



OLD NORTH STATE TRUST, LLC

Use Trust or ABLE Account to Ensure Care for Special-Needs Family Member

Caring for a child with special needs puts huge burdens on families, both emotionally and financially. Some are obvious: paying for specialized services, which may include education; medical care; physical, speech, or occupational therapies; and residential care. High among the emotional burdens is worry about the future.

While some families are fortunate that government programs can shoulder some of the financial load, many are not. In North Carolina, for example, a Medicaid-based program called Carolina Access pays for services for people with developmental disabilities. But limited state budgets mean many families that should qualify are excluded simply because all available slots are filled. The waiting list is years long.

An easily overlooked financial burden is loss of income. Parents often have to quit their jobs so they can care for a disabled family member. Similarly, the parent of a special-needs child may have limited economic mobility. For example, somebody might be unable to take a better job because relocation would end the child's eligibility for public benefits. Comparable benefits might not be immediately available in a new community, or at all. We know of cases where a parent of a disabled child had to forego an executive career track, turning down a promotion. The job's time demands were incompatible with the child's need for parental care.

Some help is available in the form of Supplemental Security Income (SSI), the Social Security Administration's program for people with disabilities. Like Medicaid, this comes with important restrictions.

Beyond current concerns, all parents of special-needs children have a permanent worry: what will happen when those children become adults, the parents age, and eventually die? Who will care for the disabled persons then? Who will be an advocate for their needs? How can parents who now provide a safe and nurturing environment be confident the same level of care will continue after they're gone?

A legal "gotcha" works against families that want to build up assets for a special-needs child's future care, much as they might save for a mainstream child's college education. Both Medicaid and SSI require that those receiving benefits have essentially zero assets. Families have been forced to liquidate investment accounts they'd set up at birth for a child's benefit, so the child could qualify for desperately needed services that Medicaid pays for.

Because of the problem of losing SSI and Medicaid, it's not sufficient to leave assets directly to a disabled child through a will. A similar problem arises in designating beneficiaries for investment accounts and insurance policies.

Fortunately, there are ways around this dilemma. The best known is a special-needs trust. Its purpose is to ensure that the money you leave for the child's support, and that others might contribute, doesn't jeopardize those essential public benefits. It also addresses the

beneficiary issue: instead of the disabled child being named directly, the trust becomes the beneficiary for investments and insurance.

A special-needs trust can be created during the parent's lifetime, or through a will. The key legal aspect is that assets placed in the trust, and the income they generate, aren't considered "available" to the child. That means the trustee has sole discretion over where these funds are used. Typically, it's to supplement the essential housing and medical needs that SSI and Medicaid cover, paying for such things as dental care, home health workers, vision care, or personal expenses like transportation, recreation, and vacations. The trustee would buy these things directly, rather than putting any money into the beneficiary's name. There is no limit to the amount of assets that a special needs trust can hold. And there's no restriction on how much can be added, or how often.

One useful approach is to set up a special-needs trust, but not fund it immediately. That will be done upon a parent's death, with assets from a will, insurance proceeds, etc.

An alternative to a trust is a new type of financial instrument called an ABLE account. In some ways it's like the popular "529" college savings plans, with specific tax benefits. Like a trust, it allows families to plan for future expenses without jeopardizing eligibility for public benefits. Set up by states, these were made possible by federal legislation in 2014, the Achieving a Better Life Experience act. We'll get into more detail about ABLE accounts in a future article.

An essential provision is to designate a guardian. Typically, a parent is named guardian of a person who is deemed legally incompetent on reaching adulthood. But since children usually outlive their parents, it's necessary to decide who will take on the guardian's role when the parent dies or becomes incapable of serving. The choice of guardian is vital: it should be someone who has the child's best interests at heart and is also capable of dealing with the legal and financial complexities that go with overseeing an incompetent adult's life.

Note that it's possible, and often desirable, to designate two guardians. One, the "guardian of the person," oversees issues of daily living, medical care, housing, and the like. That might be a relative. The other, "guardian of the estate," is in charge of assets and making financial decisions. That role can be filled by a professional, such as a financial planner or attorney who might also be named trustee of a special-needs trust.

There are costs to having a professional guardian, whose time and expertise will need to be paid for. But there are also potential costs to designating a guardian who's not capable of properly managing a disabled person's estate and/or personal needs. Every situation is different, so there's no universal best answer to this question.

Not all people with special needs require guardians. For example, a physically disabled person who is fully competent mentally may require a trust to pay for living expenses, medical care, etc., but is entirely qualified to manage their own affairs. In a case like this, a trust can be structured that sets up a cooperative relationship between the trustee and the beneficiary of the special-needs trust.

One other key tool is a letter of intent. This isn't a legally binding document but allows parents to specify how they would like future trustees, guardians, etc., to care for their disabled family member. It can give guidance about daily routines, the person's likes and dislikes, advice on how to handle behavioral issues, and any other instructions that would help to ensure a happy, comfortable way of life.

Because of their complexity, special-needs trusts require a well-qualified professional to set them up. The financial-planning experts at Old North State Trust are knowledgeable and can advise you in making provisions for a disabled relative's future care. That includes making recommendations about whether a trust or an ABLE account will best achieve your objectives and working with other professionals to provide the best care for your loved one.

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