



CAN A CHILD WITH A CHRONIC HEALTH IMPAIRMENT OR SERIOUS ILLNESS GET SPECIAL HELP FROM HER SCHOOL?

IMPORTANT: ELC's publications are intended to give you a general idea of the law. However, each situation is different. If, after reading our publications, you have questions about how the law applies to your particular situation, contact us for a referral, or contact an attorney of your choice.

When is my child entitled to help from her school district?

There are two routes to establish that your child with a chronic illness is entitled to special supports from the district. One is the "special education" route. If you and the district agree that your child has a disability and as a result needs specialized instruction, she is entitled to special education services under a federal law called the Individuals with Disabilities Education Act (IDEA) and state regulations called Chapter 14.

The other route is for children who have a chronic illness or disability and need some help or "accommodation" in school or at home, but who do not need special instruction. These children have protections under a federal law called Section 504 of the Rehabilitation Act (Section 504) and state regulations called Chapter 15.

Children eligible for "special education" under the IDEA and Chapter 14

School districts must provide special education services, including therapies and other special help, to children with physical, intellectual, and emotional disabilities who because of their disability need to be instructed differently.

Children with chronic health impairments or serious illnesses sometimes need special education because they are "other health impaired."

A child is "**other health impaired**" if she has a serious or continuing health problem that limits her strength or alertness in school, or raises her sensitivity to the school environment - *and affects her ability to learn*. **Examples of health problems** that *may* qualify your child for special education if they affect her ability to learn are: asthma, attention deficit disorder ("ADD"), attention deficit hyperactivity disorder ("ADHD"), Tourette Syndrome, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia.

If you think your child is eligible for special education, write to your school principal and ask that the school evaluate your child. If the school agrees that your child is eligible for special education, you and the district will develop an Individualized Education Program (IEP) that lists the special education and other services your child needs. For more information on the special education process, see ELC's manual *The Right to Special Education in Pennsylvania: A Guide for Parents and Advocates* and other publications that can be obtained from ELC's website (www.elc-pa.org) or from the telephone number listed below.

In addition to special education and therapies, your child can be entitled to "school health services." School health services include services that do not have to be provided by a doctor if the student must get the services during the school day. One example is "clean intermittent catheterization" for a child with spina bifida. Another is a nurse to monitor the child's health condition during the school day and to accompany the child on the school bus. The service should be listed on the student's IEP and the school district must make sure that it is provided. This doesn't mean that another system - usually the Medical Assistance system - cannot provide or fund the service. But it does mean that the school district is responsible for making sure this happens without charge to the family.

Sometimes a child with a chronic health problem who is eligible for special education cannot attend school regularly, or misses school for long periods of time. Parents and the school district should determine how the student will receive her assignments and how much in-home teaching the student needs (the minimum is usually five hours, but if more instruction is appropriate for the child, the child should receive more). Those decisions should be included in the child's IEP.

Specially designed instruction can also be provided while your child is in the hospital if the child is not too ill to learn.

Children who are eligible for accommodations, supports, and services under Section 504 and Chapter 15

If your child has a health problem that "substantially limits" a "major life activity" and needs help to participate in and benefit from the school district's education or extra-curricular program, she is entitled to special "accommodations" from her school district. Federal law recently expanded what is considered a "major life activity." This now includes *learning, walking, seeing, hearing, speaking, breathing, caring for oneself, performing manual tasks, eating, sleeping, standing, lifting, bending, reading, concentrating, thinking, and communication*. A child can also qualify because of problems with "major bodily functions" such as *functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions*.

Federal law now also provides that a school district cannot consider steps that have been taken to help the child (for example, medication, a wheelchair or a hearing aid) in determining whether the child has a physical or mental impairment that substantially limits a major life activity. The one exception is if the child uses ordinary eyeglasses or contact lenses.

A child can be eligible even if the child's impairment only occurs periodically. A child even can be entitled to accommodations if her illness is in remission if it would substantially limit a major life activity if it were active. However, the child would qualify for protection under the law only if the problem is likely to last or has lasted for at least six (6) months.

If you think your child needs special supports or accommodations to participate fully in school, **but the child does not need specialized instruction**, *write* to your school principal. In your letter, explain the type of help you believe your child needs. You can include copies of evaluations, records, or prescriptions. The school district must evaluate your child (or accept the private evaluations) and determine whether your child qualifies for a **Section 504 Plan** (also called a Chapter 15 "Service Agreement"). A Section 504 Plan lists the services and accommodations your child needs. Examples of **typical accommodations** are: permitting a child with a seizure disorder to stay indoors during recess when it is

hot outside; dispensing medication for a student with asthma; having a child with a vision impairment sit close to the blackboard; allowing a child with diabetes to go to the school nurse to get an insulin shot.

What if the school district and I don't agree on whether my child is eligible for an IEP or Section 504 Plan, or the type, amount, or location of services needed?

If you disagree with your school district over the child's eligibility, or type, amount, or location of services provided in your child's IEP or Section 504 Plan, you can:

- Request *mediation* from the Office for Dispute Resolution (ODR). Call ODR 1-800-222-3353 or get a mediation request form at <http://odr-pa.org/>. The mediation system helps families with either special education issues or Section 504/Chapter 15 disputes.
- For children with Section 504 Plans (a/k/a Service Agreements), request an *Informal Conference* with district officials by sending a written request to the principal (and send a copy to the district's Director of Special Education). Within **10 school days** of receiving your request, the district must hold the conference to try to resolve the disagreement.
- Request a *formal hearing*. For more information on mediation, the hearing system, and other options for resolving disputes, see ELC's Fact Sheet entitled *How to Resolve Special Education Disputes* at www.elc-pa.org or visit ODR's website at <http://odr-pa.org/>.

Can I get help for my child from any other source?

Medical Assistance or Medicaid ("MA") is the federal/state insurance program that pays for health screens and treatment services for low-income children and adults. In Pennsylvania, children with disabilities sufficiently severe to qualify for federal Social Security Income benefits are eligible for MA *regardless* of the amount of their families' income. They will be eligible unless they have too much income in their own name (for example, the income from a trust fund in the child's name). Child support and Social Security benefits are not considered the child's income and so will not be counted against them. *Thus,*

virtually all children with severe physical or behavioral disabilities in Pennsylvania qualify for MA coverage. Eligible children have the right to all “medically necessary” physical and behavioral health services. This includes routine medical care (such as immunizations or treatment for ordinary illness), but it can also include quite specialized and costly services.

Children who qualify for MA get an “ACCESS” card, which they can use to buy a wide range of prevention and treatment services. In most counties, these children are also enrolled in a Medical Assistance HMO. For many services and items, a child’s physician will need to request authorization from the HMO based upon medical necessity. If families also have private health insurance, MA will require them to use their private insurance first. However, MA services must be free and promptly provided, and no co-pays or additional payments can be charged to families.

Some **key behavioral health services** covered by MA are: psychiatric hospital stays, residential treatment facilities, behavioral health rehabilitation services (the most common of which is Therapeutic Staff Support or “TSS,” that is, staff who provide one-on-one support to children with serious behavioral problems), medication for behavioral problems (such as Ritalin for children with Attention Deficit Disorder), outpatient therapy, and partial hospitalization programs.

On the **physical health side**, MA pays for, among many other things: therapies, shift and intermittent skilled nursing, communication devices and other durable medical equipment, and personal care services for children who need assistance with basic activities of daily living (eating, dressing, hygiene, etc.). MA must provide eligible children with the medical services necessary to meet the child’s physical and behavioral needs during the school day, and provide services in the child’s home, community, or in the school setting.

Remember, even if MA pays for a service that your child receives during the school day, if that service is needed for her to learn or attend school safely (such as a nurse or TSS support), it is important that the service also be listed on her IEP. That way, if your child is no longer eligible or there are other problems with

Medical Assistance, you can be certain that your child will have the help needed to continue in school.

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Disability Rights Network of Pennsylvania (DRN), pursuant to the Developmentally Disabled Assistance and Bill of Rights Act, P.L. 101-496, and the P&A for Mentally Ill Individuals Act, P.L. 99-319. DRN is located at 1414 N. Cameron Street, Suite C, Harrisburg, PA 17103. Telephone: 800-692-7443 or 717-236-8110. Website: www.drnpa.org.

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