

When Your Child Has Special Needs

As the parent of a child with special needs, you face many of the same challenges that any parent faces. But you'll have to cope with some unique financial, medical, educational, and legal issues as well.

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.

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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.

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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., Supplemental Security Income (SSI) and 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.

Another way to save for future expenses is with an ABLE account. Money in an ABLE account generally does not count toward SSI and Medicaid asset limits.

An ABLE account may be opened by an individual whose disability began before age 26. As a parent, you may also be able to open and oversee an account on your child's behalf. Your child will be the account owner and the account beneficiary.

Contributions to the account can be made by you, your child, and others who want to provide financial support. Earnings on contributions accumulate tax deferred at the federal (and sometimes state) level, and distributions will be tax-free if they are used to pay qualified expenses. These include housing costs, transportation, health care, personal assistance, education, and many other types of expenses related to living with a disability.

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For more information and a list of states offering ABLE programs, visit the website of the ABLE National Resource Center at ablenrc.org.

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