

After you're gone: Parents of special needs kids bank on trusts

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Like typical parents of any young adult, Michael and Eileen Black of Scottsdale, Arizona, have watched their daughter, Maddie, hang out with friends, flirt with boys and play music too loud.

And like many parents, the Blacks hope to leave some money for her when they pass away. The difference is that Maddie, 23, has Down syndrome and will never be able to live on her own, let alone financially support herself.



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"Part of the estate plan for all parents with a special needs child has to be creating a special needs plan," said Michael Black, who also is a certified financial planner and principal of Michael Phillips Black Wealth Management.

Exact data on how many parents are in the Blacks' situation is hard to come by, but data from the 2010 U.S. Census show that about 18.7 percent of Americans, or 56.7 million people, have some sort of disability. Not all of them require special assistance, and not all young children with special needs will move into adulthood needing help, however.

Special needs can range from autism spectrum disorders and attention deficit hyperactivity disorder to cerebral palsy and genetic disorders.

Meanwhile, census data shows roughly 12.3 million people, or 4.4 percent of Americans, need help with basic daily living activities such as bathing, preparing meals or taking prescription medicine.

Special needs trusts a lifeline to some

For those who do require assistance, it's hard to generalize costs across the board.

"It depends what the exact needs of the child are," said Jorge Padilla, a certified financial planner with The Lubitz Financial Group. "Some children could be independent by the time they are 30 or 35, while others will be dependent on care for their whole life."

Advisors say the crucial step—once you determine the amount you want available for the care of your special needs child—is ensuring that the money goes into what is called a special needs trust.

"Just like you wouldn't want to leave money outright to a minor, nor do you want to do that for a special needs child for similar reasons," Black said. "But you also do it to maintain the [governmental] benefits awarded to special needs kids."

A special needs trust is not counted as the beneficiary's assets, which matters when it comes to qualifying for government aid. To receive assistance like Medicaid and Supplemental Security Income, the special needs person's assets cannot be greater than \$2,000.

The money in a special needs trust goes toward expenses beyond what is government-funded. This can include education programs, a telephone, clothes or other extras. Also, additional care expenditures might range from extra care for a few hours daily to round-the-clock extra help.

According to various data, the cost for a home-care aide can range from \$14 to \$27 per hour for help with activities such as bathing and dressing. The price tag for adult day care averages \$15,250 per year.

While current statistics for the average cost of group homes are unavailable, care in an assisted living facility can run about \$3,300 per month.

Unlike certain other trusts, federal law protects a special needs trust—no one can challenge its validity as long as it meets certain requirements. For instance, it must be created solely for the supplemental care of the beneficiary and it cannot be managed by the beneficiary.

If the special needs trust is set up with the beneficiary's own assets, the trust must reimburse state government at the individual's death for Medicaid costs. This scenario is more typical when the person is older and developed a disability after accumulating assets.

But for special needs children, the trust usually is set up with assets from the parents. Complicating matters is that those parents might also be trying to save for their own retirement.

"It's a balancing act how to fund those retirement goals and the special needs savings," said Padilla at The Lubitz Financial Group.

Life insurance and other assets

One option is life insurance, with the trustee, in his or her capacity as trustee, named as the beneficiary. Whole life or universal policies, along with survivors policies, are generally viewed as the best types of insurance to fund special needs trusts.

Assets can be gifted to the trust during a parent's lifetime but cannot exceed Internal Revenue Service guidelines. Individual retirement accounts and similar tax-advantaged retirement funds can be bequeathed to the trust, but there are potential unwanted tax consequences if not set up properly.

Another issue to think about is deciding who should serve as the trustee, said certified financial planner Andi Kang. Oftentimes, it's a family member.

"It really depends on the family dynamics," said Kang, owner of Crown Wealth Management. She added that the person who makes decisions about specific care is often not the trustee, simply as a way to separate power.

"Ask yourself what you can do as a parent to make sure [your child] will have the best life possible when you're gone." -Andi Kang, owner of Crown Wealth Management

Kang, 57, has a brother, 56, who is hearing-impaired and has autism. Their father and mother passed away in 1998 and 2000, respectively. Although Kang is a financial planner, she handed off management of the trust to another professional.

"I decided not to manage the money because I wanted to make decisions about the care," explained Kang, whose brother lives full-time in a group home.

Kang's parents emigrated years ago from Korea so they could access the best care available for their son. And that, she said, is what any parents of special needs children should do if they have not already.

"Ask yourself what you can do as a parent to make sure [your child] will have the best life possible when you're gone," Kang said. "That's the big concern and why it's necessary to have a special financial plan in place."

—By Sarah O'Brien, special to CNBC.com