

EPILEPSY



Education & Day Care

Advocating for Your Child



EPILEPSY FOUNDATION®
Not another moment lost to seizures™

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EDUCATION & DAY CARE

Parents of children with epilepsy may face a variety of barriers when they look for child care and appropriate educational services. A child care provider might refuse to accept a child with epilepsy based on misconceptions about the risks associated with seizures or the level of attention the child will need. There may be concerns about staff administering routine or emergency antiseizure medicines, for instance. In the school setting, children with epilepsy may need accommodations, or they may need special education services. Parents may have to work hard to get the services and accommodations their children need.



Children with epilepsy have the right to equal access to educational and child care services. This pamphlet provides an overview of these legal rights, along with practical tips on advocacy for parents. In addition, the Epilepsy Foundation can provide you with more detailed legal guidance or a referral to an attorney for help with a legal case involving discrimination based on epilepsy. These resources are outlined in the last section of this pamphlet and are generally available — along with a wealth of other information critical to people with epilepsy — by calling 1-888-886-EPILEPSY or visiting www.epilepsyfoundation.org.

obligations under federal Anti-Discrimination Law

The Americans with Disabilities Act (ADA)

The ADA prohibits discrimination on the basis of disability by state and local governments, and by public accommodations, such as businesses that serve the general public. The ADA's legal protections cover disability-based discrimination by child care programs that are run as private businesses and by child care programs that are operated or funded by a government agency. Almost all child care providers must comply with the ADA; even a home-based provider with no employees is covered by the ADA. For more information on the obligations of child care programs under the ADA, visit the Department of Justice's Web site to review *Commonly Asked Questions About Child Care Centers and the Americans with Disabilities Act*, at www.usdoj.gov/crt/ada/childq&a.htm.



The only type of child care program that is not covered by the ADA is one that is run by a religious organization such as a church, synagogue, or mosque. (In fact, all activities controlled by religious organizations are exempt from the ADA's requirements.) However, private programs that operate on the grounds of a religious organization but are not controlled by that organization generally must comply with the ADA.

The ADA requires child care centers to provide services for children with disabilities such as epilepsy that are comparable to the services they provide to children without disabilities. A child care provider who is subject to the ADA generally must make reasonable modifications to its policies and practices, as necessary, so that a child with a disability can fully participate in the program — unless the needed modifications would:

- cause a “fundamental alteration to the nature of the program” or
- impose an “undue hardship,” such as requiring time-consuming or expensive training of staff

A “fundamental alteration” of a child care program might include requiring a full-time one-to-one assistant for a child, assuming the facility provides group child care. This is because in a group child care situation, children do not ordinarily receive one-to-one supervision and individual assistance for more than brief periods of time. However, a child care facility probably would be required to ensure that staff provides occasional short periods of adult attention — such as help with toileting, diaper changing, zipping a jacket and medication assistance — to ensure that a child with a disability can have an equal opportunity to participate in the program. If the child has his own personal care attendant, who is paid by an outside source (including the family), the center would be required to allow that attendant to accompany the child as a reasonable modification to its policy.

Child care providers may not assume that a child’s disabilities are too severe for the child to be included successfully in the program. The center must make an individualized assessment as to whether it can meet the needs of the child without fundamentally altering its program or

imposing an undue hardship. In making this assessment, the provider must not rely on stereotypes or misconceptions about what children with epilepsy can or cannot do, or how much assistance they may require.

Section 504 of the Rehabilitation Act (Section 504)

Section 504 prohibits discrimination against people with disabilities in programs that are operated or funded by the federal government. The requirements of the ADA were modeled on those of Section 504. Publicly-funded child care programs such as after-school child care programs operated by a school system are governed by Section 504 (as well as by Title II of the ADA). Model child care programs run by colleges and universities as labs for teachers in training are also subject to Section 504, because their parent organizations receive federal funds. Section 504 requires reasonable accommodations for the person's disability, unless it would cause an undue hardship on the operation of the program.

If a private child care program, including one run by a religious organization, receives any federal funding, the program must comply with the requirements of Section 504. Sometimes, child care programs receive federal money for milk or for food that they provide to the children in their care; if this is the case, the program must comply with Section 504, even if it is run by a religious organization.

If a child care provider receives federal funds to operate a child care program, the provider may not exclude a qualified person with disabilities from the program, and must take into account the needs of the person in determining the aid, benefits or services to be provided to the person.

How Do These Laws Apply to children with epilepsy?

A child care provider may not refuse to accept a child with epilepsy simply based on that health condition. This would be illegal discrimination on the basis of disability. Sometimes, a child care provider might assume that a child with epilepsy needs a great deal of medical attention and individual care, when in fact, the child does not. Instead, the child care provider should communicate with the child's parents or guardians and any professionals (such as educators or health care providers) who work with the child in other contexts to learn about the specific needs of the child.

Remember: Child care programs must provide services to children with epilepsy that are comparable to services they already provide to other children. Some examples of services for children with conditions other than epilepsy are:

- Routine administration of over-the-counter and prescription medications
- Administration of Epi-Pen to treat an allergic reaction to bee sting or nuts
- Performing glucose finger prick tests to monitor children with diabetes
- Giving snacks during the day to children with diabetes to prevent diabetic shock
- Administration of an inhaler for children with asthma
- Toileting assistance and diaper changing for young children

Accordingly, child care programs that provide one or more of these services may be required to provide the following comparable services to children with epilepsy:

- First aid for seizures
- Escorting a child to a quiet place to recover and rest after a seizure

- Feeding a child special foods (provided by parents), if the child is on the ketogenic or other special diet

MUST ROUTINE AND EMERGENCY ANTISEIZURE MEDICATION BE ADMINISTERED?

Yes, it may be necessary for a child care provider to administer routine and/or emergency antiseizure medication to a child with epilepsy in order to make the child care program accessible to the child. While child care providers usually do not take issue with administering routine over-the-counter medications, they may argue that they should not have to administer prescription antiseizure medications, especially an emergency medication such as diazepam rectal gel (the trade name is Diastat® AcuDial™). Diazepam rectal gel is the FDA-approved standard out-of-hospital medication for treatment of prolonged or repetitive seizures. According to the manufacturer and medical experts, this medication may be safely administered by caregivers without medical training, including parents and child care staff. Administering such emergency medications will frequently avoid the need to call 911 for treatment. These medications generally must be given promptly in order to prevent serious neurological damage, or even death, that may result if a seizure persists too long.

Child care centers may claim they should not be required by the ADA to give an emergency medication like diazepam rectal gel because doing so would “fundamentally alter” the nature of their program or amount to an undue burden. They may argue, for instance, that they lack sufficient staff with adequate training or expertise and that they do not typically provide this type of emergency service.

However, this reasoning is based on misinformation and can be addressed by parents and the child's neurologist or other doctor. Child care providers often administer both over-the-counter and prescription medications with a physician's note and parental permission, and routine administration of prescription antiseizure medication should not be treated any differently. Emergency medications do not require additional significant staff time to administer or special expertise.

Diazepam rectal gel or similar medication to be administered in the event of a prolonged seizure or a cluster of seizures is, likewise, also not difficult, expensive, or burdensome to give to a child. Child care staff do not need medical training or special expertise to determine when and how to give such medication, although they may need to be educated by the parent on recognizing signs and symptoms of cluster or repetitive seizures. A training video and other instructional materials are available. Training on use of the medication is also available from the Epilepsy Foundation's affiliates around the country.

what can i do if a child care provider has discriminated against my child?

If your child has been denied services by a private or government-run child care provider based on his epilepsy, there are alternative ways you can challenge the denial. You can file an administrative complaint with the United States Department of Justice, which enforces the public accommodations (Title III) and state and local government (Title II) provisions of the ADA. Or, you may file a lawsuit under either Title II or III of the ADA directly in court without first filing such an administrative complaint.

To file an administrative complaint with the Department of Justice, submit the complaint in writing with a description of the discrimination you believe has occurred, your signature, and your address. Complaints about violations of Title II or Title III of the ADA should be mailed to:

U.S. Department of Justice
Civil Rights Division
950 Pennsylvania Avenue, N.W.
Disability Rights Section – NYAV
Washington, D.C. 20530

You may also file an administrative complaint under Section 504 with the federal agency that provides funding to the child care program. For information, call the Department of Justice at (800) 514-0301 (voice), (800) 514-0383 (TTY). Or, you may file a lawsuit in court under Section 504.

Advocacy Tips

1. Know the legal rights you and your child have and the legal obligations of your child care provider:
 - a) If it is **private** but not run by a religious organization, it is subject to the ADA (Title III).
 - b) If it is run by a **local government agency** such as a parks and recreation program or public school system, it is subject to Section 504 and to Title II of the ADA.
 - c) If it is run by a **college or university**, it is probably subject to Section 504 and to Title II of the ADA (if it is a state school).
 - d) If the program is run by a **religious entity**, it is not subject to the ADA and is not subject to Section 504, unless it receives some type of direct or indirect federal funding.
2. Provide your child care center with a straightforward assessment of your child's

needs. If the provider is subject to Section 504 or the ADA, it is legally required to provide “reasonable” accommodations for your child, so it is essential to disclose your child’s disability and request necessary accommodations. The child care provider must provide these accommodations unless they would cause the provider an undue hardship or fundamentally alter the program.

3. Make sure your child care provider has an emergency seizure treatment plan (to be completed by the treating doctor and parent) or other information necessary in order to make appropriate accommodations for your child. A standard form for the treatment plan is available from the Epilepsy Foundation’s Web site, www.epilepsyfoundation.org.

4. If the child care provider doesn’t accept your child, try to determine what the provider’s concerns are to see if those concerns could be addressed through training or support. Most Epilepsy Foundation affiliates offer training or technical assistance, and state child care agencies often offer training sessions for providers to help them address the needs of children with disabilities.

5. Document conversations with the child care provider, noting the date and the substance of the conversation, as well as the person with whom you spoke, and keep copies of any letters sent or received.

6. Try to stay calm, particularly if you end up filing a complaint. It is important to maintain a professional demeanor and show that you have attempted to resolve the dispute by clearly stating your child’s needs and offering whatever support you could to the provider.

INFANTS AND TODDLERS

Infants and toddlers with disabilities and those who are at risk of developing disabilities are entitled to early intervention services. Early intervention services can include special education, physical, occupational, speech or other therapies, nursing services, assistive technology and case management. Children are eligible for early intervention services from birth until they turn three years old. The program is part of the federal special education law, but at the state and local levels the infants and toddlers program might be run by a health department or another agency, rather than by the school system.

A child with epilepsy might be eligible for services from the infant and toddler program if, for instance, his seizures cause a developmental delay. Services are provided under an individualized family services plan. Early intervention services are designed to holistically address the needs of the entire family, whereas the education system is more focused on the needs of the individual child. In addition to therapy services designed to help your child make developmental progress, services can include case management, parent training and other services that will help you and other family members better understand your child's needs and meet them effectively.

If you have an infant or toddler with epilepsy who has a disability or is experiencing a developmental delay, you can contact your local or state infant and toddler program for information about how to get your child evaluated for services (for information on state programs, see www.childfindidea.org). Services can be

provided at home, at a child care center or at an agency or school.

Advocacy tips

1. If you believe that your child may need early intervention services, contact your pediatrician to discuss the need for a referral. Although your pediatrician does not need to agree that a referral is necessary, it will be helpful to have medical information to support the need for services. The referral can be made by you or by your pediatrician.

2. It is important to explain to the evaluators how your child's epilepsy and side effects from

any antiseizure medications affect your child's development. Consider all areas that may be affected, including learning, social skills, walking, talking and fine and gross motor skills.

3. If you disagree with services that are proposed for your child or your family, you do not have to

accept them. If you and the early intervention agency have a dispute about the services being provided, you can file a complaint, go to mediation or have an administrative hearing to resolve the disagreement.



The Americans with Disabilities Act

Title II of the Americans with Disabilities Act governs public schools. Title III governs private schools, unless they are run by a religious institution.

section 504 of the Rehabilitation Act of 1973

As noted above, Section 504 applies to all recipients of federal funding and therefore applies to public schools. Many private schools also receive federal funding — either directly or through state programs — and are also covered by the law. For instance, private schools may receive funds for food and nutrition programs, at-risk students, or they may receive grants for technology. If private schools, including parochial schools, receive any federal funding for a specific program, the entire school must comply with Section 504.

The individuals with disabilities education Act (IDEA)

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The IDEA is the main law that governs special education for students with disabilities. It sets out a framework for:

- identifying children with disabilities that negatively impact learning
- developing an individualized education program
- placing children into special education
- reviewing their placements on a regular basis

The law contains a number of requirements designed to protect the rights of children and parents in the special education process. It is important to know that if you are a non-native English speaker, you have the right to an interpreter at meetings for your child, and your parental rights documents can be translated into your native language so they will be easier to understand.

How do these laws apply to children with epilepsy in the school setting?

The IDEA does not include a specific disability category for epilepsy, but if students with epilepsy have trouble making educational progress, they can qualify for special education services as “other health impaired” students. Students with epilepsy might need special education because they:

- Have frequent seizures that cause them to regress academically
- Experience difficulty with concentration or cognitive ability due to medication side effects, or
- Have other disabilities that equally affect their ability to benefit from education and qualify for special education as “multi-disabled”

If students with epilepsy need special education, they are entitled to individualized education programs (IEPs) that set out the special education and related services they will receive. These terms are defined as follows:

- **Special education** – specially designed instruction (including adaptations in content and delivery of instruction) to meet a child’s unique needs

- **Related services** – supportive services necessary to assist a child with a disability benefit from special education such as counseling and health services
- **IEP** – a written statement developed by a team of professionals and parents that establishes measurable goals for the child and sets out the special education and related services the school will provide

The IEP must be implemented in the least restrictive environment in which the student's needs can be met. That means that to the



greatest extent possible, students with disabilities must be placed in general education (with non-disabled peers) with services in place to ensure a successful placement. Only if a student cannot be

successfully placed in the general education setting, with supplementary aids and services, may the student be removed to a more restrictive setting. School districts are required to maintain a continuum of placements to meet the needs of students.

Students with epilepsy may not need special education, but they may need accommodations such as: administration of routine or emergency antiseizure medication, extra time for tests to compensate for impairments to functioning caused by seizures or medication side effects, or reduced workloads during medication adjustments. For these students, it would be appropriate to have a Section 504 plan — an agreement that sets out reasonable accommodations for a student with epilepsy — to ensure the student has the same access to education as other children.

The ADA does not provide any additional rights to students in public schools beyond those afforded under Section 504. In private schools subject to the ADA, students have the right to reasonable accommodations that do not fundamentally alter the program.

Emergency medication Administration in schools

Administration of emergency medications, such as diazepam rectal gel, in schools is an issue of concern to families and school systems (see discussion above). Even though currently FDA-approved medications may be safely administered by caregivers without medical training, many school systems may prohibit staff other than nurses from administering them, and in many schools nurses may not be available to do so.

If a student's doctor prescribes an emergency medication for seizures, then the school system must ensure that school staff administers it. States typically have statutes (such as nurse practice laws) that indicate whether medications such as diazepam rectal gel must be administered by licensed nurses or whether other school staff may do so. In any case, there is no question that under the IDEA, the ADA and Section 504, school districts are required to ensure that someone on the school's staff, whether a nurse or other staff member, be available on-site to administer the appropriate medication.

It is illegal for an IEP team to move a student who needs emergency medication from a school without a nurse to a separate school with a nurse on staff based solely on a student's disability or for the sake of convenience. The IEP team generally must determine how to

deliver services in the student's assigned, neighborhood school.

Many school districts rely on 911 emergency services as an alternative to having school staff administer emergency antiseizure medication. Families should try to work with their school district and, if necessary, their state department of education, to design an emergency medication policy that addresses the concerns of the school district and, most importantly, meets the needs of the student.

Parents should ask their child's neurologist or other doctor to fill out an emergency seizure treatment plan form and to provide it to the school. A standard form is available from the Epilepsy Foundation's Web site at www.epilepsyfoundation.org.

what can i do if i disagree with a school district's plan for my child or if the school has violated my child's rights?

Options under the IDEA

If you disagree with a decision made by the IEP team, you may select one or more of the procedures outlined below; some may be more appropriate than others depending on the circumstances:

- Ask for a new IEP team meeting and at the meeting bring in an advocate or an attorney to help you persuade the team to revise its prior decision.
- File a written complaint with the state department of education. You can also try to resolve the situation in a less formal way, such as through a complaint to the special education director for the school district.
- Seek mediation. Mediation is a relatively informal voluntary process that may be used

to resolve disputes, involving an impartial third party who tries to negotiate a compromise. If you do not ask for mediation, you likely will be required to attend a resolution session before a due process hearing (see below) can go forward; a resolution session involves a meeting with the IEP team and an official with the authority to make decisions for the school system.

- Request a due process hearing. This involves an impartial third party, called a hearing officer, who issues a decision based on the evidence and the requirements of the IDEA. You may wish to consult with an attorney before asking for a hearing, because the hearing process has many complicated rules and the school system is usually represented by an attorney. If you disagree with the hearing decision, you have the right to file a civil suit to challenge it.

Options under Section 504

If you believe your child has been denied services or accommodations under Section 504, you may use one of these procedures:

- File a complaint with the U.S. Department of Education's Office for Civil Rights (OCR). To learn more about filing a complaint, review OCR's Web site, at www.ed.gov/about/offices/list/ocr/docs/howto.html.

Or contact the agency at:

Office for Civil Rights
U.S. Department of Education
400 Maryland Avenue, S.W.
Washington, D.C. 20202-1100
(202) 245-6800; 1-800-421-3481
FAX: (202) 245-6840
TDD: (877) 521-2172
E-mail: OCR@ed.gov
Web: www.ed.gov/ocr

- File a civil suit under Section 504 challenging the decisions of school administrators. You

have this option without first filing a complaint with the Department of Education.

Advocacy tips

1. Know the rights that you and your child have in the special education process and under Section 504. A basic understanding of the law will help you as your child progresses through his school years.
2. Be clear about whether you are seeking special education under the IDEA or services or accommodations under Section 504. Does your child need specially designed special education and related services in order to make educational progress? If so, you will want to advocate for special education and an IEP. Can your child succeed in general education with some accommodations for his epilepsy? If so, you will want to advocate for accommodations to be outlined in a Section 504 plan.
3. If your child needs medication, either routine or emergency, this should be listed on the IEP or Section 504 plan, with the dosage, the times it is to be given and the person identified who will give it. If a health plan or a seizure management plan is developed for your child with this information, the plan can be incorporated into the IEP or Section 504 plan.
4. Prioritize what you want for your child before you go to an IEP or Section 504 meeting:
 - What absolutely needs to be in the IEP or Section 504 plan?
 - What would you like to have in the document, but are you willing to compromise on?
 - For the items you feel are necessary, be sure to adequately justify your position. Do you have evaluations or other documentation recommending the services

you believe are necessary for your child? What is the position of your child's teacher or other professionals at the school? If you do not have support for your position, consider moving the item into a lower-priority category or giving it up for the time being.

5. Make use of advocacy resources. No parent can be an expert in all areas. You may feel you are expected to learn everything about epilepsy, medications and their side effects, insurance or Medicaid, the ADA and special education law. In fact, while it is helpful to have enough knowledge to understand how the systems work and to know what questions to ask, you do not have to do this all by yourself. You can obtain many helpful resources from the Epilepsy Foundation and its local affiliates (see next page).



THE EPILEPSY FOUNDATION'S ROLE

The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of the more than three million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through services, education, advocacy and research. In addition to programs conducted at the national level, persons with epilepsy throughout the United States are served by local Epilepsy Foundation affiliates in nearly 100 communities.

Legal Assistance: To directly assist people with epilepsy experiencing discrimination, the Foundation has established the Jeanne A. Carpenter Epilepsy Legal Defense Fund. The program provides legal guidance to individuals with epilepsy and their families, along with referrals to a nationwide network of lawyers who can provide advice and representation (including a free initial consultation). For more information on this program, or to request legal help for a case involving discrimination based on epilepsy, go to the Fund's Web site, www.epilepsylegal.org, or call 1-888-886-EPILEPSY.

For general information about epilepsy and its treatment, contact the Foundation at the above number, visit www.epilepsyfoundation.org, or check with the Epilepsy Foundation affiliate in your community.



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