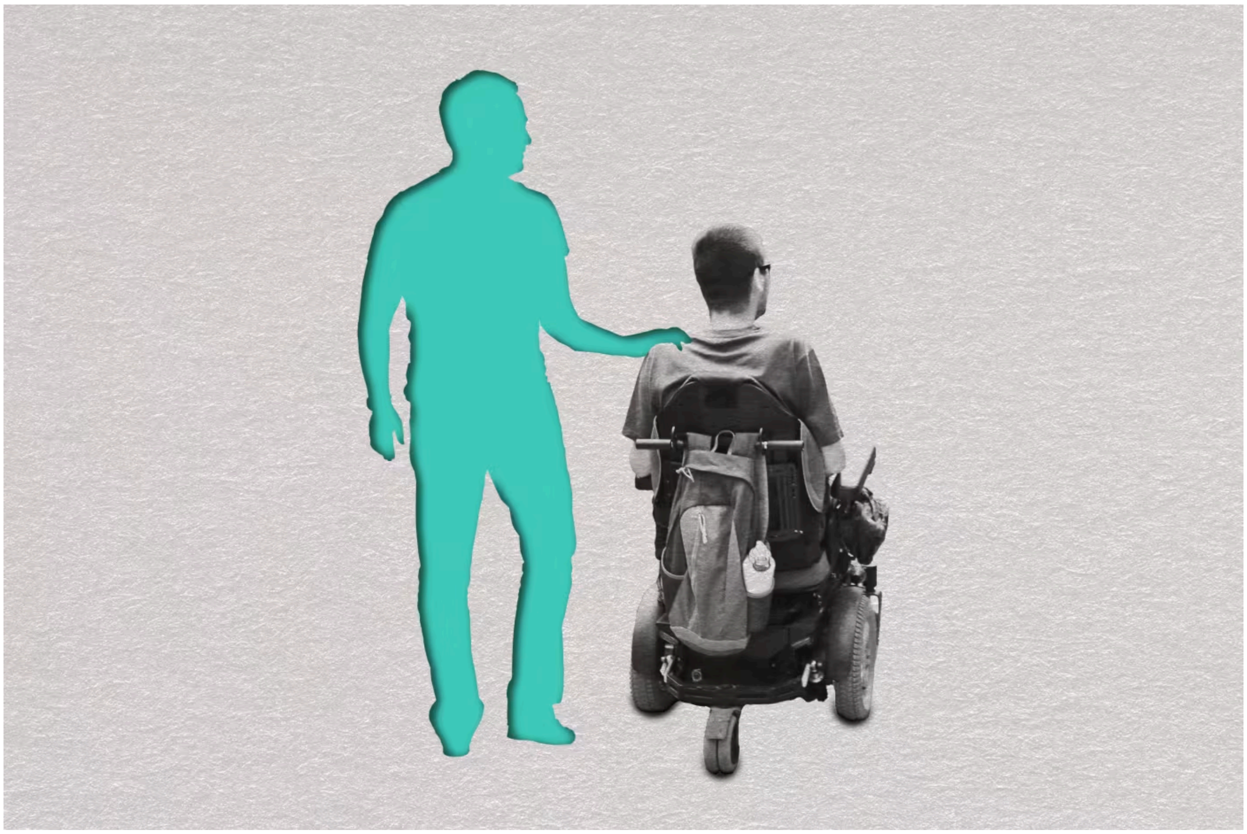
ESTATE PLANNING

Kids With Special Needs Deserve Benefits. A Trust Protects Them.

By Debbie Carlson

July 27, 2024, 2:01 am EDT



(ILLUSTRATION BY BARRON'S; DREAMSTIME (2))

Like many parents of special-needs children, financial advisor Lisa Bamburg is extra protective of her 27-year-old nonverbal autistic son, Joel.

When her mother wanted to leave Joel a $1 million inheritance, Bamburg made sure the gift wouldn't compromise his Supplement Security Income and Medicaid benefits. The Jacksonville, Ark., financial advisor set up a trust that his sister, Elise, will manage for

Joel after Bamburg dies; it is structured so that any remaining funds will stay in the family after Joel dies.

Parents of special-needs children must balance both retirement preparations and care for these children after Mom and Dad are gone. Chuck Cavanaugh, head of financial planning at Citi Personal Wealth Management, says parents sometimes neglect their own financial needs when providing for their disabled children.

"You don't want to be have your kids taken care of with a trust, and you're living on the street," he says.

Why Trusts Are So Important

Supplemental Security Income and Medicaid benefits cover basic living expenses and crucial primary medical services, but to qualify, individuals must have less than $2,000 in assets.

Special-needs trusts can cover other expenses for the special-needs child, anything from cellphone bills to travel for the individual and a companion. Setting up trusts take time and expertise from a family-law or estate-planning lawyer.

For larger estates, there are two types of trusts parents can choose, a third-party and first-party trust; the key difference is what happens to any money left in the trust after the disabled individual dies.

Financial advisors and estate planners recommend parents set up third-party supplemental trusts, says Melissa Negrin-Wiener, senior partner at Cona Elder Law. In a third-party trust, the disabled individual never has access to the money directly, allowing a trustee to designate a beneficiary if there are any leftover funds after the individual dies.

A first-party supplemental trust is used for money the child received outright, such as money from a lawsuit or an improperly planned inheritance. Money in these trusts can also be used for the individual without immediately impacting their governmental benefits, but these are “payback trusts,” Negrin-Wiener explains. At the person’s death, that means Medicaid can claw back the benefits it has paid for this individual over his or her lifetime before remaining funds go to other beneficiaries.

Parents often choose someone close to the individual as a trustee. Scott Scales, relationship manager at Rockland Trust, says trustees need to know how to manage and distribute the money because the special-needs child can never directly receive the money without impacting his or her benefits. Additionally, trustees should avoid paying for items covered by SSI, such as housing if the person doesn’t live with family or is in a group home, since it can reduce benefits, the sources say.

Private trusts can help special-needs children, but setting up and funding them can be costly. For less-affluent parents, Scales recommends parents use a pooled trust, run by nonprofit organizations, which can offer similar services for smaller account sizes.

Funding Trusts and Retirement

Advisors say parents are better off using their own retirement assets to live on. They can then take out life insurance policies on themselves to fund the trust for their special-needs child after they are gone.

Collin Gimlin, financial advisor at Prime Capital Investment Advisors, says life insurance policies make sense since money in a trust should be liquid. For younger parents trying to balance saving for retirement and supporting their child, term life insurance may be a cheaper option than whole life.

Some parents of special-needs children with other kids may be tempted to leave all their assets to that child's support; financial advisors say that usually isn't necessary. Gimlin suggests that parents could consider leaving property or less-liquid assets to siblings of the disabled child.

In the case of Joel Bamburg, his mother worked with estate-planning attorney focusing on special-needs individuals to set up Joel's third-party trust. In addition to planning for Joel's needs, Bamburg bought a long-term healthcare policy for herself in case she becomes unable to care for herself, and her estate plan has equally divided her assets between Joel and his sister, Elise.

Bamburg recommends that her clients don't forgo an inheritance for their other children, if possible. For her, it was important each child receives the same amount from her.

"I'm not going to leave more to Joel do I will than I am to Elise," she says. "I think that's important, so that you don't have any hard feelings or resentment."

Write to editors@barrons.com