



Ameriprise Financial
David F. Light, CFP®, CRPC®
Financial Advisor
1211 Hamburg Turnpike
Suite 217
Wayne, NJ 07470
973-633-0877 x14
david.f.light@ampf.com
www.davelight.com

Special Needs Planning Guide



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When Your Child Has Special Needs

As the parent of a child with special needs, you face many of the same challenges that other parents face. But you'll have to cope with some unique issues as well. The term special needs is often used to describe a wide variety of conditions and may mean different things to different people. For example, special needs can include medical conditions such as cerebral palsy. It can mean physical conditions, such as blindness or the loss of a limb. And it can mean neurological conditions, such as learning disabilities, mental retardation, or autism.

Where do you start?

Getting reliable information and support is important when you have a child with special needs. Start by talking to:

- Your obstetrician, pediatrician, and primary physician
- Social workers familiar with federal, state, and community resources
- Mental health professionals (e.g., psychologists and counselors)
- Parents of other children with special needs
- Members of a community or on-line support group
- Individuals within your local school systems (e.g., the superintendent, the principal, guidance counselors, and special education teachers)

You'll also want to find out what support programs and services are available in your community. Your state's Department of Social Services or Office for Children can help you locate state-sponsored programs such as child care, respite care, low-cost transportation, or other programs that can help you provide better care for your child.

Community volunteer agencies and parent groups can also counsel and educate you about the challenges of raising a child who has special needs. Your local United Way, as well as other nonprofit agencies, may have programs to help you care for your child. Sports events and recreational camps are often sponsored by both local and national organizations and can give your child a chance to interact with others while having fun.

Many national organizations exist for special needs information and advocacy. These groups often have local chapters you can join that may sponsor support groups. In addition, the Internet has become a leading source of information and support for parents of children with special needs. On-line sites offer both general and technical information and can connect you to informal and formal resources.

Finding and paying for medical care

Because of his or her special needs, your child may need expert medical care. Learning all you can about your child's condition and treatment options, finding ways to handle health-care costs, and organizing paperwork can cut down on the stress that inevitably accompanies frequent visits to health care providers. Here are some tips:

- Choose a qualified physician who responds to your child's needs, is knowledgeable about your child's condition, and who explains treatment options thoroughly
- Read your health insurance policy and find out what it does and does not cover
- Apply for Medicaid if your child is eligible for it (in most states, your child will automatically qualify for Medicaid if he or she meets the Supplemental Security Income (SSI) requirements or lives in a residential care environment)
- Join support groups affiliated with a national organization focused on your child's disability or condition
- Subscribe to publications that can alert you to new treatments, prescription drugs, and research that may benefit your child
- Keep copies of treatment records, correspondence with your insurance company and supporting documentation
- Draft letters that you can keep on file with child-care centers, the school nurse, babysitters, or family members that describe your child's medical needs and what to do in case of emergency

Educational issues

Federal and state special education laws, as well as the Americans with Disabilities Act, require public schools to accept children

with disabilities and take whatever steps are necessary to meet their special needs. For example, bathrooms, hallways, and other physical facilities must be designed to accommodate wheelchairs. In addition, a public school may have to create special programs, revise its policies and curriculum, and offer counseling and other services to students with disabilities.

All states must provide a "free and appropriate public education" to eligible children with disabilities. Have your child evaluated by your state and local school district to find out if he or she is eligible for special education services, including early intervention services starting in infancy or in preschool.

Ensuring your child's future

As the parent of a child with special needs, you'll want to find ways to protect your child's inheritance and ensure that he or she is taken care of when you die. If your child is a minor (under the age of majority, which in most states is 18) or an adult who is unable to make decisions related to his or her own long-term welfare, your first step should be to name a guardian (e.g., a friend, relative, or legal professional) in your will. After your death, this guardian will offer advice and make decisions for your child, manage his or her assets, and oversee his or her care after your death. Choose a guardian carefully. He or she should be someone who has your child's best interests at heart.

In order to be eligible for most government benefits (e.g., SSI, Medicaid), your child must have minimal income and assets. If you plan on leaving your child significant assets, you could put his or her eligibility for these benefits at risk. However, you can leave money to your child without risking his or her eligibility for government benefits by establishing a special needs trust to hold funds that your child might otherwise inherit directly upon your death. Funds in a properly drafted special needs trust are not considered "countable" for SSI and Medicaid eligibility purposes. A special needs trust is a complex estate planning tool, so it's best to consult an experienced estate planning attorney.

Parenting a Child with Special Needs

What are special needs?

You may have known since birth (or before) that your child has special needs. Or you may have realized it later, when your child didn't sit up at an appropriate age, or had problems learning to read. Children who have special needs have a wide range of conditions, both mild and severe, including chronic illnesses, emotional issues, developmental delays, disabling physical conditions, and learning disabilities.

Dealing with your family's changing needs

When you realize that your child has special needs, you and other members of your family may experience tremendous emotional stress. You may worry about your child's health and future care. You may worry about meeting the needs of your spouse and other family members, and how you will make ends meet. In addition, to make sure that your child receives the care and services he or she needs, you'll need to learn to become an effective advocate for your child. Here are a few ways to begin dealing with the changes in your life:

- Get help wherever you can find it—from friends, family members, other parents, support groups, counselors, and community and national organizations.
- Gather as much information as you can about your child's disability and the services that are available to your child.
- Talk to your other children. Encourage them to share their feelings, ideas, and concerns about their brother or sister, and find support groups or counselors they can talk to if necessary.
- If you're worried about your child's development, make a list of things that concern you and talk to your child's pediatrician.
- Listen to others, but trust your instincts. You know your child better than anyone, so if the advice you're getting doesn't ring true, look elsewhere for answers.

Planning your finances

When you have a child with special needs, financial planning is especially important. The services, supplies, equipment, and medical care that your child may need can really strain your budget. Your income may be reduced if you have to quit your job or cut back on your hours to care for your child. In addition, you may need to plan for your child's future, especially if it's likely that he or she will need lifelong care or financial support.

Consider working with a qualified financial planning professional who can help you assess and improve your current and future financial situation. Among other things, he or she can prepare a realistic budget, help you locate benefits available in your state, including Supplemental Security Income (SSI) and Medicaid, and assess your insurance needs.

Getting the support you need

There's a lot of help available, but you need to know where to find it. Start by looking in your own backyard. Your state's Department of Social Services or Office for Children can help you locate state-sponsored programs, including child care, respite care, low-cost transportation, and other services. Community agencies, hospitals, schools, and other parents can also help you locate the information and services you need.

You can find a wealth of information on the Internet, as well. Many national organizations advocate for children and adults who have special needs. They often publish magazines, pamphlets, and books that can help you learn more about particular conditions or disabilities, and have local support groups that you can join. You can find links to a lot of information at the [National Dissemination Center for Children with Disabilities](#) website.

Receiving quality medical care

Even if your child's medical problems aren't severe, you may spend a lot of time in the doctor's office or hospital. Not only will your child need routine care from a pediatrician or family physician, but he or she may also need to occasionally (or routinely) see specialists. Learning all you can about your child's condition and treatment options, finding ways to handle health-care costs, and

organizing paperwork can cut down on the stress that inevitably accompanies frequent visits to health-care providers. Here are some tips:

- Choose a qualified physician who responds to your child's needs, is knowledgeable about your child's condition, and explains treatment options thoroughly
- Read your health insurance policy and find out what it does and does not cover
- Apply for Medicaid if your child is eligible for it (in most states, your child will automatically qualify for Medicaid if he or she meets the requirements for SSI or lives in a residential care environment)
- Join support groups affiliated with a national organization focused on your child's disability or condition
- Subscribe to publications that can alert you to new treatments, prescription drugs, and research that may benefit your child
- Keep copies of treatment records, correspondence with your insurance, and supporting documentation
- Draft letters that you can keep on file with child-care centers, the school nurse, baby-sitters, or family members that describe your child's medical needs, and what to do in case of emergency

Finding appropriate child care

Whether you work full time or simply need occasional child care, you'll want to make sure your child is in good hands. Many types of care are available, depending on your child's needs. You may want to find in-home care for your child, or look into family day-care providers, child-care centers, or facilities that specialize in caring for children with special needs. If you need only intermittent help, you may find it through a respite care program.

As you're searching for child care, you should be aware that most public and private child-care providers must comply with the Americans with Disabilities Act (ADA). (The exception to this is child care provided directly by a religious entity.) Under the ADA, child-care providers (including family day-care providers) must accept children with disabilities unless they pose a "direct threat" to others or require a "fundamental alteration" of the program. They are also required to make facilities accessible and provide "reasonable modifications" necessary to integrate children with disabilities into their programs.

Navigating the educational maze

Under the Individuals with Disabilities Education Act (IDEA), children with disabilities are entitled to receive a "free and appropriate public education" that matches their needs. The first step is to meet with a team from the school that will assess your child's needs and recommend special services for your child if he or she qualifies for them. An individual education plan (IEP) will then be developed for your child that outlines the services your child is eligible for and that formulates short- and long-term educational goals. In general, you'll want to:

- Have your child assessed early, as soon as you suspect that your child may have a medical problem or learning disability that may interfere with his or her education or development
- Take advantage of early intervention services that may be available to your infant or preschooler
- Meet with the IEP team at least once a year to discuss your child's progress and to formulate new goals
- Take advantage of related services offered by the school, including occupational and physical therapy, counseling, transportation, and health services (available services will be listed in the IEP)

It's also very important to understand your legal rights (the school must provide you with a written summary). For instance, you have the right to have an outside evaluation done if you disagree with the results of the school's evaluation. You can find information and publications that discuss your rights under IDEA and other educational issues at the [U.S. Department of Education](http://www.ed.gov) website.

Providing for your child after your death

Because your child has special needs, you'll need to take special precautions to ensure that your child is protected after your death. Of course, like any parent, you'll want to draft a will and prepare other legal documents that outline how your assets will be divided upon your death and name a guardian for your child (and other children). But you'll face more complex issues as well. Depending on your child's needs, he or she may need lifelong care or supervision, something you'll need to account for when deciding how to divide your assets and choosing a guardian. And you may want to set up a special needs trust so that gifts or inheritances from you and other well-intentioned family members won't inadvertently jeopardize your child's eligibility for government benefits such as Medicaid and SSI.

An attorney or other financial professional who has experience with the planning issues facing families of children with special needs can help you draft an estate plan.

Support Networks and Community Resources for Parents of Children with Special Needs

You don't have to go it alone

You face many challenges as the parent of a child with special needs, and sometimes you feel that you're all alone out there. Your family and friends offer support, but they may not always be available. You know that both you and your child would benefit from having a support network--a formal or informal group of individuals and organizations that can give you emotional support, practical assistance, information, direction, and advice. Fortunately, a wide variety of public and private programs are available to assist you. Many are community-based; often they're housed in schools and run by family service agencies. Help is also available from state programs, government entitlement programs, and national organizations.

What kind of support will you need?

Advice about adjusting to life with a child with special needs

Any new addition to a family affects the entire family, and this is especially true when the new addition is a child with special needs. You, your spouse, and your other children (if any) may need assistance working through a variety of emotional issues surrounding whatever changes you'll need to make in your lives. If your child is diagnosed with a specific condition or disability at birth, the hospital may have counselors on staff who can offer initial support and make referrals to other professionals in the community.

Your health plan may also cover counseling services and refer you to providers available in your area. Low-cost counseling may be offered through your local department of social services.

One of the best sources of support, however, may be other parents who have children with disabilities. They have experienced the shock, anger, guilt, or disappointment you may have felt upon learning that your child has special needs, and they can offer emotional support and practical suggestions. They may also have first-hand knowledge of the resources available nationally and in your community.

Help with medical issues and costs

No one's ever fully prepared to be the parent of a child with special needs. You know you'll need to find a good pediatrician and specialists to manage your child's care, and you may need to learn to care for your child at home. Your child may need home health care (which may or may not be covered by Medicaid) or you may need specialized medical training in order to properly care for your child.

Although it seems overwhelming, there's a network of medical and social service resources available to help you understand your child's special needs and explore your options for paying for health care. Your obstetrician, pediatrician, or local hospital may be able to refer you to appropriate resources.

Financial and legal help

Financial professionals and attorneys who have specific credentials and experience dealing with the challenges of providing for a child with special needs can help you ensure that your child has adequate financial support throughout his or her life. It's best to get a referral from someone who has previously worked with the professionals you choose.

Educational services

Perhaps you're worried about your child's development and concerned about finding appropriate educational services. Fortunately, you can turn to your public school system for help. Under federal law, children with disabilities are entitled to special education services, including early intervention services, occupational, physical, and speech therapy, diagnostic services and transportation.

Child and respite care

Preschools and other child-care centers are required to provide children with disabilities full access to child care. But that doesn't

mean it will be easy to find a child-care arrangement that you're comfortable with. You'll have to find an arrangement where your child is able to get the proper amount of help and supervision he or she needs. In many cases, you may fall back on a less formal arrangement where care is provided in your home by family members or friends.

Another type of care you may benefit from is respite care. The word respite means "relief by an interval of care." In respite care arrangements, your child with special needs stays for a predetermined period of time with substitute caregivers. During that time, you (and other members of your family) will benefit from the "down time" respite care can provide. Respite care can also give you a chance to spend time with your other children doing what's important to them.

Many of the societies dedicated to specific disabilities maintain lists of respite-care workers who can be reimbursed from state funds. Respite care is most often provided in day-care centers or respite group homes, although sometimes a respite-care worker may come to your home. You may also be able to arrange emergency care on short notice with respite providers.

Help finding recreational programs

Ongoing recreational programs (such as play groups or after-school programs) and summer camps for children with special needs will give your child a chance to enjoy a variety of activities and to interact with others. In addition, these programs offer you a break from caring for your child. While some programs are privately run and charge for their services, others are sponsored by local and national nonprofit organizations and provide free or low-cost services. For more information on these programs, contact the local chapters of national organizations, clearinghouse organizations such as the [National Information Center for Children and Youth with Disabilities](#), schools, and local social service agencies.

What support and community resources can help?

Finding what you need

While most parents report that they need financial assistance more than any other kind of help, some states still spend very little on community support systems for children with special needs. Still, some community support is available. Medicaid directly or indirectly funds most programs, so your state determines what kinds of services it will sponsor. To begin your search for community support systems, contact your area health department, welfare department, or social services agency. You can also seek support services through your developing network of friends, relatives, acquaintances, and national organizations and associations.

Informal networks of individuals and groups

Some of the best help you'll get in caring for your child may be informal. Your friends, family members, neighbors, employer, church or synagogue group, and civic leagues may all offer a hand. Don't be reluctant to make your needs known to others.

National or local organizations

A national or local organization can be an important source of information and support. They are often dedicated to specific conditions and disorders and can give you advice and information on caring for your child. They can also refer you to specialists, support groups, and other resources that can help you. Many of these organizations have local chapters and/or Internet sites where you can access information.

These organizations commonly sponsor support groups comprised of people (often other parents of children with special needs) who share your concerns. Support groups can often give you information about research and treatment advances, help you deal with the day-to-day problems of caring for your child, and provide comfort and a change in perspective during times of crisis.

Look for a group in your community that meets your needs, but if no group is available locally, you may find one on the Internet. Soon, you'll have thousands of virtual-reality friends whose on-line "voices" will become as familiar to you as those of your neighbors.

Social service agencies

Nonprofit organizations or government agencies may sponsor in-home care, friendly visits, family counseling services, health maintenance programs, respite care, transportation assistance, and other services in your area. Check your phone book under Social Service Organizations.

Hospitals and community health organizations

Hospitals and other community health organizations frequently offer seminars, training programs, and other services that can help you learn to deal with the emotional and medical issues you face as a parent of a child with special needs. They may also offer meeting space to support groups. Call your local hospital for more information.

Finding Quality Child Care When Your Child Has Special Needs

What types of child care are available?

Many child-care arrangements are available for children with special needs. Traditional child-care settings offer children with and without special needs the opportunity to learn and grow alongside each other. Specialized child-care settings cater exclusively to children with special needs. In-home or family day-care providers care for children with special needs in an informal, less structured environment. No matter which child-care setting you choose, you'll want to find a provider who offers high quality care.

Where to find care for a child with special needs

Start out by contacting your local child-care resource and referral agency, which can put you in touch with child-care providers in your area. If you need help finding your local agency, visit the Child Care Aware website at www.childcareaware.org. You can also obtain referrals from your state's Council on Developmental Disabilities and Protection and Advocacy (P&A) agency. For more information on these programs, visit The Administration for Children and Families website at www.acf.hhs.gov.

You may also want to get recommendations from other parents who have children with special needs, community agencies and support group members. And don't forget to investigate state-sponsored early childhood programs available in your community. These are often affiliated with local schools. Special education directors are a good resource if you want to locate state-funded respite programs (including programs available to preschoolers).

State-sponsored early childhood programs

The Individuals with Disabilities Education Act (IDEA) is designed to strengthen academic expectations and accountability for children with disabilities. Under IDEA, all children with disabilities are entitled to a "free and appropriate" public education.

IDEA calls for state-sponsored early childhood programs that require all eligible children to have a written plan that lists their goals and the types of services that are needed to reach those goals. Under IDEA, there are two different plans: (1) the Individualized Family Service Plan (IFSP) and (2) the Individualized Education Program (IEP).

The IFSP is for infants and toddlers with disabilities from birth to age three. The IFSP must provide a service or family resource coordinator to parents who have children with special needs. This individual is usually part of an early intervention team. The coordinator will give you information about the types of programs and services available to your child.

The IEP is for children with disabilities age three and older (age 5 in some states). The IEP is an individualized plan that outlines the programs and services for which your child is eligible. These may include special education programs, support services such as physical therapy, occupational therapy, and speech pathology, and transportation. The IEP also formulates short- and long-term educational goals.

Tip: Keep in mind that full-time or part-time services and programs under IDEA may need to be supplemented with other child-care arrangements.

Tip: For more information on IDEA, visit the Department of Education's website at www.ed.gov.

Choosing the right child-care provider

Child care and the Americans with Disabilities Act (ADA)

As you begin your search for a child-care provider, you should be aware of how the ADA impacts child care for children with special needs. The ADA is federal legislation that is designed to protect individuals with mental or physical disabilities from discrimination. Most public (e.g., Head Start programs) and private child-care providers must comply with the ADA. Under the ADA child-care providers must provide children with disabilities an equal opportunity to participate in the child-care center's programs and services. Title III of the ADA, which governs private child-care providers, states that child-care centers:

- Cannot exclude children with disabilities from their programs unless their presence would pose a "direct threat to the health or safety of others" or require a fundamental alteration of the program

- Have to make reasonable modifications to their policies and practices to integrate children with disabilities (and their parents or guardians) into their programs unless doing so would constitute a fundamental alteration
- Must provide appropriate auxiliary aids and services needed for effective communication with children or adults with disabilities, when doing so would not constitute an undue burden
- Must generally make their facilities accessible to persons with disabilities

Tip: Private clubs and religious organizations are exempt from having to comply with the ADA

Tip: For more information on the ADA, visit the Department of Justice's website at www.ada.gov.

Questions to ask

Before settling on a particular child-care provider, you'll want to speak to the director or provider in person. In addition to inquiring about availability, hours of operation, accessibility, and fees, you'll want to be sure to ask the following questions:

- What are your qualifications? Are you a licensed and/or accredited child-care provider? How long have you been in business? Do you have references?
- Do you have activities that are developmentally appropriate for my child's age and intellectual and physical ability?
- What is the staff/child ratio? Does the staff/child ratio allow for the individual attention necessary for children with special needs and the personnel necessary to deal with emergencies?
- Is the staff well trained in early childhood education and special needs? What about safety measures, such as CPR and first aid?

In addition, you may want to make plans to visit some child-care centers unannounced. This will give you a more accurate idea of how the center operates. During these unannounced visits you'll want to make the following observations:

- Is the child-care center clean?
- Are the toys and furniture all in working order?
- Do the children seem happy?
- Do the children seem well occupied?

Is financial assistance available?

If you need help paying for child care, there are a variety of programs that offer financial assistance. For starters, contact the child-care agency that is responsible for subsidized child-care programs in your state. You'll be able to obtain information on the types of programs available, eligibility, and the application process.

In addition, your child may be eligible for the Head Start program in your community. Head Start is a federal program for preschoolers and their families with low incomes that provides developmental and social services, including education, health, and family needs assessments. For more information on Head Start, visit the Head Start Bureau Home Page at www.acf.hhs.gov.

Managing Medical Care When Your Child Has Special Needs

Introduction

As the parent of a child with special needs, you'll face certain challenges when it comes to coordinating medical care. You may often need to act as an advocate for your child's best interests. To be effective in that role, you'll need to be prepared.

Diagnosis and treatment options

To obtain a complete diagnosis of your child's medical issues, you and your child may need to visit several health professionals. While prenatal and postnatal medical testing has eliminated much of the guesswork around diagnosis, you may still want to ask for second opinions, particularly if your child's condition is difficult to assess. In addition, because doctors don't always agree on the best ways to treat some medical conditions, you may want to get advice on treatment options from at least two physicians.

Your child's health needs may be complex and require multiple services, including medical, psychological, behavioral, and educational help. Talk to your physician about any concerns you have about your child's development, and ask for referrals to other professionals who can provide testing, early intervention services, and treatment options.

Become informed and involved

It will be in your best interest (and your child's) to learn all you can about your child's condition and prognosis. Start by asking the health-care providers you've seen to explain what's going on, and insist they do so thoroughly, in language you can understand. In addition, seek out and join organizations dedicated to the treatment and cure of your child's condition. Many of these organizations sponsor local or national support groups, and publish magazines, brochures, and other materials that provide helpful information. Browse the Internet for relevant websites, and stay abreast of any promising research projects or new medical developments. The more you know about your child's health concerns, the better you can advocate for appropriate treatments.

Find a physician you can work with

Your child may require specialized treatment and care, but he or she will also need routine care for common childhood ailments. This means that your child's primary physician should probably be his or her pediatrician or family doctor. These providers are trained to care for children with special needs, as well as for those without them. In many cases, particularly if you belong to a managed care organization such as a health maintenance organization (HMO), you'll need to work through your child's pediatrician or primary care physician to obtain referrals to specialists. Since continuity of care is especially important when you have a child with special needs, try to find a physician you can work with as your child grows. Look for a physician who:

- Has extensive knowledge of medical condition and treatment options
- Stays up to date on research and available treatments
- Takes time to explain treatment options and procedures to parents and children
- Is accessible and encourages questions
- Takes parent concerns seriously
- Is empathetic and nonjudgmental
- Has a support staff of trained professionals
- Can provide referrals to appropriate specialists and community resources, if necessary

It's also wise to keep your child's pediatrician apprised of all the treatments other doctors recommend for your child, particularly if medications have been prescribed. In addition to obtaining copies for yourself, have all reports of treatments indicated by other doctors sent to your child's pediatrician (unless he or she already has access to them).

Keep detailed records

It's always a good idea to keep track of your child's ailments and medical treatment history, and particularly so when he or she has special needs. Periodically request a copy of your child's medical records and keep your own lists of doctor's visits, treatments,

surgeries, medications, and recommendations. You may also want to keep a daily or weekly log of your child's activities, noting any symptoms that might warrant follow up. In doing so, you may begin to notice patterns of symptoms or changes in your child's condition that otherwise might be missed. This information might help your child's physician refine the treatment plan for your child.

Paying for medical care

Medical care for a child with special needs can be costly, and keeping track of all the paperwork involved in paying for it can be complex and time consuming. Make sure you keep complete and well-organized records, especially when it comes to dealing with insurance providers. You should keep copies of correspondence and phone logs that record the time and date of calls and the names of claims representatives you speak with.

Private insurance for medical care

Private insurance may cover some of the costs of your child's medical care. As soon as you become aware that your child has special needs, check your policy. Here are some things to consider:

- Does your child's pediatrician or primary care physician have to make a referral to specialists or other health care providers?
- Can you choose your own providers or must you select them from an approved list?
- Do any limits exist on how much the insurance will pay for certain types of care?
- Does the insurance cover the medications your child may require?
- Will the insurance pay for assistive technology (e.g., hearing aids, prosthetics, wheelchairs)?
- Is preauthorization required for hospitalization, and/or is the length of stay limited?
- Can you work directly with a particular claims adjuster for the purpose of establishing continuity?
- What is the procedure for appealing a decision to deny payment for service?

Caution: Remember, if you're planning to change insurance policies, examine the new one carefully. Watch out especially for limitations on pre-existing conditions.

Medicaid

The Medicaid program is the most important source of funding for health services for children with special needs. The program offers:

- A basic health insurance plan for most of its beneficiaries
- Payment toward long-term care for individuals with disabilities
- Funding for programs for individuals with developmental and physical disabilities

Because it's a joint federal-state program administered separately by each state, Medicaid eligibility requirements (and some benefits) may vary from state to state. For specific information on its benefits, see [Medicaid](#) . For more information on your state's programs, contact your local health department, your state or county social services office, or your local Social Security office.

In most states, if your child qualifies for Supplemental Security Income (SSI), he or she automatically qualifies for Medicaid. To qualify for SSI, your child must meet certain disability criteria and either have limited income and resources, or come from a home of limited income and resources. If your child meets the disability criteria, but is ineligible for SSI because of income and resource considerations, he or she may still qualify for Medicaid if you live in a state that offers a medically needy program. Since their income and resource guidelines are more flexible, these programs may benefit families who are ineligible for SSI but burdened with large medical expenses for their child.

A child with a disability or who is chronically ill is automatically eligible for Medicaid if he or she is institutionalized for over 30 days. In such a situation, your income isn't considered in determining eligibility; only your child's own financial resources are taken into account. Because states want to encourage families not to institutionalize their children, they may award waivers allowing Medicaid to cover the cost of equivalent medical care at home, provided such home care doesn't cost more than the institutional care. Each waiver is individually determined, so ask about the requirements. Your child will be ineligible for this benefit, however, if you have private insurance that would cover the cost of the institutional care.

In case of emergency

When you're the parent of a child with special needs, routine preparedness for an emergency may need to go beyond keeping fresh batteries in the flashlights. Here are some considerations:

- Learn CPR and other necessary medical skills
- Know how to operate any medical equipment that your child may depend on or require in a crisis
- Keep on hand an adequate supply of any medications your child requires, and know how to administer them
- Keep a complete list of emergency numbers (including those of physicians and hospitals) clearly posted in your home, in the glove compartment of your car, and on your person. Give copies of this list to nearby relatives and/or trusted neighbors
- Carry a cell phone
- Make sure a friend, relative, neighbor, or respite care provider will be available to care for your child if an emergency arises and you're unavailable
- Keep your child's medical records and any other relevant documents (e.g., insurance paperwork, medical letter of intent, will) in a safe place, and make sure someone you trust has access to them
- Draft letters that you can keep on file with child-care centers, the school nurse, babysitters, or family members that describe your child's medical needs and what to do in case of emergency

Providing for Your Child with Special Needs After Your Death

Why is estate planning important when you have a child with special needs?

Preparing for the day when you won't be around to care for your family is a challenge that all parents face. But as a parent of a child with special needs, your estate planning needs are especially complex. Your will, and other estate planning documents you prepare, must address your unique concerns. These concerns may include:

- Providing for adequate lifetime care or assistance
- Appointing someone to manage your adult child's finances
- Maintaining your child's eligibility for government benefits
- Avoiding family conflicts

An attorney and other financial professionals experienced in planning for children with special needs can help you draft a comprehensive estate plan to ensure that your child is well provided for after your death. If you already have an estate plan in place, you should have all existing legal documents reviewed (and revised, if necessary) to make sure they address your family's needs.

Wills

A will is the cornerstone of any estate plan. It ensures that your money and property are distributed according to your wishes upon your death, and allows you to select a guardian for your child. Without a will, probate assets will pass according to the laws of intestacy, which generally assign a portion of the assets to the surviving spouse and a portion to the children. If your child requires more financial resources than other beneficiaries, it's especially important to prepare a will that reflects your wishes.

Trusts

A trust is a legal entity that enables you to leave assets to your child with special needs (and others) outside of your will. You can create a trust during your lifetime (a living trust) or in your will (a testamentary trust). As the creator of a trust, you can decide what assets will be transferred to the trust, who the beneficiaries will be, what the terms and conditions of the trust will be, and who will manage the trust. Trusts are typically used to:

- Avoid probate
- Manage assets
- Provide for minor children
- Avoid estate taxes
- Protect assets from creditors

One type of trust, called a special needs trust, can play an important role in your estate plan. Specifically designed for the benefit of individuals with special needs, a special needs trust can allow you to provide for your child without jeopardizing his or her eligibility for government benefits, an advantage not offered by traditional trusts.

Why use a special needs trust?

Government benefits, such as Medicaid and Supplemental Security Income (SSI), can be vital sources of support for your child with special needs, especially if he or she is unable to buy or afford private health insurance. But because these government programs are need-based, your child will become ineligible for benefits if his or her countable assets (e.g., cash and other liquid assets) exceed \$2,000, the limit that applies in most states. An inheritance, a gift from a relative, or a personal injury award may push your child's assets over the limit, resulting in the loss of government support.

Unfortunately, government benefits generally provide only basic support. The portion of assets your child is allowed to keep and the small allowance for personal care he or she receives under government benefit eligibility rules may not be enough to pay for necessary items and services, such as eyeglasses and dental care. It is almost certainly not enough to allow the child any

"luxuries" such as vacations or gifts for others.

If you want to provide funds that can be used for expenses not covered by government benefits while preserving your child's eligibility for those benefits, consider establishing a special needs trust. Because assets deposited into, and income generated by, a properly drafted special needs trust will not be considered "available" to your child, they won't jeopardize his or her eligibility for Medicaid and SSI.

In addition, establishing a special needs trust is often the best way to guarantee that funds you leave are used for your child's benefit. Although disinherit your child or leaving money to other family members on his or her behalf may initially preserve your child's eligibility for government benefits, your child may someday be left without adequate support if these benefits are reduced or eliminated. Another concern is that creditors may attach money left to a family member if, for instance, that family member is held liable for an auto accident or declares bankruptcy.

If you are interested in establishing a special needs trust, consult an attorney who is experienced in special needs issues (including Medicaid planning), and the laws governing special needs trusts in your state.

Letter of intent

A letter of intent is a document that describes how you want your child to be cared for after you're gone. Although it's not a legal document, it can provide important information to guardians, trustees, family members, and others involved in the care of your child. The letter may address such issues as your child's medical needs, daily routine, interests, likes and dislikes, religious practices, living arrangements, social activities, behavior management, and degree of self-sufficiency. Such a letter can prove invaluable to your child's caregivers after you're gone, and can also make the transition to a new living situation as smooth as possible for your child.

Beneficiary designations

With certain assets (such as life insurance policies, retirement plans, and annuities), you must designate beneficiaries and/or contingent beneficiaries. You'll also name beneficiaries under your will. Although your first inclination might be to name your child with special needs outright as your beneficiary, such a designation could jeopardize his or her entitlement to government benefits. Instead, consider establishing a special needs trust for your child and designating the trust as your beneficiary.

Guardianship issues

Although you are the natural guardian of your child with special needs during your lifetime, who will care for your child after your death? Selecting a guardian who can act on your child's behalf after you die is one of the most important decisions you face. The person you choose must be able to handle the complex financial, legal, and personal needs your child may have.

Depending on your child's needs, you may also need to choose a person who is committed to serving as guardian even after your child reaches adulthood. The law doesn't assume that an adult with special needs is incapable of handling his or her affairs. After reaching the age of majority (generally age 18), your child is a legal adult. He or she will be judged capable of handling his or her own affairs unless declared incapable by a court. If such a determination is necessary, the guardian you choose now may need to serve as guardian throughout your child's life.

Guardian defined

A guardian is someone with the legal power to care for another person and manage that person's personal and/or financial affairs. A guardian can advise your child, manage assets, and oversee your child's care after your death. Generally, you'll nominate a guardian, along with several contingent guardians, in your will. The court has final approval, but it will usually approve whomever you nominate, unless there are compelling reasons not to do so.

Types of guardians

There are two basic types of guardians: a guardian of the person, and a guardian of the estate. A guardian of the person is someone authorized by a court to make only personal and medical decisions about your child. Any medical procedure performed on a child requires consent from the parent or guardian. A guardian of the person is empowered to give such consent for medical procedures and also decide where your child will live. Usually, the court clearly specifies the scope of the guardian's power. (The guardian will have to report to the court on a regular basis.)

A guardian of the estate (also called a conservator) protects and manages your child's money and other assets. The guardian has the following legal duties:

- To take possession of real and personal property and manage it for the benefit of his or her charge
- To spend the estate for the necessary care and support of his or her charge
- To productively invest estate assets

You can nominate different people as guardian of the person and guardian of the estate, or you can nominate one person to handle both functions.

Caution: *Each state has its own laws regarding guardianship. Consult an estate planning attorney before choosing a guardian.*

Full guardianship

A full guardianship is also called a plenary guardianship. In this case, the guardian has control over both the personal issues and the estate of your child. This is the most common type of guardianship. Typically, you will choose a full guardianship if your child's issues are so severe that he or she cannot make any informed decisions at all.

Limited guardianship

In a limited guardianship, the guardian has authority over his or her ward only in specifically defined matters. Otherwise, the child with special needs retains some control over his or her own life. The court has to pay careful attention to this type of arrangement to be sure it remains appropriate for the child.

Caution: *One problem with limited guardianships is that your child may encounter a legal situation you haven't considered. You have to anticipate the future when you set up a limited guardianship.*

Temporary guardianship

If the court appoints a temporary guardian, it specifies the limited problem or limited time of the guardian's power. Usually, a temporary guardian is appointed only in a situation caused by drugs or momentary illness or in a special medical case.

What to consider when choosing a guardian

You may want to select a relative, friend, or trusted legal professional as the guardian for your child. Here are some points to consider as you make your decision:

- Does the potential guardian live close to your child?
- Does he or she have enough time to devote to your child?
- Does he or she have the interpersonal skills necessary to be an effective advocate for your child?
- Is he or she willing to take on the responsibility?
- Do you trust him or her to keep your child's best interests in mind?
- Does he or she already have a relationship with your child?
- Is he or she willing to keep up with new programs and opportunities for your child?
- Will he or she adapt to your child's changing circumstances?
- Does he or she have the financial ability to manage your child's estate?

Caution: *Make sure to periodically review your choice of guardian. Your child's needs may change, or the person you initially chose may become unable or unwilling to serve as guardian.*

What if you die before nominating a guardian for your child?

If you fail to nominate a guardian in your will, or otherwise die before making arrangements for a caregiver, the court may appoint a guardian for your child. If a relative does not wish to serve or does not qualify, the court may appoint a professional guardian who is a stranger to your family. The guardianship process can be expensive, time consuming, emotionally draining, and open to public view. In some cases, though, there are advantages to having a guardian with professional expertise.

Public guardian

If a child with special needs has no individual guardian, the court will appoint a public guardian for the child. Usually, this guardian has many other clients as well, so he or she may not have time to watch your child's affairs as closely as you wish. A public guardian is paid out of public funds, but since the guardian often negotiates with public agencies, he or she may experience a conflict of interest. Public or nonprofit agencies may also be public guardians.

Caution: *A public guardian is usually considered a guardian of last resort.*

Corporate guardian

A corporate guardian is part of a company that sells guardianship services. A professional staff or a volunteer manages your child's care. This type of guardianship is usually funded by advance payment from parents, life insurance policies, or bequests. The United Way and other charities also support corporate guardians.

What if your child does not need a guardian?

Even if your child does not need a guardian (if, for instance, he or she is already a legally competent adult), he or she may continue to need care, advice, and support throughout adulthood. You may want to ask a family member, friend, or other individual to act as a caregiver or mentor for your child. Make sure, though, that the caregiver you've chosen has the power to act on behalf of your child should he or she become incapacitated. This can be accomplished by having your child execute certain legal documents, including a durable power of attorney and advanced medical directives.

Special Needs Trusts

At A Glance

Definition

A special needs trust is an estate planning tool that can provide for the needs of an individual who is disabled without jeopardizing his or her eligibility for government benefits such as Medicaid and Supplemental Security Income (SSI). The goal of the special needs trust is to supplement (rather than replace) Medicaid benefits.

Prerequisites

- Goal is to supplement, rather than replace, government benefits
- The beneficiary is considered to be permanently and totally disabled
- The trust is established for the beneficiary by a proper party (generally, a party other than the beneficiary, such as a parent, grandparent, legal guardian, or court)

Key Strengths

- Provides for needs not satisfied by public assistance
- Can provide for the needs of an individual who is disabled throughout his or her life
- Supplements, rather than replaces, government benefits
- Can be established with funds that belong to someone other than the beneficiary (a third-party special needs trust) or with funds owned by the beneficiary (a self-settled special needs trust)
- Depending on the type of trust (i.e., if it is a properly drafted third-party special needs trust), the state will not have to be "paid back" for long-term care services upon the death of the beneficiary

Key Tradeoffs

- Beneficiary has no control over assets
- Complex to administer; trustee must not make payments or distributions that might interfere with government benefit eligibility
- The state may be entitled to reimbursement from the trust upon the death of the beneficiary (if trust is self-settled and has a payback provision)

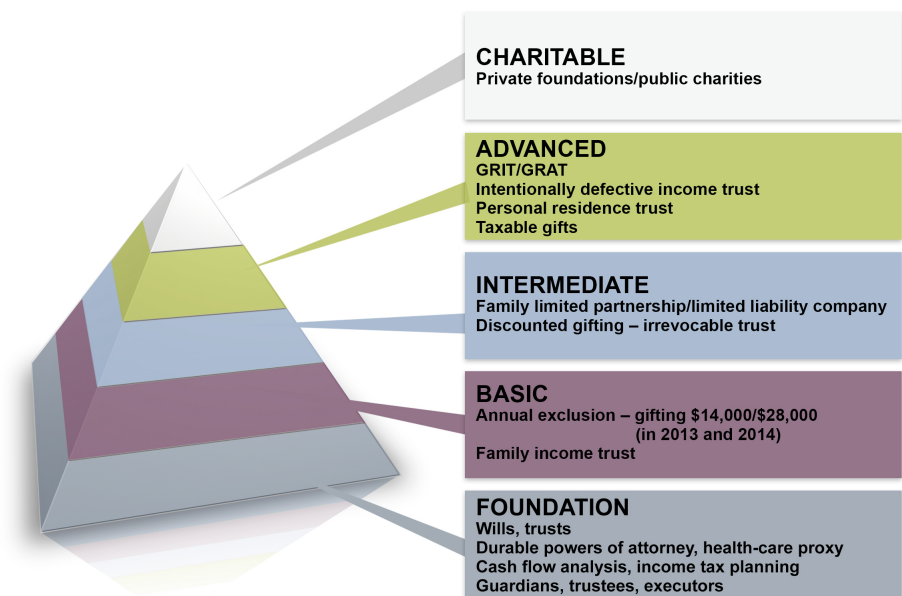
Variations from State to State

- Check the laws of your state

How Is It Implemented?

- Consult an attorney experienced in special needs issues and Medicaid

Estate Planning Pyramid



Isn't estate planning only for the rich?

Answer:

In a word, no. Estate planning allows you or anyone to implement certain tools now to ensure that your concerns and goals are fulfilled after you die. Your objective may be to simply make sure that your loved ones are provided for. Or you may have more complex goals, such as avoiding probate or reducing estate taxes.

Estate planning can be as simple as implementing a will (the cornerstone of any estate plan) and purchasing life insurance, or as complicated as executing trusts and exploring other sophisticated tax and estate planning techniques. Therefore, estate planning is important whether you are wealthy or whether you have only a small estate. In fact, estate planning may be more important if you have a smaller estate because final expenses will have a greater impact on your estate. Wasting even a single asset may cause your loved ones to suffer from lack of financial resources.

You may also want to plan your estate if you have special circumstances such as any of the following:

- You have minor children or children with special needs
- Your spouse is uncomfortable with or incapable of handling financial matters
- You have property in more than one state
- You have special property, such as artwork or collectibles

Working with a Financial Advisor

The world of 50 years ago was a lot different than it is today. An individual often worked at the same job all his or her adult life, lived in the same house, and stayed married to the same spouse. In those days, too, one spouse could support a family, paying for college ordinarily didn't require taking out a second mortgage, and people could look forward to retiring on Social Security and possibly a company pension.

Today, your hopes and dreams are no different. Like most people, you probably want to buy a home, put your children through college, and retire with a comfortable income. But the world has become a more complex place, especially when it comes to your finances. You may already be working with financial professionals--an accountant or estate planner, for example--each of whom advises you in a specific area. But if you would like a comprehensive financial plan to help you secure your future, you may benefit from the expertise of a financial advisor.

Services a financial advisor may provide

Even if you feel competent enough to develop a plan of your own, a financial advisor can act as a sounding board for your ideas and help you focus on your goals, using his or her broad knowledge of areas such as estate planning and investments. Specifically, a financial advisor may help you:

- Set financial goals
- Determine the state of your current financial affairs by reviewing your income, assets, and liabilities, evaluating your insurance coverage and your investment portfolio, assessing your tax obligations, and examining your estate plan
- Develop a plan to help meet your financial goals which addresses your current financial weaknesses and builds on your financial strengths
- Make recommendations about specific products and services (many advisors are qualified to sell a range of financial products)
- Monitor your plan and periodically evaluate its progress
- Adjust your plan to help meet your changing financial goals and to accommodate changing investment markets or tax laws

Some misconceptions about financial advisors

Maybe you have reservations about consulting a financial advisor because you're uncertain about what to expect. Here are some common misconceptions about financial advisors, and the truth behind them:

- Most people don't need financial advisors--While it's true that you may have the knowledge and ability to manage your own finances, the financial world grows more intricate every day. A qualified financial advisor has the expertise to help you navigate a steady path towards your financial goals.
- All financial advisors are the same--Financial advisors are not covered by uniform state or federal regulations, so there can be a considerable disparity in their qualifications and business practices. Some may specialize in one area such as investment planning, while others may sell a specific range of products, such as insurance. A qualified financial advisor generally looks at your finances as an interrelated whole, and can help you with many of your financial needs.
- Financial advisors serve only the wealthy--Some advisors do only take on clients with a minimum amount of assets to invest. Many, however, only require that their clients have at least some discretionary income.
- Financial advisors are only interested in comprehensive plans--Financial advisors generally prefer to offer advice within the context of a client's current situation and overall financial goals. But financial advisors frequently help clients with specific matters such as rolling over a retirement account or developing a realistic budget.
- Financial planners aren't worth the expense--Like other professionals, financial advisors receive compensation for their services, and it's important for you to understand how they're paid. But a good financial advisor may help you save and earn more than you'll pay in fees.

How are financial advisors compensated?

When it comes to compensation, advisors fall into four categories:



- Salary based--You pay the company for which the advisor works, and the company pays its advisors a salary
- Fee based--You pay a fee based on an hourly rate (for specific advice or a financial plan), or based on a percentage of your assets and/or income
- Commission based--The advisor receives a commission from a third party for any products you may purchase
- Commission and fee based--The advisor receives both commissions and fees

You'll need to decide which type of compensation structure works best for you, based on your own personal circumstances.

When is it time to consult a financial advisor?

In many cases, a specific life event or a perceived need may prompt you to seek professional financial planning guidance. Such events or needs might include:

- Getting married or divorced
- Having a baby or adopting a child
- Paying for your child's college education
- Buying or selling a family business
- Changing jobs or careers
- Planning for your retirement
- Developing an estate plan
- Coping with the death of your spouse
- Receiving an inheritance or a financial windfall

In these situations, a financial professional can help you make objective, rather than emotional, decisions.

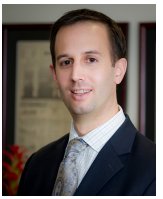
However, you don't have to wait until an event occurs before you consult a financial advisor. A financial advisor can help you develop an overall strategy for approaching your financial goals that not only anticipates what you'll need to do to reach them, but that remains flexible enough to accommodate your evolving financial needs.

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Ameriprise Financial
David F. Light, CFP®, CRPC®
Financial Advisor
1211 Hamburg Turnpike
Suite 217
Wayne, NJ 07470
973-633-0877 x14
david.f.light@ampf.com
www.davelight.com