Not long ago, in the mid-1980s, reports the National Down Syndrome Society, children with Down syndrome rarely lived beyond their 20s. But things have changed. Today the median life expectancy is 55; many live into their 60s and beyond. Medical advances, and greater educational opportunities, means the same lengthened life span for many individuals with developmental disabilities. The result: Parents of “special-needs” children must—and do—worry about their children outliving them and the loving care they provide.
Parents are caught in a bind because leaving assets to a child who receives government benefits can make that child ineligible for the benefits. The critical government safety net, consisting of Supplemental Security Income (SSI) and Medicaid, disappears when an individual has assets of more than $2,000, depending on the state of residence.

Leaving an inheritance directly to a disabled child is clearly a mistake—but so is leaving it solely to siblings in the expectation that they will provide the necessary care. In addition to placing an enormous burden on a sibling, this approach is unrealistic. The sibling’s job may require a cross-country move. The sibling may divorce, and the parent’s assets may end up in the possession of an ex-spouse. The sibling could predecease the child who needs care.

To make sure that children with disabilities will have the care you want them to have, one option is to leave money in a Special Needs Trust (SNT). This money can supplement basic government benefits to provide the “extras,” including specially equipped vans, therapy, and recreation programs, that make life comfortable.

**Special Needs Trusts Come in Several Versions.**

*Third-party trusts* can be established during life but are typically included in a parent’s will, funded with an inheritance, to take effect upon the parent’s death. The money for the trust often comes from life insurance. Where two parents are caring for the disabled child, financial professionals often recommend second-to-die policies so that the money becomes available on the death of the second parent.

As New Jersey attorney and financial planner Martin Shenkman puts it, “Life insurance can be a great equalizer.” It can make it possible to provide an inheritance for children without disabilities while caring for those who have disabilities. And it can provide the flexibility to cover financial needs that may not be initially apparent. Shenkman describes a family with a special-needs child in which a sibling was later disabled in an automobile accident. “It’s a dangerous presumption,” he says, “that other children will never need help.”

Consider obtaining a life care plan. These plans, originally developed for use in personal injury lawsuits, provide a road map of everything that might be needed throughout an individual’s life from surgery through how often a wheelchair is replaced, with the present value of the lifetime costs. Most parents’ worst fear is running out of money, and such a plan, says Kristen Lewis Denzinger, an attorney with Smith, Gambrell & Russell in Atlanta, “can provide an objective basis for determining how much life insurance to buy.”

**Caution:** Well-meaning grandparents or other relatives may undermine an entire estate plan by leaving money directly to the child with
disabilities. To prevent this, parents can establish an SNT while they are alive. Alternatively, they may want to establish what Denzinger calls a “standby” trust specifically to receive bequests from relatives and friends. Separate from a testamentary trust under the parents’ will, this would be an irrevocable inter vivos (living) trust. The parents could fund it with as little as $10, just to establish it as a valid vehicle under state trust law, then send a letter to family and friends giving them the language to incorporate the trust into their estate plans should they wish to do so.

**Self-settled trusts** are funded with assets owned by the beneficiary, typically from an inheritance or legal settlement. The catch with self-settled trusts is that Medicaid must be repaid with any money remaining at the beneficiary’s death. With a third-party trust, any balance in the account at the beneficiary’s death can pass to siblings. There is no obligation to repay government benefits, although Denzinger notes that “many people make a big mistake by including a payback provision in a third-party trust when they don’t need to do so.”

**Pooled trusts** under the auspices of a non-profit or community organization can be an affordable option. Attorney Bernard Krooks of Littman Krooks in New York notes that these function in the same way as an individual third-party trust but are less expensive to administer because each family has a subaccount within the larger trust. With a pooled trust, he says, you “have the option of repaying Medicaid [after the beneficiary’s death] or keeping the money in the pooled trust and using it to better the lives of others in the trust. Most people choose the latter.”

In addition to pooled trusts under the auspices of not-for-profits such as local chapters of ARC (formerly called the Association for Retarded Citizens), some cities and states run similar programs. Ron Pearson, a member of the
National Association of Personal Financial Advisors who became a financial planner after struggling to find advice for his two developmentally disabled sons, is a volunteer trustee with a free program in Virginia Beach, Virginia, for families with less than $100,000.

In order to maintain eligibility for government benefits, Special Needs Trusts designed to supplement government programs should specify that the trust property is not for the "support" or "maintenance" of the disabled beneficiary. Trust assets that can be used for these purposes are deemed by the government to be "available" to the beneficiary, Denzinger points out, and would rule out SSI and Medicaid.

Whatever you do, says Shenkman, "Don't use standard off-the-shelf trust forms," because they are not designed to meet special-needs standards. The forms for lifetime (inter vivos) trusts, for example, typically include a "Crummey power," which bypasses federal gift tax by giving the beneficiary the periodic right to withdraw money from the trust. The Crummey power is typically present in life insurance trusts but, if used in this situation, could invalidate the SNT.

Choosing Trustees

Most financial professionals advise using a corporate trustee. The task requires so much expertise in coordinating trust benefits with the rules surrounding government benefit programs that it can be daunting for a family member. What's more, a professional fiduciary will be in place when the parents and other family members are gone.

If parents want to use a family member as trustee or co-trustee, they should be careful to avoid possible conflicts of interest. Pearson points to a divorced mother who named her brother as trustee. Since her brother's children were to receive any money left in the trust after the disabled beneficiary's death, there was an incentive to spend as little as possible on the beneficiary during life. For this reason, some states do not permit the designation of relatives who might benefit from serving as trustees. It's unwise in any state.

Beyond the Trust Document

While the Special Needs Trust is the key ingredient in providing lifetime care for an individual with disabilities, parents can take additional steps to ensure peace of mind.

Don't focus exclusively on what happens after death. The possible disability of parents is too often overlooked in planning, says Shenkman. If you are incapacitated and unable to make decisions or provide care for your child, a durable power of attorney or a revocable trust can stand in your stead.

Write, and periodically update, a letter of intent to accompany your legal documents. Krock notes, "Legal mumbo jumbo is one thing, but there is nothing like a letter from Mother saying 'Here's what Charlie likes in food, where he likes to sleep, his favorite jacket'—all the things that are critical to the happiness and well-being of the child." The letter helps future caregivers and trustees understand the individual with disabilities. Pearson says, "Pretend you are an angel on the caregiver's shoulder, whispering information about your child."

Raising a child with developmental disabilities is a tough job. Providing care for that child after parents are gone can be even tougher. It takes careful planning, with the help of a knowledgeable attorney, to put your plans and wishes in place.

Grace W. Weinstein is Creative Living's "Time & Money" columnist. This information is not intended as legal advice. Please consult your attorney.