

A Short Guide to Planning for the Future of a Person with Special Needs

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one receives the best possible care.

Regardless of your loved one's age, you should ensure that you leave assets in a way that does not affect his or her eligibility for government benefits. If a parent dies without a will or leaves assets directly to a special-needs child, and the child receives more than \$2,000, most government benefits will be lost.

Therefore, you should leave assets for a loved one with a disability directly to a special-needs trust. Such a trust can provide money for "extras" that will improve your loved one's quality of life without endangering his or her eligibility for government benefits. Examples include a vacation, a television or home computer, or extraordinary medical care.

You can create such a trust now, or your will can direct that such a trust be created with some or all of the assets in your estate. The advantage of creating a trust now is that your loved one will not have to wait until your will is probated to have access to the funds.

Depending upon your personal and financial situation, you may want to create your own special-needs trust (either now or in your will), or you may wish to make use of a pooled trust offered by a not-for-profit organization, such as the AHRC New York City Foundation, Inc. Community Trust I for Persons with Disabilities.

Trusts offered by not-for-profit organizations may be preferred by:

- Families who do not have someone with the expertise to carry out the fiduciary responsibilities of trustee.
- Families who do not wish to incur the legal expense of creating their own trust.
- Families who wish to leave funds remaining in the trust after their loved one's passing to charity.

Some parents consider leaving assets for a

disabled child to a non-disabled sibling or other close relative. However, such an arrangement can have unintended results.

For example, the non-disabled relative may unexpectedly pre-decease the disabled person, and the assets may pass to someone without the commitment to meet the disabled person's needs.

Also, receiving substantial assets may have tax consequences for the non-disabled relative and may jeopardize his or her children's eligibility for financial aid for education.

Once your will is signed, you should review it with your attorney periodically because laws and personal circumstances change.

Do I have, or should I purchase, life insurance for the benefit of my disabled loved one?

Life insurance is an attractive way to fund a special-needs trust and can have advantages for both families of very limited means and families with substantial assets.

This option is simple and relatively inexpensive and allows families that do not have assets to bequeath, or the minimum contribution required to participate in a trust offered by a not-for-profit organization, to create a generous legacy for a loved one with a disability.

Family members with significant assets may be able to reduce their estate-tax liability by using life insurance to fund a special-needs trust.

Another important advantage of life insurance is

that the funds are quickly available to the beneficiary upon the death of the insured person.

In order to preserve your disabled loved one's eligibility for government benefits, it is essential that the beneficiary of the life-insurance policy be a special-needs trust for the benefit of your loved one, not the loved one him or herself.

A special-needs trust operated by a charity, such as the AHRC New York City Foundation, Inc. Community Trust I for Persons with Disabilities, can be named as the beneficiary in trust for your loved one.

If you already own a life-insurance policy, you can change the beneficiary designation to specify a trust for your disabled loved one.

Have I taken steps to ensure that my loved one will have an appropriate and stable living arrangement in the future?

The decision to permit an adult child to move into a residence operated by a not-for-profit agency can be an extremely difficult one for parents.

However, making this decision while you are healthy allows you to help your child make the transition and to see for yourself that he or she is happy and cared for well. Delay can mean your child will have to adjust to an unfamiliar living situation while grieving for a parent.

The wait for a residential placement is often long, so it is wise to apply early and to consider carefully a placement that is offered, even if

the timing does not seem ideal.

As a first step, you may want to consider respite services, which are offered by not-for-profit agencies. Respite services allow your loved one to be away from home for a few days, or a week or more, providing a transition into residential services.

Have I made funeral plans for my loved one?

Many people are reluctant to plan in advance for a loved one's funeral, but planning is the only way to ensure that your wishes are carried out. Many funeral expenses can be prepaid without affecting your loved one's eligibility for government benefits.

Also, an account of up to \$1,500 can be maintained for funeral expenses. Interest earned can be retained in the account as well. Some special-needs trusts may also pay funeral expenses, depending upon the terms of the trust.

By planning well ahead, you can ensure that the life-long needs of your disabled loved one are met. In making plans, you should consult with an attorney who has expertise in issues affecting people with intellectual and developmental disabilities, as well as financial advisers. Many not-for-profit organizations also offer useful information.

For more information about the AHRC New York City Foundation, Inc. Community Trust I for Persons with Disabilities, call 212-780-2682, or go to www.ahrcnycfoundation.org.

For information about AHRC New York City's programs and services, call the Central Intake Unit at 212-780-4491 or 212-780-4493.

Note: The information in this brochure is provided for information only, and the AHRC New York City Foundation does not warrant or ensure its content. Please consult with your attorney for estate-planning advice.

appoint a guardian,
as well as standby guardians,
in your will



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Our mission is to improve the lives of children and adults with intellectual and developmental disabilities.

We support programs such as

- camping and recreation
- job-training and employment opportunities
- family-style community residences
- preschool, elementary and secondary education
- health care
- legal assistance



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If you are responsible for the care of a child or an adult with special needs, you no doubt want to be sure that person's needs are met for life. This means careful planning now.

Here are some important issues to consider and to discuss with your attorney and financial advisers.

If my loved one is age 18 or older, does he or she have a guardian and standby guardian?

Many parents don't realize that, once a child turns 18, he or she is legally independent, regardless of mental capacity.

To retain control of medical and other important decisions for the child, a parent or family member must file a request for guardianship with the New York State Surrogate's Court.

As part of this process, you will designate a standby guardian to care for your child after you are gone. It is important to designate a succession of guardians in case the person you choose dies or becomes unable to serve.

Also, it is important to note that, just because a person with an intellectual or developmental disability lives in a residence operated by a not-for-profit agency, this does not mean the agency is that person's legal guardian. A guardian must be appointed by the court.

Once guardianship has been established, you should review the papers periodically, because the personal circumstances of those you have named as standby guardians may change.

Do I have an up-to-date will that provides adequately for my loved one's future?

If your child is under age 18, you should appoint a guardian, as well as standby guardians, in your will. Be sure anyone you are appointing is willing and able to ensure that your loved

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