

Important components of planning for your child's future

BY CYNTHIA CATTERSON

Special needs estate planning can go a long way to alleviate parents' anxiety about their child's future and put many common fears about money, guardianship and housing to rest.

But as with most other issues for families with children who have emotional, developmental or physical disabilities, special needs estate planning has its own unique set of considerations and guidelines that can be overwhelming for the average person to decipher. Fortunately there are a number of organizations, attorneys, financial planners and community service providers who specialize in this field.

They warn that it is never too soon to get started because without a carefully crafted special needs estate plan in place, the parents' best intentions to provide a comfortable life for their child can instead leave children vulnerable to just the opposite.

"Many parents are not aware of what they need to do to secure their child's future," says Bernard A. Krooks, founding partner at New York's Littman Krooks and president of the Special Needs Alliance, a national non-profit organization dedicated to assisting families with special needs planning. "They may think they've taken care of everything when in fact they could be making matters worse."

General guidelines

In general, the special needs estate plan should include a will, a Special Needs Trust, a Letter of Intent, an appointed guardian and trustee and a life insurance policy. Ideally, parents should assemble a team to include a special needs attorney, financial planner and community services provider to help put together a long-term picture of the costs for medical care, therapies, food and housing and other day-to-day living expenses. They can also advise parents on the best course of action to make sure that the appropriate funds will be available to meet those expenses.

According to Krooks, one common mistake parents make is to leave their estate to a healthy sibling in order to care for the special family member. By doing that, the money is considered part of the sibling's assets and can be jeopardized by a divorce or legal settlement or by the sibling's own spending habits.

Another common error, says Jo-Anne Herina Jeffreys, a special needs lawyer in Hoboken, is to leave money directly to the special child. "If a child has more than \$2,000 in his name, the inheritance will disqualify him from receiving any government benefits," she explains. Medicaid, vocational rehabilitation, subsidized housing, supplemental security income and other need-based benefits will be cut off until all of the child's funds have been spent.

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Trusts

Instead, professionals advise the best way to safeguard assets so they will be available when the child needs them is to establish a Third Party Special Needs Trust, sometimes called a Supplemental Trust. That way the child can continue to receive government aid, which on its own is at or below poverty level, and allow the trust to cover additional costs or comforts to improve quality of life. This can be set up at any time, but experts say the sooner a trust is put in place the better.

“Parents can contribute to the trust at any time and so can other people, like grandparents or aunts and uncles who want to help provide for the child’s future,” explains Jeffreys. Current assets, injury settlements, the proceeds from a life insurance policy and even a house, if the parents want the child to continue to live at home, can also be directed to the Special Needs Trust.

There is also something called a First Party Special Needs Trust. That is set up to include funds that are already in the child’s name. As with the Third Party Trust, the funds in this trust will exempt the child from losing government benefits, but upon the child’s death, any remaining funds in the trust must be paid to Medicaid to cover the expense of caring for the child throughout his or her lifetime. With a Third Party Trust, on the other hand, any remaining funds can be left to family members or another beneficiary.

A third option is a Pooled Trust. These are for parents who feel they don’t have enough money to make it worthwhile to set up their own trust, so the pool is created by a non-profit agency for the benefit of a group of disabled people. Members cannot specify how the money should be spent, and when one person passes away the money remains in the trust to benefit the other members. These trusts are not always successful, however, so it is best to find one organized by a reputable non-profit organization or the special needs division of a financial firm.

Choosing a guardian is perhaps the most emotional aspect of a special needs estate plan. Parents know firsthand how much time and effort goes into the care of their child, so they need to realistically assess the life circumstances of the family member or friend they want to name as primary caregiver. For instance, a sibling’s life may be overwhelmed by the demands of his or her own family, career or health issues when a parent dies and they may not be best suited to take in the special family member. Sometimes a third party caregiver or a group home may be the best choice.

Moreover, it is crucial that parents draft a Letter of Intent to help the new caregiver provide continuity for the child when it comes time to step in. “The letter is an operational roadmap of all the parents’ dreams and aspirations for their child,” explains Jeffreys. It also should include day-to-day instructions about the child’s specific likes and dislikes, ways to handle difficult situations and people to call in emergencies.

As for handling the money in the trust, parents should consider naming co-trustees to the task. “There should be a corporate trustee who can handle the fiduciary responsibilities of overseeing the investments of the funds and the tax filing, and there should be a guardian who knows firsthand what expenses need to be covered,” says Joanne Gruskos, the national program director for Special-Care, the special needs planning division of MassMutual. She adds, “Let Uncle Joe focus on taking care of the child and not be bothered with all the investments, taxes and reporting that needs to be done.”



Resources

To be sure, there is a lot of work that goes into a special needs estate planning and sometimes it can be difficult to know where to start. Word of mouth is always one of the most reliable resources and local support groups are a good place to start asking questions. Online, parents can turn to such organization as The Special Needs Alliance (www.specialneedsalliance.org), The National Alliance for Mental Illness (www.nami.org) and The National Special Needs Network (www.nsn.com) for background information about special needs trusts and estate planning as well as state specific information and resources.

A handful of financial firms, too, have established special needs financial planning departments whose staff are certified in financial planning and are active in the special needs community. Web sites at Merrill Lynch’s Total Merrill division, (www.totalmerrill.com), MassMutual’s SpecialCare (www.massmutual.com/specialcare) and MetLife’s METDESK (www.MetLife.com), all provide background information and resources to help get started. Individual specialists at these firms can help parents through the process, step by step, of establishing financial goals and an overall strategy about how to meet those goals. Additionally, they can act as a coordinator for all the moving pieces of a special needs estate plan and be on hand to update the plan from time to time as circumstances change.

“Our specialists consider themselves to be the quarterback in the special needs estate planning team,” explains Brian Finn at MetLife’s MetDESK division of Estate Planning for Special Needs Kids. “For us, it is not just the financial and legal planning, we employ a more holistic approach, taking into account each family’s personal circumstances and philosophy.”

Although many lawyers and financial planners know something about special needs, experts say it is crucial to use the services of those who specialize in the field.

“Special needs attorneys and financial planners know the intricacies of special needs laws and statutes,” notes Jeffreys. “They know exactly how to structure wills and special needs trusts and, more importantly, they know what questions to ask in order to provide a secure future for long term care.”

Lastly, parents should bear in mind that they are not the only ones who will be relieved once a special needs estate plan is in place. Studies of siblings as young as 4 years old suggest that they are concerned and anxious about what will happen to their special brother or sister when their parents are gone.

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