How to Plan for Retirement and Special-Needs Care

By
Debbie Carlso

Retirement planning can be difficult. Retirement planning *and* securing a future for a child with special needs can be doubly so.
The good news is there are a number of government programs that can help parents provide for special-needs children, depending on the level of disability, such as ABLE accounts, Medicare or Medicaid, nutritional assistance and Social Security programs.

The bad news, says James Fox, a certified financial planner and a chartered special needs consultant at AXA Advisors, is that missteps can cause children to lose benefits and lead to significantly higher taxes in estate planning. The twin goals need to be done concurrently and with care, he says.
Here, experts who specialize in this often-complex area share tips.

Savings for Special-Needs Children

Similar to “529” college-savings plans, ABLE accounts are tax-advantaged savings accounts for people with disabilities and their families. To be eligible for the account, the onset of a significant disability must occur before age 26. People who receive Supplemental Security Income or Social Security Disability Insurance automatically qualify. Others may qualify if they meet Social Security’s definition of disability and have a physician’s disability certification.

The beneficiary, family, or friends may contribute up to $15,000 a year in total to the account.

As with a 529 plan, the money can be invested and grows tax-deferred. Contributions to the account aren’t tax-deductible. As long as the money is used for a qualifying expense, it comes out tax-free and won’t be counted as a resource against any needs-based government programs, Fox says. To

qualify for SSI and Medicaid, a person must have no more than $2,000 in assets, excluding a few items like housing.
Qualified expenses need to be related to the disability and can include costs for education, transportation, and other expenses that help to improve quality of life, says Nancy Spain, attorney at Spain, Spain & Varnet PC, whose practice specializes special-needs trusts.

“Some families say that they will work forever. You may not be able to work forever. ”

—Kristian Finfrock, founder and CEO of Retirement Income Strategies, on why families should plan for retirement and special-needs care simultaneously

There are some limits to ABLE accounts, Fox says. The number to watch is $100,000. If the balance rises above that level, the beneficiary’s SSI payments will be suspended until the balance drops below that figure. It doesn’t affect the beneficiary’s Medicaid eligibility. Although it doesn’t happen often, he recommends families watch if the balance starts to creep to $90,000.

“Any time a benefit gets shut off, it’s a mountain to climb for families to go through the red tape to get that put back on,” he says.

He says ABLE accounts are owned by the beneficiary, even if there is a guardianship established with control. That direct ownership is key as ABLE accounts may be subject to a Medicaid payback provision once the individual dies, where the state may try to recoup some of its Medicaid costs.

Special-needs trusts are another way parents can give financial resources to adult children while protecting access to needs-based programs like SSI and Medicaid, Spain says. These trusts can be created to care for the child who isn’t able to work as an adult while the parents are alive or after the parents’ death.

There are two basic types of trusts, third-party and first-party trusts, and Spain recommends when possible parents set up a third-party trust for the child. Third-party trusts protect the funds from the Medicaid payback provision because the money is not left directly to the child. Additionally, because the trust is not in the child’s name, if the child dies while money remains in the trust, parents or the trustee can give that money to someone else.

Costs to set up a special-needs trust vary, Spain and Fox say, and can range from $3,000 to $10,000. There also are annual costs, including having an accountant file taxes for the trust and having a trustee administer the trust.

Retirement Savings

Parents of children with special needs often defer saving for retirement because their resources are limited. Often one parent may stay out of the workforce to care for the child, which also limits their ability to save for retirement.

But parents shouldn't forgo retirement savings, says Kristian Finfrock, founder and CEO of Retirement Income Strategies. "Some families say that they will work forever. You may not be able to work forever," he says.
When it comes to retirement-savings choices, Finfrock recommends parents at least save enough to get the employer match on 401(k)s and then, if possible, Roth IRAs because of their withdrawals are tax-free, before returning to max out a 401(k).

If parents realize their retirement assets won't be enough to care for their child after the parents' death, Finfrock recommends buying life insurance to have the death benefit fund a special-needs trust.

Fox says using life insurance and Roth IRAs to fund a special-needs trust is a smart tax decision, too. He recommends using a special-needs attorney to create one.

To do so, the trust needs to be listed as the beneficiary of the Roth IRA or life-insurance policy. The life-insurance policies can be new or active, he says. If the policy is already active, the owner can change the beneficiary to the trust.

The trust must file annual taxes, and trusts' tax rates are at the highest tax bracket, close to 40%. Since Roth IRAs and life-insurance money is tax-free, the beneficiary receives more money. Life insurance for the special-needs trust can also help for parents worried about inheritance equity with other children. These parents can leave funds in their tax-sheltered accounts, such as traditional IRAs, to their other children to reduce the tax hit.