

Their Child Has Special Needs. Here's How They're Planning for a Lifetime of Assistance

By [Reshma Kapadia](#) Nov. 29, 2019 8:00 am ET



Illustration by Scott Bakal

Linda Smyth has spent more than 20 years fighting her way through a complicated maze of paperwork, assessments, and denials in the attempt to secure services for her son, who is on the autism spectrum. Getting him assessed to qualify for support programs, fighting for benefits, and finding therapists became a full-time job—one that racked up “tremendous” costs, despite the family’s health insurance.

“It’s an ongoing journey—you are in it for life,” says Smyth, a 50-year-old mother of two who lives on Long Island. Her biggest worry: what happens to her son, now 23, when she and her husband are no longer around to support him.

That’s a top concern among surveys of special-needs families. About 10% of children under 18—about 7.2 million—have a severe disability, according to the Census Bureau. Almost 40% of families with special-needs children in a

2018 survey by MassMutual said they struggle to prioritize savings for the long-term, versus 27% of other families. An earlier survey done jointly with the American College of Financial Services found that 70% of special-needs families were worried they would have to compromise retirement to care for a loved one with special needs.

“If you have a special-needs child, the focus is on the health of the child. But what takes a backseat is the financial planning for someone whose life will likely extend beyond the traditional financial plan of the parents,” says Lauren Pearson, a financial planner and partner at HighTower Somerset Advisory in Birmingham, Ala., who speaks from the experience of having a brother with special needs. “What I recommend is they plan for 20 to 40 years beyond what they are predicting for their life. That’s where to start.”

The estimates of costs can leave anyone with sticker shock. The lifetime costs for a person with autism averages \$1.4 million to \$2.4 million, depending on whether the person has an intellectual disability, according to Autism Speaks, an advocacy group. Someone who needs 24/7 or residential care can easily pay \$100,000 a year.

Even those who don’t need intensive support can incur a mountain of out-of-pocket costs. Health insurance, for example, may cover a total of 60 annual visits for physical, occupational, and speech therapy, but a special-needs child could go through that allocation within six weeks. Reading specialists in the New York area can easily cost \$150 an hour, and alternative therapies like music, equine, or water therapy are rarely covered.

It’s the type of challenge that calls for a financial plan. But crafting one isn’t as easy as plugging a diagnosis into a financial-planning model. The needs of two different people with autism or Down Syndrome can vary greatly over their lifetimes, based on family situations and where they live, for starters.

And special-needs families go through a bigger array of transition points and potential complications that make the cost of raising a child less linear than for other families. The situation is complicated by the likelihood that aging parents may see care-giving duties for their special-needs children intensify at the same time that they need more help or long-term assistance themselves.

It’s important to map out a child’s needs over her adult lifetime as she lives independently, holds a job, and gets on in years. When thinking about costs and future plans, the focus shouldn’t be on the diagnosis, but rather the child’s functional ability, says Ann Koerner, president of nurse consulting firm

National Care Advisors, which works with advisors and attorneys to create such assessments and help with a myriad of other services. The firm charges \$3,500 for an assessment and spending blueprint.

The medical assessment often is the first step toward getting benefits. Benefits tend to vary by state, through Medicaid as well as developmental disability and autism programs. Before a child turns 18, parents' income and assets are counted in most aid calculations, but families can apply for Medicaid waivers to help defer costs, as long as the child has less than \$2,000 in assets in his own name.

How much and which benefits depends largely on the state, but benefits can go toward helping fund care-giver services, up to \$10,000 for home modifications and equipment not covered by insurance—but the largest benefit is to defer the cost of custodial or home care.

Where you live matters, with Medicaid waivers more likely in northern states like Pennsylvania, New York, and Ohio than in southern states like Florida or budget-strained states like Connecticut and Illinois, Koerner says. That's something to keep in mind as parents think about where they want to retire. Downsizing to a condo in Florida may mean lower taxes or housing costs but could mean losing important benefits for a special-needs child who moves with them.

Once children turn 18, they are eligible for supplemental security insurance, or SSI, based on the level of their disability, as long as their assets are under \$2,000. The average monthly benefit in most states is about \$771, which can be used for housing, utilities, and food—even if the children are still living with their parents.

Disabled children whose parents have paid into Social Security and who themselves become disabled, retire, or die could be eligible for Social Security disability income, or SSDI, and Medicare, which tends to be more generous than Medicaid benefits. Once eligible for SSDI, it's no longer possible to get SSI.

Beneficiary designations are important to maintaining benefits, since the special-needs person's assets can't be greater than \$2,000. An inheritance, or even a job, could disqualify them from accessing state programs. One way to avoid the situation is through what's known as an ABL account. It's a state-run savings account that can be funded by the special-needs individual or family members with after-tax money up to \$15,000 a year, and used for housing, education, transportation, and other services. The account's assets

aren't included in the benefits calculation as long as the total balance is under \$100,000.

Another option is a special-needs trust, which can shelter assets. For example, grandparents who want to bequeath money to a special-needs child can leave it in a trust. The same holds for life-insurance policies that pay out upon the death of the parents to care for the special-needs child. Financial planners like Carolyn McClanahan, of Jacksonville, Fla.-based Life Planning Partners, cautions against overfunding a trust prematurely. These trusts are irrevocable—money that goes in can't come out for other purposes, and the beneficiary of the trust after the special-needs child dies doesn't get a step-up in basis in terms of taxes when they inherit it. It can cost about \$3,500 to \$5,000 to set up this trust.

A cheaper option: Many states have pooled trusts that cost \$750 to \$1,000 and may also have lower investment and administrative fees. There are different kinds, with some created by nonprofits and the money that is left over after the special-needs individual dies going to the charitable organization, and others where a beneficiary can be named.

While the focus is often on the funds needed to care for the special-needs individual, selecting a [successor guardian](#) and preparing them is important. Families should provide guidance on the likes and dislikes of the special-needs individual, which type of therapies work best, and the frequency of support needed, says John Nadworny, a financial planner at Affinia Financial Group, who also has a special-needs son.

While ensuring that a portfolio will last a lifetime is a common concern for most retirees, special-needs families must extend their portfolio to cover the costs for their child's lifetime. Term life insurance often makes sense for families whose children are financially independent. But for parents of special-needs children who need payments to continue beyond a certain period, advisors recommend a "second-to-die" life insurance policy that pays out to a special-needs trust that disburses the money for care.

While many people tend to need more assistance as they enter their 70s and 80s, those with Down Syndrome, autism, or disabilities may age at an accelerated pace and require long-term care earlier in their lives. That may coincide with the time when their parents need assistance. Advisors suggest that these parents consider long-term care insurance for themselves if they can't self-insure.

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want to review portfolio allocations.

Many are too conservatively

positioned, says JJ Burns, a

Certified Financial Planner at JJ

Burns & Co., in Melville, N.Y. The

need for that portfolio to last the life

of the child could require more-

aggressive investments tilted

toward growth rather than just preservation, he says.

That doesn't mean tilting toward stocks over bonds, but also including sectors like rental real estate. Burns has helped clients who bought a house for their special-needs child to be used as a group home that they gave to a nonprofit. The down payment was considered a charitable donation, and the child is cared for in a home.

Others have also bought a home and opened it to other special-needs adults, giving their own children a say in who they live with. If the residents are getting Medicaid benefits, they may be able to pool care-giving assistance or 24/7 care, Koerner adds.

Also worth incorporating into the budget: the quality of life for others in the family. "Planning isn't just about the quality of life for the special-needs child but for everyone else—the mother, siblings," Koerner says. "We want to give the client who hasn't had a full night of sleep for 15 years the ability to hire a caregiver, to get some sleep, have a date night, or go to their grandchildren's weddings—and put that into the budget, as well."

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