

# Planning for Families of Children with Disabilities

by Minoti Rajput, CFP

For parents of dependent children with disabilities, the importance of proper financial and estate planning is far more significant than merely attempting to limit the dollars owed to Uncle Sam. Many of these young and adult-age children are incapable of caring for themselves; their future quality of life depends on their parents' abilities and desires to structure a plan to meet their needs. Unfortunately, too few professionals are well-versed in this highly specialized practice. The results of an improperly designed plan can be devastating for beneficiary children with disabilities.

This article focuses on financial and estate planning techniques for parents of dependant children with disabilities. It defines and differentiates between the special needs of these individuals and applies the rules that govern Medicaid and other governmental programs as well as income and estate tax considerations.

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While most financial professionals are knowledgeable about the important issues related to financial, retirement and estate planning, unique situations occasionally arise in which the standard practices simply do not apply. Certain segments of the population require professionals who have the comprehensive knowledge and experience to understand the complexities associated with highly specialized financial planning. Families of children with disabilities is one such population with many unique challenges.

Because of medical advancements, many of these individuals have longer life expectancies than in years past. Further, more are living with their families in their own communities, as opposed to being placed in institutions. Statistics are incomplete, but it is known that a large number of children with disabilities are not capable of supporting themselves and live in their parents' home well into adulthood and throughout their lives. Often, they rely on government benefits to meet their day-to day existence. Some are able to hold jobs and earn modest livings, yet are not independent enough to be on their own. Numerous financial and general support issues arise once the parents pass away or are no longer able to properly care for their children. For these and other reasons, financial planners are required to pay more attention to the special needs of this population when devising the most appropriate strategies for their families. Parents of children with disabilities benefit from the services and advice of a highly trained financial planning specialist.

## The Need for Planning

Planners must recognize that for parents of children with disabilities, financial planning is not an option; it is a necessity. Quality of life for these children in the future will depend upon the ability and willingness of their parents to perform proper planning today. Even though these parents typically realize its importance, there are a few reasons why they may fail to plan appropriately and in a timely manner.

1. Too many parents simply wait to initiate a well-designed program until later in life, when it may be too late to make many crucial decisions on their child's behalf.
2. Most of these parents are incredibly busy and fatigued from the day-to-day dealings with an adult-age child with disabilities, while still looking after other children and facing their own personal needs. They do not have the time to properly address these issues.
3. The professionals who specialize in this important area are scarce; most parents of children with disabilities do not know where or how to find them.

Planning for special-needs children should be coordinated directly with the parents' personal financial and estate planning needs. Professionals who work with these families must be knowledgeable about various disabilities and understand the government programs and the eligibility requirements in order to best apply retirement/estate planning techniques on their behalf. While specialists should educate the parents about the basics of investments, insurance and the tax consequences involved, they also should explain how the children will be affected by each of the planning

decisions. Bear in mind that tax rules are quite complex when intertwined with the regulations that govern Medicaid, Medicare and other benefits that many of these individuals receive.

## Disabilities Defined

Although physical disabilities certainly impair an individual's quality of life, not every such disability requires special-needs planning. Some physically challenged individuals are able to hold quality jobs and earn attractive incomes despite their disabilities. On the other hand, families of individuals with mental disabilities would almost always be well served with special-needs planning.

There are two types of mental disabilities that affect individuals' lives to varying degrees. The first type is developmental; many of these children are born with ailments such as mental retardation, autism, Down's syndrome, William syndrome and fragile X and begin showing symptoms within the first few years of life. The second type of mental disability is mental illness. Schizophrenia, manic depressive and schizo-affective disorders are examples of mental illnesses. Individuals with mental illnesses are often quite bright, but unable to function in a normal environment. These situations are not easily identifiable early in life, but often surface in an individual's twenties or thirties. Because these symptoms do not occur until later in life, planning for this population is far more challenging than for individuals with developmental disabilities.

To plan for the future, parents and their financial planners need to understand the specific characteristics of these disabilities and their child's ability to function in the future. In some states, the special education program within the school system categorizes its students based on their abilities to perform certain tasks. Thus, the specialized planners can take into account the children's individual needs as they begin their long-term planning process.

As mentioned earlier, individuals who suffer from any of these disabilities often have normal life expectancies. While they bring much joy and love into the family environment, they also carry substantial burdens of time and financial commitments. It is not uncommon for mentally handicapped individuals to be stricken with additional health problems. Some may experience seizure disorders, suffer from cerebral palsy, or possess other physical limitations. They may require significant medications and treatments that typically are very expensive. Additionally, parents often need to hire a trained advocate to assist in their everyday care.

## Basic Planning Considerations

Planners should guide parents of children with disabilities through the same process as everyone else when initially devising a financial plan. They should take an inventory of their current assets and liabilities, as well as the growth expectations to determine the size of their future estates. They should calculate their retirement needs to ensure that they can continue to live in the manner to which they have grown accustomed. They should consider the future security of a surviving spouse should the primary wage earner meet with an untimely death. They should plan for their other children's education and other expenses that will be incurred in the future. While analyzing these situations, they should review investment and insurance options that will be used to fund their specific needs.

In addition to the standard planning considerations, planners and parents must also carefully analyze the special needs and requirements of the child with disability.

The following questions should serve as a starting point for any discussion between financial planners and parents of children with disabilities:

- What is the child's age and the nature of the disability?
- How long is his or her life expectancy?
- Where will the child reside throughout his or her lifetime (today and after the parents have passed away)?
- Does the nature of the disability require the child to live in a group home or place where special care can more adequately be provided?
- What is his or her earnings potential and ability to survive without ongoing care and supervision?
- What are the major expenses today and how will they change in the future?
- How will the future care of other children and the retirement plans of parents be affected?
- How can it be ensured that the child will remain eligible for government benefits?

- What existing retirement and estate planning strategies have already been devised for the parents?
- Are there other family members who can help provide for this child today and once the parents have passed away?

When determining these special planning needs, the parents should always assume the worst-case scenario and plan accordingly. Assume the child will have a normal life expectancy and will not be able to look out for himself or herself in the future. If the situation does not turn out to be as dire, the child will be that much better off if the proper precautionary plans are in place.

Such special-needs planning should always be coordinated simultaneously with the family's normal financial planning. While it is always difficult to anticipate retirement needs of the parents and the ultimate size of the estate, it is vitally important to attempt to do so when the future of a child with disability is at stake. Assets that may be left to this child need to be identified early to ensure that they will grow and can be used for financial support in the future.

## **Government Assistance Programs**

All financial planners who work with parents of children with disabilities must possess a thorough understanding of the complex eligibility requirements for the various federal and state-run governmental programs. Knowledge of these programs and their benefits is absolutely essential when developing strategies to meet the special needs of individuals with disabilities. If not followed to the letter of the law, the children could be ineligible for future benefits that may be of great importance. These programs should be addressed at the very beginning of the planning process.

Many individuals with disabilities may be eligible for Supplemental Security Income (SSI), which consists of federal funds managed and operated by the Social Security Administrations of the respective state governments. These SSI benefits are entirely need-based (welfare); children with disabilities become eligible after their 18th birthday unless their parents' assets and incomes are below certain levels. In such cases, they can be eligible at any age. SSI consists of a monthly income and is accompanied by Medicaid. This income varies depending upon where the child lives. It can be reduced if the child lives in a place funded by state or federal government, such as a group home.

In general, Medicaid is a need-based government program that benefits the elderly, blind, disabled and poor. It represents a partnership between state and federal governments that have their own eligibility standards. Medicaid provides for various medical benefits, including medication and other key benefits such as group homes, workshops, training programs and transportation that disabled individuals (or their support group) may find helpful. Since it is very difficult and expensive to obtain health insurance for a child with a disability, Medicaid is often considered the most important government benefit.

SSI and Medicaid benefits are not entitlements for everyone; all recipients must meet certain eligibility requirements with regard to assets and income. For example, to be eligible, the individuals cannot own more than a certain amount of assets in their own names (currently no more than \$2,000 in cash and other countable assets for an unmarried individual). If they are employed, their compensation level must be below a certain dollar amount. They can own a burial plot, prepaid funeral expenses and life insurance with very low limits. Personal residences (homes) and cars are considered exempt assets for SSI purposes.

Upon the retirement, death or disability of their parents, individuals previously receiving SSI often begin receiving, as a dependent, different benefits such as Social Security Survivor or Disability (SSDI). These are non-need based benefits. SSDI and survivor benefits are funded by the federal government through the FICA taxes. Payments are based on the Social Security taxes the parents have paid into the system over the years. SSDI is available along with Medicare, which covers hospitalization. These benefits may not have asset requirements for eligibility. However, since Medicare alone will not be sufficient and Medicaid is a very important benefit, the individual with disability may still need to stay at or below the asset level required by SSI in order to continue receiving Medicaid. Children with disabilities also may be eligible for other government benefits programs such as food stamps, veterans benefits and housing assistance as made available by the U.S. Department of Housing and Urban Development (HUD).

Although all of these government benefits are extremely important, they may still not be enough to provide a quality of life that the parents desire for their children with disabilities. Therefore, additional planning is absolutely essential.

The strict eligibility requirements often impede the ability of the child with disability to hold a good job and contribute to society. The Ticket to Work and Work Incentives Improvement Act of 1999 was initiated to allow such individuals to secure employment without loss of all of their government benefits. The act expanded the availability of health care coverage for individuals with disabilities who desire and are able to enter the workforce. It enabled such individuals to obtain employment services, vocational rehabilitation and other related support services and eliminated certain work disincentives that prevented them from holding jobs. Through such programs, these individuals with disabilities develop a sense of self-esteem and feel good about the contributions they make.

If parents choose to ignore eligibility requirements and provide additional income and assets to their children with disabilities, the government benefits will be lost. Even well-to-do parents should not disregard these requirements. Though the financial aspects may not be of great concern to them, their children can certainly benefit from government-funded training workshops and the opportunities to work and interact with others.

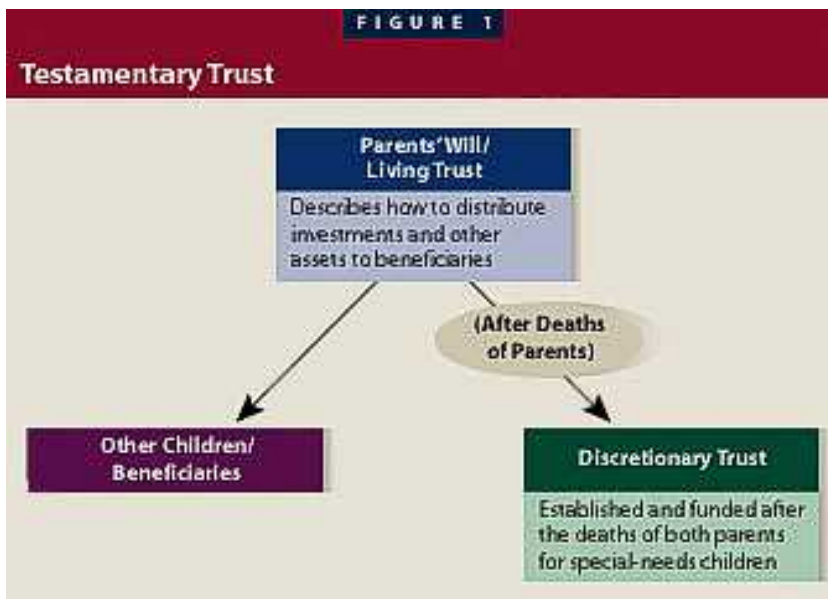
## **Implementing a Plan for the Child with a Disability**

Once the planners and parents have discussed the benefits of the important government programs and have addressed the pertinent questions about the nature of the disability as described above, they are ready to begin developing an appropriate plan. Bear in mind, as all financial planners know, there typically are several alternative strategies that may work for a certain client. Professionals often differ in their assessments of the situations and the plans they implement. As such, the information and strategies that are defined below represent one approach based on the knowledge and experiences of a planner who specializes in working with families of children with disabilities.

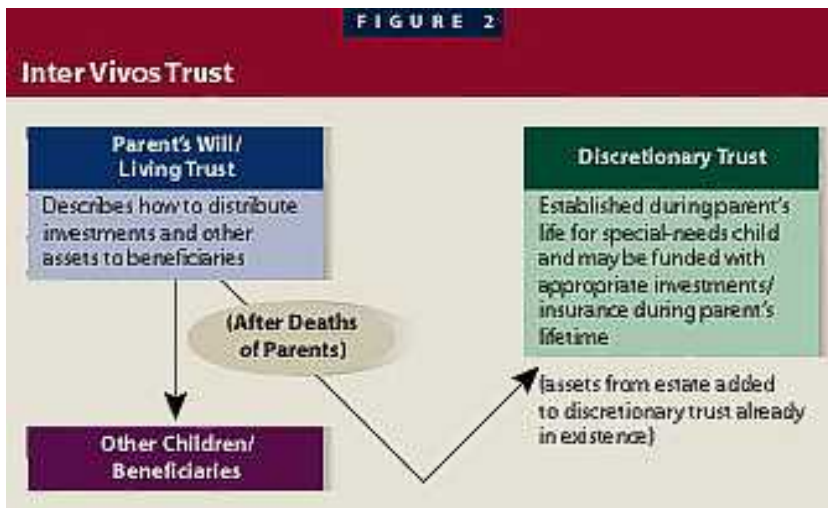
In a traditional financial planning program, planners and parents discuss not only future retirement needs but also estate matters to ensure that beneficiaries are well provided for in the most tax-efficient manner. During their lifetimes, most parents complete wills and other legal documents that describe how their assets are to be divided upon their deaths. Typically, their children are the primary beneficiaries of these accumulated assets. Often irrevocable trusts and other vehicles are used to reduce the tax liability.

Parents of children with disabilities are often best served by creating "special needs" or "discretionary" trusts for the benefit of these children. These trusts are used because the children have limited assets to remain eligible for government benefits. The language of the trust is extremely important to ensure that future benefits are not lost or reduced. The wording usually states that at the discretion of the trustee, such income and principal of the trust will be used "to supplement but not supplant government funds." While the government assumes responsibility for basic support and maintenance (food, clothing, shelter), the trust income and principal are used to "enhance the quality of life" of the child with disability. It can assist with all things that the government does not provide such as travel, training and therapy. It can pay to hire an advocate to assist in the care of the child. Medical expenses not covered by Medicaid are normally paid out of this trust.

Parents often create a discretionary trust that comes into existence after the demise of both through their wills or living trusts (see Figure 1).



Although the trust reviewed in Figure 1 is appropriate from a legal standpoint, it creates some difficulties in coordination with the family's overall financial planning. The discretionary trust can only be funded following the death of both parents using a portion of the family's remaining estate. A discretionary trust created in this manner does not allow for funding during the parents' lifetime to provide financial guarantee. This trust may not allow for allocation of an asset for funding purposes nor provide for financial guarantee. It is often difficult to coordinate this type of trust with the legal documents of other family members, such as grandparents, who may wish to contribute to the care and future well-being of an individual with a disability. Creating a separate "living" discretionary trust helps resolve many of these issues (see Figure 2).



Parents of children with disabilities may benefit from establishing and funding this discretionary trust as a separate entity during their lifetimes. It should be coordinated with their other legal documents (such as wills), as well as those of grandparents and other relatives who wish to provide assets for the future care of the child with disability. Parents can start funding the trust during their lifetimes or can identify assets that could fund the trust upon their deaths; this should bring them peace of mind in knowing that assets will be available for their loved ones.

**Structuring the discretionary trust.** When establishing the discretionary trust, the parents of children with disabilities must decide whether it should be revocable or irrevocable. A revocable trust is quite flexible; major changes regarding

trustees, beneficiary (after the child's death), funding and others can be made throughout the parents' lifetime. However, since the parents remain in complete control of this trust, it is deemed to be an extension of their estate and the assets will be taxable at the time of death if the estate exceeds the exempt amount (\$1 million in 2002). The income is taxed to the grantor(s). Additionally, the assets within a revocable trust will not be immune to any judgments against them—for example, business failures, or malpractice/liability litigation.

On the other hand, an irrevocable trust is inflexible because parents cannot subsequently change any of the pre-determined terms unless they receive approval from the probate court. Since they have no control, the assets within this trust will not be considered part of the parent's estate for tax purposes, though transfers will usually have to be reported. In both cases, the child's government benefits will not be affected since the child is not the direct recipient of any assets.

In deciding about the type of trust, planners should allow the parents to choose between two important factors: the flexibility to change the terms versus the tax implications down the road. If they are not concerned about estate tax planning, the revocable trust may make the most sense. However, if they are likely to incur such estate tax liabilities, they may wish to keep these assets out of their estate by using an irrevocable trust. The ages of the parents and the child are important considerations when making this crucial decision. If the parents are relatively young, they need to realize that changes to the terms may be required in the future. For example, trustees named today may become unsuitable down the road. (See Table 1.)

Type of Discretionary Trust	Considerations
Revocable	Flexibility and control
	Extension of estate (taxable)
	Trust income taxed to grantor
Irrevocable	Lack of control in ability to make changes
	Not taxable as part of estate
	Trust income may be taxed at the trust rate to the extent it is not distributed for the benefit of the beneficiary

**Structure example.** A couple in their late forties has combined assets of \$2.5 million. They have a 19-year-old son who was born nondisabled and was going to college when he was involved in a diving accident that left him completely paralyzed. Though he will never regain any use of his limbs, he should have a normal life expectancy. The parents are establishing a living discretionary trust for the benefit of this child with a disability. They have decided to create it now because the grandparents also wish to leave some of their assets at their deaths to help support the child.

The parents would like to have the flexibility to make changes to the trust as the years pass and situations change. However, should they create a revocable trust, the assets within it will be considered an extension of their estate and will be subject to significant tax liabilities at the time of their deaths. Therefore, the parents may consider establishing an irrevocable trust and leave it unfunded for now. Because of their secure financial situations, availability of funds at both parents' deaths should not be a major concern. They may even choose to buy a condo for their child's future benefit and include that with the trust as well. Since they are relatively young, they can hold off on some of these decisions for a few years. However, the concerns about estate tax consequences are remedied through the creation of such an irrevocable trust. Additionally, any assets received in this irrevocable trust from the grandparents will not be included in the parents' estate for estate tax purposes.

## Additional Tax Considerations

**Irrevocable trusts.** As just mentioned, if the trust is revocable, all of the assets within it are considered part of the parents' estates for estate tax calculations. Since they have complete control over the trusts and all related decisions, the assets are essentially an extension of their estates and will follow their parent's applicable tax brackets for both

income and estate tax purposes.

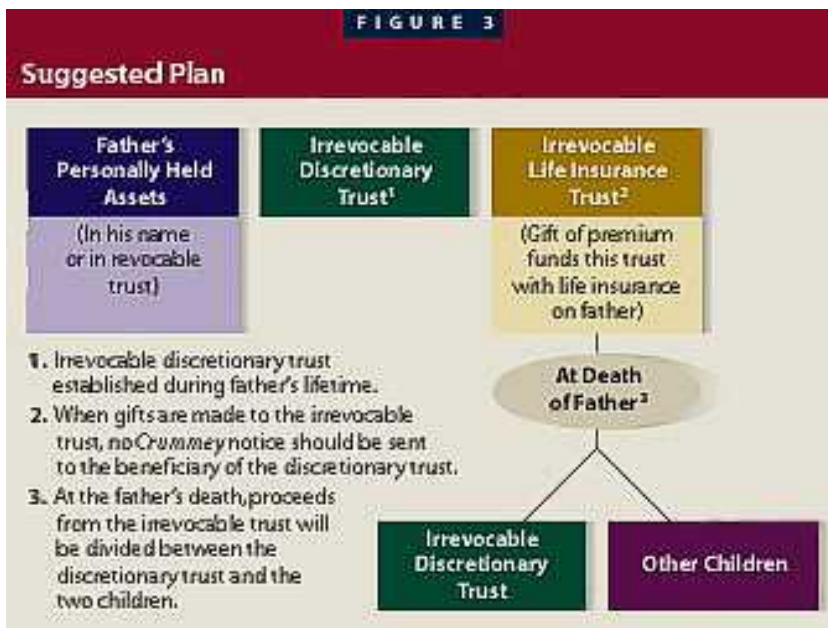
An irrevocable discretionary trust allows the parents to fund the trust and keep the assets out of the estate for estate tax purposes. Caution should always be used in devising funding strategies with an irrevocable trust. This trust is a separate tax-paying entity and must file a tax return depending upon the funding vehicle chosen. (A trust funded with life insurance and annuities may not have to file a tax return.) The trust also reaches the highest tax bracket with only \$8,650 of annual ordinary income. Trusts funded with standard stocks, bonds and mutual funds face the dilemma of filing returns each year and being subject to the higher tax brackets, except to the extent income is distributed for the benefit of the beneficiary. For these reasons, life insurance often makes an attractive funding vehicle (see "Funding the Discretionary Trust").

**Gifting considerations.** There are some standard tax planning strategies that may not be applicable for an individual with a disability. Gifts given to the beneficiary of an irrevocable trust must represent a present-value interest to qualify for the annual exclusion. *Crummey* notices are normally sent to the beneficiaries by the trustee that give them the option to use the gift if they choose. This procedure makes a future interest gift become a present interest and allows them to receive the annual exclusion.

When individuals with disabilities who receive SSI and Medicaid benefits are given such an option to use the gift, they are treated as owners of the assets (for example, \$10,000 subject to the withdrawal power) as long as they have the power—even if they do not use it. This withdrawal power, used or unused, makes them ineligible for government benefits. Moreover, lapse of the power may be treated as a "transfer" by the beneficiary, creating an additional period of ineligibility. Therefore, it is safer to fund an irrevocable trust without giving a *Crummey* notice to a disabled beneficiary and have the parents use their unified credit instead.

**Gifting example.** A father would like to purchase an insurance policy within an irrevocable life insurance trust for the benefit of his three children. One child has a disability and receives SSI and Medicaid benefits. The father has created an irrevocable special-needs trust for that child. The father plans to make an annual gift of \$10,000 to each of them, which will be used to pay the premium of the policy. Rather than gift those funds directly to the child with a disability, the gift is made to the special-needs trust. He sends the appropriate *Crummey* letter to two of his children and is not required to pay any gift tax on those amounts. The \$10,000 paid to the special needs trust and that applies to the child with a disability will either be subject to gift tax or will go against the father's lifetime exemption (unified credit). (See Table 2 and Figure 3.)

Child	Gift	<i>Crummey</i>	Gift Status	Tax Issues	SSI/ Medicaid
1	\$10,000	Yes	Present value	No gift tax	N/A
2	\$10,000	Yes	Present value	No gift tax	N/A
3 (irrevocable special needs trust)	\$10,000	No	Future value	Gift tax or apply against unified credit	Yes



Because that child never received a *Crummey* notice, he essentially did not receive a present-value gift. The insurance premium merely represents a future-value gift if the letter was not sent. Therefore, the annual exclusion does not apply and eligibility benefits from SSI and Medicaid are not affected with this gift.

## Future Care of Parents

Many of the examples described so far assume that the parents of children with disabilities have sufficient assets to fund these discretionary trusts and effectively provide for themselves and their children's well-being. Unfortunately, many parents who face these difficult times do not have the resources to care for themselves in their aging years, while tending to their children's needs. Often, they encounter situations where they must be moved to a nursing home or assisted-living facility and are forced to choose between their own needs and those of their child with disability. Without other relatives to provide the support, parents struggle with these excruciating decisions.

Nursing homes can be quite expensive and quickly cut into the financial resources available to the resident. Medicaid covers such expenses if individuals are unable to pay themselves. In anticipation of such a situation, a parent sometimes chooses to give (through gifting or other vehicles) his or her money to a healthy child who is a sibling of the child with disability. Once the parent enters the care facility, this sibling will be expected to provide the financial support for the special-needs child.

However, in order to access the Medicaid on behalf of this resident, the Medicaid program will review the assets owned or gifted by the individual 36 months before entering the facility. Any assets gifted during that prior 36-month period may need to be used to pay for the nursing home care. Thus, a 36-month look-back is applied and the parent's Medicaid benefits will be affected if the funds had been transferred during this time frame. (The look-back period becomes 60 months when assets are transferred or gifted to an irrevocable trust, or to or from a revocable trust.)

**Nursing home example.** A 72-year-old widow lived with her child with disability. Her husband had just died of Parkinson's disease and had lived in a nursing home for a few months. The mother realized how expensive that stay was and was quite concerned that she would not have adequate funds to pay the home while also supporting her child. Her healthy daughter was worried that she would ultimately become financially responsible for her brother's well-being. She did not have the finances and did not believe she was equipped to deal with his mental illness.

The mother decided to give \$72,000 to her daughter so that those funds were out of her name. That money represents the only other asset she owns in addition to her personal residence. One year after she distributed these funds, the mother was moved to a nursing home and claimed that she had no money to pay the monthly \$3,000 rate and instead must rely on Medicaid. Once the 36-month look-back was applied, it was determined that she had such

funds just 12 months ago. By transferring the funds, she had created a period of ineligibility, which in her state of domicile equaled 12 months. (At a rate of \$3,000 or the average monthly cost in the state she resides, the \$72,000 that was transferred would have covered her for two years.) Thus, the mother will be ineligible for another 12 months. The care of the disabled brother will now be greatly diminished because half the money will have to be used for the mother's care.

## OBRA '93

The Omnibus Budget Reconciliation Act of 1993 included significant changes to the financial eligibility rules for Medicaid. The following (d)(4)(A)—Exception A Trust and (d)(4)(C)—Exception C Trust are examples of these changes.

**(d)(4)(A) (OBRA '93) trust.** A (d)(4)(A) trust can be created to help parents cope with these dire situations such as in the previous nursing home example. This discretionary trust has special language written into it that allows a parent to fund it even while he or she is entering a nursing home. Often, the trust is created in anticipation of such unforeseen problems and is left empty so the parent of a child with a disability does not lose any control of the finances until the last possible minute. The individual with disability who will benefit from this trust must be under 65 years old. The funds transferred into a (d)(4)(A) trust will not be subject to any look-back period. Another family member is given a durable power of attorney with gifting provisions for financial purposes and can transfer the assets into the fund as the relative prepares to enter the home. In fact, by setting up such a trust, no one's government benefits will be affected. Medicaid will pay for the parent's nursing home; the child with disability still will receive government benefits since he or she has not directly received any assets. At the time of the child with disability's death, the state will be able to recover the remaining money in the trust (if any) to the extent of the cost of Medicaid benefits of the child.

(d)(4)(A) trusts can be established by parents, guardians, grandparents or the courts for the benefit of a child with disability under the age of 65. Additionally, if the child inherits funds or receives funds as a result of an accident or judgment in a malpractice lawsuit, he or she can fund a (d)(4)(A) trust at that time and still remain eligible for government benefits.

**(d)(4)(A) example.** In the same example above, the mother establishes a (d)(4)(A) trust for fear that she may one day be required to enter a home. The trust is left empty until such time. Her daughter maintains a durable power of attorney with gifting provisions over the finances. Once it has been determined that the mother must enter a nursing home, the \$72,000 is immediately transferred into the trust.

Since the transfer penalty does not apply, the mother receives full Medicaid benefits to cover the cost of the nursing home. The son is not disqualified from benefits because the money went into a trust. Upon his death, the moneys that remain in the trust will be subject to recovery by the state (see Table 3).

Description	Traditional Fund Transfer	(d)(4)(A) Trust
Look-back	Subject to 36-month look-back, or 60 months for transfer to a trust	No look-back
Medicaid	Possible loss of some Medicaid benefits	Retains Medicaid benefits
Use of Funds	Pay the nursing home	Enhance the quality of life of the child; subject to state recovery if funds remain

**(d)(4)(C) (OBRA '93) trust.** An Exception C trust is also known as the pooled account trust. (d)(4)(C) allows the disabled individual's assets to be transferred into a special needs trust that is established and managed by a nonprofit organization. Although separate accounts are maintained for each individual with a disability, for purpose of investment and management of funds the trust pools them all together. The trust can be established by parents,

grandparents, guardians or by the court for the individual with a disability. Upon the death of that individual, the remaining assets in the account are subject to state recovery unless used by the trust for other individuals with disabilities.

Unlike Exception C trusts, pooled income funds have been in existence for some time. These funds provide income for life for their beneficiaries while the nonprofit institutions themselves retain the principal contributed by the beneficiaries.

An Exception C trust is a great alternative to the Exception A trust. It is very helpful for families with small to mid-sized estates. It is also helpful for families that have no available trustees, have a family member with a disability who needs to create his or her own trust to save more than \$2,000 in non-exempt assets and for family members who wish to use the OBRA '93 exception transfer rule to qualify for Medicaid or their own long-term care needs.

In addition to (d)(4)(A) and (d)(4)(C) trusts, third-party disability trusts can be created by the relatives of an individual with a disability under age 65 as long as the trust is designed solely for the benefit of that individual. There can be no other beneficiary named in the trust; the spending of the trust funds must be based on the life expectancy of the individual with disability.

## Funding the Discretionary Trust

Financial planners generally are well versed in the nuances of investment and insurance products. Funding a discretionary trust, however, should not depend entirely on the performance characteristics of stocks, mutual funds or any other alternatives. These decisions require a thorough analysis of many factors: the parents' financial ability to fund the trust, the needs of those funds for the benefit of the child during the parents' lifetime and following their deaths, the revocable or irrevocable nature of the trust, the income tax consequences of the investments or other products, and the need for administrative ease in managing the funds.

Although the family may use any investment/insurance products they choose, the following are some important considerations that may be helpful in making the funding decisions. Note that some of the information below has been discussed in earlier sections of this article, but is being repeated here because it represents appropriate considerations in funding matters.

1. Investments such as mutual funds, stocks, bonds and other securities that are owned in a revocable discretionary trust are deemed to be an extension of the grantor's estate and, thus, are subject to income taxes at his or her tax bracket. Such securities are also subject to attachment by creditors. Unless supplemented with some form of life insurance, the investments alone may take a long time to appreciate or accumulate to the amount that will be required for the future care of the individual with a disability. If the parents die early, they may have not saved or earned enough through the chosen investment vehicles.
2. An irrevocable trust allows investments and other assets to remain outside of the grantor's estate. On the other hand, the irrevocable trust is considered a separate taxable entity and is required to file an annual income tax return. These trusts also reach the highest tax bracket for a much smaller amount of income.
3. Both fixed and variable annuities are popular investment choices for families with significant assets available to fund an irrevocable discretionary trust. Due to the tax-deferred nature of the products, the trust is not required to file income tax returns until distributions are taken from the annuity. However, a disadvantage of the annuity arises upon the death of the annuitant (usually a parent). Typically the entire amount of any gain on the investment is taxed at the ordinary income rate of the irrevocable trust.
4. Life insurance has proved to be the most efficient and cost-effective vehicle for funding a discretionary trust. Insurance within an irrevocable trust provides assurance of funds availability irrespective of the parents' untimely deaths or their living beyond normal life expectancy. The type of life insurance (term versus permanent, separate or second-to-die policies) would depend on many factors as determined by the financial analysis done by the planner. If the financial planner has already planned for the financial security of the surviving spouse at the death of the primary wage earner, then the need for funds for the special needs child would arise only after both parents' deaths. In this situation, the second-to-die policy may be most appropriate. The decision to use a universal life, variable universal life, or a whole life policy (either in a single life or second-to-die policy) will depend upon the comfort level of the insured and the cost of the policy.

Planners realize that, at the time of death, life insurance creates an immediate estate when used to fund a trust. There are a few other considerations with regard to life insurance as the vehicle of choice. Its use does not necessitate the filing of an annual income tax return and the proceeds of the insurance policy are distributed income-tax-free. Further, life insurance held in an irrevocable trust is also estate tax free.

Investment strategies used in a discretionary trust may change after the parents pass away. At this time, the death proceeds of the life insurance (or annuity) or other large assets will need to be invested in order to receive adequate income to provide supplemental needs to the special-needs individual.

When arranging for distributions, financial planners must carefully evaluate the current needs of the beneficiary with a disability as well as his or her need to conserve assets for the future. Income taxes are also important considerations because any amount that is not used for expenses or distributions will be subject to taxes at the higher irrevocable trust rates. Planners must be aware of the importance of the growth potential of the assets within the trust. Today, many of these individuals with disabilities are living longer and have increasing needs throughout their lives; any possibility of depletion of the value of the investments and other assets must be avoided.

## Other Issues Regarding Ongoing and Future Care

**Letters of intent.** Financial planners should always advise and assist their clients who have children with disabilities in composing a written "letter of intent" that details all of the appropriate needs and care instructions required by the special needs child. While legal documents such as wills and powers of attorney are necessary to ensure that the child's affairs are handled in the most effective and efficient manner, the letter of intent communicates crucial information to all parties who may assume some responsibility for the child both during their parents' lives and following their deaths.

The letter of intent should list names, addresses and phone numbers of family members, medical professionals and legal representatives. It should detail the mental or physical disabilities that affect the child's well-being, as well as a descriptive history of the child's family life and past and current living arrangements. There should be a section about financial information that describes jobs held, assets owned and government benefits received (that could be affected if financial situations are changed). The parents also should detail relevant personal information about the child, including likes and dislikes, entertainment choices, dietary needs, other medical issues and even religious affiliations. The letter should address legal issues such as guardianship, appointment of trustees, and the existence of wills, powers of attorneys and other important documents.

By creating a letter of intent and updating it periodically, parents can help ensure that their child with a disability is able to continue living the same quality of life to which he or she is accustomed. This is an invaluable service offered by the planner as it helps give the parents peace of mind in knowing they have done everything possible to provide for their children even after they have both passed away.

**Guardianship/conservatorship.** A guardian is an individual who has been appointed by a court to make financial, health care and other personal decisions for another who has been deemed to be by the appropriate court mentally incapacitated. Since there is no federal statute related to this issue, state laws determine when someone can be declared incompetent and in need of a guardian. All 50 states and the District of Columbia allow the court to order a guardian for individuals with limited mental capacity (which is defined differently from one state to another). Guardianship is a court appointment and does require periodic renewals.

A "guardian of the estate" is defined as a court-appointed individual who makes financial decisions on behalf of another individual who is unable to effectively manage his or her property and other affairs. Some states use the term "conservatorship" in lieu of guardian of the estate. If the parents are planning for their children with disabilities by using a discretionary trust and funds are handled for their benefits through this trust, then conservatorship will not become an issue.

In many cases, people are assumed to be incompetent merely because they have a disability. However, anyone who is older than the age of majority is considered to be legally competent unless a court of appropriate jurisdiction has determined otherwise (that they are incompetent). Often, individuals with disabilities are capable of holding jobs and

caring for themselves to some degree. Most parents are sensitive about becoming guardians of an adult child because the designation can be positioned as a means to take away all rights of the individual. Financial planners who work with families of individuals with disabilities may wish to suggest to them ways to ensure that the guardianship, if appointed, does not totally diminish the individual's independence and self-confidence. Planners, with the help of attorneys who also work with these families, may wish to educate them about how to determine the ability of the child and perhaps consider getting a limited or partial guardianship that allows parents to make decisions on medical, education and housing matters.

## Financial Planning Revisited

As more and more professionals enter the world of financial planning, many will encounter working with families of children with disabilities. The issues are complex, the government regulations are confusing, the options are many. However, the needs of these individuals and their families are so very important. Many children with disabilities rely on their parents for their day-to-day existence and complete financial support. One day, the parents will no longer be there to offer such assistance. When that time comes, these children will be dependent on whatever finances and other means of support have been provided through wills and trusts.

Financial professionals must assume a leading role in helping their clients make these vital decisions that affect their children's future. Such a role may not be as glamorous as helping a wealthy baby boomer retire in complete comfort without a financial care in the world. But it is far more rewarding.

## References

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