

Special Needs Estate Planning— Seven Overlooked Challenges

by Harry L. Ehrenberg, CLU

ABSTRACT

Parents of children with special needs face seven estate planning challenges unique to their situation. This article will address those challenges as well as provide planning tips.

Bob and Alice are 47 and 45 years old, respectively. They are interviewing a prospective financial advisor. Their net worth is about \$750,000. They remark that they have an 18-year-old son on Supplemental Security Income (SSI) and Medicaid. The advisor's initial reaction is "On what?" Discretion being the better part of valor, she informs them that she is not familiar with those programs. They explain to her that their son has a disability and will never be able to hold a job. He receives a disability income benefit from a government program called SSI. Additionally, his medical expenses are paid for by a program called Medicaid. If they were to die and leave him more than \$2,000, he would become ineligible for those programs. It is important for him to maintain his eligibility because the present value of his future health care benefit is \$2,500,000. They are looking to the advisor for advice.

Most financial advisors are not conversant with SSI or Medicaid unless they are the parent of a child with a disability. The purpose of this article is to help financial professionals navigate what for many are uncharted waters.

A few comments are in order before beginning. Parents of a child with a disability lead very chaotic lives. They encounter a great deal of frustration attempting to learn what government benefits their child is eligible for and finding organizations that can provide services for their child. They have had

Vol. 73, No. 5 | pp. 56-63

This issue of the Journal went to press in August 2019.
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to struggle to educate their child. For some, there is a concern that their child will end up in the criminal justice system. However, the greatest concerns that keep these parents awake at night are:

1. Who will take care of my child when I no longer can due to my death, disability, or old age?
2. How can I leave an inheritance to my child in a way that will enhance the quality of his or her life without disqualifying the child from government benefits?

The planning process for these parents presents seven challenges that are often overlooked because they are not fully understood.

The First Challenge: Understanding Government Benefits and How They Coordinate and Offset Each Other

Figure 1 will help illustrate the connections and differences between SSI, Medicaid, Social Security disabled child's benefit, and Medicare. Medicaid is a public assistance program which pays for medical expenses. It is often confused with Medicare, which is the federal health insurance program for people who are 65 or older and certain younger people with disabilities. Figure 1 compares government benefits.

The benefits in the left-hand column are Social Security disabled child's benefit and SSI. Both are designed to provide a disabled person with a monthly income. The right-hand column consists of Medicare and Medicaid, which are government programs that provide health coverage. Twenty-four months after a person qualifies for Social Security disabled child's benefit, he or she will become eligible for Medicare. However, the child is credited for the time he or she was on SSI. A person who qualifies for SSI is immediately eligible for Medicaid.¹ In both situations what happens in the left column controls what happens in the right column.

There is no financial needs test for Social Security disabled child's benefit. This benefit is for disabled children regardless of their age so long as their disability began before the age of 22 and they are single. The child becomes eligible for that benefit due to one

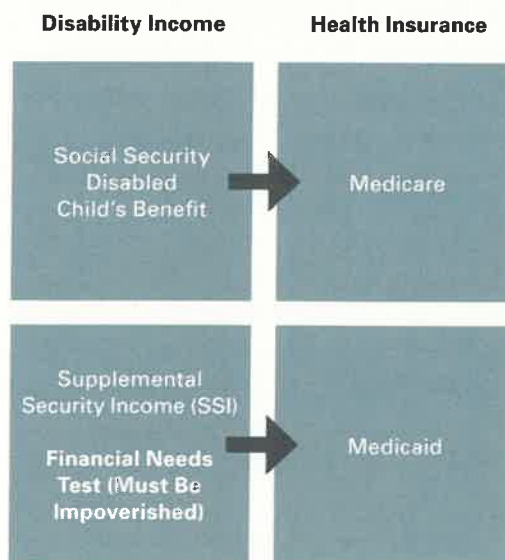
of the following three situations:

- If one of their parents who had worked and paid FICA dies; or,
- If one of their parents begins receiving Social Security disability income benefits; or,
- If one of their parents begins receiving Social Security retirement benefits.²

The Social Security disabled child's benefit is equal to half of the parent's Social Security benefit.

To qualify for SSI, a person must be disabled and must also be impoverished.³ A person will be considered impoverished if his/her assets are worth less than \$2,000 with the following exceptions: a house, a car, and a prepaid funeral. The state can set limits on those assets taking into consideration if they were purchased before or after the onset of the disability. Additionally, his/her monthly income is below the federal limit; for most states it is \$771 (2019). The monthly income amount is adjusted annually for inflation. If the child has no earned income they will receive \$771 per month SSI benefit in 2019.

FIGURE 1
Government Programs, Benefits



The purpose of the SSI payments is to cover the basic necessities of life: food, clothing, and shelter. It can be reduced if the child has other income or is deemed to have income. For example, this can occur when the child is living at home rent free. It is assumed that the value of the rent they are not paying is equal to one-third of their SSI; therefore, their SSI is reduced by one-third.

Planning Tip: Parents can charge their child rent to avoid the reduction of the SSI payment due to deemed income.

It is possible to qualify for both Social Security disabled child's benefit and SSI if the child's Social Security benefit is at least \$1 less than the maximum SSI benefit. For example, assume the following:

- The child's disability began before the age of 22;
- The child is currently receiving the maximum SSI monthly benefit of \$771;
- The child is not married;
- The parent becomes disabled tomorrow and starts drawing Social Security disability income benefits of \$800 a month.

Based on those assumptions, the child will be eligible for a \$400 per month Social Security benefit ($\$800/2$). In other words, the child is in the top left box. The child's SSI benefit will be reduced by the amount of his/her Social Security benefit. It will go from \$771 a month down to \$371 a month. The child is also in the lower left box. This means the child would receive SSDI and SSI as well as Medicare and Medicaid.

Now one assumption changes: The parent's disability benefit is \$2,400 a month. The child's Social Security disability benefit will be \$1,200 per month ($\$2,400/2$). How does that affect the child's SSI? The child would lose his or her eligibility for SSI because the child's Social Security benefit completely offsets the SSI income benefit. And, if the child loses SSI, Medicaid is also lost. The Pickle Amendment, named for its author, U.S. Congressman James Pickle, solved this problem. The child will need to reapply for Medicaid claiming the right to do so under the Pickle Amendment.⁴

Planning Tip: If a person loses their SSI eligibility due to qualifying for a Social Security

disabled child's benefit, they can have their Medicaid reinstated by requesting a reinstatement letter from their local Social Security office.

Planning Tip: Investigate Medicare Advantage plans for children who are on Medicare or on both Medicare and Medicaid. There are special plans that may provide additional benefits.

The Second Challenge: Understanding a Special Needs Trust

Creating and funding a special needs trust for the benefit of a disabled child is generally the best way to leave an inheritance or make a gift for the benefit of a special needs child and preserve the child's Medicaid eligibility. Transfers of property to the trust are not counted against the \$2,000 asset limit. The purpose of a special needs trust is to supplement, and not supplant, government benefits. The trust can pay for extraordinary items that SSI and Medicaid will not cover. For example, Medicaid does not pay for a tooth to be capped, it will only pay to have it extracted; however, the trust can pay to have the tooth capped. The trust can also pay to improve the disabled child's quality of life. For instance, if the child enjoys baseball games, the trust could pay for the expenses associated with taking the child to a game. If the child likes to play computer games the trust could purchase a computer and the games. It could also pay for modifications to their residence to make it more accommodating or pay for a limited amount of respite care for a family member who cares for the child.

Distributions from the trust are made at the absolute discretion of the trustee. The trust should not contain a provision requiring the trustee to distribute its investment income or a percentage of the assets to the beneficiary. Typically, the trust will contain a provision to defend the trust property from attachment by the state or other creditors.⁵

A trust funded by the parents, relatives, or anyone other than the disabled child is referred to as a third-party trust and a trust that is funded by the child's assets is called first-party or self-settled trust. Typically, the property used to fund a self-settled

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trust is a result of a gift to the child or the proceeds of a lawsuit in favor of the child; for example, a medical malpractice case. A self-settled trust must contain a provision to pay the state at the child's death for expenses paid by Medicaid. A third-party trust does not have a repayment provision and the parents can provide for the remainder interest to pass to the other children or family members. For a self-settled trust, the remainder interest must first be used to repay the state and if there are any funds left, those funds can pass to other family members as directed by the trust.

Planning Tip: Advisors should inform family members and friends who might be inclined to make a gift or leave an inheritance to the child about the third-party trust, thereby avoiding the establishment of a self-settled trust and the accompanying obligation to repay.

Decisions regarding the trust's creation should be made in conjunction with the parents' overall financial situation. For some parents, an inter vivos trust will be appropriate; for others a testamentary trust will be the preference.

An inter vivos trust has several advantages. Parents can have the trust pay supplemental expenses, thereby creating a record for future trustees to guide them in determining the appropriate assistance to provide the child. Also, a trust that is in existence can receive gifts from the child's family and friends without the gifts affecting the child's benefit eligibility.

Planning Tip: Recommendations regarding which type of trust is most appropriate as well as other legal issues are in the attorney's realm, not that of the financial advisor. The financial advisor should be careful not to practice law unless licensed to do so.

The parent who creates a special needs trust can serve as the trustee. If the parent serves, he or she should name a successor trustee. Many parents will initially serve as the trustee and name a corporate trustee as their successor. The advantage of using a corporate trustee is the assurance that the corpus will be properly invested. Corporate trustees are bonded, insured, and regulated. In most states they are governed by the Pru-

dent Investor Act, which sets the legal standard for a fiduciary regarding the trust's investments.⁶

It is also possible for a family member to serve as a cotrustee along with a corporate trustee. This provides the corporate trustee with a greater understanding of the disabled child's situation. It will require that one of the trustees have the majority vote in the decision-making process. An alternative to a family member serving as a cotrustee is for a family member to serve as an advisor to the trust. This is another method to increase the corporate trustee's responsiveness to the child.

Typically, a trust department has a level of investment and administrative expertise that most individuals do not possess. It is important for the trustee to understand what types of expenses can be properly paid or reimbursed. Additionally, corporate trustees do not die, become disabled, or relocate.

The Third Challenge: Understanding the Risks and Consequences of Leaving Your Estate to a Sibling(s) for the Benefit of a Child with Special Needs

Unfortunately, it is common for a parent to leave the portion of his or her estate that they could have otherwise bequeathed to their child with special needs to another sibling to be used for the child's benefit. This approach creates significant risk for both children. The nondisabled sibling will have to pay income tax on earnings of the inheritance left for their sibling who is disabled. Furthermore, the inheritance being held for the disabled sibling is subject to the creditors of the nondisabled sibling, including the IRS. It would also be included in the nondisabled sibling's bankruptcy. Furthermore, it may count as the nondisabled child's asset for determining financial aid for college. To make matters worse, it could be considered marital property, which means the nondisabled sibling's spouse has a claim against it if they ever get divorced. Each of these situations puts the nondisabled sibling in an extremely awkward situation. If the sibling claims the inheritance is held in what is referred to as a "constructive trust" for the disabled sibling, then the state has a right to terminate the disabled child's benefits. The

state can also demand repayment for any benefits it has paid. And, if the state wants to make an example of the nondisabled sibling they can pursue criminal charges. Someone—most likely the nondisabled sibling—has been signing eligibility forms under the penalty of perjury and not disclosing the trust. The wording below appears above that form's signature line:

You declare under penalty of perjury that all the information on this summary is true and correct to the best of your knowledge. Anyone who knowingly gives a false or misleading statement about a material fact in an application, or causes someone else to do so, commits a crime and may be sent to prison or may face other penalties, or both.

The Fourth Challenge: Providing for the Successor Caregiver and Their Family

The successor caregiver is the key to carrying out the parent's desires for their child. It can be difficult to find a successor caregiver due to the restrictions or limitations on using trust assets to pay or reimburse the caregiver and the enormous responsibility the caregivers are assuming, as well as the pressure it places on their family. Family members may not be willing to assume or capable of assuming that responsibility.

A second trust should also be considered: a caregiver's trust. The purpose of the caregiver's trust is to make the situation more bearable from a financial perspective for both the caregiver and the caregiver's family. The need to provide for the caregiver and the caregiver's family cannot be emphasized strongly enough. The ultimate success of the planning process will be determined by the ability to attract and retain successor caregivers.

A financially and emotionally exhausted caregiver is not in the best interest of the child. There should be resources available to relieve the pressure on the caregiver and the caregiver's family. This is one of the most overlooked aspects of the planning process. It is, however, a reasonable recommendation in light of the strain that caring for a child with a disability puts on the caregiver and the caregiver's family.

Planning Tip: A parent's church, synagogue,

mosque, or other religious organization can help find successor caregivers that share the same values as the parents.

The Fifth Challenge: Writing and Updating a Life-Care Planning Guide

A life-care planning guide is a medical history of the person with a disability and a record of desires and/or the desires of his or her parents concerning the type of care the disabled child should receive. A life-care planning guide is not a legally enforceable document; nonetheless, it is extremely useful to the trustee, successor guardians, and caregivers. It is important for the caregiver to know what treatments have and have not worked in the past. In many cases, the child will live 20, 30, 40 years or more. They may outlive their initial caregivers. If a medication did not work in the past, it is important for the new caregiver to be aware of that information. If the child is living at home it is important to know the parents' desires for their child after the parents' deaths. Will the child live with a sibling or other relative, or will he or she need to be institutionalized? If the child will need to reside in an institution, what are the parents' preferences? Another key item is what types of activities the child enjoys. The trust can pay for these expenses. This and other key information is contained in the life-care planning guide. Because of its importance, this document should be periodically updated.

Planning Tip: Although completing the life-care planning guide is time consuming and draining, it should not impede the planning process.

The Sixth Challenge: Adequately Funding the Trust

There are two issues concerning adequately funding the trust:

1. How much money does the trust need to take care of the child?
 2. How is the trust funded?
- One way to determine the amount of money needed to fund the trust is to break it down into four parts:
1. Transitional expenses that will be incurred when the parents can no longer care for the child;

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2. Expenses the parents are currently incurring;
3. Expenses being paid by public and private resources; and,
4. Assistance for the guardian/caregiver.

Transitional Expenses That Will Be Incurred When the Parents Can No Longer Care for the Child

These are the expenses associated from transitioning a child from the parent's care to that of successor caregiver. These expenses would include any modification to the new caregiver's residence; for example, making it wheelchair accessible. It might be necessary for the new caregiver to add on to their existing residence or find a new one. The transition can be emotionally stressful for the child. A stressed child can easily raise the stress level for the caregiver and other household members. Therefore, consider whether there is a need to provide additional assistance to help the child better adjust to the new situation.

Expenses the Parents Are Currently Incurring

The parents will often have a good estimate of what they are spending on their child. While it may not be necessary to specifically itemize these expenses, one should have a rough estimate of the total expenses so that can be capitalized over the child's life expectancy.

Expenses Being Paid by Public and Private Resources

Expenses being paid by public and private resources can be the most difficult to estimate. Nevertheless, these expenses must be dealt with because it is not unusual for a program to lose its funding. The question becomes, how much do the parents want to hold in reserve for this contingency? The rule of thumb is an amount equal to 3 months of the program's cost.

Assistance for the Guardian/Caregiver

The stress on the family that is caring for a child with special needs and the advisability for providing resources to assist the successor caregiver has been

previously discussed. The question becomes: What is the appropriate funding level for the caregiver's trust?

One way this issue can be resolved is by taking the parents through the following exercise, asking them:

"If there was a program that provided you with \$1,000 a month for you to use any way you saw fit and, if you needed it, there was a \$250,000 fund you could draw down at your own discretion, how would your life be different? In other words:

- You could use it, for example, to bring extra help into the house;
- You could use part of it to do something special for the other household members to offset the stress they have been through; or
- You could use it on yourself, maybe to pay for respite care.

Would \$2,000 a month and a \$500,000 discretionary fund make that much more of a difference than the \$1,000 a month and a \$250,000 fund? At what point does it not make a difference and not improve the quality of life for your family? Is it \$3,000 a month and a \$750,000 discretionary fund? What seems right for you?"

Unfortunately, that type of program does not exist for parents. They can create one for those who will care for their child by purchasing life insurance. This is a reasonable recommendation in light of the strain caring for a child with a disability puts on the caregiver and the caregiver's family. Preferably either the parent or the caregiver trust will own the policy. The caregiver trust will be the beneficiary.

Funding the Trust

Once the advisor has an idea of how much money is needed to properly fund the trusts they can address the issue of how to best fund the special needs trust. What is used to fund the trust? Technically the parent can put anything of value into the trust. They can fund the trust with savings or investments. They can transfer real estate. Real estate that generates a depreciation deduction is a unique asset to fund the trust. The deduction can help to offset taxable income.

Planning Tip: Advisors should consult with the trustee to ascertain if it will administer a trust holding real estate. Not all trustees have the expertise to manage this type of investment. Additionally, if the real estate to be transferred is a partial interest there is another potential problem. If the other owners are performing all of the management duties they may be dissatisfied assuming 100 percent of the responsibility for the property's management while receiving significantly less than that for their efforts. This situation can be exacerbated if the other owners are siblings of the disabled child and they are also the caregivers. This same dilemma can occur with a closely held business. Life insurance can be used in both of these situations to equalize the parent's estate.

The trust can be the beneficiary of a retirement account, be it a 401(k), 403(b) thrift savings plan, or an IRA. Funding a trust with qualified money raises several issues. Which is more beneficial: conveying the account as an inherited IRA or as a taxable lump-sum distribution? An inherited IRA will defer the income taxation on the account; however, it will require minimum distributions (RMDs). They could disqualify the child from government benefits if they are distributed to him or her. The alternative is for the trust to retain RMDs which will result in them being taxed at the trust's tax rate. If on the other hand the account is liquidated and conveyed in a lump sum it could incur significant income taxation; however, there will not be RMDs nor will the trustee have to comply with the prohibited transactions restrictions.

Planning Tip: Life insurance can be purchased to pay the income tax due to either retaining the RMDs in the trust or taking a lump-sum distribution.

Planning Tip: The advisor should defer to the parent's CPA and their attorney regarding the most appropriate method of taking distributions in order to avoid providing advice which the advisor is not licensed to offer.

Candidly, most parents cannot afford to give away what has been accumulated. They are going to

need everything they have acquired to maintain their standard of living during retirement. Furthermore, who knows what their estate will be worth at their death with the increases in life expectancy, inflation, and the possibility of needing long-term care?

Life insurance is the preferred funding instrument for most families; it allows families to enjoy their retirement and not worry about spending their money on themselves to the detriment of their child with a special need. Fortunately the design of life insurance has changed dramatically in recent years. Guaranteed universal life policies provide a guaranteed death benefit at a significantly lower premium than a whole life policy. Additionally, the death benefit of many of these policies can be accelerated if the parent is terminally ill, qualifies for long-term care, or suffers a critical illness such as a heart attack, cancer, or a stroke. These accelerated benefits are unique to the planning process because they can be used for either the parent's benefit or to pay for the increased cost of the child's care, given that will occur during the parent's disability. On the other hand, some parents prefer a permanent policy in which they can maximize the premium in order to produce an income stream to pay for their child's future supplemental expenses. Policy loans can be used to produce the income stream. The loans will not be subject to income taxation if the policy is properly designed and funded. A second-to-die policy might be a viable alternative depending on the liquidity needs, or lack thereof, at the death of the first parent to die. The family's situation might require a combination of different types of policies.

Planning Tip: The rent the parent is charging the child can be used to fund the trust.

The Seventh Challenge: Overcoming the Emotional Hurdle of Planning for the Child's Future

It's often not easy coming to terms with one's own mortality. The part of the brain that processes emotions works faster than the part that processes logic. Therefore, many parents' initial reaction to dealing with the estate planning process is emotional and

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understandably negative. Typically, when the logical part of the brain catches up it will justify the emotional response. In other words, the mind comes up with excuses not to proceed with the planning process.

This situation is made even more difficult because we do not adequately teach personal finance in school. It is further exacerbated by the reality that what little is taught does not address planning for a child with special needs. Unfortunately, most financial advisors are also not well-versed in this area. Their situation is similar to that of the family doctor. While he or she may be fine at treating ordinary illnesses and accidents, one would not select that doctor to perform a heart bypass. One would use a specialist. That analogy is also true for special needs planning. A financial advisor would be prudent to team up with an advisor who has the experience and expertise to work with parents in an emotionally charged environment to maximize their financial situation to benefit the child with a special need. ■

Harry L. Ehrenberg, CLU, is one of the founders of the Special Needs Estate Planning Task Force, an alliance of financial advisors, attorneys, and trust officers who work with parents of children with special needs. He has been advising in this area of estate planning for over 30 years. He has lobbied at both the state and federal levels on behalf of these families. The position he advocated became part of the tax act of 1993

(OBRA 93). His expertise in this area has been recognized by the Arkansas Bar Association. He has taught the material covered in this article at continuing legal education seminars. Harry is the parent of a child with special needs. He can be reached at harry@specialneedstaskforce.com.

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