



Achieve with us.

What's Next?

A VISION OF THE FUTURE



...the key is being prepared!

For people with intellectual and developmental disabilities

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A Vision of the Future



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For Your Information...



- ⇒ Developmental Disabilities Life Opportunities Trust/Washington State Developmental Disabilities Endowment (Special Needs) Trust Fund
Toll-free: 1.888.754.8798 ext. 1
<http://www.ddlot.org/>
- ⇒ "Benefits For People With Disabilities"
<http://www.ssa.gov/disability/>
- ⇒ More Guardianship Information
<http://www.proguard.org/guardianship/Guardianship.htm>
- ⇒ **NICHCY News Digest; "Estate Planning";** volume 2, Number 1, 1992
<http://www.nichcy.org/pubs/outprint/nd18.pdf>
- ⇒ Northwest Justice Organization; "Estate Planning & Guardianship"
http://www.nwjustice.org/law_center/pdf/senior_bulletins/12_10_98.pdf
- ⇒ **The ABC's of Special Needs Planning...made easy**, Bart Stevens, ChLAP, Published by The Stevens Group, LLC, 12406 North 32nd Street, Suite 102, Phoenix, Arizona, 85032, copyright 2002.
Toll-free: 888.447.2525. <http://www.BSSNP.com>
- ⇒ "Understanding Supplemental Security Income Home Page" at:
<http://www.ssa.gov/notices/supplemental-security-income/text-understanding-ssi.htm>
- ⇒ "What the Social Security Administration Has to Say About Special Needs Trusts" updated January 2000
<http://www.ssa.gov/notices/supplemental-security-income/spotlights/spot-trusts.htm>
1.800.772.1213 (Toll-free Phone for Social Security Office)
http://www.ssa.gov/OP_Home/ssact/title19/1917.htm

DISCLAIMER

This Publication is designed to provide general information and should not be utilized as a substitute for professional service, legal advice or other expert assistance.

A SNT's Importance (Continued)

Developmental Disabilities Life Opportunities Trust. This trust fund protects beneficiaries' eligibility for public benefits and provides state matching funds on private contributions. The individual with a disability is the beneficiary or recipient of the trust. Each trust is set up as an account where either the family or the individual (but not both) can deposit funds every month and use these funds to cover the normal supplementary or life-enhancing extras of the individual with a disability.

The Arc of Washington State provides enrollment and management of the individual trust accounts. Contact the Arc of Washington State for information regarding this opportunity. **Call toll-free at 1.888.754.8798 or visit the website at <http://www.arcwa.org>.**

There is no one who relies on you more than your son or daughter with special needs. Taking the time to create a Special Needs Trust and appointing Successor Trustees will protect the assets you leave for your loved one. It will also maintain eligibility and avoid termination of government benefits during your loved one's lifetime.



The Importance of Being Prepared

The importance of planning for the future of an adult who has a developmental disability and is receiving government medical benefits is critical. You want to protect their current level of living and care.

It is very important for you to sit down and talk with other family members regarding their role in the support of the individual with a developmental disability should something happen to you. Lifestyle Planning is where the family puts into writing a "**Letter of Intent**" which is your guidance for care, support and what you want for the future of your loved one. This includes your hopes, desires, instructions and goals. This letter is a constantly changing document as things change with your son or daughter. Give a copy to everyone that provides services to or care for your son or daughter. Ask for their feedback and make the changes you want to include. Address their questions and concerns now while you are available. A video is a great way to document daily care.

Estate planning, a special needs trust and a will are a good beginning and should be done with an attorney knowledgeable about the special needs interests of your son or daughter as well as some very stringent rules and regulations imposed on the government agencies and their benefits.

Ten Step Planning Process

- ◆ Decide what is needed for the future of your son or daughter.
 - A.) Residential Needs
 - B.) Employment
 - C.) Continued Education
 - D.) Social Activities
 - E.) Medical Records/Information
 - F.) Dietary Needs
 - G.) General Lifestyle
- ◆ Write a "Letter of Intent" which includes hopes, desires, instructions and goals for your loved one as well as final arrangements.
- ◆ Determine if there is a need for *Guardianship* which is a legal appointment of the court. A *Durable Power of Attorney* is another alternative.
- ◆ Determine the cost of the plan.
- ◆ Identify resources to fund the plan.
- ◆ Prepare legal documents.
- ◆ Consider creating a "Special Needs Trust" (SNT).
- ◆ Put all pertinent information and documents in a binder and let those who will be responsible for the future care of your son or daughter know its location.
- ◆ Hold a meeting and give copies of relevant documents and instructions to family members and care providers.
- ◆ Review your plan once a year and change it as the need arises. Legal documents usually require an attorney.



A Special Needs Trust's Importance



A Special Needs Trust shelters or protects resources while maintaining the individual's eligibility for financial need-based programs they receive currently or may need in the future.

A *Testamentary Special Needs Trust* is created by a person's will. Under certain circumstances it may be appropriate or wise to set up a special needs trust during your lifetime (*for example: Divorced parents find this appropriate for estate planning.*). The *Inter vivos Special Needs Trust's* sole function is preserving the ongoing care and needs of your son or daughter.

You should contact an experienced attorney knowledgeable about Special Needs Trusts and current government benefit programs given the complexity of this field. As of January 1, 2000, the SSI law on trusts changed. It is critical that the trust be carefully worded to meet stringent government requirements.

In Washington State we have an unique opportunity for individuals to participate in a special needs trust: **The Washington State Developmental Disabilities Endowment Trust Fund or the**

(Continued on the next page.)

A Special Needs Trust can be used to provide for the needs of an individual with a disability and to supplement benefits received from various governmental assistance programs.

The Trustee can purchase:

- ◆ Advocacy & legal services
- ◆ Assistive technology, including computers & electronic equipment
- ◆ Birthday & holiday gifts for the beneficiary to give to others
- ◆ Capital expenses, including environmental modifications & transportation
- ◆ Disability-related support groups
- ◆ Education, information & training opportunities
- ◆ Employment supports & tuition
- ◆ Individual trust account expenses including enrollment
- ◆ Living arrangements, including personal assistance services, skill building, financial management, medical monitoring, meal preparation, shopping, home maintenance & house cleaning
- ◆ Medical Care, counseling, therapies & other health related services, including alternative practitioners, not covered by public benefits
- ◆ Respite Care
- ◆ Some utilities & transportation costs
- ◆ Specialized clothing or clothing not covered by public benefits
- ◆ Social productivity & personal fulfillment activities, such as volunteering, club membership & recreation
- ◆ Unusual or extraordinary disability-related shelter expenses
- ◆ Vacation, travel & recreation
- ◆ Other items deemed appropriate & reasonable by the Trust Manager within the guidelines of the trust

A Lose-Lose Situation

Suddenly your son or daughter with developmental disabilities not only loses a loving family to care for their special needs but...because they have been left without important prior planning, the money inherited has jeopardized your son's or daughter's governmental and medical benefits, as well as the services and needed assistance so vital to their care.

This is a difficult subject to address but a critically important responsibility. With modern medical advancement and technology your son or daughter will probably survive you. You have the ability to make this transition as easy as possible by creating the best plan for your loved one to prepare a secure and comfortable future. There is comfort in knowing your son or daughter will be well cared and provided for.

You would not leave your son or daughter with someone you did not trust or in an unsafe situation. Nor would you leave them for even a short time without leaving detailed instructions while you were away and whom they should contact in an emergency. You need to leave **detailed written information** explaining the day to day support needs of your son or daughter and wishes for their future support.



Where to Begin

Assess your son's or daughter's disability and whether they will have the capability to earn a living and to manage their financial assets. Develop a plan which identifies the skills and abilities of your son or daughter. Identify areas in which the individual may need assistance and support.

Be sure to inventory your financial affairs and write a will that is flexible enough to meet life's ever-changing needs. You can change your estate plan as circumstances change with your son or daughter.

Consider their living arrangement and whether there is a need for a guardian.

Insurance and Death Benefits

If you have a special needs trust set up for your son or daughter with disabilities you will need to review the death benefits on your insurance policies and your employer-provided death benefits to make sure you have named the trust and not your son or daughter as the beneficiary. The same is true for others in your family that may have named him or her as a beneficiary of their policies. You may need special wording to avoid a problem in the future for your son or daughter with disabilities and should speak with your attorney for current information. Second-to-die insurance, purchased at a low cost, is one way to fund a trust.

Maximize Financial Resources...

It is important to check how each asset in your estate will be transferred after your death and to whom.

A Special Needs Trust is a concrete plan that can enhance the quality of life over and above the basic benefits programs by maximizing your financial resources. It can act as a repository for your son or daughter providing a life-long support and giving you peace of mind.

Money or property in this type of trust does not count toward the Supplemental Security Income (SSI) and Medicaid resource limits of \$2,000 for an individual. Money paid directly to the providers for items other than the person's food, clothing and shelter does not reduce SSI payments. *(See the next page for examples.)*

Money paid directly to the providers for food, clothing and shelter, "In-Kind Support and Maintenance" (ISM) does reduce the individual's SSI payments—but only up to a limit. Money paid directly to the individual from a trust reduces the SSI payment.

Educate your family and friends. Take charge of the planning process.

Establishing a trust...

There are many types of trusts: all of which may have Special Needs Provisions.

A third party or grantor trust is created and funded by a person other than the trustee or the beneficiary. A "self-settled" trust is created from the funds belonging to the beneficiary. A pooled trust is owned and administered by a not-for-profit organization and the funds at death may stay with the "pool" of funds to help others in the pool.

In Washington, trustees of court ordered trusts have reporting duties to the court.

For many parents the only reliable way of making sure that the inheritance reaches their son or daughter is through a legal device known as a Special Needs Trust.

The following types of contributions to a trust can be used for the person's benefit as long as the trust has been properly set up.

Contributions:

- * Cash
- * CD's
- * Mutual Funds
- * Retirement funds
- * Life Insurance Policies
- * Injury Settlements

The Trust, not the individual, must be listed as the beneficiary of policies, 401k's or other contributions

Taxation:

- * All the money contributed is after tax
- * Anyone can give money to the trust, not just family, depending on the type of trust
- * The money does not grow tax deferred
- * Money paid out is taxed at a lower rate. The individual with a disability pays income tax on any trust earnings paid out for his or her benefit.

Government Benefits and Your Child



Government Benefits can be divided into two categories.

The first category or group would be those unaffected by the financial resources of the beneficiary like Social Security Disability Insurance (SSDI) and Medicare.

The second category would have financial eligibility requirements like Supplemental Security Income (SSI) and Medicaid. Inheriting money, property or other assets could lead to a reduction or elimination of these benefits. So, it is important to arrange your estate in a way that will protect your loved one and their needed benefits.

A trust will count against SSI and Medicaid eligibility if the assets of an individual with disabilities are used to establish a trust with the exception of *trusts under Section 42 U.S.C. 1396p(d)(4)(A), often called "payback trusts;"* and *trusts under Section 42 U.S.C. 1396p(d)(4)(C), often called "pooled trusts,"* which are administered by a not-for-profit organization.

Both the payback trust and pooled trust are kinds of special needs trusts.

The Importance of a Will

It is important that parents of a son or daughter with a disability prepare a will even when they feel they have very little assets. Many have a house, a retirement account like an IRA or a 401(k) or life insurance.



Without a will your property will be dispersed according to the state's *law of intestacy*. This could jeopardize your son or daughter with a developmental disability and the very government benefits and services they need to have a quality life.

If you do not have an attorney that is familiar with the special needs associated with caring and providing for individuals with disabilities, you may want to contact a local disability group for references. They can refer you to experienced attorneys in estate planning for parents of individuals with disabilities and their special needs. Lawyer's fees can vary a lot. It may be possible to negotiate a payment plan if the price seems beyond your means.

Some items not covered by a will are joint property with right of survivorship, life insurance and the death benefits under your employer-provided pension plan and Social Security Survivor Retirement Benefits.

Establishing A Will...

A son or daughter with a disability creates a unique set of circumstances when planning your estate.

If you do not expect your son or daughter with a disability to receive government benefits in the future, leaving them a portion of your estate will be the best. If there is cognitive disability, a trust is preferable since they may not be able to handle the financial responsibilities.

It is generally unwise to leave money to siblings or friends on the promise they will care for your son or daughter because those assets may be diverted by divorce, bankruptcy or death by the person you counted on. This is called a morally obligated gift and has a built in danger that the recipient may ignore your wishes or be unable to fulfill them.

Using a Special Needs Trust avoids these difficulties.

CHOICES YOU HAVE...

- ◆ **Leave him or her with an outright gift or inheritance.**
- ◆ **Leave assets to another family member or friend (morally obligated gift) expecting them to take care of your son or daughter as you wish.**
- ◆ **Establish a Special Needs Trust for your son or daughter.**

