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FINANCIAL PLANNING FOR A SPECIAL NEEDS CHILD

The challenges of raising a special needs child can feel monumental. Fortunately, there are a number of financial planning strategies and solutions that can potentially help parents navigate a path through the uncertainty.

KEY TAKEAWAYS

- Both current expenses and estate planning need to be part of special needs financial planning.
- ABLE accounts, budgeting and even government aid should be considered.
- Special needs trusts can potentially set up a child for the future without hurting financial assistance today.

Raising children and grandchildren is challenging in the best of circumstances. But when a child has special needs or a disability, the hurdles can look more like mountains and the potholes can feel more like bottomless pits.

That's especially true when it comes to paying for the many expenses that can accompany raising a special needs child, as well as positioning assets for the child's future so he or she can live as rich and full a life as possible—especially after you're no longer there to help.

Consider that the average lifetime cost for caring for a person with a disability is estimated to be approximately $1 million—roughly four times the amount it takes to raise a "typical" child from birth to age 18.

The good news is that there is a plethora of savvy financial moves that parents and grandparents of special needs children can make that may potentially deliver big benefits to both themselves and their kids—today, tomorrow and down the road. That said, there are also special needs financial planning pitfalls that you need to know about and avoid along the journey.

MANY FINANCIAL CHALLENGES

Along with the many personal and emotional challenges of raising a special needs child comes the challenge of how to address the special needs from a financial perspective. Here are some of the biggest financial challenges these families face.

1. **Financial shock.** Often, a child's special needs are identified when problems occur after the child is born—giving parents no advance warning or time to look into what it could take financially to address the issue. Among the many questions parents have when given the news that their child has special needs, a common one is what this could mean to their incomes, their financial savings and their future financial plans.
2. **Ongoing health care expenses.** Many health care needs require a one-time expense. In stark contrast, special needs health care expenses are often ongoing—requiring monthly, weekly or even daily services that could be needed for years or even decades as the child becomes an adult. Clearly, such ongoing costs can become huge.
3. **Fluctuating costs.** The lack of financial clarity that accompanies a diagnosis is further exacerbated by the possibility that ongoing costs might be highly inconsistent from year to year. This can happen when, for example, a special needs condition improves or worsens significantly. This lack of cost visibility can make it even more difficult to plan for how much money will be needed, where it will come from and how financial assets should be positioned to generate it.
4. **Insurance headaches.** Parents of special needs kids often encounter confusion around issues such as deductibles, claims, out-of-network providers and denials of coverage— usually without anyone capable of helping them chart the right course and say the right things to make insurance companies sit up and listen.

NAVIGATING TODAY'S EXPENSES

Smart financial planning around special needs involves thinking about today and the foreseeable road ahead along with the distant and more uncertain future.

Start with current and ongoing expenses. Some basic wealth planning, such as budgeting, should be done regularly. If you conclude that the likely health care treatments and services will almost certainly require you to spend up to your annual out-of-pocket maximum, make that a fixed expense on a yearly budget.

In addition, many families qualify for financial help from government agencies. For example, monthly Supplemental Security Income (SSI) is available to some individuals who meet the SSI disability standard. And individuals with disabilities who also have a qualifying work history or are able to qualify for benefits based on their parents' records may be eligible for Social Security Disability Insurance (SSDI). Additionally, Medicaid and Medicare may cover some health care expenses and medical equipment costs.

Important: *Don't assume you earn too much or are too wealthy to get any benefits. The rules can vary from state to state, making it possible you'll qualify for some amount of financial assistance.*

That said, it's important to look beyond basic moves and the government to advanced solutions designed to help parents more easily pay for the expenses of raising a special needs child.

One tool that should be considered is an ABLE account—essentially a 529-like savings plan to help families caring for children or adults with disabilities. ABLE accounts are funded with after-tax contributions that aren't eligible for a federal tax deduction. However, contributions grow tax-free and withdrawals are tax-free when used for qualified disability expenses— which generally include rent, food, transportation, education and employment training, health care, and personal support services. Anyone can contribute to an ABLE account— including grandparents—but the annual aggregate contribution limit is $15,000.

Another key benefit of ABLE accounts is that the contributions are shielded from asset based limits that could jeopardize an individual's ability to access government assistance. Normally, special needs individuals lose eligibility to certain federal disability benefits if they have more than $2,000 in assets in their name (not counting a house and one vehicle). But that's not the case with assets held in an ABLE account. As such, it's a way to provide financially for a special needs child without making a direct financial gift to him or her that could jeopardize access to other financial support. It can also enable working-age children to earn money and develop some self-sufficiency—without affecting their access to benefits.

That said, there are some potential downsides to be aware of. If the ABLE account exceeds $100,000, the individual is no longer eligible for SSI. Also, if the account's beneficiary dies and had received Medicaid benefits during the time the account was open, the government could seek to be paid back for those benefits from the assets in the account.

WEALTH PLANNING FOR THE FUTURE

Special needs financial planning also has to address estate planning, in the event you die and are unable to care for your child.

Often, parents seeking to help ensure their special needs child will be taken care of after they're gone will set up a special needs trust that's designed to hold and safeguard assets to benefit the child. (That said, parents also set up these trusts while still alive to help supplement the cost of care.) The trust can be set up with terms and language for how and when the money should be used, although many specific terms must be met for the trust to be deemed acceptable. And as with many other types of trusts, a special needs trust can potentially protect assets if the child is sued or becomes divorced at some point.

In general, there are two main types of special needs trusts that most families with assets to invest tend to consider:

1. **A first-party trust** is set up when the assets contributed to the trust belong to the beneficiary—that is, your special needs child or grandchild. This can happen if the child inherits wealth or gets money from a legal settlement. The beneficiary is considered to be the owner of the assets in this scenario. The good news is that when those assets are put into a special needs trust, they're excluded from government aid calculations determining eligibility for the types of benefits noted above. The bad news: As with the ABLE account, when the beneficiary dies, the government can claim assets still in the trust to reimburse it for payments it made.
2. **A third-party trust** is used when the funding assets come from parents, grandparents or anyone other than the beneficiary (who in this case would not be considered the owner of the assets). A third-party trust also allows a beneficiary to retain their government assistance—but because the assets contributed belong to someone else, the government won't seek to collect remaining assets when the beneficiary dies. The upshot: A third-party trust gives you more flexibility to transfer remaining wealth to another beneficiary (such as another child or a charity).

(A third type of trust, a pooled trust, is aimed at families with relatively modest assets.)

As with other trusts, you must carefully consider who is the right person to name as trustee and how to best fund the special needs trust—two issues we'll explore in a future report that focuses on special needs trusts.

Conclusion

There are a number of steps that families with special needs children can take to help ease the financial burden of ensuring their children get the care they need—as well as set their children up for better and more stable financial lives as they get older.

Of course, there is no one-size-fits-all answer given that one family's particular situation can be quite different from another's. But for families experiencing the confusion and uncertainty that accompany raising a special needs child, knowing that there are options to consider can be a helpful foundation from which to create a plan for today and well into the future.

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ADOPT BEST PRACTICES

By and large, the self-made Super Rich have proven that they know what to do—and what not to do—in oder to create, grow and maintain sizable wealth. By avoiding major slip ups on your own path to wealth creation, you can potentially encounter fewer financial potholes along the way.

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