



First Steps When a Child Has Special Needs

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Knowledge that a child has special needs may come at any time. Through prenatal testing, birth trauma or delayed development during infancy or the toddler years. Sometimes learning disabilities aren't discovered till a child enters pre-school or elementary school. And, of course, illness or injury may come at any age. After the initial shock, parents are often at a loss about what to do first. Here are some tips.

Prenatal or Newborn

If prenatal testing has determined that your child is likely to be born with special needs, there are steps you can take right away. Begin learning as much as possible about the condition by speaking with doctors and conducting research through reputable websites. There's a lot of misinformation on the web, so be careful with your Google searches. You might begin with the [American Academy of Pediatrics](#), then branch out to national organizations that focus on your child's disability. [The Arc](#), [Easter Seals](#), and the [National Down Syndrome Society](#) are good sources. You'll want to understand what the potential effects will be on your child's cognitive, physical and behavioral development. Make copies of helpful articles.

You should also start to exploring what services may be needed and what government programs could assist you. If your child is likely to have a *developmental disability*, defined somewhat differently by each state, you can contact your local [Early Intervention Services](#) ahead of time to get an understanding of how to proceed after birth.

Early Intervention

Early Intervention is available, under the Individuals with Disabilities Education Act (IDEA), to all children with developmental disabilities from birth through age three, and sometimes longer. Certain disabilities, such as Down syndrome or cerebral palsy, automatically qualify. In other cases, Early Intervention professionals will evaluate your child, with your written permission, in order to determine eligibility and to develop an Individualized Family

Service Plan (IFSP). Early Intervention provides a wide range of medical, therapeutic and social services, including family counseling and parent support groups.

Evaluations are performed at no charge to parents. Depending on the state, some services are subject to a sliding scale fee, while others may be covered by Medicaid or personal health insurance. Services cannot legally be denied to a child due to a family's inability to pay.

There's nothing like talking to those who have had the same experience. Other families can be a great source of practical advice and encouragement. There are [parent-to-parent programs](#) throughout the U.S., as well as support groups sponsored by local advocacy organizations.

Once your child is born, continue consulting health care providers, including specialists. Take notes and keep copies of all reports. If you believe that the child's disability was caused by medical malpractice, contact a personal injury attorney. A settlement could prove critical to your child's long-term financial security.

Sometimes, long after leaving the hospital, you may suspect that your infant or toddler isn't developing physical abilities, hearing, vision or speech "on schedule." In that case, you should reach out to Early Intervention to request an evaluation. Or, you may prefer to work with a developmental pediatrician who can then refer you to Early Intervention.

Legal Safeguards

It's never too early to begin thinking about your child's long-term security, in the event that you and/or your spouse pass away. You should consider creating a [special needs trust \(SNT\)](#), either within your will (testamentary) or stand-alone, in order to prevent a child's inheritance from disqualifying him or her for means-tested benefits such as Medicaid and Supplemental Security Income (SSI). The SNT should be amendable in case your child's condition improves or the rules change regarding exempting the SNT from counting as an asset for the means-based public benefits. Your will should also appoint a guardian who would care for your child if you and the other parent no longer can.

Investigate your child's eligibility for Medicaid and [Supplemental Security Income \(SSI\)](#). In most cases, a child won't qualify until the age of 18, because parents' income is considered. However, check with a reliable advocacy organization to determine whether or not your family's financial situation would qualify.

Start a notebook to keep all of your child's information in one place. The notebook should have separate tabs for medical, educational, and legal materials.

School Years

In some cases, a child's special needs aren't apparent until they enter pre-school or kindergarten, where a more structured environment may highlight learning disabilities. IDEA requires that schools be proactive in identifying a child's requirement for special education services. However, if parents suspect something, they should bring their concerns to the school's attention. Although the school must conduct an evaluation, parents may want to pay a developmental pediatrician in order to obtain an independent opinion.

Once it's been determined that a child is eligible for special education services, parents should become actively involved in the [Individualized Education Plan \(IEP\)](#) process. An IEP, which should be reviewed and revised annually, is a wide-ranging document that lists educational services, as well as the supplemental services that will enable the child to benefit from special education. It may extend to speech, physical and occupational therapies, psychological services, therapeutic recreation, parent training and more.

Sudden Illness or Accident

Life is full of risk, and a serious illness or accident can result in a disability at any time. In such instances, first steps remain the same:

- Learn as much as possible about the disability and available services. Consult health care experts. Keep records of everything.
- Reach out to other parents and advocacy organizations.
- Take appropriate legal steps.
- Investigate eligibility for government programs.
- Work with the school to develop an IEP.
- Develop a team of professionals you can count on.

When a disability first becomes apparent, it can feel overwhelming. Remember that you're not alone. And take one step at a time as you work towards a future where your child's potential will be realized.

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