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Common Pitfalls When Planning Estates for Families with Special Needs Children

By Diane Weinberg

I recently had the privilege to attend a bar mitzvah in which the young man also has a sibling with a profound disability. His sibling is non-verbal and cannot perform a number of activities of daily living, such as dressing and bathing, without assistance. When the young man spoke to the congregation, he noted that his parents devoted a disproportionate amount of time to his sibling's care. He explained that his parents' actions did not reflect that they loved this child more than their other children. Rather, they recognized that the disabled child had greater needs than the other children and, in response, had adjusted their schedules and priorities to meet that child's additional needs. It was clear from the young man's talk that, even though the disabled child had much greater needs, his parents worked to meet the needs of their other children as well.

In many ways, estate planning for families with a disabled child reflects this dynamic – it needs to reflect the needs of both the disabled child¹ and of any siblings. The estate may not be split evenly among the children; it should be divided in a way that will make sense in light of who can benefit the most from the type of inheritance that she receives.

Volumes have been written about planning for special needs children and their families. While you don't need to know all of the aspects of planning an estate (that's why you hire us, after all), we do want to help you avoid a few of the more common pitfalls to avoid during the planning process.

1. Know what public benefits your disabled child receives and why.

The first step in making an estate plan is understanding what type of benefit your child receives, why your child receives that benefit, and whether that benefit is affected by an inheritance.

Social Security Disability and Medicare. Many of my clients have children who did not develop a disability until their 40s or 50s, after having been in the work force for many years. Adults who become disabled after having been in the workforce for a number of years qualify for Social Security Disability Insurance (SSDI) benefits. SSDI is a government insurance policy that every employee pays into through her payroll tax. Thus, when the employee satisfies the SSDI disability requirements, she begins to receive monthly disability payments. Because SSDI is a type of insurance that the disabled adult child has purchased during her working life, an inheritance will not affect these benefits.

Once that adult child has received SSDI for two years, the adult child also qualifies for Medicare coverage. Like a retired adult, the child can receive Part A (hospitalization), Part B (doctors' visits) and Part D (prescription drug coverage). In some states, the child can also purchase Medicare supplemental insurance (also called Medigap insurance) to cover the co-payments that Medicare does not cover. Again, an inheritance will not impact Medicare benefits.



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Supplemental Security Income (SSI), Medicaid and Medicaid Waiver Programs. Unlike SSDI and Medicare, both SSI and Medicaid are needs-based programs. SSI provides a monthly payment for aged, blind or disabled individuals to meet their housing needs and grocery bills. In 2012, this benefit paid an individual up to \$698, and this amount is offset by any income that the individual receives each month. In Georgia, an individual who receives one dollar of SSI benefits also receives Medicaid coverage. Medicaid pays for an individual's medical bills, including prescriptions, and there are no co-payments for covered items. Because these programs are need-based, even a small inheritance can cause the child to lose his benefits.

Developmentally disabled adults may also receive public benefits through Medicaid waiver programs. In addition to providing medical care, these programs provide additional support to the disabled individual to allow that individual to live in the community. For example, a waiver program may provide for the child's housing, home care, house cleaning services, and even meals.

2. Don't Automatically Disinherit the Disabled Child or Her Siblings. Decide Who Will Most Benefit From an Inheritance.

When deciding how to divide an estate, you may want to consider how much of the disabled child's needs are being met relative to your other children. You may want to allocate more of your assets to the special needs child, especially if the child has needs that public benefits do not meet. For example, a disabled adult child who would benefit from therapies not covered by Medicaid or whose house needs significant modification to accommodate his disabilities may benefit more from an inheritance than a self-sufficient sibling.

Sometimes, the disabled child will not benefit from an inheritance. For example, if your child's needs are being met through the Medicaid waiver program, she may not greatly benefit from the extra income. In fact, a small inheritance may cause her to lose her waiver and the entire support system she has developed through that program. However, that same small inheritance could have a huge impact on her sibling who is a single parent with three children. Despite this example, we generally do not advise parents to disinherit a disabled child outright. Public benefits are subject to change, and simply because your child's needs are being met now does not mean that they will be met in the future.

3. Don't Leave Money Outright to the Disabled Child. Create a Special Needs Trust.

Another important question is whether the disabled child should receive the money outright or whether the money should be placed in trust. A child receiving SSDI can receive an inheritance without impacting his benefits. Yet, leaving the money to the child outright may not be a good idea. Sometimes the adult child cannot handle money either due to the nature of her disability or because she never acted responsibly with her money. Placing the money in trust can protect the money from the child's creditors and ensure that it is used for the child's needs.



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If you believe that your child may qualify for a needs-based public benefit now or in the future, all money should be left to a special needs trust (SNT) that names the disabled child as the beneficiary. These trusts allow a child receiving needs-based public benefits (such as SSI and Medicaid) to retain their benefits while using the SNT funds to help supplement her needs. Once established, the SNT funds can be used in almost any manner as long as it doesn't replace the SSI or Medicaid benefits. Thus, it can be used to pay for clothing, furniture, therapies not covered by Medicaid, home care, and even for the child to take vacations with her family.

There is no one type of special needs trust; a variety of special needs trusts can be created depending the tax implications of the trust, when and how the trust is going to be funded, and the amount of money that the trust will hold. Special needs trusts are highly specialized documents and should only be drafted by individuals familiar with the laws and regulations surrounding these trusts.

4. Create a Plan for Your Child's Care For Beyond Your Lifetime. Don't Assume Her Siblings Will Care for Her.

As parents of a disabled child, you need to plan for how your child is going to live once you are no longer able to care for him. You need to find a caregiver for your child as well as a back-up caregiver, in the event that the first caregiver can no longer care for your child. Once you have identified those caregivers, prepare a "Letter of Intent" to the caregiver. Write down the information you need to relay to that caregiver, such as her food likes and dislikes, the child's daily schedule, a list of the child's activities and therapies, and whether your child does better in social situations or prefers to play on his own.

Some parents of disabled children do what I call "sibling planning." Rather than create a plan for the disabled child, they simply assume that the sibling will house and care for the disabled child. "Sibling planning" is a recipe for disaster.

Not all siblings are prepared to care for a disabled sibling. If the disabled child has a mental illness or other condition that causes inappropriate behavior, the sibling may not be willing to inflict that behavior on her own family. If the disabled child has significant physical disabilities, the sibling's house may not accommodate the disabled child's needs. The sibling also may not be prepared to handle any money left to her to use for the disabled child, especially if she is in an unstable marriage, has family members with addiction problems, or has multiple creditors.

5. Plan for your own disability.

Now that you have planned for who will care for your disabled child after you die, you need to plan for how you will care for your child if you become disabled. Review your disability insurance to determine whether the coverage will meet the family needs as well as any additional costs that may be incurred in caring for a special needs child. If you own a business, purchase business continuation insurance or make arrangements for another individual to purchase your company in the event you can no longer work.



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In addition to reviewing your insurance, you need to make sure that your powers of attorney reflect your special needs child as well. For example, your durable financial power of attorney should give your agent the ability to create a special needs trust for the disabled child. It also should allow the agent the absolute discretion to make financial transactions or apply for government benefits for the benefit of your disabled child.

This article merely highlights a few of the pitfalls that you want to avoid as you plan for your future and the future of your special needs child. Like most aspects of life, planning is a process, and even the best laid plans may be subject to revision with changes in family circumstances and with the law itself. If you have any questions about this article or concerns about special needs planning generally, we invite you to contact us at 678-720-0750 or email sollila@morgandisalvo.com.

¹ In this article, the term “disabled child” denotes a child under the age of 18 as well as an adult disabled child.