

# Financial Wellness:

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*A guide for individuals with disabilities, their families and caregivers*

In collaboration with



Helping people with special needs and caregivers plan for the future they envision.



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# The basics of financial wellness

Financial wellness is a broad and vitally important topic, especially for families that include people with disabilities. *Financial Wellness: A guide for individuals with disabilities, their families and caregivers* is here to help you on your journey.

This booklet was created by the National Down Syndrome Society (NDSS) in collaboration with Voya Cares® to help empower individuals with disabilities, their families and caregivers with knowledge about financial wellness. It has suggestions about how to prepare for the future and aims to be a resource to turn to as different financial questions and challenges emerge.

Providing and paying for a lifetime of care for a loved one with disabilities can be complex and challenging. This guide will examine government and employer benefits to fund care and look at the legal planning you will need to do for your family member. It also will cover everything you need to know about special needs trusts and ABLE accounts.

As you make your way through the guide, you'll be joined by **Jerry, Patti, Jessica and Troy**, who are on the same journey as you are.



## Don't stress out

Financial wellness is one of those things that everyone knows they should master, but few people take the time to do it. At the very least, knowing the basics of saving and spending, especially how to make and stick to a budget, helps you live the life you want to live.

Know that if you stress over money, you are not alone. The vast majority of people—72%—feel stressed about money at least some of the time.<sup>1</sup> For many people, the worry is constant, to the point where issues with personal finances distract them at work.

But it doesn't have to be this way. If you can achieve a sense of financial wellness, it will take a lot of the stress out of daily living, letting you relax, knowing that you can handle whatever the future may hold for you and your loved ones financially.

So, what exactly is financial wellness? How do you know when you're there?

You can think of it in four different ways:

- You live within your means
- You feel confident in your future
- You are prepared for the unexpected
- You feel free to indulge yourself now and again

While these would be how you would *measure* your sense of financial wellness, it's important to recognize that how you *experience* financial wellness will change over time. Your needs and those of your family will be different at different stages of life. But throughout your journey, your goal is to know that you can provide for your family—and that starts with knowing how to provide for yourself. Think of it similarly to when you board a flight, and the attendant tells you that in case of a decline in cabin pressure, affix your own oxygen mask before helping your children with theirs. While it's not necessarily your instinctive reaction, the same strategy applies here.

# The six pillars

Whether or not family members have disabilities, there are certain things to do to achieve financial wellness:

## Protect yourself and your family

To strengthen your financial security and that of your loved ones, you need to think about the worst that can happen to you. Protect yourself for today by having health insurance, accident insurance and the most disability insurance you can afford, and by contributing to a Health Savings Account, or HSA, and ABLE accounts when and where eligible. But also focus on tomorrow; protect yourself and your family with life insurance, long-term-care insurance and various legal documents, such as a will and special needs trusts when applicable.

### Jerry buys life insurance

Jerry is a 40-year-old husband and father of two, one of whom has a disability. He makes \$60,000 at work, where he is covered by a life insurance policy that will pay his beneficiaries \$90,000 should he die while still working there. The \$90,000 wouldn't replace his take-home income for more than two years, so he contacts an insurance agent and purchases an additional life insurance policy that will pay \$500,000 upon his death as long as he is still covered by the policy. The policy also allows him to use the money to pay for his long-term-care needs if necessary, with the remainder going to his beneficiaries. He must make an annual payment, called a premium, but in return he and his family get peace of mind.

## Spend and save with savvy

Good money habits start with organization, and being organized means creating and following a *realistic* monthly budget, with some flexibility and emergency-fund savings mixed in. How do you create such a budget?

First, add together your take-home income, any earnings from savings and brokerage accounts and any supplemental income you might receive. Then subtract estimated taxes you might owe the next year (if taxes haven't already been withheld).

Next, add up what you spend in a given month on essential fixed expenses, such as your mortgage or rent, utilities and other loan repayments; your additions to savings that haven't already been deducted from your pay and discretionary expenses, such as eating at restaurants.



Subtract your expenses from your income. If you have more income than expenses, you can use that surplus to establish an emergency fund (or further build an existing one) and set aside savings specifically to meet your important, lifelong goals. Those savings can be deposited in an interest-bearing bank account or bank savings product such as a Certificate of Deposit (CD). You can also consider investing in stocks, bonds, mutual funds and exchange traded funds (ETFs). However, keep in mind that these investments are subject to various investment risks and it is possible to lose money.

### Jerry and Patti save for emergencies

Jerry's take-home income is \$45,000, and his wife, Patti, brings home \$55,000 a year. Together, that's \$100,000. Their rental income adds another \$20,000 in annual income, for a grand total of \$120,000 a year, or \$10,000 a month. Their monthly essential and discretionary expenses add up to \$7,000 (including setting aside a small amount of money to pay for the taxes on their rental income). They contribute \$1,500 a month to a long-term investment account aimed at retirement and another \$1,000 into a savings account for a down payment on a house, for total expenses of \$9,500. They then put the remaining \$500 a month into a savings account at their local bank, which is intended to act as an emergency fund, and they will continue to do so until that account reaches \$28,500, the equivalent of three months' expenses. It will take them a little under five years of contributing to save three months' worth of expenses in the emergency fund if they maintain the present rate of savings, but their consistent savings will pay off, as they are able to reach their short and long-term goals.

## Honor your emergency fund

What is an emergency fund? Unlike a retirement account or real estate, an emergency fund is money—readily accessible savings—intended to protect you against unexpected financial expenditures, for example, an unanticipated medical bill for you or a loved one.

In the best-case scenario, you will never spend the money in your emergency fund. But in the worst-case scenario, you won't need to dip into retirement savings or go into debt to meet the unforeseen expense, as long as you have an emergency fund.

How much money should there be in your emergency fund? The ideal amount to save is between three and six months' spending during your working years, and as much as a year or more during retirement. If you can't feed the emergency fund from your monthly earnings, take another look at your expenses with an eye toward cutting the least necessary items.

You could also consider putting an annual tax refund toward emergency savings, or adding to it from other windfalls like gifts, bonuses or selling things you no longer need around your house.



### **Jerry and Patti use the emergency fund to pay Jessica's medical bill**

Unfortunately, just after Jerry and Patti saved that \$28,500, one of their children, Jessica, had an unforeseen medical expense of \$10,000. Fortunately, Jerry and Patti had the money in an emergency fund and didn't have to sell any long-term investments, take from retirement savings or go into debt to pay the bill.

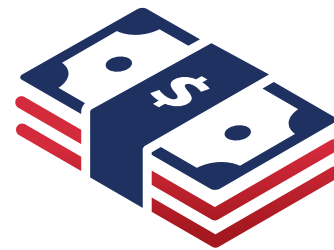
### **Save for retirement**

When you are young, it may seem far off, but the day might come when you stop working. When you do, your continuing sources of income will come down to Social Security benefits and income generated by the money you have saved along the way, or that nest egg itself. And if the nest egg is cracked, you run the risk of outliving your money and being forced to get by on Social Security benefits alone.

There are many ways to save and see the value of your savings rise over time. You can save money in an interest-bearing bank account or bank savings product such as a CD, or you could invest in stocks, bonds, mutual funds or ETFs on an after-tax basis. Or your savings may live in a tax-advantaged defined contribution plan, such as a 401(k) or Individual Retirement Account (IRA); within these plans, you can invest in mutual funds and sometimes stocks and bonds. You can also use a Roth IRA if you meet certain eligibility criteria, which allows your savings to grow free of taxes (subject to certain requirements) for retirement or other goals.

Your time horizon is a key concept in saving for retirement; the earlier you start saving, and the more consistent you are about it, the more likely you are to have enough money in retirement to maintain your lifestyle. Know that savings priorities change over time.

Risk tolerance is an investor's willingness to potentially lose money on an investment. A person's risk tolerance can change throughout their life and determines what type of investments they are likely to make.



If your money grows by 5% a year, for example, a \$10,000 investment that would increase \$500 the first year would rise \$525 the second year, and so on, escalating exponentially as time goes by. In the 10th year, the 5% return would be \$776, and you would have \$16,289. In the 20th year, the 5% return would be \$1,263, and you would have \$26,533, well more than double your original \$10,000. Of course, this example does not take in to account potential fluctuations in account values, taxes, fees or expenses involved in investing.

When you're **younger**: You may be able to take more risks with your savings because you have more time to overcome any downturns. Plus, you'll have years to enjoy watching the potential benefits of compounding returns. This is a great time to start your retirement savings in a Roth IRA or a 401(k) through your work to start building your nest egg.

When you're in **mid-career**: If you haven't started saving for retirement, it's never too late. Just remember, your savings are intended to last through retirement, so keep that long-term focus and save as much as you can.

Also, take advantage of an HSA or FSA and a company match, if available, which will help you pay for the considerable healthcare costs you'll no doubt encounter as you age.

When you're **close to or in retirement**: At this juncture, income generation—your money itself earning money—is the primary focus, particularly if you are at risk of outliving your savings. To make sure your money is still there when you need it, you may want to shift more of your savings to investments with less risk, such as bonds.

### **Jerry and Patti have a nice life in retirement, and leave an inheritance**

Jerry and Patti knew early on that long-term savings was of the utmost importance, and they started saving the very month that they got married through a variety of ways, such as contributions to a 401(k) plan and to an HSA, both of which had a company match. Because they started so early, and saved more over the years as their incomes increased, they were able to eventually retire 40 years later with a nest egg of \$750,000. That \$750,000 provided them with an annual income of \$30,000, and with \$40,000 a year from Social Security, they were able to maintain an income of \$70,000 per year in retirement—and still had the \$750,000 untouched in savings, just in case. If they never need it, then Jessica and her brother, Troy, who has a disability, will inherit that money; Troy's inheritance would be put in a special needs trust to avoid jeopardizing his government benefits.

### Pre-tax contributions

Examples include traditional IRAs, 401(k), 403(b) and 457 retirement plans.

Contributions are deducted from your taxable income.

Growth on retirement-plan contributions is tax-deferred.

Taxes are paid on retirement-plan contributions and any earnings from them when they are distributed.

Other pre-tax employer benefits include medical and dental coverage, group life insurance and health-related savings accounts.

### After-tax contributions

Examples include Roth IRAs and disability insurance.

Contributions are after-tax, so they will not reduce taxable income.

Some workplaces offer the opportunity to contribute to 401(k) plans and other retirement plans on an after-tax basis.

Potential tax-free distribution on contributions and related earnings.



### Manage your debt

It's easy to find yourself in debt. Debt takes on many forms, including student or car loans, a mortgage and using your credit card. All are part of modern-day life, and all involve the use of debt that will potentially have to be repaid with interest.

Simply, debt is the amount of money you owe, and using credit instead of using cash may mean paying interest on the amount owed until the debt is fully repaid. Debt, however, can be a convenient and expedient means to obtain goods or services you wouldn't be able to purchase with cash. On the other hand, debt also represents a slippery slope if it isn't repaid in a consistent way that doesn't accumulate further interest charges. Unpaid debt balances can compound, but in a way that's harmful to your financial health.

Here are some tips to effectively manage debt: Use cash—or a debit card—for daily purchases. Think twice before you use those tempting credit cards. If you do use them, or if you've accumulated a balance, pay down the debt with the highest interest rates first. Adjust your monthly household budget so that you keep saving for retirement even when you are paying down debt.

### Debit vs. credit: what's the difference?

**Debit card:** A debit card is used to transfer money electronically from your bank account to a merchant to pay for a good or service. Because the money is withdrawn from your account, there is no balance due (debt) that might possibly lead to interest payments.

**Credit card:** A credit card allows a customer to purchase a good or service from a merchant and pay for it later. If you pay the balance off within 30 days, you may not owe any interest. But, after that "grace period," interest may be charged on outstanding balances, and additional fees are charged on past-due payments. Some credit cards have benefits such as cash back, rewards or travel points. It is important to select a card that maximizes your benefits.

### Jessica loves—and loses—her lattes

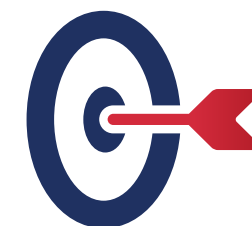
Like many 25-year-olds, Jessica loved her daily lattes. Unlike many 25-year-olds, Jessica also had started saving for retirement and had started an emergency fund, just as her parents, Jerry and Patti, did when they were her age. But after Jessica got her master's degree, she had to start paying back her student loans. She didn't have enough money each month to pay back the loans and also meet all of her other living expenses and savings needs. So, she started skipping the coffee shop and applying the money saved to pay her loans. The lattes tasted great, but she knew saving for the future would last longer.

### Think big

People have dreams. For some, that means buying a house. For others, it might mean further education, starting a business or taking that big vacation. Consistently though, being debt-free is important when retirement comes and incomes are usually vastly reduced. To help make those dreams come true, start by writing down your wishes. Know their costs and save up for them. Maximize those savings by choosing the most appropriate accounts and investments for your time horizon.

### Troy is ABLE to live on his own

Troy's disability never kept him from working, once he was old enough. His job in the back office of a big bank paid him enough that he was able to save money in an ABLE account started by Jerry and Patti many years earlier. Troy saved enough in his ABLE account to move into an independent living community and pay his own rent each month.



### Some savings (and spending) steps for people with a disability

Create and follow a realistic budget that leaves room for the occasional discretionary expense.

Once you tally your essential expenses and long-term savings needs, you'll know how much money you have left for non-essential expenses each month or even each week.

Prioritize how you want to spend your discretionary money. For example, do you prefer to go to the movies or to purchase video games—or both?

If eligible, open and use your ABLÉ account for discretionary spending, or for other goals you want to save up for.

Use cash or debit cards for all spending, if possible. If you must use a credit card, make sure you pay it off each and every month if you can.

Maximize your workplace and government benefits to increase income and savings.

*Tip: If saving for the cost of your long-term goals seems too daunting to be accomplished in a preferred time frame, don't despair. Look for some monthly expenses you feel comfortable cutting and take a long-term view.*

# Financial wellness for families in the disability community

Now that you feel more comfortable with the overall concept of financial wellness on a personal level, let's look at it in the context of a family that includes someone with a disability.

As we noted, your ultimate goal is to provide for your family and take care of those with a disability or special need. It's not the easiest process to master; the rules and regulations surrounding government and workplace benefits are numerous and complex, as are the legal considerations.

But on the positive side, there are savings vehicles, such as special needs trusts and ABLÉ accounts, that you can use to provide for your family members with a disability, and once you understand how the system works, you can make it work for you.

## Special needs financial planning

A good place to begin any discussion of special needs financial planning is with this 13-item checklist, which you can refer back to at any time to help gauge your family's progress on the road to financial wellness.

Have you:

- Created a broad, far-reaching Life Care Plan that covers long-term care for your family member?
- Written a "Letter of Intent" or "Letter of Instruction" concerning your family member's needs, both now and in the future?
- Had a family meeting to make sure everyone knows about—and where to find—the Life Care Plan and Letter of Intent?
- Identified all the ways you can create the future you and your family member envision, such as government benefits, employer benefits, insurance and personal assets?
- Reviewed all medical-health-plan options and coverages, including what it takes to qualify for Medicaid and Medicare and the Children's Health Insurance Program as well as the details of your plan at work?
- Looked at available resources for managing care, including online?



- Researched all the benefits available to you at work, especially insurance policies (both basic and supplemental coverages) and how they can help you manage your tasks and supplement your special needs plan?
- Chosen a guardian, trustee and successors to oversee the care and resources of your family member should you be unable to?
- Used a wide variety of legal tools, for example, wills, trusts, durable powers of attorney and living wills/advanced directives to devise your estate plan?
- Studied all beneficiary designations, titling or ownership to make sure any inheritances won't impede your family member's government benefits?
- Talked to an attorney who specializes in first party, third party and pooled special needs trusts to determine which is the proper fit for you and the family member?
- Considered starting an ABLE account to save for and manage disability-related spending?
- Carefully thought through the following considerations before your family member turns 18?
  - Will the family member with a disability need help taking care of themselves and/or their finances?
  - Do they have any particular social and/or recreational interests?
  - Do they plan to work?
  - Will they need any specific transportation and/or housing accommodations or anything else that improves quality of life?

# Make a plan for a lifetime of care

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A holistic financial plan is a roadmap. It lays out how to pay for the care of your family member with a disability for the rest of their life, even if they outlive you, and balances the costs of care with the cost of your other financial goals. A holistic plan considers care needs from personal, legal and financial perspectives, and is flexible over time. Using the plan lets you look at your current financial situation and focus on what you might need to do financially in the future.

Your first step in crafting a holistic plan is to create a budget. After examining your spending, anticipate how your spending will change and create an emergency fund. Find professionals who can help you: attorneys, financial advisors and accountants with expertise in the needs of people with a disability. They will ensure that no one part of your plan contradicts another or jeopardizes your benefits.

Depending on the age and diagnosis of you and your loved one, your plans may need to cover three main life stages. Here are some tips to consider at each stage:

## Up to age 3: diagnosis and early intervention

- Create a network. Friends, family, other families, professionals in the special-education community, physicians, clergy, social-service case workers and advocacy organizations are all knowledgeable resources for you to reach out to for support, including support on financial issues. And don't be shy; they are there to help.
- Consult a financial professional. It's never too soon to start planning for the future. Early in your loved one's life, it might make sense to start an ABLE account and make the most of your other savings and investment options. But, don't neglect your own retirement savings either.
- Inquire about non-federal governmental early intervention and disability services that may be available to your family—and how they are paid for. Physical and speech therapy, counseling, assistive devices and other services may all be available to you. There may be Medicaid waiver programs in your state that can help with the costs.
- Write your Letter of Intent and remember to modify it as circumstances change. The letter contains financial and other information about your loved one and provides information for their proper care when their usual care provider is no longer in the picture.
- Buy or otherwise obtain a life insurance policy through work that will replace as much of your annual income as possible. Such policies ultimately can be used to fund a trust or to leave money for your other family members. Pay close attention to the titling and ownership of policies and the naming of beneficiaries.





### An ABLE account, in brief

An ABLE account is a savings account for people diagnosed with a disability before the age of 26. It's a great place for parents to save for their child with a disability's future expenses—and to receive gifts from people who want to show their support for the child without risking the child's government benefits. All earnings are tax-free.

You can establish an ABLE account in your state, or sometimes in other states where available to non-residents. For more information, please see page 31 of this guide; the NDSS [webpage](#) on the ABLE Act; or use this [map tool](#).

### Age 3 to 22: school years, the Individual Education Plan (IEP) and transition into adult life

- Hire a special-needs attorney to develop or review existing wills, medical directives, powers of attorney and trusts. Inheritances are well meaning, but unless placed in a trust, can jeopardize the financial strategy created for a child with a disability.

*Tip: Remember that asset and income limitations may apply when seeking needs-based government benefits. Exceeding them could jeopardize eligibility for those benefits. Prior to age 18, the assets and income of the household count towards these limits, but after age 18, eligibility is based solely on the person with the disability. If necessary, consider ways to shrink the assets of the person with the disability below \$2,000 or transfer the assets to a trust, prior to their turning age 18. Doing this may qualify the person with a disability for benefits the family otherwise couldn't access.*

- Explore any tax breaks or expense write-offs if your child with a disability attends a private school. If the child goes on to some form of education beyond high school, make sure the costs are viewed holistically in the context of your entire family.
- Prepare financially for the individual with a disability's housing needs during adulthood. This might require saving for an addition to the family home, purchasing or renting a separate home or paying for placement in assisted living that may or may not include other people with a disability.

### Age 22 and beyond: the rest of the family member's life

- Supervise the creation of a special needs trust. These trusts pay for certain living expenses incurred by a person with a disability, throughout their lifetime. There are different kinds of special needs trusts, and they are financed from a variety of

sources, for example, gifts, inheritances, life insurance and other policies. Special needs trusts play a key role in the financial life of a person with a disability because the funds are not typically counted when the person seeks to qualify for government benefits.

- Find job coaching and/or on-the-job support. People with a disability are entering the workforce more than ever before, so your loved one may have opportunities for employment. If they need a little help finding or maintaining employment, there are coaching and support programs that can help, including the Ticket to Work program and Transitional Employment programs. (See [SSA.gov](#) for more information.)
- Build a plan to cover transportation costs, in the absence of a caregiver, should they factor into the daily life of the person with a disability.

### Basics on beneficiaries

If you have financial assets, such as a life insurance policy, a bank account and/or a retirement plan, or accrue them over time, then you probably also have decided who would inherit the assets when you die. These people are called beneficiaries. On paper, the naming process sounds easy enough, but it's a lot more complicated for families with loved ones with a disability.

For example, if you have an adult child with Down syndrome, your child may be receiving Supplemental Security Income (SSI) payments to help with caregiving, therapy and other associated costs. However, if your child directly inherits financial assets by virtue of being a formal beneficiary, they may exceed asset and income limits associated with certain needs-based government benefits, resulting in disqualification. Such benefits include not just SSI, but also Medicaid, housing assistance and the Supplemental Nutrition Assistance Program (SNAP).

The solution is to work with a special needs attorney to create a special needs trust and name the trust as the beneficiary instead, allowing the child with a disability to remain eligible for the needs-based government benefits while drawing from the trust.

But your role doesn't stop there. In addition to routinely reviewing your beneficiary designations and other estate-planning issues, it's important to communicate with your wider circle of loved ones to ensure that otherwise well-intentioned gifts for the child won't compromise his or her benefits. You may also have to confer with the rest of your family's financial advisors to ensure the child isn't a direct beneficiary of your family members' estates.

# Government benefits

Luckily, there are a number of financial government benefits to help your family members with a disability proceed through life. And they are not just federal-government benefits; some are available on the state and community level, too. Among these benefits, Supplemental Security Income, or SSI, and Medicaid, are what's known as means-tested government benefits, meaning qualification for them depends on income and assets. Social Security Disability Income, or SSDI, isn't means-tested and offers a potential financial lifeline to a child with a disability whose parent also has a disability.

Prior to turning 18, the eligibility of a person with a disability for SSI and Medicaid depends upon the income and assets of the person's guardian(s). Once the person with a disability turns 18, their own income and assets become the determining factor. As of 2021, to qualify for the benefits, an individual's income and/or assets cannot exceed \$2,000.

Now that you know, let's look at three of the major financial government benefits:

## Income benefits

For people with a disability, the biggest federal programs providing monthly income assistance are SSI and SSDI. A person with a disability can qualify for both simultaneously.

**SSI:** This means-tested benefit is a basic monthly income for people with a disability who have little or no income and less than \$2,000 in assets. The exact benefit amount depends on the state and how much income or housing is obtained from other sources. Medicaid access usually comes along with eligibility. The payments may provide an entry point to group housing services and vocational training. A child with a disability doesn't need to have a work history to qualify for SSI.

**SSDI:** Work history can, however, determine eligibility for SSDI; at the minimum, if you develop a disability between the ages of 21 and 27, you only need to have worked six quarters, or 1.5 years, to qualify. Meanwhile, SSDI can also provide income to the children or dependents of a worker with a disability based in part on parental earnings, and in part on other eligibility requirements. The program's benefits are available for life and are open to anyone who is eligible. Perhaps most importantly, a child with a disability with a parent qualifying for SSDI can themselves be eligible for SSDI dependents benefits without having worked at all.

**Survivor Benefits:** These benefits are paid to widows or widowers of any age caring for a child with a disability and dependent children of eligible workers.

Unpaid family caregivers of people with a disability may also apply for Social Security benefits to help cover costs. If a caregiver doesn't qualify for benefits under Social Security, there may be state programs that can help.



## Medical and healthcare benefits

Medicare and Medicaid, both federally funded, sound alike and have similar missions: alleviating all or a portion of the often-overwhelming healthcare costs involved when living with a disability or special need. The programs are quite different, however.

**Medicare:** Medicare is a health insurance program for people with a disability, as well as those aged 65 or older. The rules are the same no matter where you live. Coverage options include many of the costs associated with hospital stays, doctor visits, laboratory costs, medical supplies and equipment, home health care and prescription medicines. Medicare eligibility can kick in after two years on Social Security Disability Income. If a parent qualifies for Medicare and has a child with a disability, they will qualify after two years.

**Medicaid:** Medicaid, while federally funded, is administered at the state level. It's an assistance program aimed at people with a disability, as well as those with low incomes. People with a disability can use Medicaid to pay for outpatient and inpatient hospital services, including medical, dental and surgical services, nursing facility services for those aged 21 and older, X-rays, laboratory work and pediatric services, among other things.

## Residential and housing benefits

For the average American, housing is usually the biggest expense item in a family budget. Add in a family member with a disability, and costs may go higher still. Some people with a disability may need only occasional help with certain tasks, but others may need care 24 hours a day. There are four main options:

**Medicaid:** In addition to the health benefits listed above, this federally funded, state-administered program can also help pay for long-term care, including senior housing for certain people. Care might be in the home, or in some states, via assisted living.

**Section 8 Housing:** A Section 8 voucher may enable a loved one whose needs do not preclude living independently to do so in a community. Section 8 will help pay the rent, based on a scale that accounts for family size and income. Rental certificates or vouchers in conjunction with a government-approved designated housing allocation plan may be available to eligible people with a disability.

**Group homes/assisted living:** Loved ones with more intensive disabilities may be best suited for more supportive group homes, staffed with counselors who teach residents to become more independent.

**Skilled nursing facilities:** For those needing care assistance 24 hours a day, outside the home, there are skilled nursing facilities providing constant supervision and care. For those with limited assets and income, Medicaid may assist in paying for such care.

# Workplace benefits

Before talking in detail about benefits typically available through the workplace, take a moment to review issues surrounding beneficiary designations.

Many families assume they will use employee benefits over the long term to provide for their loved one with a disability, and in fact, they will. However, the relationship between government benefits and employee benefits must often be indirect in order to comply with the rules concerning government means-tested benefits. The goal is for the person with a disability to receive both.

In order to do so, people with disabilities trying to qualify for these means-tested benefits should have assets of less than \$2,000, as of 2021. This number is subject to change over time. If they were to inherit, as a beneficiary, money through a workplace 401(k), insurance policy or any other asset that puts them over that level, that could disqualify the person from key government benefits such as Medicaid, SSI, federal housing assistance and SNAP.

There is an alternative, however, called a special needs trust. When the trust itself stands in as the beneficiary, the funds within the trust can be used for the person with a disability without endangering the means-tested government benefits.



## Jerry's life insurance beneficiary and Troy's special needs trust

Jerry's workplace provided him with a life insurance policy that paid 1.5 times his annual income if he died while still working for that company. Jerry wanted to make sure the proceeds went to Troy without jeopardizing Troy's benefits. So he and Patti created a special needs trust for Troy, and that's where the money from Jerry's life insurance will go if Jerry should die while still working.

## 401(k)s, 403(b)s, 457s and the employer match

As part of your own financial wellness plan, and that of your wider family, including the person with a disability, try to participate in your workplace's 401(k), 403(b) or 457 retirement savings plan, and maximize your contribution. When your contribution is deducted from your pre-tax income, you won't be paying taxes on it—or its growth—until you retire and draw the account down, when there is a good chance you will be in a lower tax bracket. Even better, employers often will match some or all of your contribution. After-tax contributions are often possible, too.

## Free retirement money for Patti

Patti's employer matches almost all of the money she saves at work in a 401(k) plan. She puts in 6% of her salary, and her company kicks in an additional 5%. If that sounds like free money, it is.

## Maximizing a workplace retirement-savings plan

### 401(k) vs. 403(b) vs. 457: What's in a name?

Different classifications of employers offer employees similar ways to save, pre-tax or after-tax, for their retirements via tax-advantaged payroll deductions. The types of plans—401(k), 403(b) and 457—refer to various sections of the U.S. tax code.

**401(k):** At private, for-profit companies

**403(b):** At non-profit corporations and government employers such as schools or hospitals

**457:** At state and local governments and at non-profits for their top executives

## Hardship withdrawals: how to avoid them

The money inside a retirement plan such as a 401(k) is, by its very nature, for use in the long term. However, on occasion, a family may need to take money out of a retirement account for a more immediate—and sometimes unexpected—need, say, an uninsured medical expense or treatment, a housing issue or a tuition bill. It is preferable to take out a 401(k) loan, which you will pay back to yourself over time with interest. Otherwise, there are so-called hardship withdrawals, and while sometimes necessary, they are best avoided. In fact, some retirement plans don't even offer them.

What's the case against a hardship withdrawal? For one thing, money in a hardship withdrawal is no longer in your account, so it can't grow there. Another: if you are under the age of 59 1/2, the money is not only subject to income taxation, but also a 10% penalty; if you have a disability, however, you might qualify for an exemption to the penalty.

Furthermore, it's a complicated process to take a hardship withdrawal. You are expected to find alternative emergency funds to the extent possible, including bank loans and the liquidation of assets, and provide documentation that you need a hardship withdrawal.

Before taking a hardship withdrawal from your 401(k), consider some other options: Make it a 401(k) loan instead; see if the service provider will let you use a payment plan; explore government benefits; borrow from a cash-value life insurance policy; borrow from friends or family; establish a home equity line of credit; use money in savings, other bank accounts or mutual funds; and if it's a very short-term need, perhaps tap a credit card, as long as the expense can be paid back very quickly.

#### **Jerry avoids a 401(k) hardship withdrawal**

When Jessica and Troy were small children, Jerry's employer transferred him to a part of the country where housing costs were sky-high. Even with a raise, he and Patti found it hard to pay all of the family's bills. Instead of taking a hardship withdrawal, Jerry instead was able to borrow some money from his 401(k) plan and pay it back over a period of years.

## **Life insurance**

A life insurance policy pays a beneficiary a certain amount of money upon the death of the person covered by the policy. It's a good idea to protect your family with life insurance. Luckily, it is often a standard workplace benefit. In fact, many companies offer you an option to purchase additional life insurance coverage at a discounted price.

Should you die while still relying on job-related income to support your family, the money from the life insurance policy will take the place of your take-home salary, until it runs out (hence the attractiveness of the additional coverage).

If your family doesn't need all the proceeds of the policy at the time of your death, they can invest the remaining money and have the option of using the income the policy earns in a savings vehicle instead. In that case, the life insurance policy's proceeds become a money-producing nest egg in and of themselves.

Even better, you can use the additional coverage to fund the special needs trust of your loved one with a disability.

#### **Patti purchases supplemental life insurance at work**

As time moved on and Patti rose in her organization, so, too, did the value of her workplace life insurance coverage, which she received as a benefit. However, at 1.5 times her salary, she felt the coverage wasn't quite enough, should something unexpected happen to her. So she took advantage of her employer's offer of supplemental life insurance. While she had to pay for it, she was able to triple the amount of coverage for her family. She named Troy's special needs trust as the primary beneficiary.

## **Long-term disability insurance**

Sometimes, accidents and medical crises are so severe that people can no longer work. Workplace life insurance, of course, wouldn't kick in. But many employers offer long-term disability insurance as a benefit. Such insurance is crafted to replace part of the income loss created by injury, illness or accident. You can purchase additional long-term disability insurance privately; consider this especially if you are the main source of income for your family.

#### **Taking no chances, Patti buys additional long-term disability insurance**

Patti recognized that she would need more disability insurance in order to come closer to replacing her salary in the event that something happened to her. As she did with life insurance, Patti purchased additional long-term disability insurance through her employer.

## **Employee assistance programs**

Employee assistance programs are easy to overlook, but they fill crucial niches for employees who are financially responsible for a loved one with a disability. The programs, which provide assistance, information and solutions, include childcare and adult day care providers, flexible work arrangements, stress-management and other health-related seminars, as well as personal and legal counseling.

#### **Jerry's employee assistance program rides to the rescue**

Jerry's and Patti's parents lived long lives, but toward the end, they needed help with daily tasks that Jerry and Patti couldn't provide while working and raising Jessica and Troy. Around the same time, the person who looked after Troy when he returned from school had been called away, and the family needed a solution for this problem on a temporary basis. Jerry tapped his company's employee assistance program for help in finding an affordable solution to both of these dilemmas.

## **Health care spending accounts: HSAs and FSAs**

Even with health insurance, out-of-pocket healthcare costs can add up for a person with a disability and the people who provide for them.

For an employee and their covered spouse and dependents, there are two main forms of healthcare spending accounts that can help lighten the load: Health Savings Accounts (HSAs) and Flexible Spending Accounts (FSAs).

## Health savings accounts (HSA)

When health insurance doesn't pay for everything related to the care of a person with a disability, money in an HSA can be used to pay for copays and for new technologies, experimental drugs, home modifications, special diets, vitamins and applied behavior analysis, among other things.

HSAs are available through employers when workers have a high-deductible health insurance plan; the money is deducted from your pay on a pre-tax basis. An HSA can also be opened through a private insurance plan and be tax-deductible, again if the worker's plan is a high-deductible one. (Note, however, that not all high-deductible health insurance plans qualify for HSAs.)

Because of the tax advantages inherent in an HSA, it could make sense to contribute the maximum amount allowed. Contributing to an HSA doesn't reduce your countable income when trying to qualify for means-tested government benefits. Also, making a person with a disability a direct beneficiary of an HSA can, upon inheritance, disqualify them from means-tested government benefits. A special needs trust or ABLE account can stand in as the beneficiary for the HSA, as well as any other financial assets, without jeopardizing such government benefits.

With an HSA, the employee can roll over the money in the account from year to year and can keep the money that's in the account if they change jobs. The employee also often can invest the HSA funds, which can in turn grow tax-free. The money must ultimately be spent on qualified expenses; spending on unqualified expenses will trigger a penalty tax. HSA funds can be used to help pay Medicare and long-term care insurance premiums for you or your loved one with a disability. Once you discontinue your participation in an employer sponsored high-deductible health insurance plan and enroll in Medicare, you can no longer contribute to an HSA, but you can continue to withdraw money from it—without paying the penalty tax—if the expenses are qualified.

Finally, if you save your receipts and can afford to pay for your current qualified expenses out of pocket, you can file for reimbursement from your HSA at some point in the future, allowing the funds to grow inside the invested account.

### Patti's HSA pays Troy's policy premiums

Patti had a high-deductible health insurance plan at work, so she was able to start a Health Savings Account and take it with her when she changed jobs. As she neared the end of her career, she used part of the money, which had grown considerably and tax-free, annually to pay the premiums for a long-term care insurance policy for Troy; his ABLE account was the HSA's beneficiary.

## Flexible spending accounts (FSA)

An FSA, on the other hand, is only available through a current employer. Most commonly, they are "use-it-or-lose-it" accounts, with an annual deadline for the money to be spent.

With an FSA, each year, there is an "open enrollment" period, and you get to decide the level of your annual contribution. The account is then pre-funded, in effect, meaning you can start spending that amount even before you technically put money in it from your paychecks. If you leave the company, and thus the FSA, before the end of the account year, you may have to pay back the account funds you've spent but for which nothing has yet been taken out of your paycheck.

At-home care, after-school care and day care are three kinds of expenses that would be covered by a Dependent Care Flexible Spending Account. Contributions to a DCFSA are pre-tax as well.

### Jerry's FSA saves him hundreds of dollars

Jerry's employer offered a Flexible Spending Account. He decided to contribute \$2,080 a year to fund it. (That's \$40 a week.) He then used the \$2,080 to pay for health-care expenses. The \$2,080 in the account was activated at the start of the year, all at once, and could be spent immediately. The \$2,080 was then withheld in \$40 weekly installments from his paycheck, so he didn't have to pay income tax on that money. This saved Jerry hundreds of dollars in taxes, just for using his FSA to pay expenses he had to pay anyway.



# Education

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As a child with a disability or special needs reaches school age, you will need to prepare an important legal document called an Individualized Education Plan (IEP). This document will contain learning needs and the services to be provided by the child's school to meet them. It will outline how progress will be measured. The plan can be adjusted over the years as you learn more about your child's learning capabilities. Along with this, the IEP gives you the opportunity to plan for your child's educational costs, which may or may not include financial aid. Just remember to review the IEP—and the financial aspects of your child's education—at least annually.



# Financial planning and divorce

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Creating a financial plan for families who have a loved one with a disability is never an easy task. When divorce is involved, the challenge multiplies. That said, proper planning can make a real difference. Expert advice—from a special needs financial planner, a special needs attorney and a domestic-relations attorney—is crucial.

Here's a look at some of the most important financial items to plan for when divorce comes into play for a family with a person with a disability:

**Government benefits:** In the case of divorce, a child receiving child-support payments may lose access to important government benefits, as child-support is treated as income. Families should strongly consider establishing a special needs trust, which can receive the child-support payments and help the child avoid disqualification.

**Medical insurance:** If a person with a disability is covered under the medical insurance of one parent, it's vital to have an agreement to continue that coverage after a divorce. When the medical insurance is employer-based, the agreement should address who will pay the premiums for replacement medical insurance coverage should the responsible parent retire or otherwise leave their job. If medical insurance comes from a state health insurance program, these reimbursements may affect premiums paid. Maintenance of this coverage should be written into the divorce and custodial pacts.



**Financial decision making:** Trustees will be needed when setting up a special needs trust for a child with a disability when their parents get divorced. The trustees will decide on investments and the use of the funds and will make sure the trust complies with laws and tax codes. Guardians, meanwhile, will make financial decisions on anything not covered by a trust. Be sure to name successor trustees and guardians who can take over these responsibilities in case the primary trustee and guardian can no longer serve in the role.

# Special needs trusts

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Perhaps nothing is more important than a special needs trust for the financial wellness of a family that includes a person with a disability or special need. This trust preserves eligibility for government benefits and provides the funds that can help maintain adequate healthcare and overall quality of life, including after the passing of the caregiver. The trust should be drawn up by an attorney with experience with such trusts. Properly composed, the trust can receive assets for the benefit of the beneficiary, allowing them to accrue funds of unlimited heft while still qualifying for means-tested government benefits.

Funds held within a special needs trust are normally used to directly pay for, among other items, recreation, vacations, home furnishings, vehicles and education, as well as pets and service animals, clothing, medicines, home-care help, cell phones and computers. If possible, they shouldn't be used for items covered by public assistance, such as food, shelter and basic utilities. Trustees should also never directly distribute funds from the trust to the beneficiary.

To decide how to fund a special needs trust, take inventory of family assets and consider which to earmark for the trust and which for other beneficiaries. Retirement-plans and life-insurance proceeds are typical funding sources, but there are a number of other options depending on your family's situation. Also, don't assume that all life insurance policies serve the same need. Term life, whole life and second-to-die life insurance all have pluses and minuses and should be reviewed with a financial professional.



## The three types of special needs trusts

**First-party trusts** are utilized when a beneficiary's own assets are used to fund the trust, while not compromising access to certain government benefits. Examples of these assets would be an inheritance or a settlement after an accident. Once the beneficiary dies, any assets left in the trust would first be used to pay back the government for Medicaid coverage, with the remainder given to a "designated remainder beneficiary."

**Third-party trusts** are those funded by someone other than the beneficiary (say, parents or other family members). The assets in these trusts don't affect eligibility for government benefits and are passed on to other family members or a charity upon the death of the beneficiary.

**Pooled trusts** are used when a first-party trust or third-party trust doesn't make financial sense, or if a trustee cannot be found, among other situations. A non-profit organization, acting as a trustee, starts and administers the trust and pools resources from multiple beneficiaries for investment purposes; each beneficiary has a separate account.

### Five questions for a special needs attorney

- What's your experience in this regard?
- Is there any danger posed to the person with a disability's means-tested government benefits?
- Are you familiar with the difference between first-party trust, third-party trust, pooled trusts and trust alternatives such as ABLE accounts, regarding Medicaid qualification and recapture?
- Will you devise a customized plan for us depending on our future goals and what has already been completed?
- Will you keep up with the laws surrounding a special needs trust and revisit the special needs trust accordingly, no less than once every five years?

### Setting up a special needs trust: 10 steps

- 1)** Get in touch with a financial planner with experience in the special needs space. To locate a planner in your area, please visit the Academy of Special Needs Planners at <https://specialneedsanswers.com/>.
- 2)** Tally the assets currently belonging to the person with a disability, plus their potential future assets, like inheritances, proceeds from real-estate sales and job-related income.
- 3)** Create a Letter of Intent, which will let you document your vision of your loved one's future and clarify potential care needs.
- 4)** Estimate the person with disability's present and future expenses, including taxes, inflation and administrative costs, to help calculate how much funding the special needs trust may need.
- 5)** Prepare to collaborate extensively with the financial planner. Think through what is financially possible—and what simply isn't.
- 6)** Find and meet with a qualified special needs attorney who specializes in your loved one's particular disability. The attorney will draft the necessary documents.
- 7)** Name the trustee or trustees, as well as successor trustees. It's a good idea to choose people from multiple generations to ensure the role is filled for a long time. A professional trust administrator is a viable option. The trustee is responsible for filing the trust taxes, administering the trust and knowing what's acceptable for trust distributions.
- 8)** Consider a team approach. For instance, as co-trustees with yourself, it might make sense to have not just a professional trustee to handle legal compliance and distribution, but also a family member to look out for the best interests of the person with a disability. A fourth member of the team could be added: a trust protector, who monitors the law and circumstances for changes, and oversees all the work.
- 9)** Assign the special needs trust as beneficiary. Once the trust is legal, it can receive financial assets such as life insurance and pension plans.
- 10)** Communicate with family and friends, anyone who might want to give a gift or leave money to your loved one. Make sure they have the information and update their beneficiary instructions to reflect the trust.

## Families on the same page

Unfortunately, when it comes to money, many people keep to themselves, even in families with a person with a disability or special need. But it's important to have open conversations, especially with family members, about special needs trusts.

Everyone should understand that:

- Any inheritance or gift of money that goes directly to a person with a disability is likely to threaten their eligibility for means-tested government benefits.
- Inheritances or gift monies can still go to the person with a disability indirectly through a special needs trust. Make sure you tell everyone the title of the trust, so they can name it as a beneficiary, should they be inclined to do so.
- The trust information, as well as guardianship documents, powers of attorney, wills and other important papers, are in a specific safe place, preferably in a central location, so that family members—including successor trustees and caregivers—can easily find them.

### Gift-giving: a guide for people with disabilities and their families

It's a great thing to want to give someone you care about a gift, especially if the recipient is in turn using the gift to help someone else. But as important as it may seem, a gift is still a discretionary expense and needs to be balanced with your other spending desires.

Where does the money for a gift come from? If you have a budget and there is nothing in it for giving a gift, the money still has to come from somewhere, and that somewhere would be your indulgences, for example, the lattes, the movies or the video games.

#### Here are some things to think about when you are considering giving a gift of money:

Check your monthly budget first to make sure you have the money available. Bills have to be paid first. Savings and your emergency fund are also very important.

If you don't have money already set aside for monthly gift-giving, then you will have to forego a different discretionary expense. For example, if you drink five fewer lattes during the month, you can take the \$20 they might cost you and give it to your friend.



Think hard about whether your gift will bring lasting joy to the recipient or help them in a meaningful way. For example, giving them \$300 for chocolate-covered bonbons is probably not something you would want to do, but giving them money for a good fundraising cause might be.

Use cash from your bank account or a debit card to give money. Don't use a credit card, to avoid accumulating debt.

Remember that gifts of a certain size or for a certain reason can jeopardize a recipient's government benefits, if applicable. For more dos and don'ts, please see: <https://protectedtomorrows.com/blog/2016/01/13/gifting-guidelines-for-an-individual-with-special-needs/>

## ABLE accounts

In late 2014, the Achieving a Better Life Experience Act, or ABLE Act, created a tax-advantaged savings option for people who were diagnosed with their disability before the age of 26 and can meet certain other requirements. ABLE accounts are ideal for parents saving for their child with a disability's future expenses, for the individuals themselves if they are employed and for people who want to give or bequest funds to someone with a disability without jeopardizing their government benefits. With the ABLE Act, Congress' intent was to offer individuals with disabilities flexible savings tools similar to college savings accounts, health savings accounts and individual retirement accounts. ABLE accounts are often used alongside a special needs trust.

An ABLE account is funded with after-tax money, and all earnings are tax-free, as are distributions when used for qualified expenses. Contributions to an ABLE account are limited to \$15,000 for a single tax year, as of 2021, unless the ABLE beneficiary works and earns income while not participating in his or her employer's retirement plan. In that case, an additional \$12,760 can be contributed. Lifetime maximum contributions vary by state but can go as high as \$500,000.

Up to \$100,000 in ABLE accounts will not be counted as assets for means-tested benefits, such as SSI. If an ABLE account balance exceeds \$100,000, SSI payments will be suspended but the eligibility of the person with a disability remains. Medicaid benefits continue even if the ABLE account balance exceeds \$100,000, although states may ask for reimbursement from the estate containing the ABLE account after the beneficiary dies.





An ABLÉ account has some federal tax advantages (and sometimes at the state level, too) and can be used for short or long-term spending on housing, medical expenses, transportation, recreation, education and financial independence.

Unlike money in a special needs trust, funds held in an ABLÉ account can be used for housing expenses. Also, unlike trusts, they have low, or even no, start-up costs. Some ABLÉ accounts are accessible via a debit card, and some can be started with as little as \$50.

In 2018, Congress passed the ABLÉ Financial Planning Act, which allows parents to roll over up to \$15,000 a year from a 529 College Savings Account into an ABLÉ account without penalty.

### Setting up an ABLÉ account: three steps

**1) Choose the ABLÉ account that's right for you by exploring your options.**

If your state of residence program offers a tax deduction or credit, that ABLÉ program might be preferable. If not, then you should compare all of the available programs to choose the best fit. A good place to start researching each state's program is here: <https://www.ablenrc.org/select-a-state-program/>

**2) Ask some key questions when you explore a state's ABLÉ program:**

- Does the state's program accept out-of-state enrollees?
- What are the fees associated with the account?
- What are the investment options?
- Is the account insured by the Federal Deposit Insurance Corporation (FDIC)?
- Does the account offer a debit card, and if so, what are the associated fees?

**3) Start the account online.** Once you find a state program you like, you can start the ABLÉ account right on its website. Just remember, you can only have one ABLÉ account at a time per person.

# Financial wellness in review

When you first picked up this guide, there's a good chance that the very first thing you thought was: "This is so big!" And it is.

Financial wellness is a very important topic, especially for families like Jerry, Patti, Jessica and Troy, or perhaps your family, if it contains someone with a disability. There is a lot to it, and often, the components work hand-in-hand. To truly achieve a sense of financial wellness, you really need to take a holistic approach and look at all the aspects of your financial life together, in relation to each other.

For example, the beauty of making a budget isn't to just make a budget, it's so that you not only know where your money is going, but can control where exactly you want your money to go, and how much of it? Any dollar you spend is a dollar unsaved, and any dollar you save is a dollar you won't be spending soon. Budgeting is about balancing all your needs—and your wants, too.

Put in a more practical way, a budget will help you know not only how much money you have for those lattes, but whether you really really want those lattes instead of something else. A budget teaches you that you can't have everything you want, any time you want it, if you haven't planned ahead for it. The pot of money is only so big, and you have to choose what to spend it on.

But this booklet was not created just to help you with budgeting. It was also created to help empower individuals with a disability, their families and caregivers with knowledge about creating income through various workplace and government benefits. It covers the complex legal planning that families with children with a disability need to maximize their benefits and to minimize anything that might jeopardize those benefits.

The guide also lays out the basics of special needs trusts and ABLÉ accounts, which are vital to both short- and long-term financial wellness for people with disabilities.

With all this information, the National Down Syndrome Society (NDSS) and Voya Cares® hope you will turn to *Financial Wellness: a guide for individuals with disabilities, their families and caregivers* as a resource when you need it for years to come and that you always make sound financial choices.

# Glossary

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**529 College Savings Plans:** A tax-advantaged way to save for higher education.

**ABLE account:** A tax-advantaged savings option for people who incurred a disability before the age of 26. They can be used for a variety of disability-related expenses without interrupting government-benefits eligibility.

**After-tax contribution:** Money placed in a savings vehicle that has already been taxed once and won't be again.

**Bank:** An institution that takes deposits and makes loans.

**Bonds:** Companies and governments issue bonds to borrow money; in return, they pay interest to the lender on a regular basis and return the amount of the loan later.

**Certificates of Deposit:** A savings vehicle that pays the depositor a set interest rate over a predetermined period of time.

**Checking account:** A bank or credit union account designed to hold your money safely while also making the money in it available to you in very quick fashion.

**Childhood Disability Benefit:** A government benefit that provides income to adults with disabilities that were diagnosed prior to age 22. Benefits are typically based on a parent's Social Security income.

**Children's Health Insurance Program:** This government program provides health insurance for children in families that don't qualify for Medicaid, but cannot afford private health insurance.

**Credit union:** Similar to a bank, credit unions take deposits and lend money, but unlike banks, they are non-profit institutions.

**Debit card:** A way to easily withdraw money in an account. It would be used to purchase a good or a service without having to resort to cash.

**Debt:** Any amount of money owed to someone that will have to be repaid, typically with interest.

**Defined contribution plans:** Employees, and often employers, contribute to these retirement plans. They include traditional and Roth 401(k) plans, 403(b) plans and others.

**Defined benefit plans:** Employers fund these retirement plans, such as a pension, that provide steady income for retirees.

**Employee Assistance Program:** A workplace benefit designed to help employees resolve personal or workplace issues.

**Federal Deposit Insurance Corp.:** A U.S. government agency that insures your bank account, up to a certain maximum amount.

**Flexible Savings Account:** A workplace-related, tax-advantaged way to pay for medical expenses as well as child care. The money in the account has to be spent each year or it is lost.

**Guardian:** The person who makes parental decisions, legally caring for the personal interests and property of another person.

**Health Savings Account:** A workplace-related, tax-advantaged way to pay for medical expenses, the money can stay in the account over the long term, through job changes or even into retirement.

**Individualized Education Plan:** A legal document developed by parents and school districts for every child in public school who needs special education.

**Insurance:** A guarantee that a company or government will compensate a policyholder for specific damage (auto insurance, for example), loss (property insurance), illness (health insurance) or death (life insurance) in return for an agreed-upon premium payment.

**Interest:** Money paid regularly at a particular rate for the use of money lent; the loan amount is called the 'principal' (and has to be paid back).

**Letter of Intent:** A document that instructs future caregivers on how to care for your loved one and what the vision of their future looks like.

**Life care plan:** A document that looks at lifetime care from personal, legal and financial perspectives and is flexible over time.

**Life insurance:** A life insurance policy pays a beneficiary a certain amount of money upon the death of the person covered by the policy.

**Long-term care:** Services that meet the medical and non-medical needs of those unable to take care of themselves on an everyday basis.

**Means-tested:** Examination into the financial state of a person to determine eligibility for public assistance

**Medicaid:** A government program that helps pay medical and long-term care costs for people with disabilities and low incomes.

**Medicare:** A government program that helps pay medical costs for people 65 and older and for people with disabilities. Unlike Medicaid, it is not means-tested.

**Money market fund:** This is a highly cash-based mutual fund that makes short-term investments on behalf of its investors and pays interest accordingly.

**Mutual funds:** These funds pool money from many people (or institutions) and invest in a variety of instruments like stocks and bonds.

**Power of attorney:** Written authorization to act on behalf of someone else.

**Pre-tax contributions:** Money placed in a workplace-related savings vehicle that has yet to be taxed but will be upon withdrawal, along with the earnings accrued on it.

**Savings account:** A bank or credit union account designed to hold your money safely, but in return for some restrictions, such as on the number of withdrawals per month. It pays higher interest than a checking account.

**Social Security:** This is the federal government program that provides retirement and survivor benefits as well as disability benefits.

**Social Security Disability Insurance:** This government program, also known as SSDI, pays income benefits to workers with disabilities and may also pay benefits to their children and dependents. Children with disabilities can also take advantage of the program even if they've never worked, as long as they have a parent who is covered under Social Security.

**Special needs trusts:** For a person with a disability, a special needs trust preserves eligibility for government benefits and provides a legal structure for the funds that will maintain adequate healthcare and overall quality of life, including after the passing of the caregiver.

**Stocks (or shares):** An investor wishing to own a portion of a publicly traded company can do so by buying shares of its stock. Shares are traded between investors, usually in great volume and frequency, and may be worth more or less than their purchase price.

**Supplemental Security Income:** This government benefit, also known as SSI, is means-tested and intended to help people with disabilities and people who have little or no income and less than \$2,000 in assets. A child with a disability doesn't need to have a work history to qualify for SSI.

**Trustee:** This person governs a trust (such as a special needs trust) with a legal obligation to administer it according to its intended purposes.

**Will:** A legal document detailing what a person wants to happen after their death. This may include naming successor guardians and detailing who should inherit assets.

# Notes

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## Mission Statement

The National Down Syndrome Society is the leading human rights organization for all individuals with Down syndrome.

## Vision Statement

The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities.







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