

Planning for children with special needs

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Key highlights

- Planning steps
- Government benefits
- Need based benefits
- Guardianship
- Gifts and bequests
- Trusts

The US Surgeon General estimates that 5% of U.S. children have an acute disability. An industry study find that 29% of the parents of special needs children had made no plans for their future and 73% had not begun setting aside money.¹ By waiting too long to plan, parents may lose certain options that are critical to the length and quality of the child's life. While changes in technology create new educational and vocational opportunities for these children (that have led to an emphasis on independence and normalized living arrangements) the move from large institutions to small and scattered facilities has increased the cost of their care. The dependency of such children can last for many years and medical science is giving them a longer life span which continues to increase. The greatest danger to the welfare of these children arises after their parents are gone. The likelihood of that happening is increasing with the rise in their life expectancy. Planning for the care of special needs children, after their parents are gone, is critical and must take into consideration these concerns:

- What government programs will be available to the child?
- Who will provide care for the child?
- How can the family's assets be made available to the child without causing the loss of government benefits?

Planning steps

The planning for special needs children begins by making an estimate of the financial resources needed to care for them after their parents are gone as compared to the resources currently available. This planning should be coordinated with the parents' and other children's financial and estate planning needs. In addition, the parents must understand the specific characteristics of the child's disability and the impact that those limitations will have on the child's ability to function in the future. Specifically, the following questions should be addressed:

- What is the nature and degree of the child's disability?
- What is the child's age?
- What are the plans for where the child will reside after the parents'

death?

- What, if any, is the child's earning potential and for how long?
- What changes in major expenses can be expected?
- What other family members might contribute funds or services to the child's care after the parents' death?
- Who will take responsibility for enhancing the quality of the child's life after the parents are gone with respect to religious and family traditions such as birthdays?

Government benefits

There are three types of government benefits that are applicable to special needs children:

- **Need based** — The individual must meet rather strict eligibility requirements
- **Non-need based** — These programs provide benefits to selected groups of people without regard to their income or assets.
- **Cost of care programs** — Benefits are provided regardless of the individual's level of income or assets but there is a charge back for the benefits that is based on the individual's ability to pay.

Need based benefits

There are two types of need based benefits that may be described as follows:

- **Supplemental Social Security Income (SSI)** — This program is managed by the Social Security Administration and provides monthly income to people who are disabled, blind or aged and in financial need. Qualification depends on a person's financial resources (income & property) and as those resources increase benefits are decreased until they stop entirely. In this regard, the income of a special needs child's parents is considered to be the child's income until the child is 18 or 21 (if a full time student). This means that in many cases the parent's income will disqualify the child for SSI benefits but consideration must be given to when that income will stop such as on the deaths of the parents.
- **Medicaid** — This program is also based on need and provides medical assistance for doctors' and hospital bills to the needy including disabled people. It also covers group homes, workshops, training programs and transportation that disabled people find useful. The program is partially federally funded and administered by the states with the consequence that

benefit qualification varies from state to state.

Since medical insurance is so expensive for a disabled child this is probably the most important government benefit for a special needs child.

Non-need based

The Social Security Disability Benefits Program provides benefits to disabled children. When the child's disability begins before age 21 and they are unmarried and dependant upon their parent their benefits are based on their parent's Social Security earnings records. For this purpose a child is disabled if they can not work for at least a year or are expected to die. Payments do not begin until the child reaches age 18 and the parent retires, becomes disabled or dies. The child's benefits continue for life and are not affected by the child's assets so that gifts or inheritances do not change the child's entitlement to benefits or the level of benefits.

Cost of care programs

These programs seek reimbursement from assets available to a special needs child. An example of this type of benefit is a state residential care facility where the child would be expected to pay to the extent of his or her financial ability.

Other benefits

A special needs child may qualify for other benefits from the Federal Department of Housing and Urban Development. These may include food stamps, veterans' benefits and housing assistance.

Caring for the special needs child

As stated, the major problem in dealing with special needs children is the issue of who will take care of them once their parents are gone. Considering the resources that will be available to the child, there are five possibilities that will be discussed sequentially below:

- Informal care arrangement
- Guardianship and Conservatorship
- Gift or bequest to the special needs child
- Gift or bequest to a third party
- Creation of a trust

Informal arrangement

This approach assumes that after the parents' deaths some family member or friend will step forward to take care of the special needs child. The problem is that there is no assurance this will happen. Even if someone does assume the responsibility there is no fall back if they cease to be able to provide care for the child. Consequently, these arrangements are only

viable if the child is highly self sufficient and there are other supporting mechanisms available to the child within their local community. The result is that these arrangements are likely to be impractical and unreliable.

Guardianship

A guardianship is a relationship created by law under which one person is authorized to look after the interests of another person. A parent is the natural guardian of their child but that relationship ends when the child becomes an adult upon reaching the age of majority, 18 to 21. It is 18 in most states.

In the case of a special needs child, however, that relationship may continue after the child reaches the age of majority. Such ongoing parental care may be on an informal basis that suits the interests of all those concerned as long as the child's needs are met but that leaves the problem of what happens after the parents are out of the picture. The way to overcome this problem is to have a court appointed guardianship established once the child reaches the age of majority — usually age 18.

There are two types of guardianships for this purpose. One is the guardian of the child's person and the other is the guardian of the child's property. The guardian of the child's person is responsible for taking care of the child's personal needs as a parent would. A guardian of the child's property takes care of investing and managing the child's property and is sometimes called a "conservator".

The advantage of formal court appointed guardianships is that there is no question of who has the authority to make decisions for the child with respect to their personal or financial interests. This can be especially important as to the child's financial affairs since the guardian/conservator can protect the child from unscrupulous individuals who would take financial advantage of the child. Note that the actions of the guardian/conservator are subject to judicial review and audit, along with all the associated professional fees. This degree of oversight can be expensive.

In any case, the assets managed by the guardian/conservator are considered owned by the special needs child for purposes of qualifying for government benefits and would be subject to any governmental rights of reimbursement. This makes guardianships a poor choice for parents who want to protect and conserve the assets of a special needs child.

Moreover, a full guardianship that authorizes the guardian to act on behalf of the child's personal and financial affairs may be too restrictive. In effect, it may prevent the child from leading as full and productive life as they are otherwise capable to do.

Gifts and bequests

Another approach to meeting the needs of a special needs child after the parents are gone is to have the parents make lifetime gifts to the child or leave a bequest to the child at the parents' deaths. This is not a problem when the gifts are relatively small but when the amounts are large the child may not have the financial maturity to deal with the assets effectively. In addition, the child may become the victim of unscrupulous people who want to take the assets from the child. Further, as with guardianships government agencies may step in and demand the assets as reimbursement for services or simply deny benefits because of the child's ownership of the assets. There is also the issue of what happens to any remaining assets at the child's death. Depending on the child's age and mental capacity a will made by the child may or may not be a viable vehicle for disposing of the child's remaining assets. If the child is too young or mentally incapable to create a will, then any assets left at the child's death will pass by the state's intestacy laws and be subject to probate costs and delays. This may result in a distribution of the assets that the family finds undesirable.

Non-parental transfers — It should be noted that gifts to the child may come from a variety of sources such as friends and relatives (especially grandparents) that care about the child's welfare. Moreover, the child may receive property from unexpected and unanticipated sources such as a bequest by will or life insurance proceeds on the death of a distant relative. The problem is that gifts from any of these individuals may disqualify the child from government benefits. Consequently, it is important to anticipate and review all possible sources of funds and other assets that could flow to the child and affect the child's qualification for government benefits or duty to reimburse the government.

Gifts to third parties — An alternative to making direct gifts to the child is to give the assets to a relative or friend with the informal understanding that the funds will be used for the child's benefit. This is easy to set up and probable workable where lesser amounts are involved such as where the parent's leave a very small estate. Since the funds are not in the child's name they will not disqualify the child

for government benefits and can be used to cover “extras” that are not available under government plans. By putting the funds in the name of a third party they will not be available to reimburse the government. The gifts to third parties are, however, subject to the gift tax rules. Gifts in excess of the gift tax annual exclusion (\$15,000 in 2018) will reduce the donor’s gift tax applicable exclusion amount (\$11,180,000 in 2018). If the gifted amount is invested the donee will have to recognize income tax on the earnings.

The parents could gift funds to pay premiums on a life insurance policy on their lives with the third party as owner and beneficiary. The growth in cash value and death proceeds would not be taxable to the third party and the death proceeds could be used to provide a quality of life for the special needs child not met by government programs.

A problem with this approach and any outright giving, is that there is no legal duty for the third party to use the gifted assets or insurance proceeds for the benefit of the child. What if the third party becomes incapacitated, dies, is sued or is divorced. Any of these contingencies could cause the funds to divert from the special needs child’s benefit.

Trusts

When dealing with a special needs child the two most important goals are to provide for the child’s needs and simultaneously provide financial protection for the assets that are set up to meet those needs. As can be seen from the above discussion, informal plans, guardianships and gifts to the child or a third party fail to meet one or both of these goals. As explained below, the only remaining alternative that may meet both objectives is a trust that is established for the special needs child. Essentially, a trust is a legal entity through which the legal ownership of property is separated from the right to benefit from the property. The legal title to property that is placed in trust belongs to the trustee but the trustee is legally obligated to use the trust property only for the benefit of the trust’s beneficiary.

Types of trusts

There are two types of trusts which are identified as inter vivos and testamentary. Inter vivos trusts are created during the grantor’s life and may be further divided into revocable and irrevocable trusts. Revocable trusts may be terminated at any time by the grantor who may take back the trust property. Irrevocable trusts, on the other hand, once

established may not be terminated by the grantor. Testamentary trusts are created through the grantor’s will and have no effect until the grantor dies and the will is probated at which time the trust comes into existence. The tax implications of each trust may be described as follows:

- Testamentary trust — Where a parent establishes a testamentary trust for the special needs child, there is no gift on the execution of the parent’s will. Rather the property that goes into the trust upon the parent’s death will be included in the parent’s gross estate for federal estate tax purposes.
- Revocable inter vivos trust — There is no gift upon establishment of the trust for the child because the parent can revoke the trust and take back the trust property. Upon the parent’s death the property in the trust is included in the parent’s gross estate for federal estate tax purposes. This would include any life insurance death proceeds on policies held by the trust on the parent’s life.
- Irrevocable trust — This provides the opportunity to avoid gift and estate taxes on transfers of property to the trust by the parents. Gift tax may be avoided by utilizing the parent’s \$15,000 annual gift tax exclusion and \$11,180,000 gift tax applicable exclusion (Double these figures where both parents contribute to the trust.) Further, since the trust owns the property at the parent’s death it is not included in the parent’s gross estate for federal estate tax purposes. This is critical where life insurance is held by the trust on the parent’s life since a large amount of insurance can be purchased for a relatively small premium.

A properly drafted trust, often referred to as a “special needs” trust, may be used to meet the child’s needs without causing the loss of government benefits or incurring the obligation to reimburse the government for benefits paid. This may be accomplished by including language in the trust that subjects any payments for the child’s benefit to the trustee’s sole discretion. (This is called a “discretionary trust”.) In effect, the objective is to cause the trust assets to not be considered available to the child by giving the trustee the absolute discretion to pay or not pay amounts for the child’s benefit. It is crucial that the special needs child not be given any right to receive trust income or principal. The reason is that if the child is deemed to

have a right to receive benefits the government will step into the child's shoes and take those amounts to reimburse it for services or expenses incurred on the child's behalf. It is critical that the family's legal counsel review the applicable state's law and draft the trust with a view to preventing any interpretation of the instrument that could be deemed to give the child a right to payment of income or principal. Whether or not this can be done will depend upon state law. Legal counsel will have to check the most recent cases and rulings to determine the viability of this approach.

Funding the special needs discretionary trust

Life insurance is an ideal vehicle to fund a special needs trust. This is because the death proceeds become immediately available exactly when they are needed, at the deaths of the parents. In that respect, the parents can choose to fund the trust with a second to die policy which pays a death benefit on the death of the second parent to die. In addition, such policies are more affordable since the insurance company does not have to pay until the second death. The amount of the death benefit can be guaranteed with certain types of policies. This means that life insurance provides the proceeds exactly when they are needed and in a guaranteed amount.

Type of policy – Generally the policy selected should provide level premiums, increasing cash values and contain provisions that will sustain the policy in the face of the parents' inability to pay premiums because of disability and old age. In this respect, whole life and universal life type policies can provide increasing cash values to maintain the policy during the parents' old age and a waiver of premium provision can cover the parent's disability.



¹ I.R.C. § 212

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Letter of intent

In addition to setting up a life insurance funded special needs trust, parents need to create a "letter of intent" to guide the special needs child's caregivers and guardians after the parents are gone. This should cover the child's medical history, daily care requirements and personal preferences. This document can play a critical role in the child's quality of life. It should be updated periodically such as on the child's birthday. Examples of points to be covered are:

Medical history

- Who are the child's doctors?
- What medications is the child taking?
- Does the child have any drug reactions?
- Does the child have any allergies?

Personal preferences

- What are the child's strengths and weaknesses?
- What is the child's education and work history?
- What is the child's religion?
- Who are the child's friends and who are the people that they like and dislike?
- What goals would the parents like the child to attain?
- What does the child enjoy doing?

Daily care

- Where would the parents like the child to live after they are gone?
- What kind of clothing does the child wear and what are the child's sizes?
- What personal care matters can the child attend to?
- What personal care matters does the child need assistance with?