

Nadine and Douglas Vogel, with Gretchen and Rachel.

Peace of Mind

Kids with disabilities are living much longer, yet few parents are planning how to support them long term | BY CARRIE COOLIDGE

THE NUMBERS ARE STAGGERING. One child in nine has a disability, either physical or mental. Yet government support can't cover everything. What's needed is some smart financial planning.

Medical advances now ensure that disabled children live longer and longer, often surviving their parents. "Twenty years ago that wasn't the case, but it is now," says Nadine Vogel, who runs MetLife's Division of Estate Planning

for Special Kids.

Indeed, the average life span of people with a developmental disability (such as mental retardation) is 66 years, triple what it was in the 1930s. The increase in life expectancy is stunning for people with Down syndrome—they live to 56 on average, two times their expected life span as recently as the 1980s. The U.S. has 650,000 adults over the age of 60 with developmental disabilities. This number is expected to double by 2030.

Financial and estate planning for families with children with special needs is tricky. "There are plenty of nightmare stories," says Mary Alice Jackson, an elder-law and estate-planning attorney in Sarasota, Fla. A clumsy plan could make the person ineligible for government benefits such as Supplemental Security Income (SSI) and Medicaid, perhaps worth hundreds of thousands of dollars a year. Generally, a disabled person can't own property worth more than \$2,000 and qualify for government benefits. So a cash gift to him could be disastrous, says MetLife's Vogel.

Vogel knows about these issues firsthand. Her 12-year-old daughter, Gretchen, was born with a neuromuscular disorder that made her unable to swallow on her own. She spent her first three months in the neonatal intensive care unit.

While doctors didn't expect her to live, Gretchen beat the odds. Today, though, she still lacks muscle control on her left side, and has mild developmental issues as well as speech and swallowing problems. Vogel's second child, Rachel, 4, has a rare heart condition that can cause congestive heart failure.

Vogel expects both daughters will lead independent lives as adults, but she realizes her older daughter will always need some help. To plan for Gretchen's future, Vogel set up a special needs trust.

Crucial point: The assets in a special needs trust must not be in the name of the disabled person, and the trustee must have absolute discretion over when and how to spend the money. The trust shouldn't pay the beneficiary directly for anything (other than a modest allowance). Rather it should pay a third party, so as not to jeopardize government benefits. With attention to those details, the parent or other benefactor can have the money be used for amenities not covered by government aid.

Eligible expenses include travel, education and recreation, as well as cable televi-

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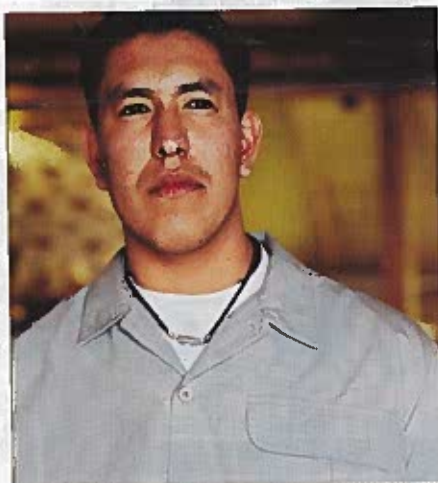
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sion, telephone and Internet service. Even massages, haircuts and manicures can be paid for by the trust. The trust can even own a home lived in by the disabled person. Christiane Delessert, a fee-only certified financial planner in Waltham, Mass., says a paraplegic client tapped into his trust to get back to skiing. The trust paid for equipment, lessons, lift tickets and travel.

Can the trust also pay for basic needs like food, clothing and shelter? Yes, but the beneficiary's SSI will then be reduced by up to one-third of the monthly benefit. Of course, the trustee must also pay that money directly to a third party (e.g., a grocery store or a landlord) and not to the beneficiary.

Think about income, gift and estate taxes when you set up a trust or add money to one. If you maintain control of the trust, the assets in it will be included in your estate, says Peter J. Strauss, an estate and elder-law attorney in New York City. So arrange for a professional adviser,

Families who set up a special needs trust should notify friends and relatives about the plan. "Tell them that should they ever want to leave something to this person, to please do it in a specific manner," Vogel says. "Because all this good planning you have done can be ruined if someone gives or leaves your kid something in the wrong way."

MetLife's Vogel also recommends parents write a "letter of intent" explaining what they want for the future of their child. Not to be confused with a will, this document covers lifestyle issues that require decisions regarding residence, education, employment, social activities, religious affiliation, medical care, guardianship and trustees.

Not all parents choose, or can afford, to fund a special needs trust while they are still alive. Robert and Marilyn Akers of Punta Gorda, Fla., parents of a 38-year-old disabled son, elected to set up a special needs trust that won't be funded until they are

To preserve benefits, a special needs trust can't be in a beneficiary's name.

bank or family member to be the trustee.

At this point parents can contribute funds and not pay gift taxes to the extent that they have lifetime gift tax exemption available. Because of SSI and Medicaid rules, however, a parent will not be able to get the benefit of the normal annual gift tax exclusion of \$11,000. Remainder beneficiaries (such as siblings) can inherit whatever is left in the trust when the disabled person dies, without incurring any further federal estate/gift taxes, except in cases where the trust is included in the parents' estate because they retained too much control. In most states the tax treatment would work the same way.

If the trust is funded with an award from an accident settlement or a medical malpractice case, or if someone unwittingly leaves a great deal of money outright to the child, all is not lost. He or she can still be eligible to receive government benefits, but upon his or her death the trust's remaining assets would have to be used to pay back Medicaid, says James Swiderski, an elder-law attorney in La Jolla, Calif.

both deceased. An irrevocable life insurance trust owns and will be the beneficiary of a second-to-die life insurance policy, which pays after the demise of the second parent. A second-to-die policy is cheaper than a single-life policy. Once the policy proceeds are paid to this trust, the funds will be transferred to the special needs trust.

The Akers' son Todd was in a motorcycle accident while attending Purdue University. Hospitalized for nine months—and after racking up \$1.5 million in hospital bills—Todd survived. The accident left Todd in near-perfect physical condition but with no short-term memory and the mental capacity of a 6-year-old. Todd now lives in a home for brain-injured adults in Palm Harbor, Fla. Government benefits pay about 15% of the monthly cost.

Now both 68 and not in great health, Todd Akers' parents hope the plan for their son will be sufficient. "Todd could live as long as anyone his age, since his life expectancy is normal," says Robert Akers. "We just want him to live as happy a life as he possibly can, until that final day." ■