

## Caring for Those in Need

Make sure your disabled heirs get the treatment they deserve. BY BOBBIE LEIGH

All family estate plans should allow for potential disabilities: unknown needs in unknown times. As New York City lawyer Martin Shenkman emphasizes, "Every single will and trust should have a 'broad clause' that provides that monies for beneficiaries with serious issues (such as potential drug or alcohol abuse or emotional problems) will be held for their benefit and not distributed outright." The key point is to protect beneficiaries, who may be children or young people, from spending or mishandling their assets or using them to support a dangerous habit.

**The goal is to give the beneficiary the best life possible.**

But it is families with known emotionally, physically or developmentally disabled children who need to plan the earliest and the most wisely. Making arrangements for the lifelong care

of the disabled is fraught with mind-boggling complications, and it takes special expertise to navigate complex trust agreements and government-benefit and medical-insurance programs. "The nagging issue for us is where Sarah, now fourteen, is going to live as an adult," says a late-fortyish New Yorker whose wheelchair-bound daughter has cerebral palsy. "She lives with us now, travels and goes to movies, theaters and restaurants, but she does need help. So the question for us is, Who is going to take care of her when we no longer can?"

For children like Sarah, who will never be able to lead fully independent lives, the prudent course is not to leave money to them directly, either outright or in the form of a traditional discretionary trust, but to set up a special-needs trust. Often funded by annuities or life insurance and overseen by a trustee, this type of trust is a security shield: it protects the child from losing specific state and federal social services that provide food, shelter and clothing (which fall under the rubric of Supplemental Security Income, or SSI), even as it maintains a disabled person's eligibility for Medicaid. The trust's money can be used only for "supplementary goods and services" over and above what government benefits provide: perhaps new furniture for a group home, a new van modified for the disabled or even a Mediterranean cruise in the company of an attendant.

Theresa Varnet, an attorney, an advocate for the disabled, and a former social worker, set up a special-needs trust for her mentally retarded daughter, Jennifer. "With the trust,

we can provide nicer clothing, haircuts, spending money, recreational opportunities, an advocate and a higher quality of medical and dental care than is available from the government," says Varnet. What's more, other family members can also leave money to Jennifer's trust.

Many parents would just as soon consign these government benefits to oblivion, preferring not to deal with a labyrinthine bureaucracy. But since no one can predict what hospital stays, doctor bills, prescription drugs and support services, such as physical therapy, may be required in the long term, many experts advise even parents with millions in assets to protect their child's access to Medicaid benefits by setting up a special-needs trust to supplement the basics.

However, for clients with extensive assets—those who can afford to set aside \$20 million or more for a disabled child—some attorneys, such as New York's John Dadakis, do prefer traditional trusts rather than special-needs trusts. "These families want the disabled to have all available options," says Dadakis. "They don't want to have to worry about losing government benefits should they select

an expensive residence, for instance. They also want the freedom to consult any doctor they choose, not just those who are willing to accept Medicaid," he says. As part of the process of drafting a trust, Dadakis has family members write a letter of intent telling the trustees their specific wishes for the future care of the disabled person. Sometimes those instructions even direct trustees to spend all of the assets if need be, because, whether you're establishing a special-needs or a traditional trust, the goal is the same: to give the beneficiary the best life possible. ❖

National nonprofit disability associations like the Arc of the United States (301-565-3842) and Disabled and Alone/Life Services for the Handicapped (800-995-0066) help families plan for the future. Disabled and Alone appoints a lifetime personal advocate for the disabled individual and helps develop a long-range care program, whose goals include maintaining the highest quality of life and ensuring that the disabled person has recreational opportunities and a circle of friends, or at least a support group. MetDESK, MetLife's division of estate planning for special kids (877-638-3375), also helps families plan for lifetime care.