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Special Needs Planning

In this article, we will focus on an area that will likely apply to you or someone close to you: planning for a loved one with special needs. We will look at the increasing need for this planning; the decrease in government benefits; the concerns families have about providing for their loved ones; whether it is worth protecting government benefits; and planning tips to help you provide for and protect your loved one for as long as he or she lives.

The Increasing Need for Special Needs Care and Planning

Chances are there is or will be someone in your family (child, grandchild, nephew, niece, parent, grandparent) who will need long-term help managing personal care and/or finances. A quick look at the following statistics confirms that the need for special needs care and planning is increasing:

- In 1992, there were 15,580 children ages 6-22 who were diagnosed as having what is now called an Autism spectrum disorder. In 2006, the number was 224,594.
- In 2006, there were an estimated 24.9 million adults in the United States with Serious Psychological Distress.[1]
- An estimated 4.4 % of U.S. adults may have some form of bipolar disorder during some point in their lifetime. [2]
- In 2006, an estimated 22.6 million people in the U.S. (9.2% of the population age 12 or older) were substance dependent or abusive in the previous year.[3]

Because many of the conditions causing a need for special care do not decrease life expectancy, families are seeking answers on how to provide the best quality of life for their loved ones for the rest of their lives . . . which, for a young child, could be 70 years or longer.

Fewer Programs Are Available

At the same time that the need for support services is increasing, government and non-government programs are being reduced and even eliminated due to the strain on state and local budgets and pressures to reduce deficit spending at the federal level. Once a program benefit is lost, for whatever reason, it may be difficult if not impossible to get it back.

Many families with special loved ones are losing faith that these programs will be there to provide the needed benefits in the future. They are wisely (and often fearfully) looking at alternatives to provide those services. Common concerns are:

- Who will care for my loved one when I am gone?
- Who will be my loved one's advocate?
- Where will my loved one live?

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- How much independence can my loved one maintain?
- Will the money I provide last for my loved one's lifetime?

Preserving Government Benefits/Special Needs Planning Today

Are government benefits for a special needs person worth preserving? For families of modest or limited means, the answer is almost always, "Yes." However, for more affluent families, the answer may be, "Maybe not."

In the past, many planners focused exclusively on preserving public benefits at all costs. Today, special needs planning is not necessarily "poverty planning." The proper focus today is how to provide the best quality of life throughout the person's lifetime. It may be better to privatize some special needs care instead of spending thousands to protect a benefit that has a low probability of being available in the future.

Careful planning is necessary to craft a plan that will supplement government benefits that are worth preserving, is flexible enough to adjust to changes in future benefits, will preserve and expand assets, will make sure this person receives proper care, and may even save taxes.

It Takes a Team

For a special needs trust, the proper funding, implementation and periodic review are especially critical because it may have to last a lifetime and often cannot be replaced. Once the plan is in place, it will be need to be managed. Who should do that? The ideal trustee would:

- use discretion, acting in the best interest of the disabled beneficiary;
- understand public benefits and keep up with changes in the law;
- wisely invest and conform to all statutory fiduciary requirements;
- understand taxes;
- keep perfect books;
- provide advocacy and prevent abuse; and
- be immortal.

Since no one person can meet all of these requirements, often the most effective solution is to divide the responsibilities into areas and have a team of professionals work together. For example:

- A Corporate Fiduciary Trustee (bank or trust company) keeps perfect books; carries insurance, is bondable or has deep pockets; is immortal.
- A Care Manager uses discretion and acts in the best interest of the beneficiary; understands public benefits; provides advocacy and prevents abuse.
- A Financial Advisor invests wisely; conforms to all statutory fiduciary requirements; understands taxes.
- A lawyer skilled in special needs matters keeps up with the ever-changing laws and regulations and provides wise counsel to the family and the other team members.

Often a professional trustee will manage the funds, make distributions, prepare tax returns and keep the records, but will be directed by a Trust Advisory Committee that makes distributions, can amend the trust or replace the trustee. A care manager can be on this committee or be appointed by the committee.

Another alternative is to have a trustee manage the funds but be directed by a care manager who interacts with the beneficiary. A trust protector or advisor would oversee the trustee and care manager from a distance and would be able to replace either for any reason.

Planning Tip: Many parents think a sibling would be the best trustee, but this is rarely a good idea. Most individuals are just not prepared to handle the responsibilities. A professional trustee likely will, in the long run, be less expensive than the mistakes that are often made by a well-meaning but inexperienced family member. Also, some siblings may be torn between using the trust assets to provide for the beneficiary and preserving the assets, especially if they will inherit the assets after the beneficiary dies. It is usually better to have a professional as trustee, and have the family member be on the Trust Advisory Committee or to be the trust protector.

Planning Tip: The role of the care manager is critical. In most families, one person has been a fierce advocate, actively seeking benefits and supervising the special needs person's care and progress. The care manager will assume that role and will become the beneficiary's advocate, seeking and evaluating benefits and programs, supervising the person's care and preventing abuse. Selecting a care manager while the current advocate is living will give families peace of mind that their loved one will have the quality of life they so strongly desire.

Managing the Trust Assets

Careful investment of the trust assets is critical, since loss of these assets could be catastrophic for the beneficiary. The assets will need to earn or grow enough to provide for or supplement the beneficiary's care. Trust income can be distributed in such a way that it is taxable to the beneficiary (because the beneficiary will typically be in a much lower tax bracket than the trust itself), but without unintentionally jeopardizing any public benefits the beneficiary may be receiving. This can often be accomplished by having the trustee make direct payments to the providers for care and/or supplemental benefits.

Planning Tip: Insurance on the life of a parent or grandparent is often used to fund these trusts. Using a separate, stand alone trust (instead of a parent's revocable living trust) will also allow other family members to make gifts to support the beneficiary.

Planning Tip: Tax planning combined with special needs planning can present some unique opportunities. For example, using qualified plans to fund these trusts can offer tax advantages. Charitable trusts can also be used to benefit both the beneficiary and an organization. Families are often grateful to organizations that have provided assistance and benefits to the family member and to them, and often want to help make sure these organizations can continue to provide services to not only their loved one but to other families in the future.

Planning Tip: Families with affluent means will be able to provide more opportunities for their special needs beneficiary. For example, purchasing a home in a residential community will guarantee your loved one will always have a familiar, safe home.

Conclusion

If you or someone close to you has a loved one with special needs, we can help with all phases of the planning and implementation. Contact our office for a consultation.

AN UPDATE ON THE ESTATE TAX: With each day that passes we are less likely to see any Congressional action this year on the estate tax; thus, it is becoming more likely the law will revert to a $1 million federal estate tax exemption in 2011. Your estate plan may need some additions or changes. If you have questions, please contact our office.

1 http://www.oas.samhsa.gov/NSDUH/2k6NSDUH/2k6results.cfm

2 http://www.pendulum.org/bpnews/archive/001884.html

3 Based on criteria specified in the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-IV).

Test Your Knowledge with This True or False Quiz

1. Government benefits for a special needs person are always worth preserving. **True** or **False**

2. The need for special needs care and planning is decreasing. **True** or **False**

3. Government and non-government programs are being increased to keep up with the need for support services. **True** or **False**

4. Siblings are always the best choice to be the trustee for a special needs trust. **True** or **False**

5. One person can usually handle all of the trustee's responsibilities for a special needs trust. **True** or **False**

6. If a government program is cut, it will usually be reinstated in the following year's budget. **True** or **False**

7. After a special needs trust has been set up, it is not necessary to review it again. **True** or **False**

8. The choice of a care manager is really not that important. **True** or **False**

9. There is no reason to select and implement a care manager while the current advocate is still living. **True** or **False**

10. The trustee should always pay distributions directly to the beneficiary. **True** or **False**

Answers: All of the above are false.

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