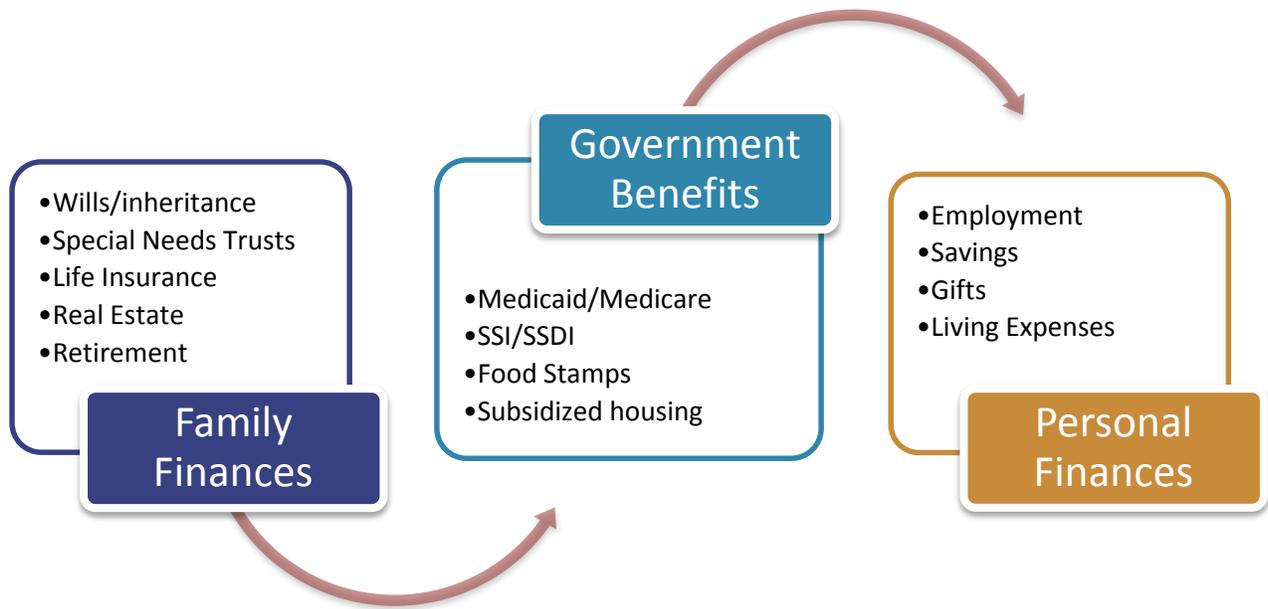




Does he have a legal guardian?
What are the options?

Do Mom & Dad have a will?
Do they have a special needs trust set up for her?
Where can I find these important documents?



It's Complicated!

What's even worse? Each state has its' own rules!

Is it possible that your sibling would move from their current state to another? How will this affect his benefits?

Do Mom & Dad have a will? Where is it?

Do they have a special needs trust set up for my sibling?

Where can I find all these documents?

An annual review of the financial and caregiving plan is necessary

A great many things can affect your strategy, including:

- a new job, the loss of a job, or a significant bonus;
- a marriage, divorce, death, or birth;
- children growing up, attending college, getting married, and sometimes moving back home;
- a person you've named as a future guardian or someone you thought could provide future care is no longer able—or capable—to handle the responsibility;
- someone once thought to be irresponsible is now up to the task and eager to help;
- a change in estate tax laws, giving you more, or fewer, opportunities to stretch your discretionary income; and
- new financial or insurance products becoming available to put your money to work in different ways than your strategy currently uses.

What to check during a review?

Beneficiary designations can sometimes cause trouble. Check your contracted instruments, such as life insurance policies, pension plans, wills, and other instruments where you've named someone to receive benefits. Sometimes these go overlooked, especially if it's something you've received as an employee benefit many years ago. Ensure that you still want the person(s) you've named to receive those benefits. Additionally, if any beneficiary you've named is a person with special needs, consult with your professional team to confirm you have the correct beneficiary designation to meet your strategy goals. *Otherwise, the money received may make that person ineligible to receive government benefits.* Look at current and future health care requirements and expenses, and what they might incorporate into their strategy to support those needs. Meet with your attorney to review wills and trusts, and an accountant to determine if any tax law changes may affect you. Of course, a general review of the strategy itself should be done to help ensure it's still in line with the goals you've set for yourself and your family.

Embrace the process

Creating and reviewing a financial strategy can seem overwhelming at first, but it's only scary if you don't actively engage in the process. The more involved you become, the easier it will seem. And when you begin to see the results, when you feel less stressed and more secure about caring for your family's finances, you'll be glad you made the effort.

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We'll help you get there!

Guardianship and Alternatives

What is Guardianship?

Guardianship is a legal relationship granted by a court between two people: a guardian and a ward. The intent of guardianship is to protect the ward from exploitation in matters of finance, property ownership, services and to receive guidance for medical decisions. However, guardianship, in some states removes certain rights from an individual (i.e. the right to marry or vote); *so it should be considered only after all available alternatives have been explored*. A guardian does not have to be a family member but should be someone who will look out for the best interest of your sibling.

What are the responsibilities of being a guardian?

The powers and duties of a guardian will depend on individual circumstances. Personal care might involve deciding where the ward will live, and arranging for meals, transportation, clothing, personal care, recreation, and health care. Financial care might involve making a budget, paying bills, investing money, collecting income, and protecting assets. Some adult children may be able to take care of their personal needs, but have difficulty managing money. Or they might need help making medical decisions. Letters of Guardianship will explain what the guardian has the authority to do.

Guardianship is a big responsibility, so it's important to choose a person who's willing and able. A special-needs child may have a loving brother or sister, but if that person is far away, or overburdened with other responsibilities, he or she may not be a good choice. It's never wise to pressure anyone into undertaking such an important position as guardianship or conservatorship.

Sometimes, the responsibilities may be shared by two people. One person may be appointed to take care of the personal needs, and another person, the finances. If a friend or relative is willing to serve, but is uncertain about having the financial expertise to do so, he or she may be appointed jointly with a bank or other institution. If no friend or relative can be found, a private professional guardian or a public agency may be appointed.

What Are Some Issues to Consider?

A guardianship will necessarily mean a lot of involvement with the legal system. The guardian may have to account to the court periodically about the status of the special-needs individual and the management of the assets. Every time the guardianship is questioned or changed, it must be done through the courts. The guardian is required, in most states, to complete a report for the court on at least an annual basis. In the case of a conservator, an initial inventory and annual accountings must be filed.

For medical management purposes, a guardianship may be the most expedient for getting information. Regulations outlined in HIPAA (the federal government's Health Insurance Portability and Accountability Act of 1996) are very stringent now. If your sibling has the inability to communicate effectively, a guardianship may be the only way to protect them, and the only way to insure that you have access to information which is otherwise private.

Guardianship and Alternatives

If a special-needs adult is receiving government benefits, such as Medicaid and SSI, and has no other assets to manage, a conservatorship of the estate may not be necessary. If family and friends want to give gifts to the child, they can be put in a special-needs trust which can be set up to pay for items and services beyond the bare necessities that government programs provide. No supervision by the court is necessary.

Should the Guardian Be a Sibling?

A sibling is often the best choice of guardian for many reasons. A sibling knows the challenges and joys the relationship can bring. Also, siblings are usually close in age. A younger guardian means there's a better chance for a long relationship because the guardian's age-related health issues, as well as lifestyle adjustments at retirement, are less likely to be factors. In addition to age and finances, the family's goals regarding the quality of life of the child with special needs should be discussed. Even if the guardian will be a sibling, creating a letter of intent, which outlines medical, financial, social, and personal facts about the person to be cared for, is recommended. It helps to eliminate questions or doubts that might arise when a new guardian steps in.

Conversations about choosing a guardian should be open and ongoing. When parents (or siblings, or aunts, or whoever the guardian may be) are trying to choose a successor guardian, they shouldn't assume they know who would want, or *not* want, the responsibility. Ask. And be aware of how the passing of time might make the perfect choice of guardian not so perfect anymore. Keep revisiting your decisions. Always be prepared for the changes life brings by having a successor guardian lined up and an alternate in mind.

Financial Concerns for Guardians and Their Wards

Note that while a guardian makes *decisions* about finances, medical care, or other services for the ward, he or she is ordinarily not responsible for *providing* that care or those services. However, when the guardian is a close relative of the ward, financial responsibility ends up falling to the guardian, even if it is not part of the legal contract. Parents of a child with special needs, when planning to name one of their other children as guardian, should also think carefully about their estate plan. Leaving assets directly to the child with special needs might jeopardize that child's eligibility for government benefits, for example. Also, any large sum left directly to an individual could have tax implications. Leaving assets to the sibling guardian with the expectation that it will always be available to the child with special needs might also backfire—if, for example, the guardian dies or divorces.

An attorney and a financial services professional experienced in the field of special needs should be consulted to help develop an appropriate plan. They might, for example, help the family set up a special needs trust for the ward. The trust could be the beneficiary of life insurance policies and other assets upon the death of the child's parents.

A guardian may need to spend unplanned time assisting the ward, which may affect his or her work schedule and income. Or the guardian may have limited income. In these cases, thorough financial reviews are recommended to see what strategies need to be changed or created to reduce the potential for bad decisions made simply because of financial insecurity. One solution may be to create a financial nest egg to help the guardian cover some expenses associated with

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guardianship. Another may be to establish a special needs trust to provide financial support for the ward.

Do What's Right for *Your* Family

No two families are alike, but every family benefits when they communicate. Having a relationship with a financial professional who'll follow your family through years of changing situations can be a big plus. Building a financial strategy that can be adaptive to changes makes life a little easier. Is guardianship the right choice for you? Or might a durable power of attorney, a health care proxy, or appointment of advocate designation suffice? Talk with your team of experts, who'll help you make the right choice.

Alternatives to Guardianship

Advance Directives - Allows your sibling to make certain healthcare decisions regarding future medical treatment. They can also designate a person to make decisions for him/her. In some states this takes the place of Medical Durable Power of Attorney.

Medical Durable Power of Attorney - This document is essentially the same as a power of attorney, but it is written in such a way as to remain in effect when your sibling is incapacitated.

Financial Power of Attorney - Allows your sibling to designate someone to manage his/her financial affairs.

Representative Payee - This person is accountable to the Social Security Administration and receives the monthly benefits of your sibling. The funds must be used in support of their daily living (i.e. buying food, paying rent, etc.).

Direct Deposit, Joint Accounts - In some cases this is all that needs to be set up for financial management. However, federal benefit programs, primarily SSI and Medicaid, will limit the assets an individual with a disability can have in his or her name to \$2000.

Special Needs Trust - This is a vehicle for your parents (or anyone else) to leave money for your sibling *without* jeopardizing their government benefits. It stipulates how money is to be handled and names your sibling as the beneficiary.

Because the law varies from state to state it will be necessary to involve an attorney knowledgeable in this area.

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We'll help you get there:

Selecting a Special Needs Attorney

What Should You Consider When Selecting a Special Needs Attorney?

Planning for the future of your loved one with Down syndrome is a complex process. Given the cost of supporting a person with a disability for his or her lifespan, careful planning must take place. Medicaid/Medicare, SSI/SSDI, waivers and other federal programs are the primary sources of revenue for supporting persons with disabilities. What medical care will be needed? Where will he or she live? Work? Go to school?

In order to find answers to all of these questions, you may need to reach out to many people, experts in various fields such as health care, social work, education, disability advocacy, financial services and law. You will need to have frank discussions with family and close friends. You may need to look for other families struggling with the same issues you are dealing with, to give you advice and support. Together these individuals help form your special needs team. A key leader of your team, because of the critical nature of his legal expertise, is the special needs attorney. It's therefore essential that you choose your attorney well.

A good special needs attorney should have the following qualities:

- The lawyer should be an expert in federal social security programs for individuals with disabilities and their families, including application processes, eligibility requirements, and continuing qualification standards for such programs as Medicare, Medicaid, Medicaid Waiver Programs, and Supplemental Security Income (SSI)
- The attorney should be an expert in the design and drafting of special needs trusts (SNTs), which allow you to leave an inheritance to your family member without needing to disqualify him for government benefits, or disinherit her, or leave his or her share to another person and hope that person will provide proper oversight and care.
- The lawyer should be an expert in the use, purpose, and preparation of legal documents essential to the implementation of the special needs strategy, including living and testamentary wills, trusts, and health care directives and proxies, letters of intent, general and special durable and non-durable powers of attorney, guardianships and conservatorships.
- The lawyer should be an expert in federal, state and local laws and regulations governing the eligibility and admission of individuals with disabilities to long-term care facilities and the standards such facilities are required to meet, elder abuse and exploitation laws (Older Americans Act—Vulnerable Elder Rights Protection under Title VII).
- The lawyer should be an expert in income, estate, and gift tax laws as they pertain to lifetime and testamentary gifts and transfers, as well as the Americans with Disabilities Act (ADA) and related state anti-discrimination laws.

Selecting a Special Needs Attorney

- **Experience.** The lawyer's practice should be focused on special needs, not merely a small part of it. The lawyer should be able to provide you with references from a number of satisfied clients. A good way to locate an experienced professional is to ask other members of your team: your financial advisor, for example, or a family dealing with the same issues that you are, who has found an attorney they like and trust.
- **Good Communication Skills.** It doesn't matter how brilliant attorneys are if you can't get a speedy response from them when you need it. Effective professionals have well-run offices with courteous, organized staff to take and relay messages. They get back to you when they say they will, and work well with other members of your team. If your attorney, financial professional, and accountant have worked together in the past, you're in luck. So once you've picked one of these experts for your special needs team, consider asking that individual for recommendations to fill the other positions. If they've worked well together in the past, they will very likely work well together as your team.
- **Resourcefulness.** Everyone's situation is unique, and the special needs attorney needs to be able to respond to your particular set of circumstances. When money is short, when the future is unclear, when medical crises arise, or when other less-than-ideal circumstances present themselves, you'll want an expert with creativity and imagination to manage your long-term special needs strategy.

The goal of the special needs team is to ensure the best possible quality of life for the individual with Down syndrome while safeguarding the assets of the family. When your team is headed up by a special needs attorney possessing these qualities, you're well on your way to reaching that goal.

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Legal Documents Checklist

1. IMPORTANT PAPERS

- Life insurance policies for parents and sibling with DS
- Health insurance policies & ID cards for parents and sibling with DS
- Real estate holdings/deeds
- Power of Attorney (parents)
- Social Security cards and benefits records
- Birth certificates for parents and sibling with DS

2. GUARDIANSHIP

- Guardianship papers
- Power of Attorney - financial (sibling)
- Power of Attorney - medical (sibling)
- Letter of Intent (from parents)
- Advance Directives (sibling)

3. FINANCIAL

- Special needs trust/Attorney contact information
- Bank records/Personal banker contact
- Federal, State & Local Tax Returns/Accountant & financial planner contact information
- Car insurance/title

4. SIBLING'S DOCUMENTS

- Medicaid, Medicare and other Health insurance cards, plus waiver information if any
- Bank account information
- Copy of last Individual Service Plan (ISP)
- Copy of medical records and psychological evaluation