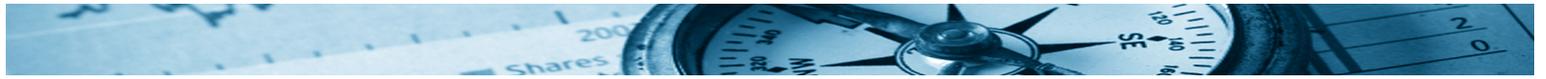


# Parenting a Child with Special Needs





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## 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.

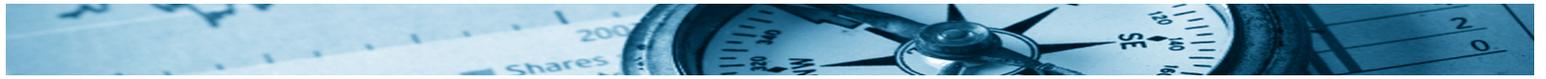
Consider working with a qualified financial planning professional who can help you assess and improve your current and future financial situation. Among other things, he or she can prepare a realistic budget, help you locate benefits available in your state, including Supplemental Security Income (SSI)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

**Note:** As the parent of a child with special needs, you may be interested in learning more about a new tax-advantaged savings option called an ABLER account. Similar in many respects to 529 college savings accounts, ABLER accounts may help individuals whose disabilities began before age 26 provide for future expenses without jeopardizing their eligibility for public benefits such as Medicaid and SSI. The Achieving a Better Life Experience (ABLE) Act that authorized these accounts was signed into law in December 2014. Many states have launched plans and more are in the works. You can find more information about ABLER accounts, as well as a list of states that are offering plans, on the ABLER National Resource Center website, [ablenrc.org](http://ablenrc.org).

## 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



[Center for Parent Information & Resources](#) 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](#) 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.

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