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How Much Is Required to Fund a Special Needs Plan?

By Matt Stagner, CFP®, ChSNC, and Jessica Tuman



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How Much Is Required to Fund a Special Needs Plan?

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Financial advisors whose clients include individuals with disabilities or special needs and their caregivers have heard this question before and understand that it poses a familiar and daunting challenge—for both the client and the advisor.

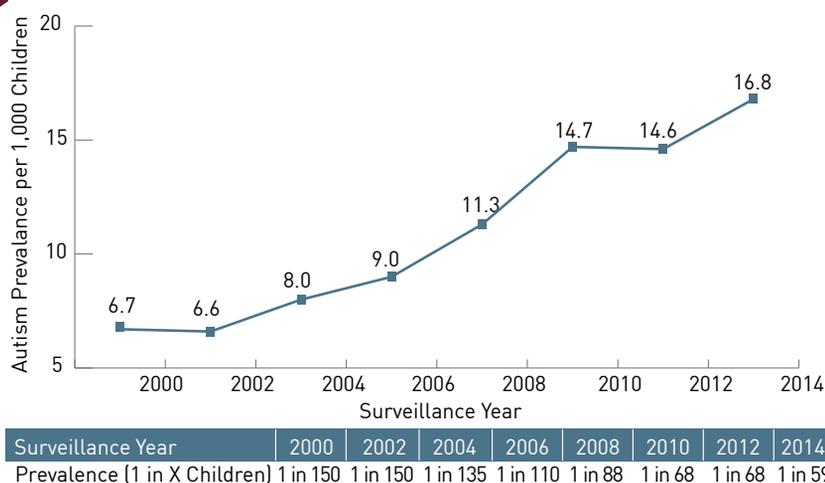
Across the United States, 43.5 million Americans¹—more than five times the population of New York City²—care for a person with a disability or special needs such as autism, Down syndrome, Alzheimer’s disease, physical disabilities, or traumatic injuries (for examples, see figures 1 and 2). For financial advisors, that represents a community of more than 105 million caregivers and people with special needs who control a combined annual disposable income of \$645.3 billion (Donovan 2016).

Along with holding full-time jobs and managing household duties, these caregivers dedicate on average nearly 25 hours a week³ tending to their loved ones with special needs. The emotional and physical demands of caregiving can be overwhelming. But the financial necessities of providing near- and long-term care for a person with special needs can have disastrous financial effects for caregivers—unless they have a plan.

IMPACT ON ADVISORS’ BOOKS OF BUSINESS

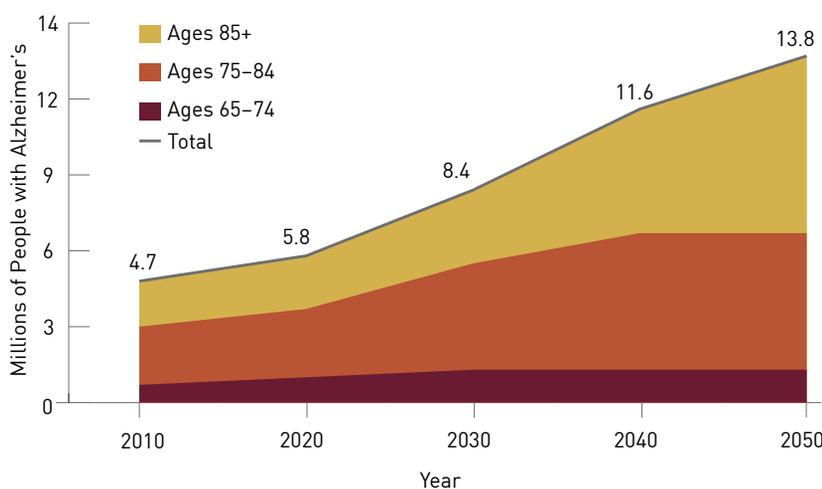
Up to 20 percent of an advisor’s book of business likely will include clients or clients’ loved ones with a disability or special needs situation.⁴ According to

Figure 1 IDENTIFIED PREVALENCE OF AUTISM SPECTRUM DISORDER



Source: <https://www.cdc.gov/ncbddd/autism/data.html>

Figure 2 PROJECTED NUMBER OF PEOPLE AGE 65 AND OLDER IN THE U.S. POPULATION WITH ALZHEIMER’S DEMENTIA, 2010–2050



Source: <https://www.alz.org/media/Documents/facts-and-figures-2018-r.pdf> (Page 23); <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3719424/>

the American College of Financial Services, 90 percent of caregivers say it is important to work with an advisor who offers specialized financial services for people with disabilities. Yet only 23 percent of caregivers have a formal financial plan in place.⁵ Additionally, about 67 percent of caregivers say they don't have an established special needs trust in place—a situation that could put the people they care for at risk of losing vital Medicaid and Supplemental Security Income (SSI).⁶ Most crucial, many advisors are not aware of their clients' special needs situations, because these needs are not uncovered in the financial planning process; the questions that probe these situations often are not asked, and hence, the opportunity to support these situations often is missed.

DEVELOPING A VISION OF THE FUTURE

How much is required to fund a special needs plan?

The answer is different for every family. Factors that may affect the calculation include the following:

- Age and life expectancy of the caregivers and persons with special needs
- Diagnosis and severity of the disability
- Lifestyle that caregivers wish to maintain for themselves and persons with special needs, while caregivers are alive and after their deaths
- Financial assets of the caregivers and persons with special needs

The foundation of a special needs plan starts with a will and a letter of intent that document a clear vision of the future. That vision may include education beyond primary and secondary schooling. It also should account for future costs of clothing, food, medical care, and durable medical equipment. Housing is a critical concern—especially after the death of caregivers—whether it is an independent- or assisted-living arrangement. Recreation, travel,

UNDERSTANDING YOUR CLIENTS' SPECIAL NEEDS

Understanding your clients' needs regarding family members with disabilities or special needs starts with a conversation about the individuals who are cared for. Below are some questions that can guide the conversation.

Integrated health care

Integrated health care involves the sharing of information among team members related to patient care and the establishment of a comprehensive treatment plan to address the patient's biological, psychological, and social needs (American Psychological Association).

- What treatment, counseling, and therapies are currently received?
- How might that mix of treatments change in the future?
- Of the services now used, which are covered by government benefits, and which are not?

Food and clothing*

- Does the individual with special needs have food allergies, dietary needs, or favorite foods?
- Does he or she need to wear or avoid wearing specific clothing because of hypersensitivity, allergies, or other conditions?

Education

- What educational needs aren't provided by the primary or secondary school that the person with special needs is attending?
- Will that person attend college, trade school, or a life-skills program?
- Who will provide and pay for services that were provided during primary and secondary schooling? In some cases, the special needs person may require additional attention and services for any education or training after high school.

Benefits

- Have all the government benefits that the individual receives—or could receive—been identified, as well as the recertification dates for those benefits?
- Does the person expect to receive money from family gifts, inheritances, or pension income upon the retirement or death of caregivers?

Employment**

- What sort of work and activities does the individual enjoy?
- Will activity result in a paycheck?
- Will the individual require a job coach or adaptive transportation to get to work, and who will pay for that?

Housing

- Can the individual live independently as an adult before and after the caregivers' deaths?
- How will current living arrangements change as he or she grows older?
- Along with rent or assisted-living fees, what other housing costs might the person with special needs incur? Examples may include accessibility modifications, separate spaces for independent living at home, and overnight caregiver accommodations.

Social environment

- What types of social activities does the individual with special needs enjoy?
- Does he or she require spending money for these activities?

* Though food and clothing might seem to be minor expenses, compared to health care, housing, and others, the costs can add up to significant amounts over a lifetime.

** Without careful planning, the person with special needs could lose Medicaid and Supplemental Security Income (SSI). Note: Any employment income earned by a person with special needs could affect government benefit eligibility.

employment, and retirement plans of the caregivers should be considered as part of the vision as well.

The vision for the future should include the concerns of the person with the disability, parents, siblings, and other relatives, as well as medical personnel, physical and emotional therapists, and others involved in the lives of the caregivers and persons with disabilities and special needs.

Upon completion of a customized vision for the future, advisors can create a unique financial plan that is integrated with a legal framework and funding vehicles.

UNDERSTANDING EXTENT OF THE NEED

Advisors will need to ask clients a number of questions before quantifying the amount of funding that will be required for their plan.

Advisors can begin by discussing these critical topics with their clients. The topics include the disabled person's detailed needs in terms of health care, food and clothing, education, and housing, as well as the disabled person's social needs, employment, and government benefits. Sample areas to explore within these topics are included in the sidebar, "Understanding Your Clients' Special Needs."

Once these questions are answered, advisors can start formulating a solution that will help caregivers and people with special needs calculate the amount required to make their vision of the future a reality (see figure 3).

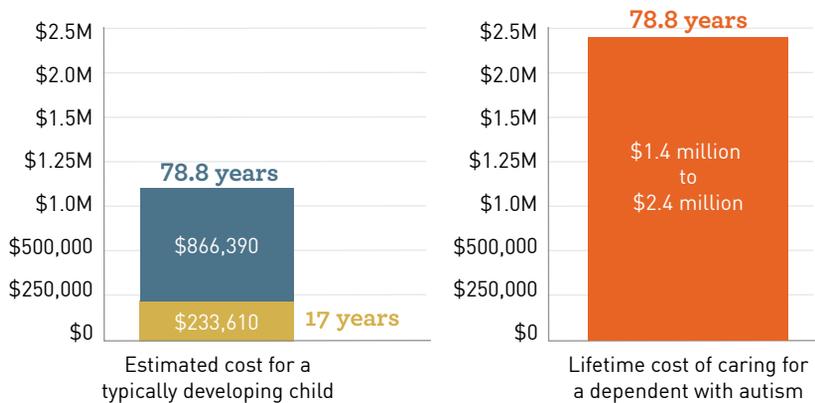
ESTIMATING EXPENSES

Developing a budget for the person with special needs, in today's dollars, is step one. Regardless of the plan for the future, families often are focused on the care of the person with special needs in the present. Advisors should start by

Figure 3

LIFETIME EXPENSES

Determine the future: It may seem daunting to try to figure out the cost for the lifetime of a person with a disability or special needs. Starting with what currently is known can help. For example, in the United States, the estimated expense to raise a typically developing child from birth through age 17 is \$233,610.* Factor in a full typical lifetime of 78.8 years,** and expenses can run close to \$1.1 million, before accounting for the added costs associated with a disability or special needs. You may be able to find some existing data on your child's particular diagnosis to help you with this process, as well. For example, a journal article in *JAMA Pediatrics* estimated that "the lifetime cost of caring for a dependent with autism is between \$1.4 million and \$2.4 million."***



Sources: *Donovan (2016); **Murphy et al. (2017); ***Buescher et al. (2014)

itemizing current expenses with their clients. Then, based on the results of the vision for the future, they can attempt to project future expenses. One challenge may be how to divide up food, utilities, and other shared living expenses that occur when the person with special needs is living with the primary caregiver, in assisted living, or in other residential situations.

The next critical step is planning for the death of one or more caregivers—premature or otherwise. Advisors must include plans for a catastrophic event that may take the lives of more than one caregiver at the same time—or in close proximity. Planning for these contingencies includes providing the necessary funding to maintain the current lifestyle of the person with special needs, with a particular focus on housing options.

Determining the future costs of caring for the person with special needs is a formidable task, especially when considering variations due to age, diagnoses, income levels, and the local cost of living. *JAMA Pediatrics* may provide

some guidance with its estimate that "the lifetime cost of caring for a dependent with autism is between \$1.4 million and \$2.4 million" (Buescher et al. 2014). However, that is only one example, and costs are dependent on the severity of the disability (see figure 3).

A holistic plan considers the entire family as a unit and as individuals. Caregivers and individuals with special needs each need to contemplate their futures individually as well as together. They need to develop financial plans for retirement, health care, education, travel, other financial goals, and future wealth transfer of their estates, where applicable.

FORMULA FOR THE FUTURE

After a clear vision of financial goals has been established, subtract a client's current and expected benefits and earnings from calculated expenses.

An inflationary factor must be included, along with an assumption of growth, and life expectancy of the person with special needs and the caregivers, to

Figure
4**TYPES OF TRUSTS**

If in the course of the planning process, the advisor and family determine that a special needs trust is an option to collect the assets needed to fund the plan, the next step in the process is determining what kind of trust will be appropriate. In general, trusts are used by families in order to maintain eligibility for means-tested government benefit, or any other named remainder beneficiary upon the death of the beneficiary.

First-Party Trust

Assets such as inheritance or accident settlement

Third-Party Trust

Funded by parents or family

Pooled Trust

Administered by nonprofit organization

A well-designed special needs plan, supported by the proper resources, legal structures, and funding vehicles, can give families much-needed peace of mind knowing that they've taken all of the available steps to plan for their own goals and the goals of their loved ones with special needs.

produce a unique calculation for each case. Based on that calculation, benefits of the family are netted, specifically as the family wants them applied. For example, some families may not want to include government benefits in their calculations of future income, because they may not qualify, may not want broader plans to be dependent on government programs, or are concerned that programs may change, over time. Those benefits may include employer benefits and government payments, such as retirement, survivor, or child disability benefits. The resulting figure represents the amount of financial assets or estate proceeds that should be set aside to fund a special needs plan.

When setting a funding goal for the plan, advisors should determine if the plan will preserve its corpus—allowing for spending of only the interest or growth—or if a spend-down approach is a better solution. This decision can make a dramatic difference in the expected funding calculation. Preserving

corpus requires a much higher initial funding amount, but it can provide more security and a greater legacy for future beneficiaries. A spend-down approach may require less up-front funding, but it leaves open a risk of outliving the assets.

Advisors need an all-inclusive fact finder to collect the information, as well as calculators, graphs, and narratives to reveal where the need gaps are in a client's vision and how to fill them. The result of this process yields a net number, which, once adjusted for various individual scenarios, could be inserted into a comprehensive financial plan. Once clients understand how much they need to set aside, advisors can help them answer the next big question: How can this goal be accomplished?

LEGAL STRUCTURE FOR SETTING ASIDE ASSETS

An important step to developing a successful financial plan for people with special needs is determining the proper legal structures for current and future

needs. Those structures should preserve eligibility for government benefits, as well as maintain the desired quality of life envisioned by the caregivers and persons with special needs.

If appropriate, the proper legal structure may include a special needs trust.

Many families rely on properly crafted trusts to maintain eligibility for means-tested government benefits. Special needs trust options include first-party, third-party, and pooled trusts (see figure 4). It is recommended that, at this stage of the special needs planning process, advisors seek appropriate legal advice from specially trained attorneys.

FIRST-PARTY TRUST

In a first-party trust, the assets belong to the person with special needs, who is also the trust's beneficiary. The trust funds may be from income, inheritance, or a settlement in the name of the person. Because the assets are assigned to the trust, access to important needs-based government benefits such as SSI and Medicaid will not be compromised. Upon the death of the trust's beneficiary, any remaining assets will be subject to Medicaid recapture. After the Medicaid payback, any remaining funds may be distributed to a designated remainder beneficiary.

A promising new option for setting up a first-party special needs trust is the ability of an individual to establish it for himself or herself, identified as "self-settled." Previously, persons with special needs had to rely on a third party to establish a trust, even if they were capable to do it for themselves. Signed into law in December 2016, the Special Needs Trust Fairness Act provides persons who have a disability, if competent, to establish the trust and set very specific guidelines regarding the use of the funds in instances when the condition of the individual may worsen. This is a tremendous step forward for individuals who are able to self-advocate and

engage with advisors and attorneys in their own financial planning processes.

THIRD-PARTY TRUST

A third-party trust is funded with assets from someone other than the beneficiary—such as a parent or other family member—who wants to assist the person with special needs. As with a first-party trust, assets in a third-party trust do not affect access to SSI or Medicaid for the person with special needs. However, third-party trusts do not include a payback provision for Medicaid, so remaining assets may be passed along to other family members or a charity upon the death of the beneficiary.

POOLED TRUST

Finally, a pooled trust can be established when other types of trusts are not cost-effective options, if a trustee to administer the fund cannot be found, or for several other factors, such as stability. A pooled trust must be established and administered by a nonprofit organization that acts as the trustee; it allows many beneficiaries to pool their resources for investment purposes and maintains separate accounts for each beneficiary's needs. A Medicaid payback provision may exist with a pooled trust upon the death of the beneficiary. In addition, a portion of the remaining assets may go to the nonprofit managing the trust or to a named beneficiary.

There also may be cases where a special needs trust is not necessary or practical. Clients with limited resources, or those families with enough resources that means-tested benefits aren't applicable, may be able to achieve their goals without a special needs trust.

After an attorney helps establish the best-suited legal structure, advisors should identify the appropriate financial vehicle(s) to fund it. First, some considerations that could affect the funding of the plan should be examined.

FUNDING CONSIDERATIONS

The burdens of caregiving can take a toll on family dynamics. If there is a divorce in the family, additional complexities may be involved. For example, child support may disrupt government benefits unless it is directed to a first-party special needs trust. Families should work with advisors and attorneys who are experienced in divorce planning and people with special needs.

If the special needs situation is the result of an accident, caregivers or the person with special needs may receive a financial settlement. Advisors must understand how those assets can affect benefits, and how using a first-party trust can help preserve eligibility.

A pooled trust must be established and administered by a nonprofit organization that acts as the trustee; it allows many beneficiaries to pool their resources for investment purposes and maintains separate accounts for each beneficiary's needs.

TAX IMPACTS ON SPECIAL NEEDS TRUSTS

Advisors need to consider how taxes could decrease the available assets, over time. Caution clients not to overfund a trust, even if they feel that the excess money will provide extra security for persons with disabilities and special needs, because tax rates on trusts can be higher than individual income rates.

A desire to leave a legacy may mean Medicaid recaptures or paybacks can affect the amount of money—if any—that the secondary beneficiary receives upon

the death of the person with special needs. First-party and pooled trusts include Medicaid recapture provisions, but third-party trusts do not. Careful planning and structure of assets can help ensure that excess funds are available for future beneficiaries rather than the state Medicaid office.

CHOICE OF FUNDING INSTRUMENTS

In some cases, clients may need the funds from the moment a trust is established. For other families, the trust is strictly a necessity after the death of the caregivers, or as a vehicle to receive inheritance from other loved ones.

If clients need immediate funding from the trust, funding options may include earned income, investments, and savings. If trust funds are required only after the death of one or more of the caregivers, life insurance could be a wise choice for future funding. If caregivers choose this route, any number of policy types and provisions are available to help address their specific needs.

Retirement plans may provide another source of funding. Defined benefit pensions, and defined contribution plans, such as 401(k) and 403(b), often are among the most significant investment assets for many families. It's critical to work with caregivers to balance the needs of their loved ones with special needs, without sacrificing their own need for financial security in retirement.

To ensure that a trust is fully funded when needed (and benefit eligibility is preserved), other legal and financial instruments may come into play for the special needs plan. These instruments may include wills, transfer on death accounts, and other ways that assets may pass to beneficiaries due to titling, transfers, and beneficiary designations. It's critical to ensure that all intended assets are set up to fund a special needs trust (where applicable), instead of going to the beneficiary directly.

The special needs planning process is an integrated one, requiring input from individuals and their families together with the experience and knowledge of a specially trained financial advisor.

THE 'ABLE' OPTION

Trusts come with several benefits, but they also may carry the disadvantages of significant set-up costs and required administration, along with potentially unexpected tax obligations that can decrease the amount of funds available to care for persons with special needs. To maximize clients' special needs funds, consider an ABLE account.

Created by the Achieving a Better Life Experience Act of 2014, ABLE accounts are tax-advantaged savings plans for people with special needs and their families that won't affect their eligibility for SSI, Medicaid, and other government benefits. The total annual contributions for a single tax year are \$15,000; in addition, ABLE beneficiaries who work and earn income but do not participate in an employer's retirement plan can add an additional amount of up to \$12,060, for a maximum annual contribution of \$27,060. Annual contribution limits aside, ABLE accounts offer several unique distinctions.

Many ABLE accounts offer users immediate debit-card access. That liquidity gives people greater ability to obtain money faster for qualified expenses, such as education, transportation, employment training and support, healthcare expenses, and other services that can improve the health, independence and quality of life for a person with special needs.⁷

Housing, in particular, is an expense that ABLE accounts are uniquely positioned to help fund. Distributions for housing expenses that come from a special needs trust may reduce government

benefits, but they are allowable under ABLE accounts. This alone may be reason enough for some families to add an ABLE account, even if they already have a special needs trust in place.

Another advantage of ABLE accounts is, due to the recently passed ABLE Financial Planning Act in December 2017, clients can roll over money from a 529 college account into a beneficiary's (or qualified family member's) ABLE account.

In most states, ABLE accounts can be established with as little as \$50. This lower initial contribution could be a significant advantage for families with limited available funds.

CONCLUSION

The special needs planning process is an integrated one, requiring input from individuals and their families together with the experience and knowledge of a specially trained financial advisor. The entire process—from visioning to funding—is extensive and requires complex projections and contingency planning. A well-designed special needs plan, supported by the proper resources, legal structures, and funding vehicles, can give families much-needed peace of mind knowing that they've taken all of the available steps to plan for their own goals and the goals of their loved ones with special needs. ●

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