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Meeting Special Needs and the Need for Peace of Mind

By HILLARY CHURA NOV. 25, 2006

On top of the therapists, doctors, medicines and other issues of daily living, the last thing that parents of disabled children may want to face — establishing a special-needs trust — could provide the most comfort.

It took Wayne and Nancy Cotiaux until this year, 18 years after their son Scott was born mentally retarded, to look into a trust. The trust, which ultimately will be valued at $750,000, can be used to pay for anything other than Scott’s food and shelter. The couple wanted to use their life insurance policies to sustain Scott’s quality of life once they died but not jeopardize his government benefits.

“You worry so much,” said Mrs. Cotiaux of Centereach, N.Y. “As you get older and closer and closer to your geriatric years, it just becomes a greater worry, and you build more anxiety over it. Last year, I was a basket case. I was on medication. I feel the weight of the world has been lifted off my shoulders.”

Most services for the disabled are provided through state-administered Medicaid programs, with federal Supplemental Security Income providing a monthly stipend for adults. To be eligible for Supplemental Security Income, however, potential recipients cannot have more than $2,000 in assets. Because that amount is inadequate for a lifetime of haircuts, hobby supplies, vacations and DVDs — expenses not covered by the government — a supplemental-needs trust can enhance quality of life. Without a trust, a lifetime of care for a disabled person could eat through even a sizable inheritance.

“I don’t care if the parents have $10 million, chances are the child needs Medicaid,” said Craig Marcott, a certified financial planner in East Patchogue, N.Y. “Most services are Medicaid-based, and you can’t pay to get into them.”

About 51.2 million Americans have some disability, according to the Census Bureau.

While the term trust tends to imply great wealth, many special-needs trusts contain less than $100,000. Because the trust does not belong to the disabled person but is used to supplement a lifestyle, it does not compromise government benefits. These so-called third-party special-needs trusts cannot be financed with the money of the disabled individual. To do so would require a different type of trust.

About 60 percent of children with special needs will require lifelong care, said Nadine Vogel, president of Springboard Consulting, which advises companies how to market products and services to the disabled and their families. It is uncertain how many people who could use trusts actually have them, but an online survey of 1,718 respondents, conducted by the Metropolitan Life Insurance Company and released in January 2005, found that 88 percent of the parents of special-needs children do not have a trust to preserve eligibility for government benefits.

Still, many parents are reluctant to start a trust because they fear making the wrong decision, do not want to face the idea that one day they will be unable to care for their child, or do not know how to establish one or whom to ask. In addition, they may not like the notion of putting their child on what is perceived to be welfare.

Some may believe they can avoid drawing up a trust by leaving the money to a trusted relative or friend. Specialists universally discourage that. Even people who intend to follow up on a moral obligation to care for the disabled child could lose the money in a divorce, bankruptcy, lawsuit, premature death or other unforeseen calamity, the specialists say.

Karin and Randy Tuurie of West Chicago, Ill., set up a special-needs trust for their son, Noah. Now 5, he was born with a genetic chromosomal abnormality that prevents his standing. He is unable to talk or feed himself and can walk only with assistance. He is expected ultimately to develop the cognitive abilities of a 2- or 3-

year-old. Pondering guardianship and the associated issues was painful, Mrs. Tuurie said, but she and her husband feel better for having done so.

"It's an added expense," she said. "It's the last thing you want to spend your money on, but I feel a much greater sense of peace having done it — knowing there are plans for him that I have approved of, where we would know Noah is living the life we wanted him to live."

The trusts are usually thought to benefit adult children because parents of younger offspring ostensibly would be around to care for them. But even young families should consider creating a supplemental-needs trust in case of a catastrophic event, said Joseph A. Straka, executive director of PACT, which administers trusts and coordinates services for people with disabilities in Illinois.

Establishing a supplemental-needs trust can cost $1,500 and up, depending on the level of complexity and the state in which it is written.

"The trust is like a bucket, and if you don't put anything in the bucket, it's almost worse than not having the bucket," said Mark Merenda, a Naples, Fla., marketing adviser for lawyers. "It gives you the illusion of peace of mind."

Kirsten Izatt, an estate planning lawyer in Wheaton, Ill., said the best situation was having a family administer a trust but coordinating with legal professionals.

"It takes someone who knows the beneficiary well as a human being, and it takes a special knowledge about public benefit laws and trust laws," Ms. Izatt said. "In the absence of professional advice, it's more likely that family members will make a mistake that might result in the beneficiary's losing eligibility."

In addition to advising the Cotiaux family on the trust, Mr. Marcott suggested that they have a letter of intent that they periodically update with Scott's habits, medication and even details including where he likes to vacation and whether he prefers baths over showers.

He also urged them to find a permanent home for Scott when he is in his mid-20's or early 30's rather than when they die so that he would not have the double trauma of losing his parents and moving.

Mrs. Cotiaux said that the family was looking at several generations of guardians and that past anxiety was gone.

“Everything is taken care of right through Scott’s funeral arrangements. I don’t have to worry about where the money would come from or how it will be funded,” she said. “I know everything’s going to be fine.”

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