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# Making Sure the Kids Are All Right

*For parents of children with special needs, financial planning can be especially complicated—and especially important*

By VERONICA DAGHER

For parents of children with special needs, keeping up with the day-to-day care is challenging enough. Planning for the child's financial *future* is sometimes too much to contemplate.

### Journal Report

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But, say financial advisers, proper planning can be the difference between children becoming homeless or thriving once their parents are gone. As daunting as such planning is, they say, it has to be done.

"Any parent or caregiver has to talk about their own mortality and their dependent's life without them, and that can be scary," says George Orefici, a certified financial planner for MetLife Inc. in Hauppauge, N.Y. But not planning "could cause children to lose important government benefits and limit their choices later in life."

### Trust Is Key

The most important move parents of children with special needs can make is to set up a special-needs trust, also known as a supplemental-needs trust. This is crucial, financial planners say, because a child can be denied significant Medicaid and Social Security benefits if more than \$2,000 of assets are in his or her name, excluding a residence, car and basic personal items. Assets in a special-needs trust aren't counted against that limit.

### Special Handling

A checklist for families who have children with special needs

- ✔ **Interview** financial advisers, lawyers and accountants to find experts who have worked with families and their children with special needs
  - ✔ **Take time** to do long-term financial planning despite busy day-to-day schedules
  - ✔ **Create** a "letter of intent" that outlines the wishes of the family
  - ✔ **Carefully consider** guardian and trustee choices
  - ✔ **Have a strong support system** of educators, friends, advocacy groups
  - ✔ **Coordinate financial planning** with relatives
- Source: WSJ reporting

Ideally, a trust should be set up by a lawyer with special-needs planning experience as soon as parents learn their child may not become self-supporting, says Dan Kline, a planner based in Omaha, Neb., for MassMutual SpecialCare, a unit of Massachusetts Mutual Life Insurance Co. Waiting until later leaves the child vulnerable to the unexpected death of the parents.

One thing to consider at the start: Making a trust irrevocable upon signing, which limits the ability to revise its terms later, may be ideal for tax reasons but generally should be avoided, says Diedre Braverman, an attorney

who co-founded the Academy of Special Needs Planners, which is based in Providence, R.I. Most parents prefer to retain the right to fine-tune the trust as the years go by, she says.

Funding for special-needs trusts typically comes mainly from the parents' life insurance. Other assets can also be placed in a trust, but parents should be aware that tax issues come into play again here. So, for instance, if parents want to leave assets in retirement accounts to a special-needs trust, they should choose an attorney familiar with the tax implications, says Ms. Braverman, who is the principal attorney at the law firm of Wachbit Braverman PC, based in Westlake Village, Calif.

Money can also be placed in a special-needs trust while the parents are still living. Indeed, this is one way for grandparents and other relatives, or anyone else, to contribute to a child's care without jeopardizing government benefits. Mike Walther II, a certified financial planner and founder of Oak Wealth Advisors LLC in Deerfield, Ill., has a client whose well-meaning parent gifted \$20,000 to the client's child with special needs. The gift disqualified the child from receiving Social Security and Medicaid benefits. If the grandparent had made the gift to the child's trust, the disqualification would have been avoided, says Mr. Walther, who also is the treasurer of the National Association for Down Syndrome.

### *A Visit to Florida*

Money put in a trust while the parents are still living can be used for expenses that may not be covered by government benefits, like certain adaptive equipment, equestrian therapy or a yearly visit to Florida that the child enjoys, says Mr. Kline.

Some parents may think a trust is unnecessary because their other children will take care of the child with special needs, using their own money or their inheritance. But Ms. Braverman discourages that thinking. While that arrangement might work at first, it could become a problem if a sibling loses half of his or her assets in a divorce, or if a sibling dies or becomes incapacitated while the child with special needs is still living, she says.

A well-crafted special-needs trust takes a lot of the pressure off everyone in a family, and that may help strengthen the relationships among the siblings, Ms. Braverman says.

It's not enough, though, to simply set up a trust. It's also crucial for families to find the right people to manage the care of a child with special needs after the parents are gone. Stephen Craffen, a partner at Stonegate Wealth Management LLC in Fair Lawn, N.J., typically recommends families choose one person to serve as guardian and another to act as trustee.

The guardian should be someone who has a good relationship with the child and understands the child's needs, he says. But since the best guardian may not be financially savvy, another person who understands the management of a trust and can handle potentially large sums of money may be a better candidate for trustee, he says.

Choosing separate people for those roles also provides a check on both and gives the child another person in his or her life, says Ms. Braverman.

To help prepare the guardian, planners recommend families create a letter of intent outlining their wishes for the child, along with specifics about the child's medical condition and lists of his or her likes and dislikes—all the way down to details such as a favorite pizza topping.

### *Building a Network*

In addition to appointing a trustee and a guardian, it's crucial for families to establish a network of financial planners, lawyers, advocacy groups, educators, and friends and relatives interested in the welfare of a child with special needs, experts say. Such a network provides emotional and practical support and helps ensure that the family won't miss out on opportunities for financial help. For instance, an accountant can help families sort through the tax breaks available for child-care and medical expenses, credits for various medical devices, and new legislation, says Mr. Walther.

**Jorie Johnson, founder of the planning firm Financial Futures LLC in Manasquan, N.J., has personal experience with the power of networking. One of Ms. Johnson's clients has a daughter with special needs who receives an annual allocation from Easter Seals distributed through the Family Support Center of New Jersey.**

Ms. Johnson mentioned this resource to a neighbor, whose brother is in his late 20s and has Down syndrome. The neighbor hadn't heard of the center, even though it's just a mile from her house. After becoming aware of it, the neighbor managed to secure about \$15,000 annually for her brother to attend social and developmental activities.

"He made the cutoff for applying for the benefits by only two years," Ms. Johnson says. "A network is even more important for families who have children with special needs."

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