A Question of Special Needs

How Much Do We Need to Fund a Special Needs Plan?

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caregivers plan for the future they envision.

How Much Do We Need to Fund a Special Needs Plan?

According to a report from the U.S. Department of Health and Human Services, about one in four Americans lives with a short- or long-term physical or developmental disability,[1] which doesn't even take into account all forms of disabilities, such as those resulting from mental health diagnoses. In addition, one in five American workers[2] report that they devote up to 32 hours each week acting as caregivers to loved ones with a short- or long-term physical or developmental disability.[3] This group of people with disabilities and special needs and their caregivers represents a significant group of individuals in our communities, states and counties. While these statistics tell us that caring for people with disabilities and special needs is a widespread issue and concern, they don't tell us if anyone is addressing the growing and specialized need for long-term financial planning.

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[1] Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: http://dx.doi.org/10.15585/mmwr.mm6732a3 (2018)

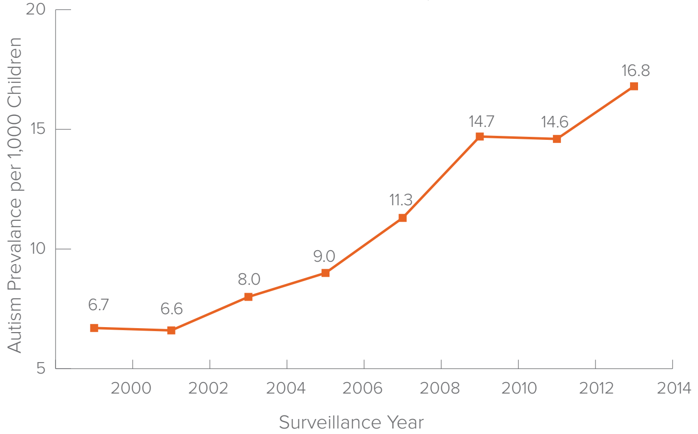
[2] U.S. Department of Health and Human Services. Caregiver Resources & Long-Term Care (2017)

[3] Age Wave/Merrill Lynch. The Journey of Caregiving: Honor, Responsibility and Financial Complexity. (2017)

A Closer Look

According to the U.S. Centers for Disease Control's most recent report in 2014, one of every 59 children in the United States had a diagnosis of autism spectrum disorder (ASD).[4] The estimated total annual costs for caring for all children and adults in the U.S. with ASD ranges from $11.5 billion to $60.9 billion. This significant economic burden represents a variety of direct and indirect costs, from medical care to special education to lost parental and employee productivity. On average, medical expenses for children with ASD were 4 to 6 times greater than for children without ASD. In 2005, the average annual medical costs for Medicaid-enrolled children with ASD were $11,000 per child, or about six times higher than costs for children without ASD ($1,800). And in cases where children with ASD required intensive behavioral interventions, the average annual costs per child were $40,000 to $60,000.[5]

Identified Prevalence of Autism Spectrum Disorder

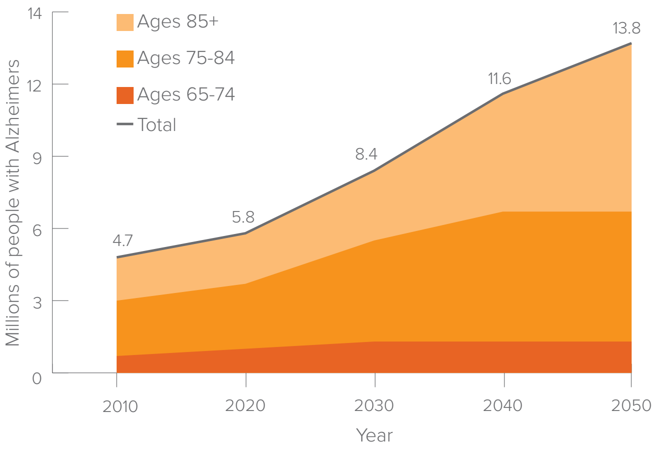


Source: https://www.cdc.gov/ncbddd/autism/data.html

On the other side of the caring issue, 5.8 million older Americans have Alzheimer's disease. By 2050, that total is expected to reach 13.8 million people. Right now, the annual cost of caring for those living with Alzheimer's is $277 billion, with that number projected to exceed $1 trillion annually by 2050. Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers. Nearly half of all caregivers who provide help to older adults do so for someone with Alzheimer's or another dementia.[6]

While millions of Americans live with ASD or Alzheimer's, many more require care because of a variety of disabilities and special needs, including those related to aging.

Projected Number of People Age 65 and Older in the U.S. Population with Alzeimer's Dementia, 2010 to 2050



Source: https://www.alz.org/media/Documents/facts-and-figures-2018-r.pdf

Regardless of the age or diagnosis of a person with a disability or special needs, one of the most common questions asked by families who are working through the special needs financial planning process is, "How do we know how much money we need to fund a lifetime of care for my loved one?"

Determining the amount to fund a plan to care for a person with a disability or special needs throughout his or her lifespan is a process that varies by case. That amount of funding is a key driver of the overall financial plan for caregivers and people with special needs and disabilities. Although there is not a one-size-fits-all answer, Voya Financial, through its Voya Cares® program, is addressing the need for a more exacting procedure through a proprietary process that estimates the amount of funding needed for disability and special needs planning. This paper will explore a number of variables to consider to help all parties build an individualized and customized plan.

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[4] Christensen DL, Maenner MJ, Bilder D, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 4 Years — Early Autism and Developmental Disabilities Monitoring Network, Seven Sites, United States, 2010, 2012, and 2014. MMWR Surveill Summ 2019;68(No. SS-2):1–19. DOI: HYPERLINK "http://dx.doi.org/10.15585/mmwr.ss6802a1"http://dx.doi.org/10.15585/mmwr.ss6802a1External

[5] Centers for Disease Control and Prevention. Autism Spectrum Disorder (ASD) Data & Statistics, Prevalence: https://www.cdc.gov/ncbddd/autism/data.html.

[6] Alzheimer's Association. Alzheimer's and Dementia: Facts & Figures: https://www.alz.org/alzheimers-dementia/facts-figures.

Helping Families Envision the Future

The answer to the question, “How do we know how much money we need?” will be different for every family. Several factors that may affect the calculation include:

- Age and life expectancy of the caregivers and persons with disabilities and special needs
- Diagnosis and severity of the disability or special needs
- Lifestyles that caregivers wish to maintain for themselves and their loved ones with disabilities and special needs, while the caregivers are alive, as well as after their deaths
- Financial assets of both the caregivers and persons with disabilities and special needs

A foundational key to successfully funding a special needs plan is determining the vision for the future for the person with a disability or special needs, including input from the person whom the plan addresses. At the same time, a similar vision should be considered for current and future caregivers. This visioning process looks at all aspects of the individual’s future life, such as his or her hopes and dreams regarding education, housing, social and recreational activities, employment and healthcare. In disability and special needs situations, an instrument like a Letter of Intent (LOI) can capture the required specifics needed to achieve the desired vision of the future.

Creating a Letter of Intent

While the LOI isn’t a legally binding document, it can serve as a syllabus or guidebook to guardians and caregivers. At a very minimum, your LOI should include information about family and medical history, as well as the following:

- ✓ General overview of the present and vision for the future
- ✓ Daily schedule
- ✓ Food likes, dislikes and allergies
- ✓ Current education, Individual Education Plan and vision for future education
- ✓ Benefits received and recertification dates
- ✓ Current and potential employment
- ✓ Residential environment
- ✓ Social activities enjoyed
- ✓ Religious affiliation and practices
- ✓ Successful behavior management programs, as well as those that have not been successful

Below are special considerations to supplement the conventional planning process that can help determine a complete vision of the future for a person with a disability or special needs.

1. **Healthcare:** Estimating healthcare expenses is generally an important step in all future financial planning.
   - Medical insurance and maintenance healthcare
   - Treatment, counseling and therapies currently being received, if any
   - Possible changes to that mix of treatments in the future
   - Of the services now used, those that are covered by employer benefits, insurance, government benefits, and those that are not

2. **Food and clothing:** Food and clothing may seem to be minor expenses when compared to healthcare, housing and other services, but these costs can add up over a lifetime.
   - Food allergies, dietary needs or favorite foods
   - The need to wear or avoid specific clothing because of hypersensitivity, allergies or other conditions

3. **Education:** Planning for education begins at diagnosis, as early as birth, through early intervention programs. From preschool through 12th grade, the educational services required by a person with a disability or special needs likely will be addressed by the local school system, as mandated by the Individual with Disabilities Education Act (IDEA). A key consideration in this category is post-secondary education, when a child with a disability or special needs ages out of the school system, generally between 18 and 22 years old. While some colleges, universities and vocational schools offer programs that cater to people with disabilities and special needs, these programs may not be required, as defined by IDEA. Note that additional education and services within or outside

of the school system may be preferred at any age for a person with a disability or special needs.

- Additional accommodations needed in primary and secondary school
- College, trade school or a life skills program enrollment
- Transportation or assistance needed to attend school

4. **Benefits received:** Without careful planning, a person with special needs could lose government benefit programs.
    - Identify all current and potential government benefits received by the person with a disability or special needs—or that could be received in the future
    - Apply for all benefits, whether or not a person with a disability of special needs may or may not qualify, to make sure nothing is missed. When in doubt, apply
    - Be aware of recertification dates and requirements to maintain benefits after initial application
    - Money from family gifts, inheritances or pension income that may be received upon the retirement or death of caregivers
5. **Employment:** Any employment income earned may affect government benefit programs.
    - Types of work and activities enjoyed by the person with a disability or special needs
    - Salary resulting from that work or activity
    - Need for a job coach or adaptive transportation to travel to work and the source of payment for those services
6. **Residential environment:** The vision of the future should provide details regarding living arrangements throughout the lifetime of the person with a disability or special needs.
    - Residing in the family home or in another residence
    - Residing in the same community as his or her caregiver
    - Independent living as an adult before and after the caregivers' deaths
    - Changes to current living arrangements, as the person with a disability or special needs grows older
    - Type of home desired—an apartment, home, group facility, etc.
    - A growing trend toward community inclusion has led to families purchasing a home or transferring ownership of their own homes to become a group home, often with the help of a local nonprofit organization
    - Along with the expense of purchase, rent or assisted-living fees, other housing costs that the person with special needs may incur. (Examples may include accessibility modifications, separate spaces for independent living at home and overnight caregiver accommodations.)
7. **Recreation and social environment:** While other factors are more quantifiable, the emotional and social well-being of people with disabilities and special needs is also critical for a well-rounded and positive lifestyle.
    - Types of social activities enjoyed by the person with a disability or special needs
    - Money allocated toward social and recreational activities

It's important to remember that the holistic special needs planning process includes consideration of the entire family—caregivers and dependents who will be living together—including the person with a disability or special needs. Caregivers, family members and individuals with disabilities and special needs each should contemplate their own futures and develop financial plans for education, retirement, healthcare, travel and other goals, as well as future wealth transfers of their estates, where applicable.

Once the vision of the future is completed, it is helpful to think through a **two-step process** to determine the best special needs plan for families caring for people with disabilities and special needs.

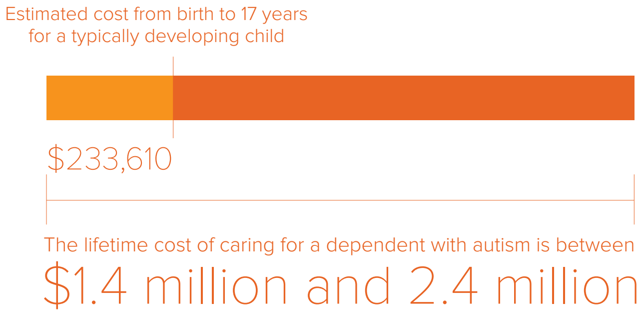
STEP 1: How Much Do We Need?

Using the established vision for the future as a reference, the cost of providing each of the elements that make up that scenario can be estimated and captured. Credit all current financial resources, along with future income flows, against the total cost to determine the amount needed to make up any shortfall.

Below are some key steps in this process:

1. **Start with a budget based on the family's current situation:** Based on the visioning session, near-term and not-too-distant future expenses for the person with a disability or special needs are itemized. One of the most challenging parts of this process might be dividing up food, utilities and other shared living expenses that occur when the person with a disability or special needs is living with primary or other caregivers.

2. **Account for future changes:** There may be resources and studies that can help quantify projected total lifetime costs by diagnosis. These national averages can serve as a benchmark that can be applied to a family's personal situation. For example, in the United States the estimated expense to raise a typically developing child from birth through age 17 can provide an initial reference point: $233,610.[7] However, that amount will most likely be much higher for care provided to a person with disabilities and special needs, depending on the type and severity of the diagnosis. Existing data on a particular diagnosis may be available to help with this process. An article in *JAMA Pediatrics* estimated that "the lifetime cost of caring for a dependent with autism is between $1.4 and $2.4 million.[8]



3. **Create an estimated budget for after the caregivers have passed away:** Building on the current-situation budget, changes that are needed upon the death of one or more caregivers must be determined. The plan also should take into account contingencies in case of premature death of one or both parents or caregivers, such as when a husband or wife passes away. Plans must be in place in case of an event, such as catastrophic injuries or disabilities, that leave one or more caregivers unable to attend to the person with a disability or special needs. Planning for these contingencies includes providing the necessary funding to maintain the current lifestyle of the person with a disability or special needs. Naming a successor caregiver to assume the duties of the primary caregivers is also an important part of the planning.

4. **Consider the special needs plan in the context of retirement and other financial goals:** It's a balancing act for those with loved ones with a disability or special needs, as so much of their time and financial resources go into advocacy and day-to-day activities related to care. When planning, the needs of the entire family should be taken into consideration, including education for other family members and leaving a legacy. Caregivers must be able to fund their own retirement, health care, travel and other future goals. While this balancing act may seem extremely difficult at times, it is possible to balance other saving and spending priorities for caregivers.

A Sum of the Parts: Arriving at a Total

Now that the hard work of estimating expenses has been accomplished, it's time to determine how much funding needs to be set aside or accumulated to help make that vision of the future a reality.

Voya Cares has developed a unique formula that uses an inflationary factor and an assumption of growth, along with a prediction of the mortality of the individual with a disability or special needs and successor caregivers. From that calculation, financial resources are then considered, as the individual and or caregivers want them applied. These calculations indicate gap amounts, based on the various scenarios, which could be inserted into a financial plan.

STEP 2: How Do We Accumulate the Needed Funding?

One of the keys to financial planning for people with disabilities and special needs—once the amount required to set aside is identified—is determining the proper legal structure for current and future assets, while preserving eligibility for government benefits and maintaining the desired quality of life.

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[7] Lino, M., Kuczynski, K., Rodriguez, N., and Schap, T. (2017). Expenditures on Children by Families, 2015. Miscellaneous Publication No. 1528-2015. U.S. Department of Agriculture, Center for Nutrition Policy and Promotion.

[8] Ariane V. S. Buescher, MSc; Zuleyha Cidav, PhD; Martin Knapp, PhD; et al: JAMA Pediatrics: 2014;168(8):721-728. doi:10.1001/jamapediatrics.2014.210.

Legal Structures

If in the course of the planning process, a determination is made that a special needs trust is an option to collect the assets required to fund the plan, the next step in the process is determining what type of trust will be appropriate. Along with providing funds for adequate healthcare and lifestyle needs, trusts are typically used to maintain eligibility for means-tested government benefits.

A Matter of Trusts

A special needs trust may be an effective way for caregivers to ensure that the person for whom they are caring with a disability or special needs receives financial, physical and mental health support, without depleting the caregiver's retirement funds and other savings. Equally important, a special needs trust can protect the eligibility of a person with a disability or special needs to receive government benefits that aid in his or her care. Monetary limits (assets and income) for a person with a disability or special needs are extremely restrictive. Unfortunately, if the assets of persons with disabilities or special needs are even one dollar over the limit, their benefits may be reduced or eligibility jeopardized. Special needs trusts go a long way in preserving this eligibility.

A trust generally includes three main roles: the person setting up the trust, known as the grantor; the person receiving trust funds, the beneficiary; and the person who manages the trust, the trustee. A trust document names the trustees and should designate a successor trustee to assume control, if the original trustee can no longer oversee the trust because of disability, illness or death. In most cases, caregivers will name a family member or friend as a trustee. Other times, caregivers may name a third-party trustee to help manage the funds.

Whether the grantor serves as trustee, chooses another person or turns to a third party, naming a successor trustee is recommended—preferably multigenerational successors—as are co-trustees, which may be an option. While some families may initially decide not to create a trust because they feel they don't need to rely on government benefits, establishing a special needs trust is still a wise move. First, special needs trusts offer benefits and protections that other types of trusts don't provide. Second, a caregiver's financial situation could dramatically change and leave him or her unable to look after the person with special needs. Third, the condition of the person with special needs could worsen dramatically. Whatever the case, a special needs trust is sometimes the best way to ensure that a person with a disability qualifies for government benefits, when needed, and to protect the caregiver and beneficiary from financial losses and other unforeseen issues that could reduce those assets.

Know Your Trusts

On a high level, below are different types of special needs trusts:

- **A first party trust** is used when assets that belong to the individual with a disability or special needs—the trust's beneficiary—fund the trust, such as an inheritance, child support payments as a result of a divorce or an accident settlement. Because the assets are owned by the trust, the eligibility of the beneficiary for important means-tested government benefits like Medicaid and SSI—which are dependent on an applicant's income and assets—will not be compromised. Upon the death of the trust's beneficiary, remaining trust assets will be used to pay back the government for any Medicaid benefits the person with a disability or special needs received. Any remaining assets after this Medicaid payback can go to a designated remainder beneficiary.
- An exciting new option for setting up a first party special needs trust is the ability of the beneficiary to establish a **self-settled** first party trust on his or her own. Previously, persons with disabilities or special needs had to rely on a third party to establish a trust, even if they were mentally capable to do so themselves. This alternative was signed into law in December 2016 as part of the Special Needs Trust Fairness Act and provides persons who are disabled but mentally capable to not only establish the trust, but also set very specific guidelines regarding the use of the funds, in instances when his or her condition may worsen.
- **A third party trust** is funded with assets from someone other than the beneficiary, such as parents or family members who want to financially assist the individual with special needs or a disability. Like a first party trust,

assets in a third party trust do not affect the beneficiary's access to SSI, Medicaid and other means-tested benefits. However, third party trusts do not include a payback provision for Medicaid benefits received, so remaining assets can be passed to family members or any other named remainder beneficiary upon the death of the original beneficiary.

One of the more common ways to fund a third party trust is with direct monetary contributions from sources other than those belonging to the beneficiary. However, real estate, jewelry, patents, businesses, paintings, stocks and bonds, vintage cars or other items of worth may be held in the trust, and the money received from the sale of those items may be used to fund the trust. Caregivers also may establish guidelines so that, upon their deaths, proceeds from their Individual Retirement Accounts (IRAs), stock investments, mutual funds and other sources can be placed in a trust. In some instances, retirement plans, when deposited in one lump sum, could jeopardize the beneficiaries' benefits eligibility and result in excessive taxes, if not liquidated first. Naming a special needs trust as the beneficiary of an employer-sponsored retirement plan, if not rolled over into an IRA, will result in liquidation and taxation of the funds.

Although parents and grandparents often are contributors to a third party special needs trust, anyone can contribute, including siblings and other relatives, family friends, co-workers, community and religious groups and others. Too often, however, well-meaning relatives, not just caregivers, will give money, property and other items of value through a will or as a gift to a person with a disability or special needs. Though generous, those bequests could jeopardize public assistance government benefits, if directly inherited or presented to a person with special needs. Because eligibility for public assistance government benefits is means-tested, as long as the resources of persons with disabilities and special needs are less than a specified amount of assets and income, they likely will be eligible. When these gifts and inheritances are directed to a third party special needs trust, which is not controlled by the beneficiary, they will not affect eligibility.

- **A pooled trust** is established and administered by a non-profit organization that allows caregivers and beneficiaries to pool their resources with those of other caregivers and beneficiaries for investment purposes, while still maintaining separate accounts for each beneficiary. This is sometimes an option when no trustee can be found or the caregiver's assets for funding the trust are limited. The type of pooled trust chosen—first or third party—will impact the remaining benefits after the beneficiary dies. A Medicaid payback provision exists with a pooled trust option upon the death of the beneficiary. In addition, a portion of the remaining assets may go to the non-profit managing the trust or to a named beneficiary.

  Keep in mind that although first and third party special needs trusts must be established while the beneficiary is less than 65 years old, contributions can be made to both types of trusts, even after the beneficiary passes age 65. In contrast, a pooled trust can be created for a beneficiary at any age.

A Trust for Everyday Living

While a special needs trust can protect a person's eligibility for government benefits, this is not the only reason they are established. The main goal of the trust is to guarantee a comfortable and enriching lifestyle for the person with special needs during the primary caregiver's life and beyond. For that reason, the guidelines for distributing trust funds need to be clearly defined in writing. This is especially important in cases where the caregiver may not be the trustee, or a successor trustee assumes control of the funds.

Suppose that the beneficiary likes to play video games, and the current trustee uses trust funds to buy new games for the beneficiary every other month and a new gaming console every other year. If not included in the trust guidelines, a successor trustee could decide not to buy new games or equipment within specified periods—or at all. If the gaming provision is part of the trust language, all trustees of the fund have a legal and fiduciary obligation to buy new games and consoles. In another example, a beneficiary may have a provision in the trust plan that he or she must receive a new vehicle every three years. Though a successor trustee may believe that such a purchase is extravagant or unnecessary, he or she will remain legally obligated to purchase a new vehicle, as per the trust guidelines.

Arm the Trustee with Knowledge

A special needs trust will provide long-term peace of mind for caregivers and protect trust funds and government benefits—as long as the trustee understands the rules for distributing funds. A misinformed trustee who lacks the necessary knowledge could put at risk both the financial assets and government benefits of the person with special needs.

A good rule of thumb is that a trustee should never directly distribute funds to the beneficiary. Doing so could disqualify the beneficiary for government benefits and enable others to claim both those funds and items purchased with them through lawsuits, tax liens and other methods. Caregivers should be advised not to set up personal bank accounts in the name of the person with a disability or special needs.

Instead, the trustee should use funds from the trust to pay for clothing, gaming equipment, medicines, home care help, adaptive equipment, travel, cell phone and internet service, pets and service animals, computers, clothing, transportation, tickets to concerts or sporting events, furniture and even groceries and other everyday necessities.

In addition, the trustee is responsible for keeping detailed records on fund contributions and distributions, submitting reports to government benefit agencies, if required, and filing state and federal tax returns. Trustees must understand various and often hard-to-understand IRS rules governing the allowable dollar amount of gifts people may give to a person with special needs, without affecting his or her benefits. The trustee will also distribute any remaining funds in the trust, when the beneficiary dies or if the trust is ended for reasons other than the beneficiary's death.

Funding Options and Considerations

For families who decide to establish a special needs trust, the next step is to identify the best funding options. Understanding the considerations regarding the sources of the funds and how they will be used can help make that process easier to navigate.

The burdens of caregiving often bring into play another important consideration. Often the stress of caregiving takes a toll on family dynamics. If there is a divorce in the family, additional logistical, caregiving and financial complexities may be involved. For example, child support may disrupt government benefits, unless directed to a first party special needs trust. Families should work with advisors and attorneys who are experienced in divorce planning and the financial concerns of people with disabilities and special needs.

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

Other considerations when funding a special needs trust include:

- Determining if the trust needs to be funded immediately or upon the death of the caregivers can have a dramatic effect on the amount of funds needed.
- Preserving the trust corpus, or principal, requires more funding to ensure the balance is large enough to generate income without spending it down. This preservation strategy is a very conservative approach that allows the assets to be sustainable for long-term caregiving. The opposite, a spend-down strategy, will require less funding, because both the corpus and the interest and growth can be spent. With a spend-down strategy, caregivers take on more risk of running out of assets, if the future doesn't go exactly as they've planned. The time horizon is also an important factor in determining funding options.

Tax Impacts on a Special Needs Trust

Caregivers should consult a tax attorney to help consider how taxes might decrease their available assets, over time, as tax rates on trusts can be higher than individual income tax rates.

A desire to leave a legacy may mean Medicaid paybacks can affect the amount of money—if any—that the secondary beneficiary receives upon the death of the primary beneficiary. First party and pooled trusts include Medicaid payback provisions, while third party trusts do not. Careful planning and structure of the assets can help ensure that excess funds are available for future beneficiaries, instead of being recaptured by the state Medicaid office.

A Choice of Trust Funding Instruments

So what are the most appropriate instruments for special needs trust funding? The above factors are all important considerations, but the ultimate decision will depend on the situation of the caregiver and person with special needs, as they go through the planning process. Below are a few of the more common sources to fund a special needs trust and considerations for each:

- **Current assets:** Assets can be added to a trust at any time. But if a trust must be funded immediately so that it can be used now, a family's current assets are the best source, including earned income, investments, savings and proceeds from the sale of real estate and personal possessions.
- **Retirement plans:** Defined benefit pensions, and defined contribution plans, like 401(k) and 403(b), are often among the most significant investment assets for many families. It's critical to remember, however, to balance the caregivers' retirement goals with those of loved ones with special needs, without caregivers sacrificing their own future financial security. Also, remember that only the proceeds of a retirement plan—and not the plan itself—can be used to fund a trust.

  For military and civil servant retirees, after their death the Survivor Benefit Plan (SBP) ensures a continuous lifetime annuity for their dependents. The annuity, which is based on a percentage of retired pay, is not taxable nor will it affect the government benefits eligibility for a person with a disability or special needs.
- **Life Insurance policies** are a recommended funding source, if the person with special needs does not need special needs trust funds until after the death of his or her caregivers. Depending on the needs of the loved one and the caregiver's resources, any number of life insurance policy types and provisions are available to help address a family's specific need. One advantage of this source of funding is that contributions made to a special needs trust from life insurance proceeds are tax-free.

The type of life insurance selected as a funding vehicle depends on a variety of factors:

- **Second-to-die life insurance:** Also known as survivorship policies, second-to-die life insurance provides a way to fund a special needs trust when a secondary caregiver dies after the primary caregiver, and because it is based on two lives, premiums are often more affordable. One consideration is that if the main wage-earner dies first, before retirement, the remaining caregiver may need payouts from a life insurance policy for everyday living expenses, healthcare and other costs. If that's the case, a second-to-die policy could create unforeseen financial hardships for the remaining caregiver and person with a disability or special needs. One prudent option, if the main earner in the relationship makes it to retirement, is to switch from a term- or whole-life policy to a survivorship policy, at that time.
- **Term-life insurance:** Another option for funding a special needs trust, term-life insurance policies generally cost less than whole-life policies for younger individuals and come with guaranteed payouts, if the policyholder dies within a defined period. If the policyholder outlives the initial policy term (e.g., a specified number of years or during employment with a certain company), he or she can renew that policy. The cost of renewing term life policies may increase, however, as a policyholder's age increases and health may decline.
- **Whole-life insurance:** While term life insurance covers a specified period of the policyholder's life, such as 20 years, a whole-life insurance policy remains in effect until the policyholder dies, assuming premiums are paid. Along with paying a death benefit, whole life carries a cash value, since a portion of the premium

accumulates and grows in an investment account while the policy is in effect. In addition, some whole-life insurance will pay a dividend, which can be contributed to some special needs trusts. If a person with a disability or special needs requires extra or emergency funding before the policyholder dies, a loan can be made against the value of the policy. In that case, fees and loan repayments, with interest, may be incurred by the policyholder.

A Final Word on Trusts

All sources should be considered to fund a special needs trust, depending on the circumstances of the contributors. Other legal instruments may be called into play to be sure that the trust is fully funded when it is needed, such as wills, Transfer on Death (TOD) and Paid on Death (POD) accounts and other assets that may pass to the trust as a beneficiary due to titling, transfers and named beneficiaries. Whatever the source of trust funding, caregivers need to remember that it's critical to ensure that all intended assets are directly contributed to the trust (where applicable), instead of going to the trust beneficiary.

Other Funding Vehicles for Special Needs Plans

Health Savings Accounts (HSAs) are another way to prepare for unreimbursed healthcare costs for a person with special needs. HSAs offer tax savings for participants, but anyone opening an HSA must be enrolled in a High-Deductible Health Plan (HDHP), which means the plan's annual deductible for 2020 can be no less than $1,400 for individuals and $2,800 for families, and out-of-pocket expenses must be at least $6,900 for individuals and $13,800 for families, as well as other restrictions.

The tax benefits of HSAs allow participants to take withdrawals for qualified expenses from both their savings and earnings on the account tax-free, even if the contribution was made with pre-tax dollars. Any unused HSA funds at the end of the year can be rolled over to the next year, and all funds remain intact in an HSA, even if the account holder switches healthcare plans, changes jobs or retires.

Because ABLE Accounts often are used for special needs planning in conjunction with special needs trusts, the following charts explore the features of both.

Features	First Party Trust	Third Party Trust	Pooled Trust
May be best for small funding amounts			x
No limit on amount of funds	x	x	x
Ease of access to assets- debit card			
Housing expenses allowable			
Low/no start-up costs			
Maintains needs-based government benefits eligibility	x	x	x
May be subject to Medicaid payback	x		x
Can be established by the individual with his or her own money	x		x

Features	ABLE Accounts
May be best for small funding amounts	x
No limit on amount of funds	
Ease of access to assets- debit card	x
Housing expenses allowable	x
Low/no start-up costs	x
Maintains needs-based government benefits eligibility	x
May be subject to Medicaid payback	x
Can be established by the individual with his or her own money	x

Created by the Achieving a Better Life Experience Act (ABLE) of 2014, these accounts are tax-advantaged savings options for people with disabilities and special needs that, within limits, do not affect their eligibility for SSI, Medicaid and other means-tested benefits. The total allowed annual contribution for a single tax year is $15,000 (2020). Plus, in the case of ABLE beneficiaries who work and earn income but do not participate in their employer's retirement plan, an additional amount of up to $12,490 (added to the $15,000 annual maximum contribution) can be contributed, for a maximum annual contribution of earned income up to $27,490. Annual contribution limits aside, ABLE accounts offer several unique distinctions:

- **Immediate Access:** With debit card access to some accounts, the funds in an ABLE account can be easily withdrawn for qualified disability-related expenses. That liquidity gives the account holder 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 of a person with special needs.[9]
- **Start-up and taxes:** Many ABLE accounts can be established with a minimum contribution of as little as $50, and earnings in an ABLE account aren't taxed when used for qualified expenses, including those for maintaining or improving health, independence or quality-of-life.[10]
- **Rollovers from 529 Plans:** As of 2018, Congress passed the ABLE Financial Planning Act that allows parents to roll over money from a 529 College Savings account into a beneficiary's (or a qualified Member of the Family's) ABLE account, without being penalized.

  NOTE: Be mindful that there is still a $15,000 annual contribution limitation.

Conclusion

The special needs planning process is an integrated one, requiring input from individuals and families, as well as the experience and knowledge of a specially trained financial advisor and tax consultant. The entire process—from visioning to funding to distribution—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 and required steps to plan for their own goals and the goals and care of their loved ones with disabilities and special needs.

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[9] ABLE National Resource Center. "What Are ABLE Accounts?": http://www.ablenrc.org/about/what-are-able-accounts

[10] Publication 907 (Cat. No. 15308H) Tax Highlights for Persons With Disabilities For Use In Preparing 2018 Returns: https://www.irs.gov/pub/irs-pdf/p907.pdf.

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