GILFIX & LA POLL
ASSOCIATES LLP
Legal and Consulting Services

2300 Geng Road, Suite 200
Palo Alto, CA 94303
Telephone: (650) 493-8070
Gil-Fax: (650) 493-4668

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By Rachel Emma Silverman

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# An Estate Plan Built for Special Needs

By RACHEL EMMA SILVERMAN

Gabe Molitor is no ordinary trust-fund kid: He has epilepsy and Asperger's syndrome, a form of autism. His mother, Shelby Valentine, recently set up what's known as a special-needs trust, which will provide funding to pay for some of her 30-year-old son's expenses when Ms. Valentine and her husband are no longer able to care for him.

Ms. Valentine and her husband, who live in Calistoga, Calif., are serving as the trustees while they are alive and have named their two daughters as successor trustees. "It was such a relief," says Ms. Valentine. "It gives him a better quality of life after we are gone."

Parents of children with special needs often face years of expensive care for their children. Now a growing number of financial-services companies, lawyers and financial planners -- often calling themselves "special-needs planners" -- are springing up to help parents provide for kids with disabilities, especially when parents are no longer alive to provide care. These professionals guide families through the intricate maze of federal and state programs for disabled individuals, and help set up trusts, insurance policies, retirement plans and estate-planning documents.

Families with special needs have been in the spotlight recently with the vice-presidential candidacy of Alaska Gov. Sarah Palin, whose infant son has Down syndrome, a chromosomal disorder. The financial crisis has also added urgency to families' concerns about how their children's money will be managed when they're not around to oversee it.

More than 41 million Americans, or almost 15% of the population age 5 and older, have some type of disability, according to 2007 Census survey data. Some 6.2% of children ages 5 to 15, or 2.8 million kids, have disabilities, the Census Bureau found. And individuals with disabilities are living longer than ever before. That means that many disabled children will outlive the parents who support them.

At least two professional groups -- the Academy of Special Needs Planners and the Special Needs Alliance -- provide referrals to lawyers familiar with special-needs planning, and other resources. Financial-services firms such as MetLife Inc. and MassMutual Financial Group also have divisions devoted to special-needs planning.

## *Special-Needs Trusts*

Experts often recommend that families create a "special needs" or "supplemental needs" trust as the centerpiece of their plan. Such trusts will provide funds to pay for certain expenses that enhance a disabled person's quality of life -- from residential treatment programs to movie tickets or haircuts -- while not cutting off access to government benefits, such as Medicaid or Supplemental Security Income (SSI), which is administered by the Social Security Administration.

Government payments can cover much of a disabled person's expenses. But in order to qualify for them, individuals cannot have assets in their own names that exceed $2,000 (not including a home, a vehicle and basic personal items). In 1993, Congress permitted special-needs individuals under age 65 to have trusts funded with their own money -- such as assets from a legal settlement or an inheritance -- and still have access to government benefits. More common, however, are so-called third-party trusts, in which parents provide funding for trusts that benefit their children.

Funds transferred to a trust are not considered to be assets of the special-needs individual, as long as there's an independent trustee who controls distributions of the money and the disabled person can't just grab cash from the trust at will. A trust also insures that a qualified individual will be watching over the money, a particular concern for families since many disabled individuals cannot manage money on their own, says Michael Carris, a senior vice president at the trust division of Regions Financial Corp. in Fort Lauderdale, Fla.

Barry Nelson, a Miami lawyer, set up a special-needs trust for his autistic son, Jesse, who is now 14 years old. The trust will be funded by life insurance when Mr. Nelson dies, and can be used to pay for expenses beyond what Medicaid or SSI would pay for, including "travel, companionship and cultural experiences" and "purchase of small visual and/or audio equipment for entertainment purposes," such as iPods or DVD players, according to the trust document. A special-needs trust "gives me -- and it gives every parent -- peace of mind," says Mr. Nelson, who says medical and educational expenses for his son run between $50,000 and $100,000 a year.

Rules governing special-needs trusts are complicated and vary by state and by the source of the funds. Relatives or parents themselves can be the trustees of the funds, although some experts recommend naming a financial-services company or a trusted adviser, such as a lawyer or accountant, to help manage the money and make distributions.

Ideally, the trustee should communicate regularly with the disabled person and be able to work closely with doctors, therapists and a maze of government agencies. Trustees also need to be very careful when making distributions. For instance, they should avoid paying money directly to the person with special needs, since that may disqualify him or her from government benefits, says Andrew Hook, a Virginia Beach, Va., lawyer and president of the Special Needs Alliance.

## *Coordinating Estate Plans*

It's also crucial for grandparents and other relatives to retool their own estate plans to leave gifts or inheritances to the special-needs trust, rather than to the person with disabilities directly, in order to preserve eligibility for government programs. Beneficiary designations on retirement accounts and life-insurance policies should also go to the trust.

"You've got to make sure that the relatives' estate plans are coordinated," says Sebastian V. Grassi Jr., a Troy, Mich., estate-planning lawyer. He created a special-needs trust for his 19-year-old daughter, who has cerebral palsy.

Setting up a special-needs trust can cost $4,000 or more, depending on the trust's complexity. Trust companies often charge about 1% of assets annually in management fees, depending on the size of the trust.

Another option are "pooled" trusts, in which funds from many special-needs families are bundled together and managed by nonprofit groups that focus on disability issues. Families typically use pooled trusts if they can't find appropriate individual or bank trustees, or if they have a small trust account that would benefit from bunching with other families.

## *Letters for Caregivers*

There are some other key steps families with special needs should take. Parents should create power-of-attorney or guardianship documents for finances and health care, naming themselves as their child's agent or guardian when their child turns 18. Without this formality, parents of kids over 18 may not be able to have access to their child's medical records or make health-care or financial decisions, says Boston lawyer Harry S. Margolis, the co-founder of the Academy of Special Needs Planners.

It's also smart to create a "letter of guidance," a document spelling out everything another caregiver should know about their child's special needs, including medical diagnosis, treatment and medications, specific likes and dislikes, and food preferences or aversions. "You know things about your children that no one else on this earth knows," says Michael Gilfix, a Palo Alto, Calif., lawyer who does a lot of special-needs planning. "This includes little things, like what breakfast food makes them happy or what breakfast food makes them really angry."

Ms. Valentine, a client of Mr. Gilfix, recently wrote a letter of guidance for her son, Gabe. The document describes how Gabe is a huge San Francisco Giants fan, so any caregiver should make sure he gets tickets to home games. He doesn't like ice cream or cake, but likes pizza. His epilepsy medication affects his teeth, so the letter recommends that he get his teeth cleaned regularly. "He actually loves the dentist," she says.

**Write to** Rachel Emma Silverman at rachel.silverman@wsj.com