Financial Planning for Special Needs Families

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More American families are grappling with the high cost of raising children and the increasing cost of college education.

Families who have a child with special needs, however, face a unique set of expenses. The additional medical and educational expenses could easily elevate the cost of raising a special needs child to $500,000, if not much higher. Since health insurance doesn't cover the full cost of medical treatments, families bear the burden of large out-of-pocket medical expenses every year. Financial planning for special needs families is a must.

Although the prospect of financial planning for the rest of the child's life can seem difficult in the midst of all the everyday challenges, having a plan can provide a greater sense of security.

Special Needs Financial Planning Checklist

Financial planning for special needs families involves making plans for medical expenses, caretaking, and preserving the child's government benefits. This checklist provides a guide for navigating all of the legal and financial needs families need to address.

1. Create a Special Needs Trust

A Special Needs Trust is a legal trust specifically designed to care for a special needs beneficiary. The trust is the recipient of funds rather than the child, so it helps to legally preserve any government benefits that the child receives.

The trustee can pay for medical expenses and other needs the child has that are not covered by Medicaid as well as clothing, entertainment, and other discretionary spending needs. In most states, parents can set up a basic discretionary trust as a Special Needs Trust.

The trust must be structured so that the parents set up the trust, the child is the beneficiary, and someone other than the beneficiary serves as the trustee. Parents can then fund the Trust with gift funds and funds from retirement accounts.

2. Choose a Legal Guardian

Choosing a legal guardian is important because this is the person who would love and care for their child in place of the parents. The legal guardian should be someone who is willing to provide the level of care the child needs for the rest of his or her life.

Parents should carefully consider who in their lives is willing and able to fulfill that role. They should also have conversations with that person about the child's routine and needs as well as their hopes for the future of the child. Parents may even want to create a type of manual about how they would want the guardian to handle specific situations.

One additional consideration that at the age of 18, children are legally adults. Special needs children, however, may not be capable of independence and legal responsibility. If that is the case, the parents actually need to apply to be the child's legal guardian. Parents should begin the process well before the child turns 18 because it can take several months to complete.

3. Write a Will

A will is an important legal document for any adult to have, but it is especially important for the parents of a special needs child. Parents can identify whom they want to serve as the child's legal guardian in the will.

The will also identifies the people who would be the recipients of the deceased's assets. Parents may be inclined to name their child as the beneficiary of the assets, or someone else if the child does not have the capacity to effectively manage those assets.

In addition, inheriting a large sum of money could cause the child to lose eligibility for government benefits. If the child needs government assistance, it is important to establish a trust for the inheritance and name the child as the beneficiary of the trust.

4. Name a Trustee

Parents must name a trustee when they file paperwork to establish the Special Needs Trust for their child. The same person can serve as legal guardian and trustee, but parents may want to name separate individuals since the roles and responsibilities are quite different.

The legal guardian's main responsibility is the love for and care of the child's daily needs. The trustee, on the other hand, needs to be organized and familiar with personal finance and investments. The trustee's job is to execute the financial wishes of the parents and ensure that the funds in the trust meet the lifetime needs of the child.

5. Write a Letter of Intent

A letter of intent is simply a document that describes the details of the child's situation and special needs. The letter of intent gives all the information the rest of the family should have about how to care for the child.

Some parents use the letter of intent to explain all of the child's medical needs, routine, challenges, and their instructions for providing for the child's daily needs. It can also describe the vision the parents have for the child's adult life. For example, the parents may want to express their desire that the child not be placed in an institutional care facility.

Parents may also use the letter of intent to explain how to preserve the child's eligibility for government benefits. A letter of intent, however, is not a legally binding document, but a way for parents to convey their wishes to the entire family. So, parents still need a will or trust.

6. Create a Personal Savings Plan

Special needs children often require procedures, treatments, and therapies that are not covered by insurance.

Parents should create a personal savings plan to have the funds set aside to cover any unexpected financial needs that may arise. In addition to their own savings accounts, many parents of special needs children choose to set up special savings accounts such as 529 plans for their children.

While 529 plans have great tax advantages that can fund a child's college education, parents should take care not to set up the 529 account in their child's name. If the child does not go to college, the money in the 529 account could disqualify him or her from receiving government benefits.

Others choose to set up ABLE accounts, which are special accounts for people with an onset of a disability prior to age 26. The money can be withdrawn for qualifying expenses tax-free, and the funds in the account are exempt from limits for government benefits.

7. Determine Eligibility for Federal Benefits

Since caring for a special needs child can involve a lot of extra expenses that may last for the lifetime of the child, it's important to research the child's eligibility for federal benefits.

These benefits can include Medicaid, social security, grants, and other types of educational and care assistance. In order for the child to continue to receive these benefits, however, the child's financial situation must meet certain requirements. If parents don't take special care when creating a financial plan, the child could end up with too much money in his or her name and lose all federal government benefits.

8. Consider Life Insurance

A life insurance policy is another way that parents can make sure their child's financial needs will be met if they pass away. The policy, however, should name the Special Needs Trust as the beneficiary of the insurance policy.

Again, naming the child directly as the beneficiary would cause the child to lose eligibility for federal benefits. Parents should also consider whole life or variable life plans rather than term life insurance as the needs of the child will last longer than the parent's life.

Final Considerations

Parents should not be overwhelmed by the checklist but use it as a tool to guide their long-term and short-term financial planning. They will have the confidence to know that their child will continue to receive a lifetime of care and support.

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