

Special Needs Planning Guide: Putting the Structure in Place for Your Child and Yourself

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I. Introduction

Contemplating the fact that we will not live forever is especially fraught for parents of children with special needs. Properly executed documents can determine how your money is distributed and help you protect your special needs offspring when we are gone. Below are some of the estate-planning tools to consider. A qualified attorney who is knowledgeable in disability laws and government benefits should prepare these, but your basic knowledge of these tools will be helpful in understanding and implementing your options.

II. Wills

A will is the basic legal document that allows you to direct to whom your property will be distributed. The personal representative (formerly known as the executor or executrix) is the individual you name in your will to execute your wishes. In the absence of a will, under state law the assets in your name alone will go directly to your spouse and children, if any.

Keep in mind that many if not all of your assets that you pass on will not be governed by your will. Beneficiary designations from retirement plans, life insurance policies and annuities will dictate these distributions. Assets held “joint with rights of survivorship” will pass directly to the surviving owner.

Some parents give equal shares of their estate to all of their children, wanting to be fair to each. Be aware that receipt of even a minimal amount of money could jeopardize public benefits for the son or daughter with special needs. The same can happen if the second parent dies without a will.

Well-meaning relatives or friends can also disqualify a person from benefits by naming that individual in their will or by giving them a large amount of money.

III. Trusts

Trusts permit one or more people, known as “trustees,” to manage investments and real estate for the benefit of one or more “beneficiaries.” The trust document sets out the ground rules as to how they must operate including, for instance, the standards that govern the distribution of trust income and principal. The trust document also states what happens to the trust property after the beneficiary or beneficiaries pass away.

1. Special or Supplemental Needs Trusts

Individuals with disabilities must be protected from the possibility of being defrauded by the unscrupulous. Assets owned directly by the individual are under his or her control unless a court has appointed a legal guardian. It is easier to hold assets for the individual in trust for protection than it is to go to court and have the individual declared incompetent and in need of a guardian.

It is important that you do not leave an inheritance outright to the name of your child with a disability if you want to protect his or her eligibility for government benefits and to make sure that the funds you leave are well managed and not subject to predators. Some parents recognizing this choose to disinherit their child or to leave his or her share to another person who will provide care.

We recommend against both choices. Even beneficiaries of public programs can use resources to pay for extras, whether that's extra therapy, a care manager, travel, or even a special dinner from time to time. Leaving extra funds to another child is sometimes referred to as a "morally obligated" gift, meaning that it creates a great burden on the sibling to make decisions about how the funds are held and spent. Clearly delineating what funds should be spent on the child with the disability is easier on all concerned. By funneling the disabled child's share to a special needs trust to provide supplemental financial support and still protect against loss of government benefits, you can protect all of your children.

A special needs trust allows a trustee (often a trusted sibling or other individual or a bank) to use this money to provide for the supplemental or special needs of your child during his or her lifetime. You may wish to authorize the trustee to pay an advocate or service provider to monitor and help, especially if members of the family are not close by. The language of the trust is the key to protect your child's eligibility for government benefits.

2. Choice of Trustee

Trustees must manage the trust. Since the individual with special needs will have no claim to the funds except as decided upon by the trustees, the selection of trustees is especially important. Qualities of good trustees for a special needs trust are:

- ability to make sound financial decisions and to invest and properly report trust transactions;
- availability and the time to spend to perform the duties needed;
- honesty; and
- emotional attachment to the individual.

We often find that a professional and a family member acting as co-trustees can best provide these qualities. A bank, attorney or accountant can provide the professional management that will make certain that the trust funds are well managed, while a family member can help make sure those funds are best used for the beneficiary.

3. Trust Funding

The trust can be funded in various ways either during your lifetime or upon your death. It is like a bucket that must be filled, and you provide directions to the trustees as to how the money in this bucket is to be distributed. Without making provisions for assets to funnel into the trust, you would provide only an empty bucket. Some portion of your estate can be designated for the trust in your will. Another option is to use life insurance to fund the trust upon your death. Second-to-die life insurance policies which pay out on the death of the survivor of two parents are often used to fund special needs trusts because the premiums are lower than those for policies on a single life.

A special kind of trust must be used when sheltering a disabled individual's own funds (as opposed to those he or she may receive from a parent, grandparent or other third party). If the trust does not fit within special safe harbor rules set out in state and federal laws, its contents will be counted in determining the beneficiary's own eligibility for public benefits. Often referred to as "(d)(4)(A)" or "payback" trusts, these trusts provide that after the beneficiary's death, any remaining funds must be used to reimburse the state for its Medicaid payments on the beneficiary's behalf. Only if further funds remain, may they be disbursed to family members or other beneficiaries.

4. Pooled Trusts

Federal and Massachusetts laws permit non-profit organizations to set up so-called "pooled" trusts to manage funds for disabled individuals. Whether those funds belonged to the beneficiaries themselves or were contributed by third parties, they are not counted for purposes of determining eligibility for public benefits such as MassHealth and Supplemental Security Income (SSI).

These pooled trusts can be ideal vehicles for smaller trusts that cannot afford the fees of professional trustees or when no family member is available or appropriate to serve as trustee. The added benefit is that the agencies that operate these trusts have extensive experience working with individuals with a variety of special needs and knowledge of programs available from government agencies and private organizations. For information on the two principal pooled trusts in eastern Massachusetts go to the following websites:

The PLAN of Massachusetts and Rhode Island
617-244-5552
www.planofma-ri.org
info@planofma-ri.org

The Arc of Bristol County Pooled Trust
508-226-1445 x3102
www.arcnbc.org
jsweet@arcnbc.org

IV. Letter of Intent

We generally recommend that parents of children with disabilities draft a so-called “letter of intent” to include with your estate documents. It gives you the opportunity in your own language to communicate to future trustees and other caretakers your desires for and concerns about. It can cover vital statistics, your child’s financial picture, details about what works well or not so well for your child, suggestions about what changes might be needed for the future, and a list of the locations of all pertinent documents, records and people in your child’s life. It can also include medical information, including names and contact information for doctors and therapists.

V. Power of Attorney & Health Care Proxy

A durable power of attorney and health care proxy are vital documents both for you, and for your child as well if he or she has reached age 18 and is competent to execute them. The power of attorney names an individual to act on your behalf during your lifetime to make legal and financial decisions for you if you become disabled or incapacitated and cannot make decisions yourself. Similarly, through your health care proxy you appoint an agent to make medical decisions if you are unable to do so. It is important in this day and age to execute a HIPAA release as well so that family members can communicate with medical providers even if you are not incapacitated, in which case the health care proxy would be invoked.

You may be told that when your child reaches age 18, you have to go to court to be appointed guardian. Depending on the circumstances, this may be the best course of action. However, it involves expense, the taking away of rights from your child, and continuing reporting to the court, all of which may be unnecessary if your child has the capacity to execute a durable power of attorney and health care proxy, giving you or another person the ability to step in when and if necessary.

VI. Guardianship and Conservatorship

Guardians and conservators are appointed by the probate court to manage financial (conservatorship) and personal (guardianship) matters for the protected person, who is determined by the court to be unable to make these decisions himself or herself. (For parents who are seeking guardianship when their special needs child turns 18, ordinarily a conservatorship is not necessary, because the child has no assets.) In most cases, the appointments are comprehensive, but the appointments may be limited, transferring only certain named rights and powers to the guardian or conservator. Both the guardian and conservator (who can be the same person) must make annual reports on their activities to the probate court.

Parents are the natural guardians of their minor children, so in most cases there’s no court involvement until age 18. The court would become involved, however, if a non-parent had to become guardian of a minor.

VII. Estate Taxes

Federal estate taxes affect very few people since the threshold for taxation is \$11.4 million in 2019, which is adjusted each year for inflation. However, the Massachusetts estate tax applies to all estates exceeding \$1 million. With appropriate planning, a couple can exclude up to \$2

million from Massachusetts estate taxes, and potentially more through appropriate gifting techniques. Properly addressing your estate tax liability could save your family significant dollars in taxes, thus preserving their inheritance.

VIII. Planning For The Long-Term Illness Of A Parent

One common objective for all families is to guarantee that resources are always available to provide for their son or daughter's supplemental needs. A long-term illness of a parent can deplete the family resources rather quickly. Nursing homes in Massachusetts can cost as much as \$200,000 a year. The question then becomes what happens to the child with special needs when a parent's assets are depleted due to unexpected nursing home or long-term care costs, and what can be done.

There are three basic ways in which the cost of long-term health care can be funded:

1. Cash from personal income, savings and investments

As a private-pay consumer (non-Medicaid), you will have the freedom to choose any services or long-term care facility. Many nursing homes would rather have a private-pay consumer than have to wait for Medicaid coverage. You also maintain control over how your dollars are spent. The disadvantage is that the income and assets needed for your spouse or child may be depleted.

2. Medicaid ("MassHealth" in Massachusetts)

MassHealth will cover the cost of nursing home care once the resident qualifies. To qualify, the resident is limited to \$2,000 in countable assets and a spouse living at home is limited to \$126,420 in 2019. Most assets are counted against these limits except for a home, personal belongings, one car, and a prepaid funeral plan.

Further, in most instances if a nursing home resident transfers assets to get down to these levels, he will be ineligible for benefits for the subsequent five years. However, there is an important exception which permits transfers into trust for the benefit of a disabled individual under the age of 65. In other words, if you do no planning, even at the last minute you can transfer your assets into trust for your child with special needs and rely on MassHealth to cover your nursing home costs.

There are, however, a few drawbacks to this approach. First, if you have a spouse at home, he or she will still be limited to about \$126,420 in countable assets. Second, while most nursing homes accept MassHealth, its coverage of home care and assisted living is much more limited. Third, this approach will provide for your child with special needs, but not any other children you may have as the trust must be only for the benefit of the child with special needs. And, fourth, at his or her death any remaining funds must be used to repay the state for any MassHealth paid out on your child's behalf (not for MassHealth paid for your nursing home care). Only if there are funds left after the state is paid, may they be distributed to other family members.

3. Long-Term Care Insurance

This type of insurance provides you with the dollars needed to pay for services in your home or for nursing home care that you otherwise would have to pay from your own resources. Ultimately, it allows you to preserve your assets for your spouse and your family's needs.

The disadvantage to purchasing a long-term care insurance policy is that the premiums can be costly. As a general rule of thumb, if you must significantly change your lifestyle to pay for the annual premiums, then you should consider retaining the risk rather than buying the insurance. (In this situation, it may be possible to qualify for Medicaid rather quickly.)

To fund the cost of long-term care of a parent, one or more of these options (use of cash, Medicaid, or long-term care insurance), may be the most suitable solution to protect and preserve your assets for your family if you become sick and need extended care. By taking appropriate steps to incorporate these considerations in your plan, you can ensure that the resources needed to allow your son or daughter to continue to live in his or her home will be there -- and the residential model will continue to work.

IX. Beneficiary Designations

Many assets now have their own beneficiary designations which govern who will receive them after the death of the owner. This is especially true with respect to retirement plans, life insurance policies and annuities. It is crucial in any estate planning, and especially in special needs planning, to check all of these beneficiary designations and to make sure that they are consistent with your estate plan. A stray designation can wreak havoc on a carefully prepared plan, especially if it means assets pass directly to an individual dependent on public benefits or unable to manage finances. Make certain that all assets are properly coordinated with your plan.

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All of your estate planning documents, which include wills, trusts and other means of providing financial support, should be reviewed with an attorney at least every five years. It is important to note changes in your family situation as well as changes in laws relating to taxes, trust, wills, government benefits and financial assistance, as well as inflation and program costs. And remember, proper planning may be the most important thing you can do for your loved ones.