

One of the most frightening questions a parent of a child or adult with a disability faces is how to plan for the time when that parent will no longer be able to care for their child.

We all want to make sure our son or daughter with a disability will have an accept-able quality of life when we are gone. Comprehensive future planning is essential if our children are to have the best care and security.

Although it is not pleasant or easy to look ahead to the day when, because of death, illness or other life change, we will no longer be able to provide for our children's day-to-day needs, it is particularly important for parents of children and adults with disabilities to make very careful and complete provisions.

Should a parent of a child with disabilities die without making a will, for instance, their property would be divided according to the state's intestate succession law – which takes no consideration of the ability of a person to handle an inheritance, nor of the effect on the person who receives the assets. This could result in mismanagement, could jeopardize the person's qualifications for such benefits as SSI and Medicaid, or could result in the state seizing the assets for previous "cost-of-care."

Letter of Intent

As parents we are the ones who know our child or adult with disabilities best. We know their likes and dislikes, their abilities, their interests – and we usually have very definite ideas of what we want for them in the future.

Writing a "Letter of Intent" can help us to ensure the future we wish for our child. It leaves nothing to chance, and can help us provide future caregivers with a sort of road map.

The letter should address everything that is important in your child's life: residential, social, community integration, religion, employment, likes and dislikes, food preferences, medical, behavior management, names of guardians/advocates, trustees who will manage your child's estate – even such things as information on preferred sleeping positions or favorite music.

While the "Letter of Intent" is not a legal document, it is the means by which explicit information can be communicated to future caregivers. Because it does not have to be prepared by an attorney, the "Letter of Intent" can be updated easily, and should be reviewed yearly (perhaps on your child's birthday), to be sure that the information is current.

Those who take on the care of the person with disabilities will need to know everything, and can't *assume* they know *anything*. List the full name, social security number, gender, race, current address and telephone number, height, weight, clothing and shoe size, employment, religion and citizenship.

Include complete medical information, starting with birth, and the names, addresses and phone numbers of doctors, hospitals and therapists who have treated your child – and personal notes about which doctors your child likes best or ones you would not visit again.

Diagnoses, immunizations, surgeries, illnesses, seizures, levels of functioning, vision, hearing, speech, mobility, blood type, insurance, allergies, birth control – and any other medical information should be listed.

Information about special friends and relatives, guardians (and successor guardian), advocates, trustees, representative payees, power of attorney and funeral and burial arrangements should be included.

Residential and community integration details, as well as information about daily living skills, leisure and recreational activities, hobbies, and religious choices are important.

Basic financial information should be included, listing assets, income, services and benefits, expenses and changes which will occur upon the death of both parents.

The "Letter of Intent" should include information about the parents and siblings (names, social security numbers, family and medical history, marital status, children, etc.), as well as general and specific information about the person for whom the letter is being prepared.

It is also a good idea to include an overview of the person's life and your feelings and visions for the future.

Special Needs Trust

A "Special Needs Trust" is the **only** reliable way to make sure that assets go to a person with disabilities when he or she needs them. This can protect the individual's eligibility for various government assistance (SSI, Medicaid, etc.) and protect the assets from being seized for past or current "cost of care."

While there is some question about the fairness of someone receiving government assistance when there are assets available, most assistance programs do not provide enough actual cash benefits to allow any kind of meaningful lifestyle. Once the basic necessities have been paid (food, lodging, medications, transportation, etc.) there is very little left over for clothing, entertainment and personal items, especially if the individual also needs dental care, eyeglasses, or other services that are not provided on the adult Medicaid Waiver.

Having assets in a "special needs trust" paid out by a trustee can make the difference between poverty level existence and quality of life.

It is vitally important for the "Special Needs Trust" to be set up properly. The trust is protected only if it is IRREVOCABLE. Having a "Living Special Needs Trust" allows parents to contribute to the trust before their death and provides a repository for assets from other sources.

The person or organization (bank, etc.) named to manage the resources of the trust is the trustee. This can be one person, a group of people, or an organization. It is important to name an advocacy or disability organization as the last successor trustee, in case the person with disabilities outlives the named trustees.

Estate planning is one of the most critical and important issues families of children or adults with disabilities face. These are plans we parents must make independently of our child's educational plans and services.

Important Terms

- **Guardian** – A person who has been appointed by the court to have decision-making authority for an individual with disabilities who is judged unable to manage his or her own affairs.
- **Limited Guardian** – A person who has been granted decision-making authority in certain areas (such as financial). The person with a disability retains responsibility for the decisions he or she is capable of making.
- **Representative Payee** – A person or organization who is authorized to manage the funds a person with disabilities receives from programs such as Supplemental Security Income, Disabled Adult Child Benefits or Social Security Disability.
- **Advocate** – A person who looks out for the interests of an individual with disabilities, but who does not have court authority or oversight. The advocate can help the person with disabilities, but cannot legally make decisions for them.
- **Power of Attorney** – A written document that authorizes another person to act on behalf of the person with disabilities. This is a simple document to draft and gives limited authority – such as making medical or financial decisions.
- **Will** – A legal document that gives instructions about who will serve as your personal representative in settling your estate, who will be guardian of your minor children and their property, and lists property and money gifts to survivors. The will of a parent of a person with disabilities should also indicate which assets go into a “Special Needs Trust” for the individual with disabilities.
- **Special Needs Trust** – Assets are transferred into a Trust so that a Trustee can disperse the assets to meet the needs of the person with disabilities, preventing them from losing benefits such as Social Security or Medicaid.
- **Age of Majority** – In Wyoming a person (with or without disabilities) becomes an adult at the age of 18, and may sign legal documents, contracts, IEP's, etc.

For more information about ESTATE PLANNING

CONTACT:



Information & Referral for Parents
of Children with Disabilities

Parent Information Center

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For Families Who Have Children or Adults with Disabilities

Parent Information Center

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