisions about adult services.

If your student is still receiving special education services until his twenty-second birthday, you will continue to be informed, and your due process rights remain in effect. This potential change in roles underscores why it is so important for him to be an active participant in developing the IEP and transition plan. It clarifies the importance of building and maintaining open lines of communication with him.

LIVING ARRANGEMENTS

“Where I am going to live?” is a question you may have asked yourself when you completed your high school education. It’s not surprising that young adults with disabilities ask the same question. A variety of living arrangements are available to adults with disabilities. The level of care and type of living arrangement should be based on the needs of the individual. Arrangements can extend from 24-hour care to living independently in the community.

Types of living arrangements can include the following:

- living with the family,
- living independently,
- living in supervised living arrangements,
- living in their own apartment,
- living in a residential care facility,
- living in a family life, and
- living in an intermediate care facility.

The type of living options available in your community depends greatly on where you live. If your young adult needs a state-supported living arrangement following high school, contact the Division of Services for People with Disabilities (DSPD). This contact should be made early because there can be a three to six year waiting list for many community residential service programs.

Utah Parent Center

230 West 200 South
Suite 1101
Salt Lake City, UT 84101
801.272.1051
1.800.468.1160
info@utahparentcenter.org
www.utahparentcenter.org

LIVING WITH THE FAMILY

Many young adults live with their parents while attending school, looking for a job, or working. Living at home may be an appropriate short-term option for young adults with disabilities. Some families, however, may not want to have the young adult live at home forever. Families also may not always be able to care for the young adult; thus, future living arrangements need to be discussed and planned. Young adults who live with their family should be encouraged to develop or improve independent living skills such as housekeeping, shopping, washing clothes, and budgeting.

LIVING INDEPENDENTLY

When young adults live independently, they live by themselves or with roommates in a house or apartment. In this living arrangement, little or no help is necessary. If help is needed, it is given by family members or adult service providers through visits or telephone contacts.

SUPERVISED LIVING ARRANGEMENTS

The purpose of supervised living arrangements, such as supervised apartments, is to offer a structured living situation for individuals who, because of their disability, need some support or supervision. Young adults in supervised living arrangements receive continued assistance and training in independent living skills such as meal planning, use of community resources, and money management. Supervision of the young adult is usually provided by personnel from a local adult service provider or agency. This person is trained in working with young adults who have disabilities.

RESIDENTIAL CARE FACILITY

Residential care facilities include group homes that offer help to young adults who cannot live independently, but are capable of spending time in the community with a minimum amount of supervision. Community resources are used for recreation, medical, or social services. The staff works with the young adults to develop independent living skills. Group home staff are employed by a local agency or adult service provider and are trained in working with adults who have disabilities.

PROFESSIONAL PARENT OR HOST HOME

A professional parent or host home is a private household that offers protective social living for individuals who are unable to live independently. The family offers the young adult room and board. Opportunities for participation in social, educational, and recreational activities within the community are also provided by the family life home.

INTERMEDIATE CARE FACILITY

An intermediate care facility provides 24-hour care for individuals who, through an illness or disability, require ongoing nursing and medical services. These medical services must be provided by a registered or licensed practical nurse or doctor. DSPD has a list of the various provider resources funded by them.

SELF-ADMINISTERED SERVICES – SAS

Self-Administered Services (SAS) offer an alternative to Provider Agency Services by allowing people with disabilities and their families the choice and opportunity to select providers that offer services within the home. People with disabilities and their families hire, train, and supervise employees who provide direct supports in a home setting. More information and training about how to use this model is available through DSPD or through the Family to Family Network.

Employment Options

There are three main kinds of employment options. They include:

- competitive employment
- supported employment, and
- sheltered workshops or work activity centers.

COMPETITIVE EMPLOYMENT

The majority of individuals with disabilities leaving school can learn to get and keep a job without any special support services. This is called “competitive employment”. Competitive jobs are found within public or private businesses or industries. Employees are paid and receive the same benefits (vacation, insurance, sick leave) as all workers, depending on whether they are considered full- or part-time. Competitive jobs are found in a number of ways – through friends, parents, relatives, agencies (Workforce Services, Vocational Rehabilitation), or newspapers. A good strategy is to use any or all of these resources to find a job. Another form of competitive employment is for individuals to own their own business (painter, seamstress, data entry, Braille service, childcare provider).

SUPPORTED EMPLOYMENT

Supported employment is a service for individuals with significant disabilities, which provides support to individuals seeking competitive employment. The job coach assists with job placement and on-the-job training and coordinates ongoing supports and other appropriate services needed to sustain paid employment. This type of employment may occur in a variety of work settings. Providing the ongoing support services necessary continues as long as the person is employed. Supported employment services may begin in school programs. Vocational Rehabilitation and the Division of Services for People with Disabilities sometimes provide supported employment services for adults. Contact these agencies directly for more information on their programs.

SHELTERED WORKSHOP OR WORK ACTIVITY CENTERS

Sheltered workshops or work activity centers are facilities that serve people with disabilities by providing supervised work and other rehabilitative activities. The goals of these facilities are to help individuals develop skills so they can be employed in the community and to employ people who are viewed as incapable of competitive employment. Some individuals and advocacy groups oppose this type of service. However, they often promote inclusive programs that result in people with disabilities working in the community alongside people without disabilities.

ESTATE PLANNING

Parents like to think that someday when they die and are no longer able to help their children by being there, that they can leave behind some kind of inheritance that will help them. An outright inheritance may actually jeopardize the public program benefits received by sons or daughters with a disability. This needs to be taken into account when planning an estate for an heir with a disability. Some guidelines to consider include: the seven planning questions, team of qualified professionals, necessary legal documents, and funding for a trust.

For someone on an assistance program such as Medicaid (Medical Assistance), receiving an outright inheritance means the public assistance money would stop while the inherited money is used to pay for needed services or programs (such as medical care, group homes, or a day activity program).

Only when the inheritance is gone does the public program money, such as Supplemental Security Income benefits, become available again.

Often, unless the family or charity provides supplementary assistance, an individual with a disability receiving monthly SSI or SSDI with medical benefits payments may experience serious challenges managing on only that amount of income. However, doing careful estate planning parents can ensure the inheritance they leave will add to and not take the place of funding received. Through careful estate planning, proceeds from the estate can be used to add to the quality of life for the heir with disabilities.

WHERE SHOULD YOU START?

There are seven important planning issues unique to families with members with disabilities which are reflected in the following questions:

- 1.** Who will care for the child with a disability if I am physically unable to do so?
- 2.** How can we maximize government benefit programs that currently assist families of people with disabilities? (SSI, SSDI, Medicare, Medicaid, military pensions, etc.)
- 3.** How can we coordinate our personal resources with government benefit programs to provide the best possible lifestyle for the disabled individual, both now and in the future?
- 4.** How can we provide sufficient resources to ensure a comfortable lifestyle without the government having claim on the inheritance?
- 5.** How can we manage our resources so they are available for the life of the disabled person?
- 6.** How can we ensure a dignified funeral and burial services when my son or daughter dies?
- 7.** How can we get the rest of the family to understand and support the plans we make?

These questions are best answered with the assistance of professionals experienced in these matters. Besides an attorney, the planning team could include an accountant, a financial planning professional, and an advocate. Together the team can often better help families develop and implement appropriate estate plans for their needs. Even if you already have a family attorney, you may want to ensure that they have knowledge about disability estate planning.

One of the best ways to find legal and financial experts in estate planning for families with people with disabilities is to ask others in similar circumstances if they know or have used someone they liked. The person under consideration should be familiar with estate planning for families with a member with a disability. It takes longer to plan a will for a family including a person with a disability than a simple will, so don't be afraid to ask how much the professional's services will cost. Also, ask the professionals if they already have colleagues who work as a team to provide maximum benefits at the least cost. Remember to obtain references for a professionals working with you on this important issue.

Estate planning should be approached as a team with professionals and families working together to accomplish the following:

- Letter of intent: this is a letter by the parent regarding the child with a disability. It is an in-depth letter regarding the child – likes, habits, special communications, medical information, housing needs, etc.
- A complete analysis of resources: both family and individual, including government programs and other private resources and a plan for optimizing them.
- Appropriate execution of all legal documents: wills, trusts, transfers, etc. The appointing of a trustee, a successor trustee, and final disposition of the trust when the person with the disability dies.
- Funding of the trust: to ensure the wishes can be carried out.

When planning an estate, two categories of assets should be taken into account: those that would be listed in your will (assets subject to probate), and assets not subject to probate, such as life insurance or proceeds from an IRA (Individual Retirement Account).

In both cases it would be important not to name the person with a disability as an outright heir or beneficiary. It may be helpful to discuss potential inheritances with grandparents or other relatives. Grandparents, with all the love and good intentions in the world, but no acquaintance with the requirements of the programs upon which their grandchild is dependent, may have written an outright inheritance into their wills. Three routes can be used to accomplish this. They are:

- 1.** Omit the person with disabilities from the will. In some states, you must state clearly it is your intent that the individual in question (when they are your daughter or son) not receive an inheritance from you. The statement of omission is sometimes accompanied by the next action.
- 2.** Make a specific gift to an individual other than the person who has the disability with an unofficial understanding that the proceeds are to be used for the person with a disability. This cannot be an official, written agreement. If it were, the gift in question would be considered an asset of the person with a disability and jeopardize their public assistance. The informal nature of this option makes it a risky one since there are no guarantees that the gift will be used as the parents intended.
- 3.** Establish a trust. A trust is a way to ensure an estate's proceeds, or a portion of them, are used for the benefit of the heir with a disability, enriching their life and not jeopardizing public assistance benefits otherwise available.

A trust is a complicated document that must be drafted very carefully. Trust funds, if and when spent, have to be used for the benefit of the person named as the trust's beneficiary (in this case, the son or daughter with a disability). Yet, in order that the trust funds not jeopardize their eligibility for the assistance programs they are on, the trust fund's assets cannot be considered their assets. The trust's funds are considered the trustee's assets and the trustee is legally granted total discretion not to spend – as well as to spend – any of the funds. However, when funds are spent, they must be used for the beneficiary. When developed carefully, trust funds can help parents add to the quality of their offspring's lives, even after their deaths.

For more information, contact:

Guardianship Associates of Utah, Inc.
180 South 300 West, Suite 202
Salt Lake City, UT 84101
(801)533-0203

There are also a number of private attorneys and financial planners who can provide assistance.

GUARDIANSHIP

Guardianship is a legally authorized relationship between a competent adult (the guardian) and an adult with a disability. In this relationship, the guardian is given the duty and right to act on behalf of the person with a disability in making certain decisions affecting his or her life. When a guardian is appointed, the court gives the guardian the authority to exercise certain rights and correspondingly takes those rights away from the person with a disability. For this reason, guardianship is a very restrictive procedure and should only be used when necessary.

Guardianship may be considered for adults with disabilities who are 18 years of age and older and who, by reason of the decision of a judge or jury, are found to be incapacitated. An incapacitated person might be any person whose decision-making process is impaired by reason of:

- mental deficiency,
- physical illness or disability,
- chronic use of drugs,
- chronic intoxication,
- unusually bad judgment,
- highly impaired memory, and/or
- severe loss of behavioral control to the extent that the person is unable to care for his or her personal safety or is unable to attend to and provide for such necessities as food, shelter, clothing, and medical care, without which physical injury or illness may occur.

Regardless of an individual's disability, a parent is not automatically the guardian of a son or daughter when the child becomes 18 years old. If a parent wishes to become the guardian of his or her adult child, only a court order can make the child a ward and appoint the guardian.

A person will be made a ward only if a petition, complaint, or will is filed in a court and the court finds guardianship or conservatorship necessary to protect the individual. Upon such a finding, the person with a disability may be placed under guardianship despite the individual's objection or refusal.

The appointment of the guardian limits the civil and legal rights of the alleged incapacitated person. To ensure that rights are not limited unjustly, Utah law provides the following due process protection to the potential ward:

- 1.** To be notified of the time and place of hearing in plain language and large type.
- 2.** To be represented by legal counsel. If the respondent cannot afford counsel, it shall be provided at no cost to the individual.

- 3.** To be present at all proceedings. If the respondent cannot be present, a court visitor will do an assessment. There are certain medical exceptions when a court visitor or presences in court are not required. They are: profound mental retardation, fourth stage Alzheimer's disease, and extended comatose.

When the court grants guardianship, the powers and duties of the guardian must be specified but may include the following:

- authority to determine the ward's residence, care, habilitation, and employment;
- responsibility to make sure the basic needs of the ward for food, clothing, and shelter are met;
- authority to consent to medical care needed by the ward;
- responsibility to make decisions for the ward such as whether to marry or be adopted; and/or
- responsibility to keep the ward's financial affairs in order.

The guardian is responsible for the debts of the ward only to the extent of the ward's resources. The guardian accepts no personal liability for debts incurred by the ward.