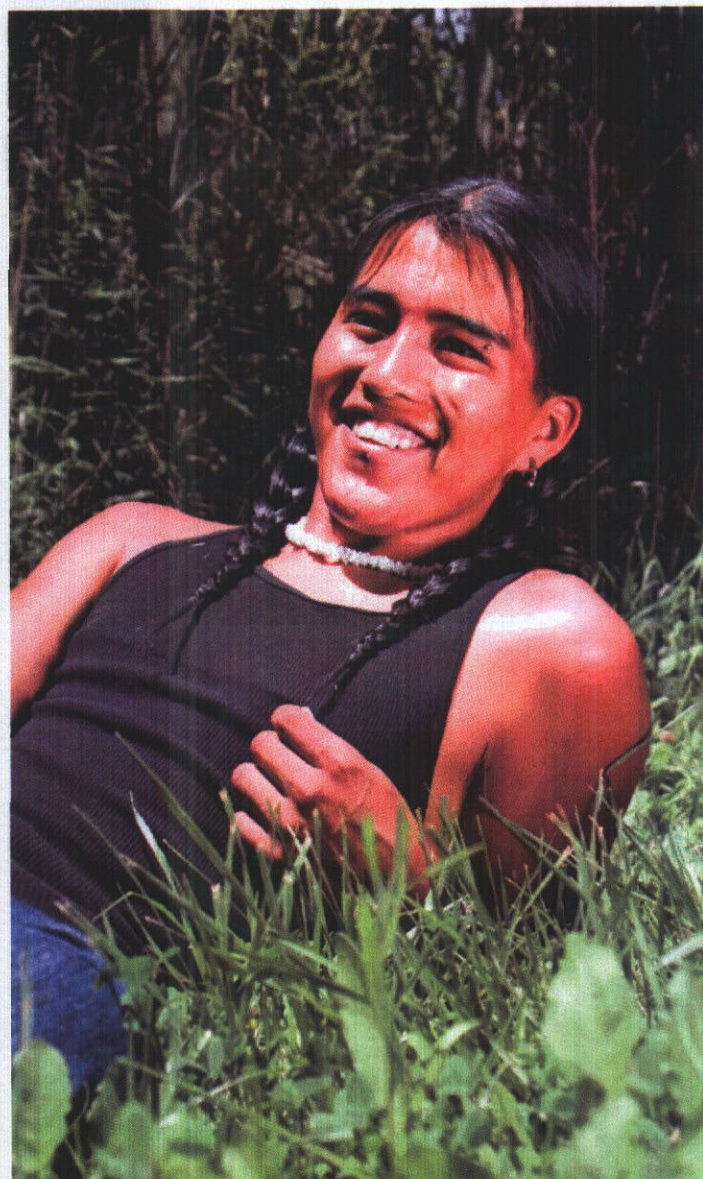


Legal Rights of Children with
Epilepsy in School and Child Care
An Advocate's Manual



**EPILEPSY
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Legal Rights of Children with Epilepsy in School and Child Care – An Advocate’s Manual

Second Edition

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Leslie Seid Margolis

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Leslie Seid Margolis is a managing attorney at the Maryland Disability Law Center (MDLC), Maryland's protection and advocacy agency, where she has worked since 1985. She graduated *summa cum laude* from Princeton University, where she received an A.B. degree in comparative literature. She obtained her J.D. degree from Stanford Law School. In her practice at MDLC she handles individual special education cases and systemic litigation, and engages in special education policy work at the state and national levels. Ms. Margolis is a frequent presenter at local, state, and national trainings and conferences, and she has contributed a number of special education technical assistance documents to the protection and advocacy network.

In addition to her professional background in disability and legal issues, Ms. Margolis has a great deal of practical experience as the parent of a fourteen-year-old daughter with lissencephaly, a rare brain development disorder that includes intractable seizures.

INTRODUCTION

Despite recent advances in treating epilepsy — a common neurological disorder causing recurrent seizures — the condition continues to evoke negative stereotypes, fear and misunderstanding. The hundreds of thousands of children living with epilepsy are affected in a variety of ways: For some, it will be a temporary problem, easily controlled with medication, outgrown after a few years. For others, it may be a lifelong challenge affecting many areas of life. Medical treatment of childhood epilepsy is getting better, and research toward a cure continues.

While most children with epilepsy can participate with the other students in the classroom, some may require additional services or specialized instruction. Federal law, as well as many state laws, grants children with epilepsy the right to receive those supplemental services, and if necessary, special education. Frequently, schools may fail to provide children with epilepsy adequate special education services or accommodations to address learning or cognitive impairments caused by their seizures or the side effects of antiepileptic medication. For instance, they may unjustifiably refuse to provide assistance in taking medication during school hours, or fail to make modifications to school policies on attendance, assignments or testing that may be necessary to help children compensate for these impairments. And child care programs may refuse to administer emergency medication for seizures, placing children's health at risk, or they may deny other accommodations, such as an opportunity to rest after a seizure.

Parents, along with the Epilepsy Foundation's affiliates, can play an important role in ensuring appropriate services are available in school and in child care programs. Formal legal training is not necessary for effective advocacy in these areas. This manual is designed to provide detailed practical guidance to help parents/guardians and other non-attorney advocates understand the rights of children with epilepsy to school and child care services — and to effectively advocate to secure those rights.¹ This manual also provides extensive information that lawyers will find useful in the event that legal action becomes necessary. Schools and child care providers, as well as their attorneys, may also find this manual useful in understanding the responsibilities they have with regard to children with epilepsy.

Above all, this manual is intended to provide tools to help families advocate on their own and reach a voluntary resolution of most disputes regarding their children's rights. When additional legal guidance or a referral for an attorney for specific legal advice becomes necessary, families are invited to contact the Epilepsy Foundation for assistance.

¹ Only federal law is covered in this manual. States have independent laws that govern the rights of children with epilepsy with regard to services in school and day care; advocates should be sure to review these laws also. Parents or guardians should understand that that this manual does not provide legal advice and cannot substitute for the advice of a licensed attorney.

The Role of the Epilepsy Foundation — Legal Guidance and Referrals to Attorneys

The Epilepsy Foundation of America, founded in 1968, is the national non-profit 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 prevent, control and cure epilepsy through services, education, advocacy and research. The Foundation has taken a leadership role in fighting discrimination affecting both children and adults with epilepsy since its founding.

In addition to Epilepsy Foundation programs conducted at the national level, local Epilepsy Foundation offices in nearly 100 communities serve individuals with epilepsy. These local affiliates advocate on behalf of people with epilepsy to ensure access to benefits, services and employment; provide information and referral services tailored to their communities; and sponsor public education campaigns. For more information, go to www.epilepsyfoundation.org.

Through its Jeanne A. Carpenter Epilepsy Legal Defense Fund, the Epilepsy Foundation seeks to protect the civil rights of people with epilepsy by promoting education, advocacy and increased access to legal services. A primary strategy of the Fund is to manage a technical assistance and attorney referral service for people with epilepsy experiencing discrimination. The Fund also provides legal support to attorneys that accept its referrals and to other attorneys nationwide who handle epilepsy-related discrimination cases. Individuals and their families, who experience epilepsy-based discrimination are invited to request legal guidance or a referral to an attorney through the Fund's Web site, www.epilepsylegal.org, or by calling 1-888-886-EPILEPSY. The lawyers to whom the Fund refers cases have agreed to provide at least an initial consultation and services to a maximum of three hours at no cost. Once a referral is made, the lawyer will evaluate a potential case and advise on the next steps.

The Fund is eager to help families ensure their children have equal access to school and child care services.

A Note to Non-Attorneys: An Explanation of Legal References Used in this Manual

Throughout this manual there are references to statutes, regulations, court cases and administrative decisions. While non-attorneys can successfully use this manual without consulting these references, some understanding of the differences between these sources is helpful. While the sources referenced here are all important parts of the legal framework governing the responsibilities of schools and day care programs to students with epilepsy, some types of legal authorities are more persuasive and more binding on school districts and child care providers than others. Recognizing the differences between these sources can be important:

- Statutes (or laws) are passed by federal and state governments and are binding on schools, districts and child care providers and their employees. An overview of major federal laws relevant in these areas is provided in chapter 2. Federal statutes are cited by the chapter and section in the U.S. Code (U.S.C.), for example, 42 U.S.C. 12133.
- Regulations are developed by government agencies to clarify the law and give more detail about their meaning and application. Many of the regulations discussed in this manual were issued by the U.S. Department of Education to implement the federal civil rights laws that protect students with epilepsy and other disabilities. Many states also have regulations that may need to be considered. Federal regulations are cited by the chapter and section in the Code of Federal Regulations (C.F.R.), for example, 34 C.F.R. 104.7(a).
- Court cases can affect the rights of students with epilepsy if they result in published opinions. Courts are organized hierarchically, and decisions from higher courts are more likely to be persuasive than decisions from lower courts. For example, the federal court system has three levels: the U.S. Supreme Court; circuit courts of appeal, which are generally numbered and cover different geographic regions of the country; and district courts (trial courts) in each state. Court opinions are legally binding on courts that are lower in the hierarchy than the deciding court. For example, a decision by the federal 9th Circuit Court of Appeals would be binding on federal district courts in the region covered by the 9th Circuit, which covers much of the western U.S., but not on district courts in other regions. Even when not binding, however, a court's interpretation of the law will often be persuasive to another court. The way court cases are cited differs depending on which court the opinion is from, but all case citations in this manual include the abbreviated name of the court and the year of the decision in parentheses.
- Administrative decisions are issued by government agencies which have responsibility for investigating individual cases of discrimination. These decisions are only legally binding on the parties involved in the case, and the same agency investigating similar facts in a different case may come to a different conclusion. Administrative decisions may be persuasive to a court, but generally hold less weight than the other types of legal documents discussed above. Most of the administrative decisions cited in this manual were issued by the U.S. Department of Education's Office for Civil Rights (OCR), but some are issued by state agencies hearing appeals from due process hearings. OCR agreements are only binding upon the subject school district. However, they might be used as a negotiation tool by advocates. Many administrative decisions cited in this manual are published in the *Individuals with Disabilities Education Law Reporter*[®]

- (IDELR), published by LRP Publications, and are cited by the volume and section number from that publication; for example 34 IDELR 102. These citations also include, in parentheses, the agency that issued the decision (typically OCR) and the year the decision was issued.

Although it is not necessary to read these documents in order to effectively use the information contained in this manual, the text of the statutes and regulations cited is generally available on the Internet. A helpful link to statutes and regulations is provided through Cornell University Law School's Legal Information Institute at www.law.cornell.edu. Although some are available on the Internet or through the Epilepsy Foundation's Web site, the usual source for copies of cases and administrative laws.

CHAPTER ONE

*What Do Attorneys and Advocates Need to Know About Seizures and Epilepsy?*²

1.1Q: What is a seizure?³

A: A seizure is an event in the brain which is characterized by excessive electrical discharges. Seizures may cause a myriad of clinical changes. Some of the possible changes may include unusual mental disturbances, such as hallucinations, abnormal movements, such as rhythmic jerking of limbs or the body, or loss of consciousness. In addition to abnormalities during the seizure itself (the ictal period), individuals may have abnormal mental experiences immediately before or after the seizure (perictal/postictal periods), or even in between seizures (the interictal period).

1.2Q: What is epilepsy?

A: Epilepsy, also referred to as a seizure disorder, is generally defined by a tendency to have recurrent seizures, unprovoked by any known cause such as hypoglycemia. There are a variety of causes for epilepsy, including head trauma, cerebrovascular disease, encephalitis, bacterial meningitis, and neurological deficits at birth such as cerebral palsy and mental retardation.

1.3Q: How common is epilepsy?

A: Epilepsy is one of the most common serious neurological conditions, affecting between four and ten school-aged children per every thousand. Overall, more than three million people in the United States have epilepsy.

1.4Q: How is epilepsy classified?

A: Epilepsy should be considered a general clinical term describing many different conditions rather than as a specific diagnosis. Epilepsy has been classified in multiple ways, each of value for different purposes. One form of classification is by the clinical description of the seizure type (see Question 1.5). This is useful for describing what happens to the person during the seizure, for educating care providers, aides and teachers on what to expect, and for planning necessary services, accommodations or modifications in the school or child care setting. A second way of classifying seizures is by etiology or cause: epilepsy can be

²Most of the material in this chapter is drawn from “Managing Students with Seizures: A Quick Reference Guide for School Nurses,” First Edition, published by the Epilepsy Foundation in 2006.

³ The author acknowledges Dr. Russell Margolis, professor of psychiatry and neurology at Johns Hopkins School of Medicine for the information contained in answers 1.1, 1.2 and 1.4.

idiopathic, which means it is of unknown cause, though often it is familial, or caused by a brain injury. Epilepsy can also be part of a more complex syndrome in which the brain and possibly other organs are affected. If this is the case, seizures may be only one of many issues that will need to be addressed in the education or child care setting. A third classification scheme is based on how well seizures are controlled by medicines.

1.5Q: Are there different types of seizures?

A: Yes. There are a number of different types of seizures, but they fall into two major groups — partial seizures and generalized seizures.

1.6Q: What are partial seizures?

A: Partial seizures are seizures in which the electrical short-circuit of the neurons is limited to a specific area of the brain. Partial seizures are divided into two categories: simple partial seizures, in which the person experiencing the seizure does not lose consciousness, and complex partial seizures, in which the person having the seizure loses consciousness or has impaired consciousness.

Simple partial seizures result from “abnormal neuronal activity in specific limited areas of the brain that affect movement, sensation or emotion.” *Managing Students with Seizures* at 16. During a simple partial seizure, a person remains aware of what is going on, but may be limited in how he or she can react. He or she may not be able to speak, or may experience tingling or nausea, visual distortions, or other symptoms that may serve as a warning of a more severe seizure to come.⁴

Complex partial seizures begin in one area of the brain but usually spread to other portions of the brain, including the opposite side, and involve a change in consciousness. The person who has the seizure usually will not remember what happened during the seizure. While having the seizure, the person may engage in automatic behaviors such as lip smacking, chewing or swallowing, fidgeting, or other repetitious behaviors. In some cases, complex partial seizures may cause a person to engage in more significant behaviors such as undressing, screaming, running and flailing. If a person experiencing such a seizure is touched or restrained, he or she may become combative. These behaviors are much less common but create obvious difficulties for the people who experience them. *Managing Students with Seizures*, p. 16.

⁴ As with the visual and other neurological disturbances that may precede a migraine headache for some people, these pre-seizure events or symptoms are called an “aura.”

1.7Q: What are generalized seizures?

A: Generalized seizures are seizures that affect both sides of the brain and produce loss of consciousness. There are several types of generalized seizures: absence, atonic (drop), tonic, clonic, myoclonic and tonic-clonic seizures:

- Absence seizures (sometimes called “petit mal seizures”) are usually just a few seconds long. They happen suddenly and the person will stop whatever he or she was doing and then resume the activity as soon as the seizure is over. The person may have many absence seizures or clusters of seizures during the course of a day. More common in children than in adults, absence seizures are frequently so brief that they escape detection.
- Atonic seizures (also known as drop seizures) produce a sudden loss of muscle tone. The person’s head will drop, or the person may fall to the ground. These seizures occur with no warning and can result in injury. Antiepileptic drugs usually have limited effectiveness in controlling atonic seizures.
- Tonic seizures are seizures in which the person’s leg, arm or body muscles stiffen. His or her arms or legs may extend. The person usually remains conscious.
- Clonic seizures make a person’s arms and legs jerk rhythmically. Clonic seizures by themselves are not common.
- Myoclonic seizures are seizures in which the person experiences quick, brief muscle contractions that usually occur on both sides of the body at the same time. They look like muscle jerks.
- Tonic-clonic seizures (sometimes called “grand mal seizures”) are the most common type of generalized seizure. They begin with a tonic phase, in which the person’s arms and legs stiffen, and then continue with a clonic phase, in which the person’s limbs and face jerk. During the tonic portion of a seizure, a person may have an initial vocalization followed by slowed or stopped breathing; during the clonic portion, breathing usually returns, but may be irregular, noisy or seem labored. The person may be incontinent and may bite his or her tongue or the inside of his or her mouth during the seizure.

1.8Q: Are there particular epilepsy syndromes or conditions?

A: Yes. There are many syndromes associated with epilepsy. Classifying epilepsy by seizure type alone leaves out other important information about the patient and the episodes themselves. Classifying epilepsy into syndromes takes a number of characteristics into account, including the type of seizure, typical EEG recordings, clinical features (such as behavior during the seizure), the

expected course of the disorder, precipitating features, expected response to treatment and genetic factors.

Epilepsy syndromes include, but are not limited to, frontal lobe epilepsy, temporal lobe epilepsy, childhood absence epilepsy, Landau-Kleffner syndrome, Benign Rolandic Epilepsy, Lennox-Gastaut syndrome, Rasmussen's syndrome and Juvenile Myoclonic Epilepsy.⁵

The temporal lobes are the parts of the brain just above the ears. People with temporal lobe epilepsy most commonly have complex partial seizures with automatic behaviors. Many people with temporal lobe epilepsy also have simple partial seizures during which they may experience nausea or vomiting, or feelings that are difficult to describe (auras). Auras may include hallucinations of smells, tastes, voices, music or visual phenomena.

People with frontal lobe epilepsy have partial seizures that may cause muscle weakness, thrashing movements, or posturing with their head jerking to one side while one arm lifts into a frozen position. Frontal lobe complex partial seizures are usually less than one minute in length and often occur during the night, causing a disruption in sleep, which can make the person sleepy during the day and cause behavior problems and poor performance in school. Frontal lobe seizures can involve screaming, bicycling movements and other socially difficult behaviors. (*Managing Students with Seizures*, p. 20). In many cases, these seizures tend to cluster.

Childhood absence epilepsy is also known as petit mal epilepsy and causes frequent absence seizures. It manifests itself between ages three and ten and about 40 percent of children with the condition will outgrow it or go into remission by the time they reach their teens.

Landau-Kleffner syndrome is rare. It manifests itself between ages three and seven and causes seizures and regression in speech. Children with this syndrome have simple partial and tonic-clonic seizures.

Benign Rolandic Epilepsy accounts for more than one third of the cases of epilepsy that begin in middle childhood between ages three and thirteen. Seizures occur primarily at night and are of the simple partial type, causing drooling and an inability to speak, although this may be followed by a convulsion of the body. These seizures tend to occur most often as the child is getting drowsy or attempting to go to sleep. Children are otherwise normal, and 95 percent of children with this condition outgrow it by age 15.

⁵ Unless otherwise noted, all information in this answer was obtained from <http://www.epilepsyfoundation.org/about/types/syndromes/index.cfm>, downloaded April 18, 2007

Lennox-Gastaut syndrome causes mixed types of seizures and is difficult to treat. Seizures begin between the ages of one and eight. Children with Lennox-Gastaut syndrome often have developmental delay and may have mental retardation.

Rasmussen's syndrome, also known as Rasmussen's encephalitis, is a rare disorder in which one half of the brain is affected and produces seizures on the opposite side of the body. Among the treatments that have been tried is surgery to remove the affected half of the brain.

Juvenile myoclonic epilepsy, also known as Janz's syndrome, generally begins in adolescence with a generalized seizure. Seizures are not likely to be outgrown.

1.9Q: Can seizures be triggered by anything in particular?

A: Yes. For instance, for some people, flickering or strobe lights are a trigger for seizures. Lack of sleep, stress, and failure to take seizure medications can also trigger seizures. In some cases, the trigger can be very specific and somewhat unusual. For many people, there are no known triggers for their seizures.

1.10Q: What is status epilepticus?

A: Status epilepticus is a period of prolonged seizure activity, caused by one seizure that does not end or by a series of seizures that continue without the person returning to baseline. Ten minutes or more of uninterrupted seizure activity is currently considered status epilepticus. It is possible that brain damage or death can result from status seizures. During status seizures, problems can arise if there is pulmonary or cardiac arrest that is not promptly treated. More often, however, serious negative consequences occur hours or days after the onset of status as a result of prolonged stress, oxygen deprivation and systemic complications such as organ failure.

1.11Q: How is epilepsy treated?

A: Epilepsy is generally treated with medications. Other treatments include the ketogenic diet, the vagus nerve stimulator and surgery.

1.12Q: What are the standard antiepileptic drugs (AEDs)?

A: Common AEDs include the following:

Ativan (lorazepam)	Lamictal (lamotrigine)
Carbatrol (extended release carbamazepine)	Lyrica (pregabalin)
Depakene (valproic acid)	Mysoline (primidone)
Depakote (divalproex acid)	Neurontin (gabapentin)
Diastat AcuDial (diazepam rectal gel)	Tegretol (carbamazepine)
Dilantin (phenytoin)	Phenobarbital (phenobarbital)

Felbatol (felbamate)	Topamax (topiramate)
Gabitril (tiagabine)	Trileptal (oxycarbazepine)
Keppra (levetiracetam)	Versed (midazolam)
Klonopin (clonazepam)	Zarontin (ethosuximide)
Zonegran (zonisamide)	

Each of these drugs is generally most effective for particular types of seizures. For example, Zonegran is most effective for partial seizures and generalized tonic-clonic seizures, but Zarontin is most effective for absence seizures. Diastat AcuDial (diazepam gel), which is rectal valium, is intended to break a prolonged seizure or a cluster of seizures; it is not intended for daily use.

Ativan (lorazepam) and Versed (midazolam) are benzodiazepines often used to control seizures in hospitals. Many doctors favor pre-hospital use of these agents for seizure clusters and to break a prolonged seizure prior to the development of status epilepticus. These medications have undergone some testing in which the drug is placed or sprayed inside the cheek or under the tongue of a person who is seizing. However, since the clinical trials required for approval by the Food and Drug Administration (FDA) for this purpose have not yet been completed, these medications are not widely available for seizure treatment, and their use has been limited to physicians who feel comfortable prescribing them for this use to their patients.

1.13Q: What are the side effects of AEDs?

A: The side effects of AEDs are not all the same, but many of them have similar side effects, such as sedation or sleepiness, loss of appetite and dizziness. A side effect of some AEDs may be weight gain or loss. Some AEDs cause dry mouth while others cause hypersalivation. More significantly, some AEDs can cause kidney stones, behavior changes, liver failure, or other serious complications. (*Managing Students with Epilepsy*, Appendix C).

1.14Q: What is the ketogenic diet?⁶

A: The ketogenic diet is a high fat diet that imitates starvation in the body by keeping the body in ketosis, which makes the body burn fat instead of carbohydrates for energy. It is not clear why this is an effective seizure treatment, but for a number of children, it has proven quite effective, either by itself, or in combination with medication. The diet is extremely rigid, as food and liquid must be carefully measured so the ratio of fats to carbohydrates and proteins is exact. Often, even the tiniest deviation from the diet, such as use of toothpaste, an over-the-counter cough medicine or suntan lotion can throw a child out of ketosis and cause seizures. Currently, variants of the diet, including the Atkins diet, are also being used as treatments for epilepsy.

⁶ Much of the information in the answers to questions 1.15 and 1.16 is drawn from "Ketogenic Diet," downloaded from www.epilepsyfoundation.org/about/treatment/ketogenicdiet.

1.15Q: Does the ketogenic diet have side effects or drawbacks?

A: Yes. Side effects can include dehydration, constipation and kidney or gall stones. Additionally, people on the diet need vitamin supplements because the diet lacks certain vitamins. For children and adolescents who are aware of the limitations of the diet, the small portions and restricted foods can be a big issue. The strict requirements of the diet can also impose a burden on families. However, a great deal of information and support for families is available from Johns Hopkins Hospital, online family support networks, the Epilepsy Foundation and other sources.

1.16Q: What is the vagus nerve stimulator (VNS)?

A: The VNS is similar to a pacemaker, but it stimulates the vagus nerve in the neck instead of the heart. It is a device that delivers “preprogrammed electrical impulses to the vagus nerve on an ongoing basis.” (*Managing Students with Seizures*, p. 33.) The VNS is usually implanted in the upper left chest or under the arm; it stimulates the vagus nerve, which then sends electrical impulses to the parts of the brain that affect seizures. *Id.* If a person has a seizure aura or begins to have a seizure, the VNS can be swiped with a magnet to send an additional burst of stimulation to abort or minimize the seizure. Depending on the student’s ability, he or she, a child care worker, a school nurse, or other trained personnel can swipe the magnet if a child with a VNS has a seizure in school or in a child care setting.

1.17Q: Does the VNS have side effects or drawbacks?

A: Reported side effects include hoarseness, tingling in the neck when the VNS is activated, insomnia and difficulty swallowing. The magnet must be kept away from anything that is sensitive to magnetic fields such as computers, credit cards and videotapes.

1.18Q: How may epilepsy affect a student?

A: Epilepsy can affect a student in a number of ways, depending on the type of seizures he or she experiences and on other factors. It is important for all staff who work with a student to know that a student has epilepsy and to understand the effect of the student’s particular seizures on his or her educational performance. For example, if a student has absence seizures, he or she may have many seizures in a day, but they may not be immediately obvious. However, they will interrupt the student’s ability to concentrate, and his or her learning or educational performance may be affected. If absence seizures are not identified, a teacher may think the student is not paying attention and may penalize him or her for poor performance in class or on tests. Tonic-clonic seizures may leave a student lethargic or sleepy, or with a headache. It may take several minutes or hours to recover fully. Students with drop seizures are at risk of injury, as are students with other types of seizures, depending on the student’s location and situation at the time of a seizure.

The student's mental state before, during, and after a seizure may be affected, and can have an impact on his or her educational performance, as can the medications he or she takes to control seizures. Medications may have an impact on the student's mental and physical state.

Students with epilepsy that is not well-controlled are likely to be more significantly affected educationally. They may have significant side effects from the medications they take, as well as effects from the many seizures they experience. Additionally, they may be limited in the sports or physical education activities they can participate in at school, and may experience social isolation or teasing. They may also be absent or late to school more frequently, depending on when seizures occur and how long it takes to recover from the seizures. In addition to the immediate effects of the seizures themselves, students with epilepsy may also experience anxiety about having seizures or because they know that school staff are afraid of their seizures.

1.19Q: What is the appropriate intervention for a child who has a seizure at school or in a child care setting?

- A:** If a child has epilepsy, it is essential that he or she have a health plan that describes the care he or she will need at school or while at child care. The plan should address administration of any routine or emergency medications, how to handle seizures if they occur, and whether emergency personnel need to be contacted and, if so, under what circumstances. If the child receives special education, the health plan should be incorporated into his or her individualized education program. The rest of this manual will address these issues in great detail.

In general, it is important for teachers and staff to remain calm and reassuring, both to the student and to other students or children. Staff and teachers need to speak calmly, and to observe and time the seizure and what is happening. They should protect the student's privacy as much as possible and ensure that the student is safe and that there are no potentially harmful objects near him or her. The student should not be restrained. Nothing should be placed in his or her mouth. If the student has a seizure action plan, it must be followed. If necessary, emergency medical staff must be contacted, and/or diazepam rectal gel or as-needed medication needs to be administered if a student's health plan so requires for a lengthy seizure or cluster of seizures. The purpose of diazepam rectal gel, other emergency medications or emergency medical intervention is to avoid the onset of status epilepticus or to minimize the risks if it occurs.

1.20Q: What are the practical implications of this information for attorneys and advocates working with children with epilepsy and their families?

A: In order to provide effective advocacy, attorneys and advocates need to have a full understanding of epilepsy, the child's seizures, and his or her medications and any side effects. Also, the attorney or advocate will need to be able to communicate effectively with school or child care nurses and other staff about any accommodations, services, or supports the child may need. Some children have well-controlled epilepsy and may never have a seizure in school or the child care setting; others may have occasional seizures. Some children — the children that attorneys and advocates are most likely to represent — may have frequent seizures and need special education, health services or other accommodations at school or in child care.

CHAPTER TWO

What Laws Apply to Children with Epilepsy?

Note: This chapter is a general introduction to the relevant laws. Chapters 4 and 5 discuss the application of these laws to children with epilepsy in detail.

2.1Q: What are the primary laws that apply to children with epilepsy?

A: Three laws in particular apply to children with epilepsy as well as children with other disabilities. The Individuals with Disabilities Education Act (IDEA) governs the provision of early intervention services to infants and toddlers as well as education services to children ages three through 21. Section 504 of the Rehabilitation Act of 1973 (usually referred to simply as Section 504) is a general anti-discrimination law that prohibits disability discrimination in federally funded and federally conducted programs and activities such as public schools. Finally, the Americans with Disabilities Act (ADA) is a law that prohibits disability-based discrimination in state and local government activities such as parks and recreation programs and schools, and in programs and public accommodations such as businesses, child care programs and doctors' offices.

2.2Q: What are the major provisions of the IDEA?

A: The IDEA guarantees a "free appropriate public education" to children with disabilities that "emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living." 20 U.S.C.1401(d)(1)(A); 34 C.F.R.300.1. Children are entitled to receive special education and related services in the least restrictive environment in which the services can be provided. The services are provided in accordance with an individualized education program (IEP).

2.3Q: What is a "free appropriate public education?"

A: A free appropriate public education means special education and related services that are provided at public expense, under public supervision, at no cost to the child's parent or guardian. These services must meet the standards of the state department of education, and the applicable requirements of the IDEA and its implementing regulations, and must include an appropriate educational program for the child, provided in accord with the IEP. 20 U.S.C. 1401(a)(9); 34 C.F.R. 300.17. Generally, an "appropriate" education has been found by courts to be one that enables children to make meaningful educational progress.⁷

⁷ The seminal case addressing this issue is *Board of Education of the Hendrick Hudson Central School District v. Rowley*, 458 U.S 176 (1982), which held that the requirement of an appropriate education is satisfied when the student receives sufficient support services to benefit educationally from instruction. If the child is educated in the regular classroom, the child's education is appropriate if the IEP is reasonably calculated to enable him or her to achieve passing marks and progress from grade to grade. Subsequent

2.4Q: Are all children with disabilities entitled to special education services under the IDEA?

A: No. Under the IDEA, a child with a disability is eligible for special education and related services only if he or she has a disability that is included in the definition set out in the law, the disability has an adverse effect on his or her educational performance, and he or she needs special education as a result. Infants and toddlers with developmental delays or those who have a diagnosed condition that has a high probability of resulting in developmental delay are entitled to early intervention services, as are at-risk infants and toddlers if states choose to make services available to them. The IDEA lists the following disabilities within its scope: autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury and visual impairment. 34 C.F.R. 300.25; 34 C.F.R. 300.8.; 20 U.S.C. 1402(3)(A).

2.5Q: Since epilepsy is not included as one of the listed disabilities, does that mean students with epilepsy are not protected by the IDEA?

A: No. Although epilepsy is not one of the thirteen named disabilities, it is listed in the definition of “other health impairment.” If a student’s epilepsy adversely affects his or her educational performance so he or she needs special education and related services, that student is covered by the IDEA. 34 C.F.R. 300.8(b)(9). See Chapter 4, Question 15 for additional information regarding this issue.

2.6Q: How does a school system decide that a student needs special education?

A: A student must be evaluated to determine if he or she has a disability that adversely affects his or her educational progress and if he or she needs special education. Students are referred by parents, teachers or others for special education. The evaluation must be conducted within 60 days of parental consent for evaluation unless a state has a different timeline. 20 U.S.C. 1414(a)(1)(C)(1). See Chapter 4 for a more specific discussion of the referral process for students with epilepsy. Based on the evaluation, a team — often called an IEP team, a multi-disciplinary team or a child study team and which includes the parent — determines if the child has a disability that adversely affects his or her education. If so, the team should develop an IEP and determine an appropriate placement.

cases specified that in order to be “appropriate,” the educational program offered by a school district must provide more than trivial or “de minimis” educational benefit. *Hall v. Vance County Board of Education*, 774 F.2d 629 (4th Cir. 1985); *M.C. ex rel.J.C. v. Central Regional Sch. Dist.*, 81 F.3d 389 (3d Cir. 1996). Many education attorneys and advocates argue that the No Child Left Behind Act has raised the basic floor set by *Rowley* to a higher level because of its emphasis on achievement for all students and its focus on adequate yearly progress.

2.7Q: Does the IDEA impose requirements for the evaluation process?

A: Yes. The school district or public agency⁸ must use a variety of assessment tools and strategies, including information provided by the parent, to gather functional, developmental and academic information about the student. The district may not use any one assessment or single measure as the only criterion for determining whether a student has a disability or determining an appropriate educational program for him or her. The district must use technically sound assessment instruments that may assess the relative contributions of cognitive and behavioral factors in addition to physical or developmental factors. Also, the district must ensure that the assessment materials are not selected or administered in a racially or culturally discriminatory manner, are provided and administered in the student's native language or other mode of communication, and that they are in a form most likely to yield accurate information about what the child can do academically, functionally and developmentally, unless it is clearly not feasible to provide or administer the assessment in such a manner. The assessments must be used for the purposes for which they are valid and reliable, must be administered by trained and qualified personnel, and must be administered in accord with instructions provided by the producer of the assessment.

Assessments must include those tailored to assess specific areas of educational need, and may not be selected so as to assess only a single general intelligence quotient (IQ score). Assessments must also be selected and given in a way that takes into account a student's disability and accurately tests the student's aptitude or whatever the test is measuring, rather than the student's impaired skill, unless that is the purpose of the test. The student must be assessed in all areas of disability. 20 U.S.C. 1414(b); 34 C.F.R. 300.304. For a student suspected of having a learning disability, the district may use a process that determines if the student responds to scientific, research-based instruction. Additionally, in order to determine that a student is eligible for special education as a student with a learning disability, the team must document the results of an observation of the student. 34 C.F.R. 300.311.⁹ See Chapter 4 for a more specific discussion of the evaluation process for students with epilepsy.

⁸ This manual will use the term "school district," rather than "public agency," the term used by the IDEA, because the majority of students with epilepsy attend schools operated by local or intermediate school systems. It is important to note, however, that the IDEA's requirements extend to educational programs operated by public agencies such as departments of juvenile services, departments of mental health, and schools for the blind and deaf, as well as departments of correction.

⁹ There are a number of requirements regarding identification of a student as having a learning disability. See 34 C.F.R. 300.307-311.

2.8Q: What is an IEP?

A: The IEP is, essentially, the blueprint for the education of a student with disabilities. It is a document that sets forth the special education and related services to be provided to the student. The IEP must contain information regarding:

- The student's present levels of academic achievement and functional performance
- The student's measurable annual goals, including academic and functional goals
- How the student's progress toward the goals will be measured and when periodic reports on the student's progress will be provided
- The special education, related services, supplementary aids and services to be provided to the student
- The program modifications and supports to be provided to school personnel that will enable the student to advance toward meeting his or her IEP goals, make progress in the general education curriculum, participate in extracurricular and nonacademic activities, and be educated and participate with other students with and without disabilities

The first element, the present level of performance, must address how the student's disability affects his or her involvement and progress in the general curriculum. The annual goals must address the student's disability-related needs as they relate to the student's ability to make progress in the general curriculum, as well as the student's other educational needs that result from his or her disability. For students with significant cognitive impairments who take alternate assessments aligned to alternate standards under the No Child Left Behind Act,¹⁰ the IEP must contain benchmarks or objectives to implement the annual goals. 20 U.S.C. 1414(d)(1)(A); 34 C.F.R. 300.320. See Chapter 4 for a more specific discussion of IEPs for students with epilepsy.

2.9Q: Who develops the IEP?

A: The IEP is developed by a team that includes the following individuals:

- The student's parents

¹⁰ Approximately one percent of students fall into this category. According to 2007 regulations promulgated by the United States Education Department, an additional two percent of students will be eligible to take modified assessments aligned to modified standards. These students are working on the general curriculum, but at a different pace. The students who fall into the category of the one percent of students with the most significant cognitive disabilities are generally students working in what is often called a "life skills" or "community-based instruction" curriculum. They are not diploma-track students.

- At least one regular education teacher of the student, if he or she is participating or may participate in regular education
- At least one special education teacher or provider of the student
- A representative of the school district or the public agency who is qualified to provide or supervise the provision of special education and is knowledgeable about both the general education curriculum and the availability of the agency's resources
- An individual who can interpret the instructional implications of evaluation results
- The student, whenever appropriate
- At the discretion of the parent or the agency, other people who have knowledge or expertise regarding the student, including related services personnel, as appropriate. 20 U.S.C. 1414(d)(1)(B); 34 C.F.R. 300.321(a).

2.10Q: What are the related services referred to above?

A: Related services are the developmental, corrective, and supportive services that help a child with a disability benefit from his or her special education. Related services include, but are not limited to, transportation, speech and language therapy, audiology, interpreting services, psychological services, physical therapy, occupational therapy, recreation (including therapeutic recreation), early identification and assessment of disabilities in children, counseling services (including rehabilitation counseling), orientation and mobility services, medical services (for diagnostic or evaluation purposes), school health services, school nurse services, social work services and parent counseling and training. 20 U.S.C. 1402 (26); 34 C.F.R. 300.34.

2.11Q: What does “least restrictive environment” mean?

A: The IDEA requires school districts to maintain a continuum of placements in which special education and related services can be provided. The placements can range from the general education classroom, which is the least restrictive environment, to a residential special education facility, which is the most restrictive because it is a separate, full-time, special education facility housing only children with disabilities. The IDEA requires that a student be placed in the least restrictive environment in which his or her IEP can be implemented. 20 U.S.C. 1412(a)(5); 34 C.F.R. 300.115; 34 C.F.R. 300.116. See Chapter 4 for more general information about least restrictive environment as well as about least restrictive environment regarding students with epilepsy.

2.12Q: Does the IEP team have additional responsibilities as it develops the IEP?

A: Yes. When the purpose of the meeting is transition for students out of the education system, the team must invite the student and, if he or she does not attend, the team must take other steps to ensure consideration of his or her

preferences and interests. 34 C.F.R. 300.321(b).¹¹ When a student has behavior that interferes with his or her learning or the learning of others, the team must consider positive behavior supports, interventions or strategies. For a student with limited English proficiency, the team must consider the student's language needs as they relate to his or her IEP. For a student who is blind or who has a visual impairment, the team must provide for instruction in and the use of Braille unless, after an evaluation, the team concludes that Braille is not appropriate for the student. The team must consider the communication needs of a student who is deaf or hard of hearing and, for all students, the team must consider whether the student needs assistive technology devices and services. 34 C.F.R. 300.324(a)(2).

2.13Q: Can students with disabilities be suspended for disciplinary reasons?

A: Yes. The IDEA sets out a procedural framework governing the discipline of students with disabilities. School personnel may remove students with disabilities to an appropriate interim alternative education setting, such as an alternative school or another setting, or suspend them for up to 10 consecutive school days if students without disabilities are subject to the same treatment. An appropriate interim alternative education setting is one that permits the student to receive educational services that enable him or her to continue to participate in the general curriculum and progress toward meeting his or her IEP goals. Students may be removed for subsequent periods if the removals do not constitute a change in placement.¹² Subsequent removals would amount to a change in placement if they form a pattern of removal. 34 C.F.R. 300.530; 300.536.

Services are not required during these removals (if they are not provided to students without disabilities) until a student has been removed for more than 10 school days in the same year. Additionally, the student must, as appropriate, receive a functional behavioral assessment and behavioral intervention services that will address the behavior violation so that it does not recur. 20 U.S.C. 1415(k); 34 C.F.R. 300.530.

Except as described below, within 10 school days of a decision to change a student's placement, the parent and relevant members of the IEP team must

¹¹ Transition planning and services must begin for students no later than when they turn 16, although some states have maintained the requirement from an early incarnation of the IDEA that transition planning begin when students turn 14. Transition services are a "coordinated set of activities for a child with a disability that are designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation." 20 U.S.C. 1402(34); 34 C.F.R. 300.43(a).

¹² A change in placement would occur if the student's program were substantively different from what he or she had been receiving. If the location is changed but the program remains substantively the same or similar in all major respects, a change in placement will not be considered to have occurred.

meet to determine if the student's behavior was a manifestation of his or her disability. In making this determination, the team must review all relevant information in the student's file, including the IEP, any teacher observations and any information provided by the parents. The team must ask:

- 1) If the behavior was caused by, or had a direct and substantial relationship to, the student's disability and
- 2) If the conduct was the direct result of the school district's failure to implement the IEP

If the answer to either of those questions is yes, the team must find that the behavior was a manifestation of the disability, and the team must take steps to remedy the problems, and must conduct a functional behavior assessment and develop a behavior intervention plan or revise the existing plan if a plan is already in place. Additionally, the student must return to his or her placement, unless the parents and school district agree otherwise. This manifestation meeting must occur for any disciplinary removal of more than 10 days at one time, or any cumulative removal of more than 10 days if the removals amount to a pattern.

There are three general exceptions to the requirement that the student be returned to his or her placement:

- 1) The student has possessed or used weapons at school or a school event
- 2) The student has possessed, used, sold, or solicited the sale of drugs at school or a school event and
- 3) The student has inflicted serious bodily injury upon another person while at school or at a school function

In these situations, a school administrator may remove a student to an interim alternative education setting for up to 45 days. A hearing officer may remove a student for up to 45 days if a school district seeks a hearing on the basis of dangerousness and convinces the hearing officer that the student should be removed. 20 U.S.C. 1415(k); 34 C.F.R. 300.530; 34 C.F.R. 300.532.

2.14Q: Do parents have rights in the special education process?

- A:** Yes. Parents have the right to review their child's educational records, to be notified of and participate in meetings regarding their child, and to obtain an independent educational evaluation of their child if they disagree with the evaluation done by the school district. 34 C.F.R. 300.501, 34 C.F.R. 300.502. See Chapter 4 for a discussion of independent evaluations. Additionally, parents have the right to file complaints with the state department of education, to

pursue mediation and to seek due process hearings and court appeals if the school district or public agency proposes or refuses to take a particular action. Parents may obtain attorney's fees if they prevail. 20 U.S.C. 1415(d)(2)(L); 34 C.F.R.300.517. Expert fees are not available. *Murphy v. Arlington Central School Dist. Bd. of Educ.*, 126 S.Ct. 2455 (2006). See Chapter 8 for further discussion of complaints, mediation, due process hearings, and appeals to court. Students whose parents cannot be identified or located, who are wards of the state, or who are unaccompanied homeless youth are entitled to surrogate parents to act as educational decision makers on their behalf. 20 U.S.C. 1415(b)(2); 34 C.F.R. 300.519.

2.15Q: What rights do parents and students have under the IDEA if English is not their native language?

A: Parent notices must be translated into the parents' native language unless it is not feasible to do so. 34 C.F.R. 300.503(c)(1)(ii). Notices must be translated orally if the language is not a written one. 34 C.F.R. 300.503(c)(2)(i). Generally, schools provide interpreters for parents who speak common languages such as Spanish. Students must be evaluated in the language that is likely to produce the most accurate results. 34 C.F.R. (c)(1)(iii).

2.16Q: What is Section 504 of the Rehabilitation Act of 1973?

A: Section 504 is a statute that prohibits discrimination in federally funded and federally conducted programs and activities against people with disabilities on the basis of disability. Section 504 mandates that people with disabilities cannot be excluded from participation in or be denied the benefits of any such program or activity. Additionally, Section 504 requires the provision of reasonable accommodation in order to provide a person with a disability equal opportunity to participate in federally funded and federally conducted activities and programs offered to people without disabilities.

2.17Q: Who is protected by Section 504?

A: People are covered under Section 504 if they have a physical or mental impairment that substantially limits one or more major life activities, have a record of such an impairment, or are regarded as having such an impairment.

2.18Q: What is considered a "physical or mental impairment" under Section 504?

A: The Education Department's Section 504 regulations define the term as "(A) any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs; respiratory, including speech organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and lymphatic; skin; and endocrine; or (B) any mental or psychological disorder, such as mental

retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.” 34 C.F.R. 104.3(j)(2)(i).

2.19Q: Are all people with epilepsy automatically covered by Section 504?

A: Probably not. The United States Supreme Court held in *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999), a case interpreting the ADA, that, in determining if an impairment “substantially limits” a major life activity, it is necessary to look at any measures the person has taken to mitigate or minimize the impairment, such as medications or assistive devices like eyeglasses or prosthetics. Because the definition of disability under the ADA is identical to the definition contained in Section 504, the *Sutton* holding appears equally applicable to Section 504. Therefore, if a person with epilepsy has well-controlled seizures or has mild seizures that do not substantially limit a major life activity, and does not have significant side effects from antiepileptic medication, he or she will not be considered disabled unless he or she meets one of the other prongs of the definition — i.e., has a record of such an impairment or is regarded as having such an impairment. However, a student who requires school personnel to administer antiepileptic medication to him or her during the school day would be covered under Section 504 even if his or her seizures were well controlled. See Chapter 5 for further discussion of Section 504 and special education.

2.20Q: What is a “major life activity” under Section 504?

A: Major life activities include functions such as walking, seeing, hearing, caring for one’s self, speaking, breathing, learning and working. 34 C.F.R. 104.3(j)(2)(ii).

2.21Q: What are the requirements of Section 504 for public school systems?

A: Public school systems must provide a free appropriate public education to each “qualified handicapped person” in the jurisdiction regardless of the nature or severity of the person’s disability. A person is qualified if he or she is of an age at which children without disabilities attend school or at which state law mandates that education services be provided to children with disabilities. An appropriate education is regular or special education with related aids and services that “are designed to meet individual educational needs of handicapped people as adequately as the needs of nonhandicapped people are met” and that meet the requirements of the regulations. 34 C.F.R. 104.33.¹³

¹³ The Education Department’s Section 504 regulations use the terms “handicap” and “handicapped persons.” However, Section 504 itself, consistent with the language used in the ADA, instead makes reference to “disability” and “individuals with disabilities.” The regulations have not yet been revised to adopt this more current and preferable language.

At its heart, Section 504 requires that services for people with and without disabilities be comparable and that people with disabilities have equal access to services available to people without disabilities. Services, benefits and aids must be equally effective, but they do not have to produce identical results for people with and without disabilities; Section 504 is designed to ensure that people with disabilities have equal access to equally effective services, and that they are not discriminated against in their enjoyment of those services.

2.22Q: Does Section 504 require placement of students in the least restrictive environment?

A: Yes. Section 504 requires that students with disabilities be educated with students without disabilities to the maximum extent appropriate to the needs of the person with disabilities. A student with disabilities must be placed in the regular education environment unless the school system demonstrates that the education of the student cannot be achieved satisfactorily with the use of supplementary aids and services. Additionally, students with disabilities are to participate in nonacademic and extracurricular services and activities with students without disabilities to the maximum extent appropriate to the needs of the student with disabilities. 34 C.F.R. 104.34.

2.23Q: Does Section 504 have requirements about evaluation and placement?

A: Yes. A school system must evaluate a student believed to have a disability before initially placing the student in regular or special education and before making any significant change in placement. The evaluation requirements are similar to those in the IDEA. 34 C.F.R. 104.35. Although the placement requirements are not as detailed as those in the IDEA, the placement decision must be made by a group of people knowledgeable about the child, the meaning of the evaluation data, and the placement options (including the requirement that students be placed with students without disabilities to the maximum extent appropriate). 34 C.F.R. 104.35.

2.24Q: Does Section 504 have requirements about physical accessibility of buildings?

A: Yes. Section 504 requires that a recipient of federal funds make its program or activity “readily accessible” to people with disabilities, but does not require that every existing facility or every part of the facility of the program be accessible to and usable by people with disabilities. 34 C.F.R. 103.22(a). A program can achieve accessibility by many means, including but not limited to redesigning equipment, reassigning classes to another floor or building, assigning an aide to a student, delivering services at an alternate site, altering the existing facility, or building a new facility. 34 C.F.R. 103.22 (b).

2.25Q: Does Section 504 apply to students with disabilities beyond the age of 21?

A: Yes. Section 504 applies to postsecondary education programs and activities, including postsecondary vocational programs and activities. The regulations cover admissions and recruitment, academic and nonacademic programs, housing, and financial and employment assistance. Such programs and activities cannot discriminate against qualified people with disabilities by using tests or admission criteria that have a disproportionately adverse effect on people with disabilities except in certain circumstances, and cannot limit the number or proportion of people with disabilities who may apply to the program. Additionally the program may not ask a person before admission if he or she has a disability, but after admission may ask the person if he or she has disabilities that may require accommodation. 34 C.F.R. 104.42.

Section 504 requires postsecondary programs and activities to make accommodations to avoid discrimination. These accommodations can include academic adjustments such as permitting course substitutions or additional time to meet degree requirements. Additionally, a program may not adopt rules, such as prohibitions against recorders in classrooms or guide dogs in buildings, that would limit the participation of students with disabilities. The program must also ensure that students with impaired sensory, manual or speaking skills have access to necessary auxiliary aids such as interpreters, readers, recorded texts, or special classroom equipment so that material will be accessible. 34 C.F.R. 104.44.

2.26Q: What happens if a school district or other recipient of federal funding violates Section 504?

A: The person who has been discriminated against or, if the person is a child, the child's parent or representative, can file a complaint with the U.S. Education Department's Office for Civil Rights. See Chapter 8 for additional information.

2.27Q: What is the Americans with Disabilities Act?¹⁴

A: The ADA is a civil rights statute that 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 basically extended the protections of Section 504, which only applies to federally funded and federally conducted programs and activities, to other government agencies and private entities that serve the public. Programs that are subject to the ADA must provide

¹⁴ Because the majority of students with epilepsy are educated in public schools, this manual focuses primarily on the IDEA and Section 504. For students in the public school setting, the ADA's substantive protections are co-extensive with those offered by Section 504; therefore, this manual will discuss the ADA only briefly.

reasonable accommodations or modifications unless doing so would cause a fundamental alteration to the nature of the program or impose an undue hardship or a direct threat to the health or safety of others. The only programs not subject to the ADA are those which are run by a religious organization such as a church, synagogue, or mosque; activities controlled by religious organizations are exempt from the ADA. See Question 2.30 for additional information.

2.28Q: Does the ADA apply to schools?

Yes. The ADA applies to public schools, but its protections do not offer students any substantive rights that they do not already have under the IDEA and Section 504. However, the ADA also applies to private schools, which are not covered by the IDEA or Section 504 (unless the school receives any federal funds). So a private school that is not run or controlled by a religious organization must comply with the ADA in its admissions policy, its operation, and all aspects of its policies and practices.

2.29Q: What happens if a school violates the ADA?

A: A person with a disability or, if the person is a child, the parent or representative, can file a complaint with the regional Office for Civil Rights for the region in which the person lives. General information about the Office for Civil Rights is available at www.ed.gov/about/offices/list/ocr/index.html. A list of the regional offices can be obtained at <http://wdcrobcolp01.ed.gov/CFAPPS/OCR/contactus.cfm>.

2.30Q: Must parochial schools comply with Section 504 or the ADA?

A: It depends on whether the school receives any form of federal financial assistance. Often, parents find that private schools may be reluctant to accept or accommodate their child with epilepsy because of the school's budgetary concerns, misconceptions about the needs of the child, or the fact that the school does not have to accept the child or provide accommodations under federal anti-discrimination laws. Although the ADA applies to private schools and requires them to make reasonable accommodations, similar to the requirements of Section 504, the ADA does not apply to parochial schools or other programs operated or controlled by religious organizations.¹⁵

Such schools are subject to the non-discrimination requirements of Section 504 only if they receive funding, directly or indirectly, from a federal agency. Therefore, schools operated by religious organizations that do not receive federal funding are not covered by either the ADA or Section 504 and, unless there is an applicable state anti-discrimination law, children with epilepsy or

¹⁵ The ADA contains a specific exemption for "religious organizations or entities controlled by religious organizations, including places of worship." 42 U.S.C. 12187.

other disabilities are not protected from discrimination by private parochial schools.

Examples of direct funding that would establish coverage under Section 504 include school food and nutrition programs, including a school milk program; assistance for at-risk students; and grants for technology, school improvement, or other purposes. Indirect funding occurs when a federal grant is made to a state, which then allocates funds to local agencies which then provide funds to individual schools. At least one court has found that a parochial school within a Roman Catholic diocese was covered under Section 504 as a recipient of federal funds, although the funds were disbursed by the state through a local public school. See *Dupre v. The Roman Catholic Church of the Diocese of Houma-Thibodaux*, 1999 U.S. Dist. LEXIS 13799, 31 IDELR 129 (E.D. La. 1999).

Section 504 obligations are enforced by the government agency that administers the federal funding the school receives. For programs administered by the U.S. Education Department, these obligations are enforced by its Office for Civil Rights. If a program is administered by another federal agency, that agency will be responsible for enforcement. The U.S. Department of Agriculture (USDA), for instance, would enforce Section 504 when the only federal funds a school receives are for the school lunch program.

Families with concerns involving parochial schools may wish to consider pursuing a complaint with the USDA if the school participates in the school lunch program. For information about the complaint process, see the Web site of the USDA's Office of the Assistant Secretary for Civil Rights at www.ascr.usda.gov/complaint_filing.html.

CHAPTER THREE

What are the Legal Rights of Children with Epilepsy in the Child Care Setting?

3.1Q: Can a child care provider reject a child from care on the basis of the child's epilepsy?

A: No. A child care provider cannot turn away a child solely because the child has a disability such as epilepsy. To reject a child on the basis of his or her epilepsy or the provider's beliefs about epilepsy would be a violation of Section 504 and Title III of the ADA.

3.2Q: What general obligations do child care providers have under the ADA and Section 504?

A: Title III of the ADA prohibits public accommodations from discriminating against a person solely on the basis of a disability. 42 U.S.C. 12182. Public accommodations include child care centers that are open to the public. 42 U.S.C. 12181(7)(k). Under the ADA, a child care center must provide comparable services to people with disabilities as it provides to people without disabilities. 42 U.S.C. 12182(b)(1)(A)(ii). A child care center must also make reasonable modifications in its policies to enable an individual with a disability to participate in its program unless doing so would fundamentally alter the nature of the service provided, impose an undue burden, or create a direct threat to the health and safety of others.¹⁶

Almost all child care providers must comply with the ADA; even a home-based provider with no employees is covered by the ADA. However, child care programs that are operated or controlled by religious organizations are not subject to the ADA. For general information about 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" (DOJ Guidance) at www.usdoj.gov/crt/ada/childq&a.htm.

Child care programs that receive federal financial assistance are also covered by Section 504, which provides similar protections to the ADA. Child care programs are covered by Section 504 only if they receive federal funding; some child care programs receive federal financial assistance for milk programs or other nutritional programs. Section 504 may provide different remedies for discrimination than the ADA, including monetary damages.

¹⁶ Because it is extremely unlikely that a child with epilepsy would pose a direct threat in the child care setting, this issue is not addressed in this chapter.

3.3Q: Can a child care provider reject a child with epilepsy from care because the child needs routine administration of antiepileptic drugs (AEDs) to prevent or minimize seizures?

A: No. Even if a child care provider has a policy prohibiting the administration of medication to any child, it may be necessary to make an exception to that policy in order to make the child care program accessible to a child with a disability. In one particularly helpful case, a court rejected the defendant private preschool's arguments that altering its "no-medication policy" and requiring staff to administer asthma care amounts to a fundamental alteration. *Alvarez v. Fountainhead*, 55 F. Supp. 2d 1048 (N.D. Ca. 1999). In this case, the parents of Jeremy Alvarez, a four-year-old boy with asthma, challenged the policy, which prevented the child from bringing his hand-held Albuterol asthma inhaler to the preschool. The court, granting a preliminary injunction,¹⁷ found that no fundamental alteration would be required in providing the child with necessary care. The court stated that it "is not convinced at this time that requiring teachers to recognize symptoms of wheezing and supervising Jeremy's use of the inhaler would fundamentally alter the nature of Fountainhead's educational program." *Id.* at 1052. Also, the court found that Jeremy's asthma was stable and did not require intensive monitoring or care and, therefore, contrary to the school's suggestion, did not require the continual focus of one teacher's attention.

The court observed that "Fountainhead's teachers are not being asked to engage in a function that is wholly different from those duties already being performed for other children." *Id.* The court noted that "as part of their daily duties, teachers routinely maintain custodial supervision over all children in the program, which includes tasks such as providing toileting assistance, changing diapers, changing clothes, and administering first aid to children when they need it." *Id.*

Regarding potential child care provider liability for injuries related to administering medications, the DOJ Guidance referenced in Question 3.2 provides direction. The Guidance notes that "while some state laws may differ, generally speaking, as long as reasonable care is used in following the doctors' and parents' or guardians' written instructions about administering medication, centers should not be held liable for any resulting problems." See DOJ Guidance, Answer to Question 14.

¹⁷ The court, in granting the preliminary injunction, found that irreparable harm would occur in the absence of the injunction because there was no readily available alternative program for the child. A similar ruling was reached in *Burriola v. Greater Toledo YMCA*, 133 F.Supp. 1034, 1039 (N.D. Ohio 2001) (boy with autism denied access to YMCA day care program).

3.4Q: Can a child care provider reject a child with epilepsy from care because the child would require administration of emergency antiepileptic medication, such as diazepam rectal gel, in the event of a prolonged seizure or cluster of seizures?

A: A child care provider cannot reject a child with epilepsy from care on the basis of the child's need for administration of such medication, unless the provider can demonstrate that performance of this task would cause a fundamental alteration of the child care program or impose an undue burden. Administration of diazepam rectal gel or similar medication in the event of a prolonged seizure or cluster of seizures is not difficult, expensive or burdensome. For instance, it takes less time than taking a child's rectal temperature and child care staff do not need medical training or expertise to determine when and how to give medications such as diazepam. This particular medication is approved by the FDA for use by parents and other caregivers, and it may be given after review of the manufacturer's instructions, which are easy to read and have step-by-step pictures. There is even a training video and other instructional materials available free of charge, and training on use of the medication is also available from the Epilepsy Foundation's affiliates around the country. For more information regarding administration of emergency antiepileptic medications such as diazepam, see Chapter 7.

With regard to showing a fundamental alteration of the program, this would be extremely difficult if the child care program already administers comparable medications and treatments to children for other medical reasons. For instance, most child care programs provide comparable services, such as administering prescription medications; administering EpiPen and EpiPen Jr. to children with various allergies, such as to bee stings and nuts; providing inhaler assistance to children with asthma; providing gastrointestinal (tube) feedings; and performing glucose tests for children with diabetes, monitoring them for signs of hypoglycemic shock and giving them certain foods to prevent such shock.

Similarly, it is extremely unlikely that a child care provider would be able to show that administering emergency antiepileptic medication to a child with seizures would impose an undue burden, that is, that it would cause significant difficulty or expense. See 28. C.F.R. 36.104. Administration of this medication does not require a day care provider to expend funds or other resources, nor does it require time-consuming or expensive training.¹⁸

¹⁸ The necessary training for diazepam, for instance, is basic and brief, and takes less than one hour. See *Alvarez v. Fountainhead*, 55 F.Supp. 2d 1048 (N.D. Ca. 1999), in which the court found that less than one hour of training regarding asthma care would not impose an undue burden on the child's preschool. Nor is it difficult to administer a medication such as diazepam once training has been completed, or to monitor the child after the medication has been administered.

Although there are apparently no adjudicated decisions involving the administration of emergency antiepileptic medication by a child care provider, child care providers and other public accommodations such as preschools have been required by the courts and through settlement agreements to provide similar

3.5Q: What level of individualized attention must be provided to a child with epilepsy?

A: A child care provider is generally not required to hire additional staff or provide its own constant one-to-one supervision of a child in a group child care situation. However, most children need individualized attention at times. If a child who needs some individual attention can be included successfully into a child care program without fundamentally altering the program, the child cannot be excluded from the program just because he or she needs some one-to-one attention.

Child care centers have been required to provide some level of temporary individualized attention to a child with a disability as long as providing such care does not fundamentally alter the nature of the program.¹⁹ Such individualized attention can include, for example, administering diabetes medication and monitoring for signs of hypoglycemic shock,²⁰ operating a blood-glucose meter and insulin pump²¹ and monitoring wheezing.²² Required individual care may also involve providing a disability-related service such as changing diapers and removing leg braces, if such services can be provided at minimal expense and with basic, non-medical training.²³

However, courts and enforcement agencies have been reluctant to require day care centers to administer some medications, such as insulin, when use of

medications and care. In particular, the Department of Justice has actively enforced this requirement through litigation and settlements. See, e.g., *Settlement Agreement under the ADA between the United States of America and La Petite Academy, Inc.*, available at <http://www.usdoj.gov/crt/ada/lapetite.htm>. The complaint filed by the Department of Justice in this case alleged that La Petite Academy discriminated against children with severe allergies by maintaining a policy of refusing to administer epinephrine through the EpiPen (a disposable device used to administer a premeasured dose of epinephrine to people experiencing anaphylaxis). The agreement called for, among other things, a total payment by La Petite of \$55,000 to three individual complainants. A similar settlement was reached by the Department of Justice in a case involving "finger prick" blood glucose monitoring for children with diabetes. See *Settlement in Stuthard v. KinderCare Learning Centers, Inc.*, available at <http://www.usdoj.gov/crt/ada/kinder1.htm>.

¹⁹ DOJ Guidance, Question 7.

²⁰ *Settlement Agreement between KinderCare, Department of Justice, and American Diabetes Association*, available at <http://www.usdoj.gov/crt/ada/kinder1.htm>.

²¹ *AP ex rel Peterson v. Anoka-Hennepin Independent School Dist. 11*, 538 F. Supp. 2d 1125 (D. Minn. 2008) (finding on motion for summary judgment that it is likely that plaintiff can establish at trial the reasonableness of a request that day care staff operate a blood-glucose meter and insulin pump for a boy with diabetes in the event he is unable to do so on his own).

²² *Alvarez v. Fountainhead*, *supra*.

²³ See settlement agreement between Department of Justice and the Sunshine Child Center, which involved a four-year-old child with cerebral palsy who required diaper changing, at <http://www.usdoj.gov/crt/ada/sunchil.htm>. Prior to the settlement, the center was willing to change her diaper only if she remained in the center's section for children three years old and younger, and staff refused to remove her leg braces. Under the settlement agreement, her mother trained staff on how to remove the braces and the center agreed to change her diapers while she was in the classroom for four year olds.

medical discretion and judgment is necessary,²⁴ or when, based on reasonable judgment, the provider believes the child may be harmed by administering the prescribed medication.²⁵

If a child with a disability needs one-to-one attention in order to participate in and benefit from the child care program and the one-to-one assistant will be provided at no cost to the child care program (e.g., because the parents will provide the assistant or because the child has an insurance-funded or Medicaid-funded private duty nurse), the child cannot be excluded from the program simply because of his or her need for one-to-one services. The program must make reasonable accommodations to include the child with his or her assistant, unless to do so would fundamentally alter the program.

3.6Q: What accommodations must a child care provider make for a child with epilepsy?

A: A child care provider must make any accommodations that are reasonable and that do not fundamentally alter the program. Depending on the child's needs and any other disabilities he or she may have, such accommodations might include administering routine antiepileptic medications, administering emergency antiepileptic medication, permitting a child with epilepsy to bring a seizure dog or service animal to child care, ensuring that a child maintains the ketogenic diet while in child care, swiping a vagus nerve stimulator magnet over an implant to abort a seizure, logging seizures on a chart, or allowing a child to rest after a seizure. These are only a few examples of the types of accommodations a child with epilepsy might need.

3.7Q: Are all child care providers required to make the same level of accommodations for a child with epilepsy?

A: No. What is considered reasonable will vary depending on the size and resources of the child care provider. What is considered reasonable for a child care center that is part of a national chain may not be considered reasonable for a single provider who takes children into her home; the large chain has more staff and more resources available to it than the single provider and will, therefore, be expected to do more to accommodate a child with epilepsy or other disabilities.

²⁴ *McDavid v. Arthur*, 437 F.Supp. 2d (D. Md. 2006). The court found that it would be a fundamental alteration of the program, not required by Title III of the ADA or Section 504, for a county-run aftercare program to ensure that trained staff always be available to inject glucagon and insulin, since the county would have to train virtually every staff member. The county also provided affidavits of a physician and a registered nurse to prove that the county would have to employ medical professionals to administer insulin injections. See *University of Wisconsin Colleges*, 2002 NDLR (LRP Lexis 581, 102 LRP 32973 (April 2002)) (U.S. Dept. of Educ. Office of Civil Rights held that to require a day care center to administer insulin would require the center to alter its fundamental nature).

²⁵ See, e.g., *Davis v. Francis Howell School District*, 138 F.3d 754 (8th Cir. 1998) (holding that a school nurse was not required to administer a child's attention deficit disorder medication when the dosage grossly exceeded the recommended dosage in the *Physicians' Desk Reference*).

3.8Q: May child care providers charge parents of a child with epilepsy for the cost of needed accommodations?

A: Parents of children with disabilities may not be charged for services that are required by the ADA or Section 504. However, if a child care provider chooses to provide additional services beyond what the law requires, the provider may charge families for those services. For example, if a student with epilepsy needs routine administration of medication, the child care center cannot charge parents for that service. However, if the child were to need a medical service that did not need to occur at child care, e.g., periodic resetting of a vagus nerve stimulator, and the child care provider chose to contract for the provision of that service, the provider could charge the family for that service because the provider is not legally required to provide it.

3.9Q: May a child receive early intervention services at a child care site?

A: Yes. Children should receive early intervention services in the “natural environment.” Infants and toddlers usually spend their time at home or at child care, rather than at separate special education schools, where early intervention services are often provided. Although special education schools provide such services, because early intervention services can be most effective in a child’s natural environment, it actually makes greater sense to put early intervention services into place in child care settings.

Case Scenarios

Case Scenario 1 — Discrimination on the Basis of Epilepsy

Billy is a two-year-old child with epilepsy. He typically has several seizures a week. His parents attempt to enroll him in Garden of Love, a home-based child care program. The owner, Mrs. Love, rejects Billy, telling his parents that she does not know anything about epilepsy. Billy’s parents offer to connect Mrs. Love with training resources about epilepsy and support from organizations that assist providers who care for children with disabilities, but she still refuses to accept Billy into her care, saying that she does not want to take care of a “child like that who has fits” and that his parents must have “committed a terrible sin to have a child like him.” Billy’s parents contact an attorney for assistance.

Discussion and Possible Advocacy Strategy: Mrs. Love’s rejection of Billy is clearly discriminatory. Section 504 applies if Mrs. Love receives *any* federal funding (e.g., money for milk or food, or funding from any other federal programs). This is unlikely but possible. More likely is that Mrs. Love is subject only to Title III of the ADA. She has made a decision based on misperceptions, stereotypes and ignorance about Billy’s disability. Billy’s parents face a dilemma: On the one hand, this encounter was appalling, and they want to seek legal redress because Mrs. Love should be held accountable for her

behavior. On the other hand, Mrs. Love's attitude raises serious concerns about the quality of care Billy might receive with her, so Billy's parents must determine if they want to seek other child care and still put the energy into challenging Mrs. Love, or fight to have Billy placed with Mrs. Love. If they do challenge this decision, they will have to determine what will happen to Billy in the meantime, as they have no other child care. The following advocacy strategy may be helpful to Billy's parents:

- 1) Discuss with Billy's parents about whether they have any other immediate child care options: Are there any child care centers with openings? Any other providers who could accommodate Billy? Any relatives, neighbors or friends that Billy's parents could pay to provide child care? Is there an agency or organization in the state that offers assistance to parents in locating child care? Even if Billy's parents want to challenge Mrs. Love's refusal to accept Billy into their program, it will take some time to do this, and they will need child care in the meantime. Unless one of Billy's parents is able to stop working, some other child care arrangement will need to be made.
- 2) Determine if the state has an informal or formal complaint or dispute resolution process. If so, advise Billy's parents to try to resolve the issue using the state's administrative process.
- 3) If the state does not have a dispute resolution process or if the process is not successful in resolving the dispute, then consider filing a federal discrimination complaint. If Billy's parents know that Mrs. Love receives federal funds, a Section 504 complaint can be made to the Office for Civil Rights of the agency that provides the funding. Otherwise, the complaint should go to the Department of Justice as an ADA complaint.
- 4) If Billy's parents do not have any other child care options and feel they have no alternative other than to force Mrs. Love to take Billy into Garden of Love immediately, they may file for injunctive relief in court under the ADA or Section 504. Litigation should be the action of last resort, however. It would be much more preferable to attempt to resolve this matter informally or to find alternative child care and then file a complaint.

Case Scenario 2 — Medication Administration

Ashley is a four-year-old child with epilepsy. Her mother enrolls her in Joyful Children Rainbow Center, a child care program that is part of a large national chain. Ashley attends a morning preschool program four days a week and child care one morning and five afternoons a week. She needs one dose of antiepileptic medication each afternoon while in child care. Additionally, on occasion, she needs a dose of emergency antiepileptic medication when she has a prolonged seizure or, as is more likely for her, a cluster of seizures. Joyful Children has reluctantly agreed to administer Ashley's daily medication, although a specific person has not been designated to take responsibility for this task, and the timing varies each day. Occasionally, Ashley misses a dose because

nobody has remembered to give the medication to her. Joyful Children has drawn the line at emergency antiepileptic medication, believing it to be “too hard to administer,” “too medical in nature,” and “too time consuming,” given the other responsibilities of staff. Consequently, Ashley’s mother always has to be on standby to rush to Joyful Children if necessary, which defeats the purpose of having child care, or 911 will be called, an equally unsatisfactory option. Ashley’s mother has contacted an attorney for legal assistance in resolving this matter.

Discussion and Possible Advocacy Strategy: Joyful Children has obligations to Ashley with respect to both her daily medication and the emergency medication. The following strategy may be helpful to Ashley’s mother:

- 1) Arrange a meeting for Ashley’s mother, counsel, and the director of Joyful Children. Make it clear that this is an effort to try to resolve the situation, and suggest that the director include counsel if his or her presence would be helpful in moving the parties toward resolution.
- 2) At the meeting, try to persuade the center to designate a staff person who will administer Ashley’s daily medication, and to set a time each day that the medication will be given to her. Additionally, ask the center to identify a second staff person who can be a backup in case the designated staff person is absent or unavailable for some reason. The staff people’s names should be documented and a log should be kept of when the medication is administered. A sheet could be made up for each month with Ashley’s name, the date, the name of the medication, and a space for the staff person to initial.
- 3) It is important to demystify the administration of the emergency medication for Joyful Children’s Director and staff. Come to the meeting with information about the medication, but do not bring so much that it seems overwhelming to staff, who may not have much time to watch training videos or read a lot of training materials. It would be preferable for Ashley’s parents and doctor to complete in advance an emergency treatment plan form, which could be presented to the center. This plan can provide detailed information about the types of seizures Ashley experiences and any triggering stimuli and warning signs. The plan can also detail instructions about when and how emergency medication should be administered and about when emergency medical services should be called. A standard form is included in this Manual as Appendix A. It may be helpful to supplement this form by also including a letter from Ashley’s doctor explaining the purpose of the medication and its benefits. The plan and/or letter should also describe her typical reaction to the emergency medication. For example, if Ashley typically falls asleep and will need a place to sleep for a few hours, this should be mentioned. Offer a brief training for the director and staff, and offer to put them in touch with resources that may be able to connect them with other child care providers who routinely administer the medication without incident.

- 4) Particularly because Joyful Children is part of a chain of child care centers and, therefore, has more resources than a sole provider, it is quite likely that Ashley's mother would be able to make a successful argument that Joyful Children has discriminated against Ashley if the center continues to refuse to administer emergency medication. She could file a complaint under the ADA with the Department of Justice or pursue a claim in court.

Case Scenario 3 — Private After-School Child Care Program on School Grounds

Teddy is a six-year-old child with epilepsy and cerebral palsy. He is fully included in a first-grade class in his local elementary school. His parents tried to enroll him in "Busy and Safe Kids" (BASK), an after-school child care program run by a small private agency on the grounds of his school. Teddy is mobile with a walker or crutches, but he is not toilet trained. BASK has refused to accept him because of his toileting needs and because it has a "no medication" policy, and Teddy needs a dose of his antiepileptic medication after school. Teddy's parents contact an attorney for legal assistance.

Discussion and Possible Advocacy Strategy: As a private program, the BASK program is subject to Title III of the ADA and cannot reject Teddy simply because he needs medication after school. A reasonable accommodation of his epilepsy would be to modify the "no medication" policy or to make an exception for Teddy so that he can attend the program and receive his afternoon dose of medication. With regard to his toileting needs, whether changing his diapers is a reasonable accommodation will depend on whether the program provides diapering or toileting assistance to any other children in the program. For example, since BASK is located at an elementary school, if the program is open to preschoolers who might be attending the school, it is possible that staff are providing diapering or toileting assistance to these younger children. If this is the case, then the program will need to provide such assistance to Teddy as a reasonable accommodation. If the program does not provide diapering or toileting assistance, then Teddy would still be entitled to the assistance as a reasonable accommodation if the assistance does not fundamentally alter the program. The following strategy may be of assistance to Teddy's parents and their attorney:

- 1) Arrange a meeting with the director of the BASK program to explain what Teddy needs beyond the standard care provided to all children in the program. It is likely that in the three-hour period Teddy is in after school care each day, his extra needs would be limited to one administration of oral medication and one diaper change. These needs should be easily accommodated.
- 2) If the director continues to be resistant, try to facilitate a meeting or conversation between the BASK director and the school staff who work with Teddy during the school day. School staff should be able to allay any concerns the BASK director has about administering medication to Teddy or about the time involved in addressing his toileting needs.

- 3) If necessary, file an ADA discrimination complaint with the Department of Justice or pursue a private lawsuit.

Case Scenario 4 — Public After-School Child Care Program on School Grounds

Same facts as in Case Scenario 3, but the after-school program that Teddy's parents wish to enroll him in, "Children in Action" (CHIA), is jointly operated by the school district and the county department of parks and recreation.

Discussion and Possible Advocacy Strategy: Because CHIA is operated by public agencies, the program is subject to Section 504 and Title II of the ADA. The strategy outlined in Case Scenario 3 would still apply, but if a discrimination complaint is filed, the complaint should go to the designated enforcement agency, rather than to the Department of Justice. Nine federal agencies are designated to investigate disability-related discrimination complaints filed against state and local government programs under Title II of the ADA. In addition, under Section 504, these agencies investigate complaints involving the programs they fund. Complaints about public child care programs most likely should be filed with the U.S. Department of Health and Human Services or the Department of Education. For more information, see <http://www.usdoj.gov/crt/ada/investag.htm>.

CHAPTER FOUR

*The Special Education Process for Children with Epilepsy: The Individuals with Disabilities Education Act (IDEA)*²⁶

4.1Q: What are the rights of children under the IDEA?

- A:** Under the IDEA, children with disabilities have the right to a free, appropriate, public education in the least restrictive environment in which their needs can be met. A school district must find children with disabilities, assess them to determine if they have disabilities that adversely affect their ability to benefit from education, and, if so, provide them with individualized special education and related services that enable them to make meaningful educational progress and reevaluate them periodically. In addition, the district must provide procedural safeguards to the child and his or her parents governing all aspects of the special education process, from access to records and notice of meetings, to proposed school district actions and administrative due process hearing rights.

Additionally, 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, or case management. Children are eligible for early intervention services from birth until they turn three. The program is part of the IDEA (Part C of the IDEA, as distinguished from Part B, which governs school-aged children's services), but at the state and local levels, the early intervention program might be run by a health department or another agency, rather than by the school system.

An infant or toddler with epilepsy might be eligible for services from the early intervention program if his or her seizures interfere with development and either cause him or her to be disabled or to have a developmental delay and be at risk of having a disability. Some children who receive early intervention services do not need further services when they turn three; others transition into the special education system. The early intervention services to be provided are set out in an individualized family services plan. The services are designed to address the needs of the child and his or her family. In contrast, the special education system is focused on the needs of the child. Early intervention services can be provided at home, at a child care center or provider's home, or at an agency or school. If epilepsy does not affect the development of an infant or toddler or if the child's

²⁶ See Chapter 2 for a basic introduction to the requirements of the IDEA.

state does not serve infants and toddlers who have developmental delays or are at risk of having a disability, the child will likely not be eligible for early intervention services. For more information on state programs, see www.childfindidea.org.

In many cases, a school-aged student's epilepsy might not adversely affect his or her educational performance, but he or she may need some accommodations to be successful or safe at school. In these cases, the student should have a Section 504 plan that outlines all necessary accommodations. See Chapter 5 for more information about Section 504.

4.2Q: Are children with epilepsy automatically entitled to special education and related services?

A: No. In order to qualify for special education and related services under the IDEA, a child's disability must adversely affect his or her educational performance and the child must need special education as a result. 34 C.F.R. 300.8.

4.3Q: Does a school district have any responsibility to locate children with epilepsy who may be eligible for special education and related services?

A: Yes. The "child find" requirements of the IDEA place the responsibility on states to have policies and procedures to identify children within the district who may be eligible for special education and serve them appropriately. 34 C.F.R. 300.111. This means that local educational agencies must have child find procedures for the children within their boundaries, although the effectiveness of these procedures varies from district to district and state to state.

4.4Q: What are the steps of the special education process?

A: Although the steps of the process may have different names in different states, essentially the special education process consists of an evaluation process, which is the process of determining whether a child has a disability and the nature and extent of the special education and related services the child needs (34 C.F.R. 300.14); development of an individualized education program (IEP) (34 C.F.R. 300.324); placement (34 C.F.R. 300.327); review (34 C.F.R. 300.324(b)(1)); and reevaluation (34 C.F.R. 300.303).

The evaluation process consists of several steps: referral for special education, assessment, and identification of the student as having a disability that adversely affects his or her educational performance. Following the evaluation, if a student is identified as needing special education, an IEP is developed for the student, and he or she is placed into an education program that is supposed to meet his or her needs appropriately. The student's IEP is required by law to be reviewed and revised annually, and the student must be formally reevaluated at least every

three years. Parents have the right to be full participants in this process and must be notified of each step of the process and each action the school system proposes or refuses to take.

4.5Q: Who may refer a child with epilepsy for special education?

A: Anybody may make a referral of a child for special education. Most frequently, referrals come from parents; outside professionals, such as pediatricians or specialists; or a child's teacher.

4.6Q: What happens when a child is referred for special education?

A: When a child is initially referred for special education, a team of specialists is supposed to meet; generally, the team comprises staff from the child's school and usually includes the child's teacher, a special education teacher, a psychologist, a social worker, and other specialists, such as the school nurse or a speech pathologist, depending on the child's possible disability. The parent is always a member of the team.

4.7Q: What is the timeline for referral of a child for special education?²⁷

A: Federal law does not set a timeline for when the team must meet after a written request for referral is made. However, state law may impose a timeline for this step of the process, and attorneys and advocates need to check their state statutes and regulations. Other steps of the process have timelines and will be addressed later in this chapter.

4.8Q: What kinds of decisions might the team make at the referral stage and what happens if a parent disagrees with the team's decision?

A: The team could decide that the student has a disability and needs special education. They would then develop an IEP for the student. More likely, the team might decide that the student may need special education because he or she likely has a disability that is adversely affecting his or her educational progress. They would then assess the student further to determine the disability and needed services. Or the team might decide that the student has a disability but that there is no indication that the disability adversely affects his or her educational progress. Finally, the team might decide that there is no evidence to conclude that the student has a disability or is in need of assessment.²⁸ The student's parents may appeal any decision of the team by requesting mediation

²⁷ See the end of this chapter for a chart with the federal timelines for the steps of the special education process with legal cites.

²⁸ The student might have a disability that impairs a major life activity but does not adversely affect his or her educational performance. In this situation, it would be appropriate to seek a Section 504 plan for the student. See Chapter 5: Special Education and Section 504 of the Rehabilitation Act.

or a due process hearing, or by filing a complaint with the state department of education. See Chapter 8 for more information about dispute resolution.

4.9Q: What kinds of assessments might be warranted to determine special education eligibility for a student with epilepsy?

A: The school district is responsible for using a variety of assessment tools to determine the functional, developmental, and academic needs of the student. 34 C.F.R. 300.304. See Question 4.10. For a student with epilepsy, it will be important to first establish that the student has epilepsy. Often, parents provide medical information to an IEP team regarding their child. Parents may wish to provide current medical reports from the student's neurologist and pediatrician, including a diagnosis, a list of current medications, and any information or recommendations that relate to the student's performance or needs in school. An IEP team must consider any private evaluations provided by parents, although the team is not obligated to adopt the findings or recommendations of the evaluation.

If the IEP team chooses not to accept the reports provided by the student's parents, the school district will be responsible for obtaining its own medical evaluation of the child. Medical services are included as a related service in the IDEA for "diagnostic or evaluation purposes" and are defined as "services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services." 34 C.F.R. 300.34(a) and(c)(5).

It is also necessary to assess the student's educational performance. A complete educational assessment is important and perhaps a cognitive psychological assessment will be warranted as well. It is also important to have a nursing assessment done if the student's seizures are not completely controlled and if the student will be taking medication during the school day. Depending on other areas of need, assessments for psychosocial issues, speech and language, functional behavioral issues, occupational therapy, and/or physical therapy might also be warranted.

4.10Q: What are the requirements for evaluation?

A: The school district must use a variety of assessment tools and strategies to collect relevant functional, academic and developmental information about the child. Information provided by the child's parents must be included in the assessment. The district may not use a single measure or assessment as the only criterion for determining whether a student has a disability or determining an appropriate educational program. The district must use technically sound assessment instruments that may assess the extent to which cognitive and behavioral factors, as well as physical and developmental factors, contribute to the student's situation. 34 C.F.R. 300.304(b). Assessment tools cannot be

racially or culturally discriminatory, must be provided in the student's native language or mode of communication, and must be in the form most likely to provide accurate information about what the child knows and can do academically, functionally and developmentally, unless it is clearly not feasible to provide or administer the assessment in such a form.

Additionally, assessments must accurately reflect what the test is supposed to measure and not the student's impaired skills, unless that is the purpose of the test. 34 C.F.R. 300.304(c). For example, a cognitive psychological assessment of a student with epilepsy must be administered in a manner that takes into account the side effects caused by student's seizure medication, which may cause the student to work more slowly than would otherwise be expected; otherwise, the assessment will measure the student's impaired skills rather than his or her true cognitive level. Additional evaluation requirements apply for students suspected of having learning disabilities. 34 C.F.R. 300.307-309.²⁹

4.11Q: What is the timeline for evaluation?

A: Evaluations must be conducted within 60 days of receipt of parental consent or within the timeline established by state law. 20 U.S.C. 1414(a)(1)(C)(1)(i); 34 C.F.R. 300.301(c)(1)(i).

4.12Q: Are there requirements for reevaluating students who have been receiving special education?

A: Yes. A student must be reevaluated at least once every three years unless the parent and the school district agree that a reevaluation is not necessary. A student must be reevaluated sooner if the district determines that the educational or related services needs of the student, including his or her improved academic achievement and functional performance, warrant reevaluation or if the parent or the student's teacher requests reevaluation. The student should not be reevaluated more than once a year unless the parent and district agree otherwise. 34 C.F.R. 300.303.

When a student is reevaluated, the team must review existing evaluation data and obtain input from the student's parent. The team must decide if additional data are needed to determine if the student continues to have a disability, to determine the student's educational needs and if he or she continues to need special education and related services. If so, the team must then determine if any additions or modifications are needed to the student's special education and

²⁹ Many districts and states are now in the process of developing a Response to Intervention framework for identifying students with learning disabilities. Under this model, all children are screened to identify those who may be at risk for learning problems, and those who are at risk receive interventions prior to being referred and assessed for special education. The IDEA does not mandate Response to Intervention but displays a clear preference for it over the traditional method of determining if a student has a discrepancy between his or her performance and potential. 34 C.F.R. 300.307.

related services to enable the student to meet the measurable annual goals set out in his or her IEP and to participate, as appropriate, in the general education curriculum. 34 C.F.R. 300.305.

4.13Q: What happens if parents disagree with an evaluation that has been done by the school district?

A: Parents may request an independent educational evaluation at public expense. The school district must either ensure that the evaluation is provided at public expense or initiate a due process hearing, at which the district will have the burden of proving that its evaluation is appropriate and, therefore, that it should not have to fund an independent evaluation. The district must either initiate a hearing or pay for the independent evaluation “without unnecessary delay.” 34 C.F.R. 300.502. The district may ask parents why they disagree with the district’s evaluation, but parents do not have to provide a reason, and the district cannot delay payment or its due process hearing request if parents do not provide a reason. Parents are entitled to only one independent educational evaluation at public expense each time the school district conducts an evaluation with which the parents disagree. 34 C.F.R. 300.502.

4.14Q: Does a school district have to adopt an independent evaluation obtained by parents at their own expense?

A: No, but the IEP team must “consider” the evaluation. 34 C.F.R. 300.502 (c)(1). The law does not define “consider,” but a common-sense interpretation is that the team must review the evaluation and have a meaningful discussion about the recommendations.

4.15Q: Is epilepsy an identified disability under the IDEA? If not, how would a child with epilepsy be identified as needing special education?

A: Epilepsy is not specifically listed in the IDEA as a standalone disability that qualifies students for special education. However, epilepsy is listed in the definition of “other health impairment” in the IDEA’s regulations at 34 C.F.R. 300.8(b)(9):

limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that —

- (i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome, and
- (ii) Adversely affects a child’s educational performance.

If a child has epilepsy but the condition does not adversely affect his or her educational performance, the child will not be eligible for special education under the IDEA. However, as with each of the other disabilities listed in the IDEA, if the child's educational performance is adversely affected, the child will qualify for services under the IDEA, if the child needs special education in order to make educational progress.

4.16Q: If a child with epilepsy is identified as needing special education services, what happens next?

A: The team will develop an individualized education program (IEP).

4.17Q: What are the components of an IEP?

A: In accord with 34 C.F.R. 300.320 and 34 C.F.R. 300.324, the IEP must contain the following components:

- A statement of the student's present levels of academic achievement and functional performance, including how the student's disability affects his or her involvement and progress in the general education curriculum or, if the student is in preschool, how his or her disability affects his or her participation in activities
- A statement of measurable annual goals, including academic and functional goals, set so as to show a student's involvement and progress in the general education curriculum and to ensure that the student's other educational needs that result from his or her disability are being met
- Short-term objectives or benchmarks for students who take alternate assessments aligned to alternate standards, which in practice means benchmarks set for students with significant cognitive disabilities³⁰
- The intervals at which progress reports will be provided
- A statement of the special education and related services the student will receive, along with the supplementary aids and services, based on peer-reviewed research to the extent practicable, to be provided to the child or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided³¹
- An explanation of the extent to which the child will not participate with non-disabled children
- A statement of any individual accommodations that are necessary for testing

³⁰ Some states have chosen to retain the requirement that IEPs contain short-term objectives or benchmarks for all students.

³¹ The program modifications and supports for school personnel are meant to enable the student to make progress toward the annual goals, to be involved in and make progress in the general curriculum, and to be educated and participate with other children with and without disabilities in academic and nonacademic and extracurricular activities.

- A transition plan, for students 16 and older
- A start date, and the frequency, duration and location of services³²

4.18Q: What are some of the typical special education services that students with epilepsy might require?

A: Because the hallmark of special education is the individualization of services to meet the unique needs of a student, it is impossible to list specific services that should automatically be included on any IEP for a student with epilepsy, especially because epilepsy affects students in different ways, and many students with epilepsy do not need special education. However, if epilepsy adversely affects a student's educational progress such that the student needs special education, the student needs programs and services that address his or her educational needs. The following are questions that should be considered:

- Does the epilepsy affect the student's progress in reading? Math? Other academic areas?
- Does the student's cognitive ability fluctuate depending on seizures and side effects from medication?
- Does the student have memory impairment from seizures?
- Does the student make progress then regress because of seizures?
- Does the student have particular dietary needs?
- Does epilepsy affect the student's social relationships in the school setting?
- How old is the student?
- If the student is approaching or is of transition age, is he or she able to manage medical care independently or is that an attainable transition goal?
- Where will the student live after he or she leaves school?
- What will he or she do during the day?

In addressing these questions, the IEP team needs to consider all aspects of the student's epilepsy, including frequency of seizures; level of seizure control; what happens before, during, and after seizures; side effects of medications, needed accommodations for homework, testing, and class work; and any needed restrictions on activities such as physical education or driver's education if it is offered at the school. The team then needs to develop a program for the student that takes these issues into account. The team cannot look at the student's disability in isolation but must, rather, develop an IEP for the student that looks at all of his or her educational needs that stem from the epilepsy.

³² For students who are blind or visually impaired, deaf or hearing impaired, who have disruptive behaviors, or who have limited English proficiency, the IEP team has certain additional considerations, and for all students, the IEP team must consider the appropriateness of assistive technology. 34 C.F.R. 300.324.

4.19Q: What are some of the typical related services that students with epilepsy might require?

- A:** Related services are services that enable a student with disabilities to benefit from his or her special education. For a student whose only disability is epilepsy, who needs special education because of the adverse effect the epilepsy has on his or her educational progress, school health services might be the only needed related services. Or, depending on the student's situation and needs, counseling might be an important related service to assist the student in coping with his or her epilepsy in the school setting with his or her peers.

Other related services may also be needed. Parent counseling might be a helpful service to assist parents in meeting their child's needs so the student will benefit from educational services. For a student with Landau-Kleffner syndrome, for example, where speech loss is part of the syndrome, speech and language services may be an important related service. Depending on the needs of a student with epilepsy and on whether he or she has other disabilities, occupational or physical therapy might be educationally necessary to enable him or her to benefit from the special education he or she receives. For a student with behavioral issues, the team should be asked to conduct a functional behavioral assessment and develop a behavioral intervention plan based on positive behavior supports and interventions to minimize the chances of disciplinary action against the student. For a student who becomes fatigued easily or needs to sleep because of seizures or medication he or she takes to control seizures, the IEP team can include sleep or rest time on the IEP as a program modification or support or as part of the health services plan. For a student on a special diet for seizure control, such as the ketogenic or Atkins diet, the IEP should reflect that the student is on that regimen for seizures; the school system is not required to provide the food but needs to implement the diet during school hours and maintain the integrity of the diet to ensure that the student remains safe. Maintenance of the diet during school hours should not be viewed any differently than administration of medication to a student.

4.20Q: Is a child with epilepsy entitled to a one-to-one aide or to a nurse?

- A:** A student with epilepsy is not automatically entitled to a one-to-one aide or a nurse. If a student's individual needs require that he or she receives the assistance of a one-to-one aide or a nurse in order for the student to receive a free appropriate public education, the student will be entitled to the aide or nurse as an IEP-related service.

In the case where the child's doctor does not believe that an aide or nurse is necessary, it is important to remember that the issue for the IEP team to consider is whether such a staff person is necessary for the student to attend school and receive an appropriate education. Although the physician's opinion about whether a nurse is necessary will likely carry a great deal of weight because the

physician would probably be the one who would be prescribing any health services the nurse would need to provide during the school day, the physician's opinion about the need for a one-to-one aide, an educational position, might carry much less weight precisely because the physician would be rendering a medical, rather than an educational, opinion about the student's needs. In this case, the parents might want to turn to an educational expert who could observe their child across school settings—in class, the cafeteria, the playground—and make a recommendation about the level of staffing that would enable the student to be served in a way that facilitates the student's safe participation in school activities and allows him or her to make meaningful educational progress.

4.21Q: If a child with epilepsy needs a one-to-one aide or nurse, is the parent entitled to choose the provider or staff person who will be assigned to the child?

A: No. Parents do not have the right to choose the staff who will be assigned to work with their child. However, if a school team and a student's parents have a good working relationship, they may be able to agree that it is educationally appropriate for the parents to have some involvement in the process, or at least to meet the person who is identified and to be part of the training process.

4.22Q: Can training of the aide or nurse be included on the IEP?

A: Yes. Training can and should be included on the IEP. The type and amount of training the provider will need should be specified on the IEP, along with who will provide the training. Training should be viewed as a support service for staff in accord with 34 C.F.R. 300.324(a)(3)(ii), which requires that the IEP team make a determination of "[s]upplementary aids and services, program modifications and support for school personnel" that will enable a student to participate in the general education curriculum and participate in extracurricular and nonacademic activities.

4.23Q: Who participates in the development of the IEP?

A: The IEP team must include the student's parents, at least one general education teacher if the student participates or may participate in general education, at least one special education teacher, a representative of the school district who is qualified to provide or supervise special education and is knowledgeable about the general education curriculum and the district's resources, a person who can interpret the instructional implications of evaluation results, the student whenever appropriate, and, at the discretion of the parents or district, other individuals who have knowledge or special expertise regarding the student. 34 C.F.R. 300.321.

4.24Q: Are there any requirements regarding meeting attendance?

A: Yes. A member of the IEP team may be excused from attending a meeting if the parent and the district agree in writing that the team member's attendance is not necessary because the member's area of the curriculum or the related service the member provides is not being changed or discussed in the meeting. 34 C.F.R.300.321(e)(1). A member of the IEP team whose area of expertise is being discussed or whose area is being modified may be excused if the parent consents in writing and the district agrees, and if the member provides input into the development of the IEP to the parent and the IEP team before the meeting. 34 C.F.R.300.321(e)(2).³³

4.25Q: What steps can attorneys and advocates take to prepare for an IEP meeting?

A: First, an attorney or advocate can help the family prioritize their goals for the meeting. What is most important to the family and is an absolute must? What is important but could be set aside if the IEP team will not agree? What would be nice to have but could be dispensed with if the IEP team will not agree? How long is each list? Should some items be deferred for another meeting so as not to dilute the list of the most important items? Once this task has been accomplished, the attorney or advocate can identify the evidence that is necessary to support the family's position. Are there current evaluations, reports from outside service providers, physicians, teachers, others? Are there outstanding assessments that will be reviewed at the IEP meeting? If so, the attorney or advocate can ask for copies ahead of time. Although the IDEA does not require that IEP teams make copies of evaluations available to parents or their representatives ahead of time, it is good practice, and some districts or schools do provide advance copies of documents to parents; parents and their representatives should always ask.

Sometimes, IEP teams draft IEPs in advance. This is a permissible practice, so long as parents have input into the final IEP, which must be developed at the meeting. If the team has a draft of the IEP, the attorney or advocate should ask for a copy ahead of time and work with the parents to determine what changes

³³ Parents and their advocates should be wary of these provisions and if requested by a district to consent, should consider the circumstances very carefully. The team process benefits from the participation of a diverse group of service providers, and not all issues or the course of a discussion can be anticipated prior to a meeting. Even when a provider's area may not be discussed, that provider may have valuable input into the discussion. The provisions may be useful in a situation in which parents have a longstanding, good relationship with their IEP team and need an IEP meeting to discuss particular, circumscribed issues that do not require the entire team. For instance, if a child with epilepsy has changed medications and simply needs a revision to the health services portion of his or her IEP, the parent might want to consent to an IEP meeting without the presence of the occupational therapist, the speech therapist, and the school social worker. Or the parent could choose to agree to a school system request to revise the school health services portion of the IEP without any IEP meeting at all, which is another option under the IDEA regulations. 34 C.F.R. 300.324(a)(4).

they would like to propose. On occasion, drafts can be exchanged prior to the meeting; when this is able to occur, the meeting will tend to be more efficient.

If the district has sent a meeting notice that does not include all of the items that the parents would like to discuss, the attorney or advocate can send a letter requesting that the additional items be added to the agenda. The attorney can ask that additional time be allotted for the meeting or that the team be prepared to continue the meeting to another day as it may not finish on the scheduled day. Additionally, the attorney or advocate should be sure to provide written notice or have the parents provide notice that the attorney or advocate will be in attendance; many, but not all, districts send their own lawyer to IEP meetings if the parents bring an attorney or even, sometimes, an advocate.

4.26Q: What happens if a parent disagrees with an initial or subsequent IEP?

A: The parent can file an IDEA complaint with the state department of education or can ask for mediation or a due process hearing. Generally, mediation or a due process hearing request will be more effective in resolving an IEP dispute than a complaint if the issue is the appropriateness of the IEP, as state departments of education will usually not second-guess the substantive decision of an IEP team. See Chapter 8 for more information regarding mediation, due process hearings, and complaints.

4.27Q: Is there a timeline for IEP implementation?

A: No, federal law simply requires that special education and related services be provided in accord with an IEP as soon as possible after the development of the initial IEP and that, at the beginning of each school year, each child with a disability must have an IEP in effect. 34 C.F.R. 300.323. The federal timelines for the special education process are set out at the end of this chapter. However, states may have their own regulations that set specific IEP implementation timelines.

4.28Q: Where do students with epilepsy or other disabilities receive special education services?

A: The IDEA requires a continuum of placement options for students with disabilities. Depending on their needs, students with epilepsy may receive special education in the general education classroom, a separate classroom, a separate school, a residential school, at home or in the hospital, or in some combination of placements. The continuum ranges from least restrictive to most

restrictive. In the least restrictive placements, students with disabilities are educated with students without disabilities, and in the most restrictive placements, they are educated only with other students with disabilities or, as in the case of home teaching, no other students.

4.29Q: How is a special education placement made?

A: A group of people knowledgeable about the student, his or her evaluation data, and placement options must make placement decisions. The group must include the student's parents. 34 C.F.R. 300.116(a)(1); 34 C.F.R. 300.327. Generally, the IEP team determines where the IEP can be implemented. Placement must be determined at least annually and must be based on the student's IEP. 34 C.F.R. 300.116(b). In making placement decisions, the team must place the student in the least restrictive environment in which the IEP can be implemented.

4.30Q: What is placement in the "least restrictive environment"?

A: The IDEA requires that students be placed in the least restrictive environment in which their needs can be met. This means that if possible, a student should be placed in the general education classroom with students who are not disabled. 34 C.F.R. 300.114. The school has an obligation to provide supplementary aids and services to the student and programmatic supports and modifications to school staff in an effort to educate the student in the general education program. 34 C.F.R. 300.114; 300.320(a)(4). Students with disabilities should attend the school they would attend if not disabled, unless their IEPs require some other arrangement, and should attend the school closest to home ("neighborhood school"), unless their IEPs require some other arrangement. 34 C.F.R. 300.116(b)(3) and (c).³⁴

4.31Q: Does a school district have any responsibility to students to help them be placed successfully in less restrictive settings?

A: Yes. Only if the student cannot be educated satisfactorily, even with the use of supplementary aids and services, should he or she be moved to a separate class or school. 34 C.F.R. 300.114.

4.32Q: Must a school district place a student in a general education classroom if it would be harmful to the student?

A: No. In determining the least restrictive environment possible for a student, the IEP team must consider any potential harmful effects on the student or on the quality of services that he or she needs. 34 C.F.R. 300.116(d).

³⁴ See discussion of least restrictive environment cases at the end of this chapter for more information.

4.33Q: Must a child fail in general education before he or she can be moved to a more restrictive environment?

A: No. The IDEA does not impose a requirement that students fail before they can be moved to a more restrictive setting. Rather, the IEP team must determine that, even if supplementary aids and services and program supports and modifications are put in place, the student cannot be educated satisfactorily.

4.34Q: What if a child needs access to a licensed person to administer emergency antiepileptic medication such as Diastat AcuDial (rectally administered diazepam gel) or other health care services at school and the school district tells the parent the child must go to a separate special education school in order to have access to the person and the service?

A: Although courts have held that cost can be a consideration when addressing inclusion of students with disabilities into regular education, the Department of Education has made clear that students must be placed on the basis of their abilities and needs and their individual IEPs, not solely on factors such as category of disability, severity of disability, availability of special education and related services, the configuration of the service delivery system, availability of space, or administrative convenience. *See* Comments to IDEA Regulations, Federal Register, Vol. 71, No. 156, August 14, 2006, p. 46588. *See also Letter to Veazey*, 37 IDELR 10 (November 26, 2001). Placement of a student with epilepsy into a separate special education school simply to have access to a licensed health care professional who is authorized under state law to administer emergency antiepileptic medication would constitute placement for administrative convenience or placement made because of the way the service delivery system is setup. It would be unlikely to withstand a challenge. However, if there is a school other than the neighborhood school that could meet the student's needs and provide a person who can administer the medication, such placement will likely be upheld. There is no absolute entitlement to placement in the neighborhood school. *See, e.g., Barnett v. Fairfax County Public Schools*, 927 F.2d 146 (4th Cir. 1991); *Murray v. Montrose County Sch. Dist.*, RE-1J, 51 F.3d 921 (10th Cir. 1995), *cert. denied*, 516 U.S. 909 (1995). (IDEA creates, at most, a preference, but not a mandate, for neighborhood school placement.) For a detailed discussion of the obligation of schools to ensure that students have access to emergency antiepileptic medication, see Chapter 7.

4.35Q: What happens if a parent disagrees with a placement decision?

A: The parent may appeal the decision by requesting mediation or a due process hearing. See Chapter 8 for more information.

4.36Q: Is a student with epilepsy entitled to services during the summer?

A: If a student with epilepsy needs services during the summer in order to continue to make educational progress during the school year, he or she may qualify for extended school year services.³⁵ There is no absolute entitlement to these services; eligibility will depend on a student's individualized needs. Generally, school districts look at factors such as whether a student will likely regress or take extra time to recoup lost skills, and may also look at other factors, such as the rate of the student's progress, whether or not the student has emerging skills, and whether the student's progress during the year will be significantly jeopardized. How a district approaches extended school year services depends very much on whether there is any controlling case law in the circuit in which the district is located. See the discussion of extended school year services in the Summary of Cases at the end of this chapter for more information.

4.37Q: What happens if a parent wants to place his or her child, who has epilepsy, in a private school?

A: Parents may withdraw their child from the public school system and place him or her in a private school because they want a private school education for their child for any number of reasons. However, parentally placed private school children do not have an individual entitlement to a free appropriate public education. The school district is required to consult with the private schools in the district to determine the needs of privately placed students within its boundaries, and then allocate among the private schools the amount of federal money that would otherwise be allocated per student in the public school system. 34 C.F.R. 300.130-144. This means that some students might receive no services and others might receive some of the services they would receive if they were in the public system.

Parents may also choose to place their child in a private school because they believe the school district's special education program is inappropriate. In this situation, parents may find a school that serves students with disabilities and then seek reimbursement for the private placement from the district. The IDEA regulations impose strict notice requirements on parents who will be placing

³⁵ 34 C.F.R. 300.106 of the IDEA regulations define extended school year services as special education and related services that

- (1) Are provided to a child with a disability —
 - (i) Beyond the normal school year of the public agency;
 - (ii) In accordance with the child's IEP; and
 - (iii) At no cost to the parents of the child; and
- (2) Meet the standards of the [state education agency].

their child in a private school and asking for tuition reimbursement. It is important that parents and their attorneys or advocates be thoroughly familiar with these requirements, as failure to comply with them carries the risk that tuition reimbursement will be denied by a hearing officer or a judge. 34 C.F.R. 300.148.

4.38Q: Can a student with epilepsy be disciplined?

A: Yes. Students with disabilities can be disciplined, but certain procedural safeguards apply.

4.39Q: What happens during the discipline process for a student with epilepsy?

A: A student with epilepsy is treated the same as a student with any other disability. If the student has an IEP, how he or she is treated will depend on whether he or she is suspended for 10 or more days, whether this is the first suspension or another of several and, if not the first, whether it constitutes part of a pattern of suspensions. If the student is suspended for 10 or fewer days, the student can be removed to an interim alternative education setting if non-disabled students are so removed. Administrators have the discretion to consider unique circumstances on a case-by-case basis in determining if a change in placement should occur. 34 C.F.R. 300.530 (a). If the suspension is for more than 10 days or is part of a pattern of suspensions, the IEP team will need to meet to determine if the student's conduct was caused by, or had a direct relationship to, his or her disability or if the student's conduct was the direct failure of the school district to implement his or her IEP. 34 C.F.R. 300.530(e). This is known as the *manifestation determination*.

A student who brings or possesses a weapon or drugs to or at school or a school function, or a student who has inflicted serious bodily injury upon another person while at school or a school function can be removed by the school administrator to an interim alternative education setting for up to 45 days, regardless of whether or not a manifestation is found. 34 C.F.R. 300.530(g) A hearing officer may remove a student whom the school district believes poses a substantial likelihood of harm and may order placement of the student into an interim alternative education setting for no more than 45 days. 34 C.F.R. 300.532(a).

Case Scenarios

Case Scenario 1 — Possible Learning Disability Related to Epilepsy

Melissa is a ten-year-old fifth grader who has epilepsy; she has a health care plan at school to address her seizures when they occur. She is struggling in her classes, and her

reading and writing skills are significantly below average. Her parents think she may have a learning disability in addition to her epilepsy. The school staff thinks she is lazy and using her epilepsy as an excuse not to work. Melissa is becoming increasingly frustrated and depressed about going to school, and has begun to have more frequent seizures. Her parents seek advocacy assistance.

Discussion and Possible Advocacy Strategy: Melissa's parents may be correct and Melissa may have an unidentified learning disability. Her seizure medication may also be having an impact on her academic performance, and she may also be showing signs of depression. If they have not already done so, Melissa's parents should make a written request that Melissa be evaluated for special education. While an attorney or advocate may not be necessary at this early stage, Melissa's parents may benefit from some technical assistance as they begin the special education process. A possible strategy might include the following steps:

- 1) Melissa's parents should make a written request to the principal of Melissa's school asking that Melissa be evaluated for special education. They should hand-deliver a letter and have the secretary date-stamp a copy for their records, or should send the letter by certified mail, return receipt requested. Melissa's parents should retain copies of any documents they send to the school district.
- 2) Melissa's parents should gather all the information they have to support their position that Melissa may have a learning disability or disability other than epilepsy. Do they have any report cards, teacher reports describing poor performance or a decline in performance, or outside evaluations that support their position? These documents should be provided to the team that will be convened to determine if Melissa should be evaluated for special education.
- 3) If Melissa and her parents are in a school district that is utilizing Response to Intervention³⁶ as an element of determining if students have learning disabilities, Melissa's parents should be aware of the importance of finding out if Melissa has been screened and how she has performed on subsequent progress monitoring tests. This information is essential, as it will provide an indication of how she is performing on a standardized test that is administered to all of the children in her grade or her school. The Response to Intervention process cannot delay a referral for special education if Melissa's parents make such a request, however.
- 4) At the initial meeting, Melissa's parents should ask that Melissa be assessed to determine the full range of her disabilities. She should receive a full educational assessment and a psychological assessment to determine if she has a learning disability. However, because of her seizure disorder, her seizure medicines, and the recent increase in her seizures, she should also have a neurological evaluation

³⁶ Response to Intervention is a process for screening students for possible learning problems and providing increasingly intensive interventions, ultimately referring for special education only those students who do not respond to the interventions. The 2004 reauthorization of the IDEA incorporated Response to Intervention as a permissible element of the identification process for students with learning disabilities.

to rule out a medical cause for her academic difficulties. Additionally, it would be appropriate to ask the team to order a psychiatric assessment, since Melissa may be depressed, and it is important to determine if she has an emotional disability in addition to her epilepsy and possible learning disability.

- 5) If the team refuses to order assessments for Melissa, her parents should consider filing a due process hearing request, assuming they have documentation to support their position. Given the information available, it is possible that Melissa qualifies for special education as “other health impaired” on the basis of her epilepsy, or as a child with a learning disability, or even as a child with an emotional disturbance. Depending on the extent of her disabilities, she might qualify on the basis of multiple disabilities, if her disabilities each adversely affect her educational performance to the extent that they each need to be addressed in order for her to make educational progress. Without assessments, it is difficult to know what is going on with Melissa. The chances are that once her parents make a formal request for evaluation, the team will agree to assessments. If not, it is likely that if her parents ask for due process, the case will be resolved when the district’s compliance officer or attorney becomes involved.
- 6) If the team does order assessments, Melissa’s parents should keep track of the 60-day timeline and request copies of the assessments in advance of the team meeting at which the assessments will be reviewed. Although the district does not have an obligation to provide the assessments in advance, it is helpful if parents can see them ahead of time, and the meeting will be more efficient if Melissa’s parents are not listening to or reading the test results for the first time during the meeting.
- 7) If an advocate is involved, he or she should continue to provide technical assistance and be prepared to attend IEP meetings with Melissa’s parents if necessary as the process unfolds.

Case Scenario 2 — Administration of Emergency Antiepileptic Medication and Placement in the Least Restrictive Environment

Lizzie is a four-year-old student with epilepsy, cerebral palsy, and mild mental retardation who has been fully included in a private preschool program. She has made friends in this program and has made significant gains educationally as well. At the IEP team meeting to determine a kindergarten placement for her, Lizzie’s parents seek placement in their neighborhood school with the assistance of a licensed practical nurse (LPN) who can administer emergency antiepileptic medication as necessary, as well as other supports and services. The team recommends placement in the district’s separate special education school because there is a nurse assigned full-time to the school who would be able to administer her medication if necessary. Lizzie’s parents are strongly opposed to this recommendation and seek assistance in obtaining their neighborhood

school placement, although they are willing to have their daughter placed at another elementary school nearby, even though it is not their zoned school. Their zoned school has a health aide assigned five days per week; the other elementary school has a school nurse on-site five days per week.

Discussion and Possible Advocacy Strategy: There are several possible ways in which this case could be resolved. If Lizzie's family lives in a state in which emergency antiepileptic medication administration can be delegated to an unlicensed health aide, then it is possible that the nurse who supervises the health aide at Lizzie's zoned school could delegate the medication administration to her. Alternatively, because the other nearby elementary school has a school nurse on-site every day, arrangements could be made to send Lizzie to that school instead of her zoned school, since she would still be included in general education and would still be close to home. The following strategy can be applied to Lizzie's situation:

- 1) If Lizzie's family lives in a state that permits delegation of emergency antiepileptic medication administration, determine if there is a medically compelling reason why Lizzie would require an LPN to administer her medication. If there is no such reason, advocate for placement of Lizzie in her zoned school with delegation of her medication to the health aide by the supervising nurse.
- 2) If Lizzie's family lives in a state that permits delegation of her medication, but the nurse refuses to delegate, or there is a medically compelling reason why her medication must be administered by a nurse, then advocate for the provision of a nurse as a related service on Lizzie's IEP and for placement of Lizzie in her zoned school. Her successful inclusion in preschool, combined with the fact that it is illegal to place students solely on the basis of their disability, the configuration of the service delivery system, or administrative convenience, support placement in her neighborhood school.
- 3) If the school district will not agree to placement in Lizzie's zoned school and her parents do not wish to challenge the decision through due process, a compromise position would be placement in the nearby elementary school that has a nurse full time. Lizzie would still be fully included, but she would have access to a nurse who could administer her medication. The school district might argue that the nurse is busy with other children and might not be able to respond quickly, but the same could be argued of the nurse at the separate school. In fact, in a separate special education school, the nurse might be busier with more complicated medically oriented tasks than a regular school nurse, who could easily be trained to administer the medication.
- 4) If the school district refuses to agree to an inclusive placement for Lizzie, request a due process hearing. Lizzie should not have to be segregated into a separate setting simply to get access to a person who can administer her medication to her in the event that she needs it at school.

See Chapter 8 for an alternate scenario with these facts.

Case Scenario 3 — Suspension for Misbehavior

Mark, a 12-year-old student with epilepsy and behavior challenges gets into a fight with another student in the school cafeteria. The assistant principal breaks up the fight and while doing so, gets hit in the face by Mark, who was trying to get in one last swing at the other student. Mark then taunts the assistant principal, saying, “You can’t suspend me; I’m in special ed.” Mark is suspended for 15 days, and his parents seek legal assistance.

Discussion and Possible Advocacy Strategy: Mark’s reliance on his special education status to protect him from suspension is misplaced; administrators absolutely can suspend students with disabilities, but they must follow certain procedures and afford students and their parents procedural safeguards in order to do so. Assuming these procedures have been followed, an attorney or advocate becoming involved in Mark’s case may want to point out to Mark and his parents that, under the circumstances, a 15-day suspension is fairly minimal. Many other administrators would have sought an interim alternative education placement, or even expulsion. Some administrators might even have pressed charges in juvenile court. It is important to determine, however, if Mark’s IEP is meeting his needs and this incident offers an opportunity to review his program and make any necessary changes. The following advocacy efforts may assist Mark:

- 1) Review Mark’s records, including all discipline records. Is this the first suspension for Mark? If not, how often has he been suspended? For how many days at a time? How far apart were the suspensions? For what kinds of incidents? Has Mark had a functional behavioral assessment? Does he have a behavioral intervention plan? If so, does it use positive behavioral supports and interventions? Was the school nurse involved in its development? Does the school staff appear to understand Mark’s epilepsy and the medications he takes, along with the relationship between the medications and his behavior?
- 1) Because Mark’s suspension is for more than 10 days, the team will need to meet to determine if his behavior was a manifestation of his disability. In making this determination, the team will look at whether the behavior was caused by or had a direct and substantial relationship to the disability or if the behavior was a direct result of the school district’s failure to implement Mark’s IEP. The attorney or advocate should attend this meeting. While the team will look at Mark’s identified disability of epilepsy, the attorney or advocate may want to raise the question of whether Mark’s behavior challenges rise to the level of an emotional disturbance under the IDEA’s definition. This needs, of course, to have been discussed with Mark’s family ahead of time and will depend on what evidence exists to support such a determination.
- 2) Even if Mark has not previously been identified as having an emotional disturbance, his IEP should contain academic and functional goals to meet not only his needs that result from his disability (to enable him to be involved in and make progress in the general curriculum) but also to meet the other educational

needs that result from his disability. Therefore, his IEP should contain goals to meet his behavioral needs. If it does and they were not implemented, then the team should find that the behavior was a manifestation of his disability. (See question 4.39.) Additionally, the team should explore whether Mark's seizure medication has any effect on his behavior.

- 3) If Mark has not had a functional behavior assessment, the team should conduct one and should then develop a behavior intervention plan designed to minimize the likelihood that Mark's behavior will recur. Fighting and insolence seem to be the two behaviors that need to be targeted, but the record review will have turned up any other behaviors or issues that need to be addressed.

Case Scenario 4 — Extended School Year Services When Seizures Impede Progress

Manny is a 17-year-old student with multiple disabilities, including intractable epilepsy. His educational progress is very slow and often the progress he makes is reversed by periods of intense seizure activity that cause him to regress. Regaining his skills does not come easily to him, as even during periods of less intense seizure activity, he still has several seizures a week. He has had a difficult year with a number of medication changes and several hospitalizations. In addition to special education and school health services, he receives physical, occupational and speech therapies. The IEP team decides at his annual review that he has hit a plateau and would not benefit from services during the summer, so the team finds him ineligible for extended school year services. The extended school year program offered by the district is a four-week program that anyone found eligible for extended school year services receives. Manny's parents did not have representation at the IEP meeting.

Discussion and Advocacy Strategy: The IDEA regulations do not go into great detail about extended school year services, but they do state that a public agency “may not [l]imit extended school year services to particular categories of disability; or unilaterally limit the type, amount, or duration of those services.” 34 C.F.R. 300.106. The law governing extended school year services has emerged primarily through cases, and circuit courts have applied a variety of standards to the issue.³⁷ Essentially, however, to a greater or lesser degree, depending on the circuit, eligibility for extended school year services tends to rely on whether a student will regress without services during the summer or, since all students regress to some extent without services during the summer, take a longer time than would be expected to recoup skills if regression occurs. Several courts have added additional factors that must be considered, such as the nature or severity of the disability, interfering behaviors, emerging or breakthrough skills, rate of progress and special circumstances. The primary question courts ask is whether the student's progress during the school year will be significantly jeopardized if he or she does not get services during the summer. For Manny, a possible strategy might include the following steps:

³⁷ See discussion of cases and relevant policy letters and rulings at the end of this chapter.

- 1) Request another IEP meeting at which an attorney/advocate can be present along with Manny's parents. If there is relevant case law from the circuit in which Manny's family lives, bring it to the meeting, or at least be familiar with the standard applied to extended school year services. Manny's seizures cause significant regression and very slow recoupment even when he is getting services. It seems likely that without services, any progress he is likely to make during the year would grind to a halt because he will spend all of his time trying to get back to where he was when school ended. If Manny has any outside therapists or service providers who can speak about this issue, they should provide something in writing to present to the IEP team. If possible, find a school-based therapist who agrees and who will be able to attend the meeting. Have specific plan regarding the amount and type of services Manny will need during the summer in order to make continued educational progress during the school year. If Manny needs more than four weeks of services, it is possible to build an appropriate program around the four-week program offered by the school district by adding individualized services before and after the district's program.
- 2) Point out to the team that, in addition to significant issues of regression and recoupment, there are a number of factors weighing in support of extended school year services for Manny: his multiple disabilities make his progress slow, his hospitalizations and changes in seizure medications are special circumstances that have an impact on his ability to benefit from his education, and his multiple disabilities combine to make him a person with severe disabilities.
- 3) Counter the team's "plateau" argument by asking for all of the records, evaluations and other information the team members are relying on to establish their position that Manny will not make any further progress. This is consistent with the prior written notice requirements of the IDEA regulations. 34 C.F.R. 300.503.³⁸ Do they mean no further progress educationally? In physical therapy? Occupational therapy? Speech? All areas? It is unlikely that the team has evaluations or data to justify its position that Manny has reached a plateau in every area of his education, and it runs completely counter to the fundamental idea of the IDEA that all children are capable of making educational progress. Pushing the team members will likely get them to back down.
- 4) Request a due process hearing if necessary.

³⁸ Under the prior written notice requirement of the IDEA regulations, the school district is required to give notice to parents a reasonable amount of time before the agency changes the identification, evaluation, or educational placement of their child or the provision of a free appropriate public education to the child, or refuses to take such actions. The notice must include "A description of the action proposed or refused," along with "an explanation of why the agency proposes or refuses to take the action" and "a description of each evaluation procedure, assessment, record, or report the agency used as a basis for the proposed or refused action." 34 C.F.R. 300.503(b)(1), (2) and (3). The notice must also include: a statement about the parents' procedural safeguards, sources for the parents to contact for assistance to understand the provisions of this requirement, a description of other options the agency considered and the reasons they were rejected, and a description of other relevant factors. 34 C.F.R. 300.503(b)(4)-(7).

Selected Cases

Free and Appropriate Public Education

Board of Education of the Hendrick Hudson Central School District v. Rowley, 458 U.S. 176 (1982)

The Court held that an elementary school student who was deaf was not entitled to a sign language interpreter in school. The Education for All Handicapped Children Act (EHA) [now IDEA] requirement of a “free appropriate public education” is satisfied when the student is provided with personalized instruction with sufficient support services to permit him or her to benefit educationally from that instruction. If the student is educated in regular classrooms, as in this case, the IEP should be “reasonably calculated” to enable him or her to achieve passing marks and to advance from grade to grade. The EHA was meant to open the door of public education to students with disabilities, rather than to guarantee them any particular substantive level of education once they are inside the school. The state is not required to maximize the potential of each student with disabilities commensurate with the opportunity provided to non-disabled students. In EHA suits, the court must first decide if the state has complied with statutory procedures, and then to decide if the IEP developed through such procedures is reasonably calculated to enable the student to receive educational benefits. If so, the state has met the requirements of the EHA.³⁹

Timothy W. v. Rochester, New Hampshire School District, 875 F.2d 952 (1st Cir. 1989), *cert. denied*, 110 S.Ct. 519 (1989)

Education includes the teaching of basic functional life skills as well as traditional academic skills. A school system cannot refuse to provide any education to a child with disabilities on the basis that the child cannot benefit from educational services. The EHA mandates that all children receive a free appropriate public education, regardless of the severity of their disabilities. A child’s ability to achieve academic benefit from such services is irrelevant. All children, regardless of their ability to achieve academic benefit from a public education have the right to a free, appropriate public education.

J.L. v. Mercer Island Sch. Dist., 575 F. 3d 1025 (9th Cir. 2009)

The 1997 IDEA amendments did not override the Rowley Case. In particular, the transition services definition does not change the FAPE standard.

³⁹ Many attorneys who represent children and families in special education matters believe that the *Rowley* holding has been effectively nullified by the No Child Left Behind Act because of its emphasis on adequate yearly progress and achievement for all students. While a discussion of this issue is beyond the scope of this manual, it is clear that because of No Child Left Behind, the “floor” of appropriateness established by *Rowley* is higher than it was when the case was decided.

Eligibility for Services

N.B. v. Hellgate Sch. District, 541 F.3d 1202 (9th Cir. 2008)

A school district's failure to evaluate a student in all areas of suspected disability constituted a procedural error that amounted to a denial of a free appropriate public education. In this case, the district had referred the family to an outside agency for free testing for autism but had not ordered a comprehensive evaluation. The court ordered a year of reimbursement to the family.

Ellenberg v. New Mexico Military Institute, 572 F. 3d 815 (10th Cir. 2009)

The fact that a student is eligible for services under the IDEA does not mean that the student is a qualified student with disabilities under Section 504; the statutes have different standards for establishing eligibility. IDEA eligibility for services does not automatically establish that a student is substantially limited in a major life activity.

Related Services

Irving Independent School District v. Tatro, 468 U.S. 883 (1984)

Clean intermittent catheterization (CIC) is a "related service" under the EHA. Without this service, affected students would be unable to attend school and benefit from special education. CIC is "no less related to the effort to educate than are services that enable a child to reach, enter, or exit a school." 468 U.S. at 891. CIC is not an excluded "medical service," which is defined by the EHA as a service that is provided only by a licensed physician. Related services include school nursing services.

Cedar Rapids Independent School District v. Garret F., 526 U.S. 66 (1999)

Nursing services, including continuous nursing services, are a "related service" under the IDEA. Related services must be interpreted broadly. This case reiterated the *Tatro* holding after a long line of circuit court cases undercut *Tatro* by finding that continuous nursing (constant nursing services throughout the school day) was a medical service that is not covered as a related service under the IDEA.

IEP Development/Placement

Spielberg v. Henrico County Public Schools, 853 F.2d 256 (4th Cir. 1988), *cert. denied* 109 S.Ct. 1131 (1989)

A student's IEP must be developed prior to his or her placement. Placement prior to IEP development is a procedural violation of the statute that constitutes a denial of a free appropriate public education.

Least Restrictive Environment

Roncker v. Walter, 700 F. 2d 1058 (6th Cir. 1983), *cert. denied* 464 U.S. 864 (1983)

If a segregated facility is considered superior for a student, a determination should be made if the services that make the placement superior could feasibly be provided in a non-segregated setting. If they can, then placement in the segregated setting would be inappropriate under the IDEA. The court noted that some students must be educated in segregated settings because any marginal benefits received from mainstreaming are far outweighed by the benefits gained from services which could not feasibly be provided in the non-segregated setting, or because the child with disabilities is a disruptive force in the non-segregated setting. Cost is a proper factor to consider. Standard reiterated in *Kari H. v. Franklin Special School District*, 125 F. 3d 855 (6th Cir. 1997).

A.W. v. Northwest R-1 School Dist., 813 F. 2d 158 (8th Cir. 1987), *cert. denied* 484 U.S. 847 (1987)

Adopted the *Roncker* standard and discussed cost issues at length in denying regular education placement to student with severe mental retardation.

Daniel R.R. v. El Paso Independent School District, 874 F.2d 1036 (5th Cir. 1989)

The Fifth Circuit set out a two-part test: First, can education in the regular classroom with the use of supplemental aids and services be achieved satisfactorily? It is necessary to look at whether supplementary aids and services have been provided, whether the program has been modified, and whether the efforts of the district have been sufficient. It is also necessary to ask if the student will receive an educational benefit from regular education, since academic achievement is not the only reason to place a student with disabilities into general education. The court also stated that it is necessary to look at the student's overall educational experience, comparing the benefits of special and regular education for the student, and to look at the effect of the student's presence on the regular classroom environment and on the education the other students are receiving. Second, if the student cannot be educated satisfactorily in the regular classroom, has he or she been mainstreamed to the maximum extent appropriate? The court specifically notes that the IDEA does not take an all-or-nothing approach, and that students can be placed in both regular and special education classrooms to varying degrees. The *Daniel R.R.* holding was reiterated in *Brillon v. Klein Independent School District*, 100 Fed. Appx. 309 (5th Cir. 2004).

DeVries v. Fairfax County Board of Education, 882 F.2d 876 (4th Cir. 1989)

The Fourth Circuit essentially adopted the holding of *Roncker v. Walter* to deny neighborhood school placement to a student with severe disabilities. In *Hartmann v. Loudoun County Board of Education*, 118 F.3d 996 (4th Cir. 1997), the court reiterated its *DeVries* decision and overturned the district court's order of an inclusive placement for an elementary school student with autism. The court stated clearly that mainstreaming is not required when the child with a disability would not receive an educational benefit, when any marginal benefit from mainstreaming would be significantly outweighed by

benefits which could feasibly be obtained only in a separate instructional setting, or when the child with a disability is a disruptive force in a regular classroom setting.

Barnett v. Fairfax County Public Schools, 927 F.2d 146 (4th Cir. 1991)

The court denied home school placement to a student who used cued speech interpreting, finding that whether a particular service or method can feasibly be provided in a specific special education setting is an administrative determination; it was acceptable for the school district to centralize its cued speech interpreting program at a different school and to consider cost as a factor.

Greer v. Rome City School District, 950 F. 2d 688 (11th Cir. 1991)

The Eleventh Circuit adopted the two-part *Daniel R.R.* test and found that the district failed to accommodate the student appropriately in a regular classroom. The court held that before a district may decide to remove a student from the regular classroom, it must consider whether supplemental aids and services can permit satisfactory education in the regular classroom; it must consider the full range of supplementary aids and services. The court outlined a non-exhaustive list of factors to be considered, including the comparative benefits of the regular versus the special education classrooms, the effect of the child with a disability on the rest of the children in the regular classroom, and the cost of the supplementary aids and services that would be necessary for the child with a disability to obtain a satisfactory education in the regular classroom.

Oberti v. Board of Education of Borough of Clementon, 995 F.2d 1204 (3d Cir. 1993)

In holding that a district failed to make adequate efforts to include a child with Down Syndrome in regular education, the Third Circuit adopted the *Daniel R.R.* test, holding that the court should first ask whether a student can be educated satisfactorily in a regular class with supplemental aids and services and then, if not, whether the school has included the child with non-disabled children to the maximum extent appropriate. In asking the first question, the court should consider a) whether the school district has made reasonable efforts to accommodate the child in a regular classroom, b) the educational benefits available to the child in a regular class with appropriate supplementary aids and services, compared with the benefits available in a special education class, and c) the possible negative effects of the child's inclusion on the education of the other students in the class. When addressing the second question, the court noted, the school district should take intermediate steps when appropriate, such as including the child in nonacademic classes or other activities.

Sacramento City Unified School District v. Holland, 14 F.3d 1398 (9th Cir. 1994)

The Ninth Circuit affirmed an inclusive educational placement for a student with mental retardation and adopted a four-factor test that blended elements of the *Daniel R.R.* and *Roncker* standards. The court held that the following must be considered in determining

placement: a) the educational benefits of full-time placement in a regular class; b) the nonacademic benefits of full-time placement in a regular class; c) the effect the child with a disability has on the teacher and other children in the regular class; and d) the costs of including the child with a disability in the regular class.

Beth B. v. Van Clay, 282 F.3d 493 (7th Cir. 2002)

The Seventh Circuit declined to adopt a test for deciding least restrictive environment cases. The court found the IDEA's framework sufficient, stating that if the student's placement was satisfactory, the district would be in violation of the statute by removing her and, if not, the district's recommended placement would not violate the statute if the placement mainstreamed her to the maximum extent appropriate.

Girty v. School District of Valley Grove, 60 Fed. Appx. 889 (3d Cir. 2002)

The Third Circuit affirmed the district court's decision (163 F.Supp. 2d 527), which had applied *Oberti* to order the inclusion of a student transitioning from elementary to middle school.

L.B. v. Nebo School District, 379 F.3d 966 (10th Cir. 2004)

In finding that the district violated the student's right to placement in the least restrictive environment, the court adopted the *Daniel R.R.* test, but did not specifically apply the cost factors to the case at hand.

Tuition Reimbursement

School Committee of Burlington v. Department of Education, 471 U.S. 359 (1985)

The Court held that the EHA permits a court to order a school authority to reimburse parents for their expenditures on private special education for their child if the court ultimately determines that such placement, rather than the proposed IEP, is proper. Parents do not waive their right to reimbursement if they change their child's placement while waiting for the courts to review the appropriateness of a proposed IEP. However, if the court ultimately determines that the proposed IEP was appropriate, the parents would not be reimbursed for the costs of having their child privately schooled while waiting for a decision.

Florence County Sch. Dist. Four v. Carter, 510 U.S. 7 (1985)

Parents are entitled to reimbursement for private placement if they demonstrate that the public school placement was inappropriate under the IDEA and that the private school placement complied with the minimum standard of appropriateness established by the IDEA: that the placement is reasonably calculated to provide an educational benefit. The private school placement does not have to meet all of the specific IDEA requirements applicable to educational placements made by public school systems.

Forest Grove School District v. T.A., 129 S.Ct. 2484 (2009)

A school district may be responsible for tuition reimbursement for a child who has not previously been found eligible and who has never received special education services from the public school system.

Compensatory Services

Miener v. Missouri, 800 F.2d 749 (8th Cir. 1986)

Post-*Burlington*, this case came to the Eighth Circuit for the second time, and the court held that a plaintiff who establishes a denial of a free appropriate public education in violation of the EHA is entitled to compensatory services. The court noted that a child's entitlement to a "free" education does not turn on the parent's ability to front the cost of that education and that when parents do not have the money to purchase educational services for their children, education officials cannot escape liability.

Sobol v. Burr, 888 F.2d 258 (2d Cir. 1989), *cert. denied* 110 S. Ct. 1298 (1990)

The Eleventh Amendment and the EHA do not bar the award of compensatory education beyond the age of 21 to a student who has been denied a free appropriate public education.

G. ex rel. RG v. Fort Bragg Dependent Schs., 343 F.3d 295 (4th Cir. 2003)

The court held that courts and hearing officers may award compensatory educational services to be provided prospectively to compensate for a past deficiency. 343 F.3d at 308.

Reid v. District of Columbia, 401 F.3d 516 (D.D.C. 2005)

In upholding a compensatory education award to a student, the court rejected an award of one hour for each day the district denied the student an appropriate education. Instead, the court adopted a qualitative standard, finding that compensatory education should aim to place students with disabilities in the same position they would have been in had the district not violated the IDEA. The court noted that compensatory awards must rely on individualized assessments. The court also held that IEP teams do not have the authority to reduce or discontinue compensatory service awards.

Board of Education of Fayette County, Kentucky v. L.M., 478 F.3d 307 (6th Cir. 2007)

The court agreed with the *Reid* court that a flexible approach to compensatory education, rather than an hour-for-hour award, was appropriate, because some students might need short, intensive compensatory programs while others might need more extended programs that would exceed the number of hours of service they had missed. The court held that the IEP team cannot be given the power by a court or hearing board to reduce or terminate a compensatory education award.

Extended School Year Services

Alamo Heights Independent School District v. State Board of Education, 790 F.2d 1153 (5th Cir. 1986)

The court held that if a child will experience “severe or substantial regression” during the summer months without a summer program, the student may be entitled to year-round services. The question is “whether the benefits accrued to the child during the regular school year will be significantly jeopardized if he is not provided an educational program during the summer months.” 790 F. 2d at 1158.

Johnson v. Independent School District No. 4, 921 F.2d 1022 (10th Cir. 1990)

The court held:

- a) Regression-recoupment analysis is not the only factor used to determine the necessity of a structured summer program. Other factors to be considered include the child’s degree of impairment, the ability of the child’s parents to provide the educational structure at home, the child’s rate of progress, his or her behavioral and physical problems, the availability of alternative resources, the ability of the child to interact with non-disabled children, the areas of the child’s curriculum which need continuous attention, the child’s vocational needs, and whether the requested service is extraordinary to the child’s condition or an integral part of a program for those with the child’s condition
- b) This list is not intended to be exhaustive and it is not intended that each element impact planning for each child’s IEP
- c) The analysis of whether or not a child’s level of achievement would be jeopardized by a summer break in services should include the application not only of retrospective data such as past regression and rate of recoupment, but also “predictive data, based on the opinion of professionals in consultation with the child’s parents as well as circumstantial considerations of the child’s individual situation at home and in his or her neighborhood and community.” 921 F. 2d at 1028

Cordrey v. Euckert, 917 F.2d 1460 (6th Cir. 1990), *cert. denied*, 499 U.S. 938 (1991)

The legal standard for determining eligibility of a student for extended school year services is “significant skill losses of such degree and duration so as seriously to impede his progress toward his educational goals.” A student need not demonstrate past regression in order to prove his or her need for a summer program. Where there are no such empirical data available, need may be proven by expert opinion, based upon a professional individual assessment. 917 F.2d at 1472. Extended school year services must be necessary in order to avoid “something more than adequately recoupable regression.” 917 F. 2d at 1473. Decision relied on by court in *Kenton County School District v. Hunt*, 384 F.3d 269 (6th Cir. 2004).

Reusch v. Fountain, 872 F.Supp. 1421 (D.Md. 1994)

Class action lawsuit resulted in order that the school district cease and desist from its IDEA violations and provide:

- a) Notice to parents regarding the consideration of extended school year services at each annual review meeting
- b) Determination of extended school year services early enough so that parents can appeal a denial in time to obtain extended school year services if their child is found eligible
- c) Establishment of six eligibility criteria including regression, recoupment, degree of progress, emerging skills/breakthrough opportunities, interfering behavior, nature and/or severity of the disability, and special circumstances
- d) Individualized extended school year services
- e) Written summary of extended school year services discussion within 10 working days after the meeting

LIH v. New York City Board of Education, 103 F.Supp.2d 658 (E.D.N.Y. 2000)

The procedural safeguards, including the discipline requirements, of the IDEA apply equally to summer school programs. The IDEA applies to every school day. Summer school days satisfy that definition.

M.M. v. School District of Greenville County, 303 F.3d 523 (4th Cir. 2002)

Extended school year services are necessary for the provision of a free appropriate public education when the benefits gained by the child during the regular school year will be “significantly jeopardized” if he or she does not receive an educational program during the summer. A showing of actual regression is not required; the need for extended school year services may be established by expert testimony based on a professional individual evaluation. The mere fact of likely regression is not sufficient. Rather, extended school year services are required under the IDEA only when such regression will “substantially thwart the goal of meaningful progress.” 303 F. 3d at 538.

JH v. Henrico County School Board, No. 02-1418 (4th Cir., April 28, 2003)

The court vacated the district court’s decision in light of the *M.M.* decision. In remanding the case to the district court to remand to the hearing officer, however, the Fourth Circuit ordered that the hearing officer consider evidence regarding “window of opportunity” evidence presented by the family. This refers to evidence that there is a window of opportunity for children with autism such as JH to learn effectively to overcome their deficits, to the extent that such evidence is relevant to the determination of whether the

extended school year services that had been provided to the student were sufficient to prevent the gains he had made during the school year from being significantly jeopardized.

Board of Education of Fayette County, Kentucky v. L.M., 478 F.3d 307 (6th Cir. 2007)

The court reiterated its previously adopted standard set forth in *Cordrey v. Euckert*.

Extended School Year Services: Office of Special Education Programs (OSEP) Policy Letters and Office for Civil Rights (OCR) Rulings

Over the years, OSEP has issued a number of policy rulings addressing extended school year services, and OCR has issued a number of rulings as well. These are published by LRP Publications in the Individuals with Disabilities Education Law Reporter (IDELR) and online in Special Education Connection, a subscription service run by LRP Publications. A brief summary of selected important policy letters and rulings is included below, along with citations.

Letter to Baugh (July 2, 1987), 211 EHLR 481: When the issue is relevant, extended school year services must be discussed at an IEP meeting; a school system cannot limit extended school year services to students with severe and profound disabilities or limit programs in duration.

Letter to Gramm (July 25, 1988), 213 EHLR 149: Extended school year programs must be made available when necessary to provide a free appropriate public education to a child.

Letter to Myers (August 30, 1989), 213 EHLR 255: IEP team determines number of services a student needs for appropriate extended school year program. IEP for extended school year will differ from regular school program. Reasonable that extended school year IEP will focus on areas in which child may experience regression or on skills that are needed to keep child from regressing in academics. Least restrictive environment requirements apply to extended school year services through both school district programs or alternative means, such as private placements.

Letter to Harkin (September 15, 1989), 213 EHLR 263: IEP team makes the ultimate determination as to whether a student needs extended school year services in order to receive a free appropriate public education. Parents have right to request a due process hearing at any time to resolve a disagreement about extended school year services.

Letter to Myers (December 18, 1989), 16 EHLR 290: Options on the continuum of services must be made available to the extent necessary to implement a student's IEP. A student's IEP for extended school year services will probably differ from regular IEP, since purpose of extended school year program is to prevent regression and recoupment problems. Federal funds can be used for services in private school placement if that is determined to be the appropriate extended school year services placement. Modification necessary to implement a student's IEP for extended school year services must be determined on a case-by-case basis.

Letter to Libous (November 15, 1990), 17 EHLR 419: Eligibility for extended school year services must be based solely on each student's unique educational needs, rather than on category of student's disability. Students may require related services as sole component of special education program during summer months to benefit from school year programs.

Letter to Anonymous (November 15, 1993), 22 IDELR 980: Children who turn three during the summer months must be provided with extended school year services if needed for the provision of a free appropriate public education. Decision must be individualized. No disability category may be excluded. Evidence appropriate to meet state standards for eligibility must be determined on a case-by-case basis, depending on needs of individual student.

Letter to Kleczka (September 29, 1998), 30 IDELR 270: No federal requirement that if student does not meet goals of IEP, he or she must participate in extended school year services.

Letter to Sims (June 27, 2002), 38 IDELR 69: IDEA's "at no cost" provision includes incidental fees if normally charged to parents of students without disabilities as well as parents of children with disabilities, but parents of children with disabilities may not be charged for a summer program that is part of the student's extended school year services.

Baltimore (MD) City Public Schools (April 18, 1986), 352 EHLR 185: District violated Section 504 because it did not determine provision of extended school year programs and services based on student's individual needs. Only students with severe disabilities in special day schools or residential facilities were considered for extended school year services.

Clark County (NV) School District (November 2, 1989), 16 EHLR 311: District violated Section 504 by failing to consider extended school year services for students, limiting summer school enrollment on the basis of disability and charging some families fees for services.

Rockwood (MO) R-VI School District (November 8, 1989), 16 EHLR 506: District did not violate Section 504 by having policy that extended school year programs were generally one-half the amount of services received during the school year.

Mesa (AZ) Public Schools (November 9, 1989), 16 EHLR 316: Districted violated Section 504 by limiting extended school year services to self-sufficiency areas, thereby mainly serving students with severe cognitive impairments and discriminating against other students with disabilities by failing to consider their unique needs.

Discipline

Goss v. Lopez, 419 U.S. 565 (1975)

Suspensions of 10 or more days cause a sufficient deprivation of property and liberty to trigger the protections of the Due Process Clause of the U.S. Constitution. School systems, therefore, have developed constitutionally sound suspension procedures. These procedures allow for notice of charges, an opportunity for the student to present his or her version of the story, and the opportunity for a hearing. If these procedures are not followed correctly, the suspension is can be reversed.

S-1 v. Turlington, 635 F.2d 342 (5th Cir.), *cert. denied* 454 U.S. 1031 (1981)

Students who meet the definition of disabled under Section 504 cannot be punished for behavior that is a manifestation of their disability.

School Board of the County of Prince William v. Malone, 762 F.2d 1210 (4th Cir. 1985)

The court held that the student could not be expelled for selling drugs because his action was a direct manifestation of aspects of his learning disabilities, including low self-esteem, desire for acceptance by peers, and a particular susceptibility to peer pressure, among others.

Honig v. Doe, 484 U.S. 305 (1988)

The Court refused to allow school administrators to simply exclude students on the basis of perceived dangerousness, and held that unless the parents consent to an alternative placement or the school system obtains an injunction to exclude the student on the grounds that the student's continued attendance would be "truly dangerous," the school system must permit the student to remain in his or her current placement pending agreement to an alternative placement or the completion of any administrative or court proceedings to challenge any proposed change in placement.

Much of the *Honig* holding was incorporated into the IDEA when it was reauthorized in 1997 and it was changed significantly when the IDEA was reauthorized again in 2004, particularly with regard to when a student may remain in his or her current placement and when he or she may be removed from school by administrators. However, the *Honig* decision remains instructive both for what seems to constitute "truly dangerous" behavior and for the alternatives to suspension that the Court lists. With respect to "truly dangerous" behavior, it is instructive to note the standard had not been met in this case. The Court found that the school district had failed to show a substantial likelihood that continued attendance of either student involved would result in injury to fellow students or others: one student had been suspended indefinitely for choking a fellow student with sufficient force to leave abrasions and for kicking out a school window, and the second student had been suspended indefinitely for disruptive behavior which included stealing, extorting money from fellow students, and making sexual comments to female classmates. With respect to alternatives to suspension, the Court listed the use of study carrels, time outs, detention, or the restriction of privileges.

Light v. Parkway C-2 School District, 41 F.3d 1223 (8th Cir. 1994), *cert denied* 515 U.S. 1132 (1995)

A school district should not take measures to remove a student from his or her current educational placement until reasonable steps have been taken to mitigate the student's threat of injury by accommodating the student's disability.

Couture v. Bd. of Educ. of the Albuquerque Public Schools, 535 F.2d 1243 (10th Cir. 2008)

The court did not find a problem with the school system's repeated placement of a six year old child in floor restraint and in a time out room for up to two hours at a time, even for minor conduct, and even though the child's behavior escalated when in the room and he begged to be let out to use the bathroom. The court found that although the timeouts may have been seizures, they were not unreasonable seizures because of the extent of the child's behavior problems, and whether or not the room was effective was irrelevant. The court further found that the loss of educational services (12 hours over a two month period) was de minimis, and not subject to procedural protections.

Special Education Timelines

Referral for Special Education — No timeline in federal law; state laws vary

Assessments — Federal law sets a deadline for completion of 60 days after parental consent; state laws might have alternative timelines

Development of IEP — No federal timeline; state laws vary

Implementation of IEP — Federal law requires implementation as soon as possible after development; IEP must be in effect at beginning of school year. Check state laws for specific timelines

Re-evaluation — At least once every three years

CHAPTER FIVE

Special Education and Section 504

5.1Q: What are the rights of school-age students under Section 504?

- A:** Section 504 prohibits discrimination against a “qualified individual with a disability.” 29 U.S.C. 794. A school-age student who is covered by Section 504 has the right to a free appropriate public education, regardless of the nature or severity of his or her disability. The student may receive regular or special education, which must include related aids and services that are designed to meet his or her individual needs to the same extent as the needs of people without disabilities are met. Additionally, Section 504 requires compliance with certain procedural requirements. Section 504 applies to federally conducted and federally funded programs and activities. With respect to educational programs, Section 504 applies to preschool, elementary, secondary and adult education programs and activities. 34 C.F.R. 104.33.

A person is considered a “qualified person with a disability” with respect to educational services if he or she is of an age during which people without disabilities are provided with education services, of an age during which state law mandates that people with disabilities be provided with education services, or if he or she is a person to whom a state is required to provide services under the IDEA. 34 C.F.R. 104.3(1)(2).

5.2Q: Are students with epilepsy automatically covered under Section 504?

- A:** No. In order to be covered by Section 504, a student’s epilepsy must substantially limit one or more of his or her major life activities, the student must have a record of such a condition, or the student must be regarded as having such a condition. For example, if a student who has epilepsy takes medication, but he or she still has several breakthrough seizures a week and experiences side effects from the medication, such as sleepiness, that affect his or ability to concentrate in school and to complete all work on time, he or she will be protected by Section 504, because the major life activity of learning is substantially limited by his or her epilepsy. On the other hand, if a student has epilepsy that is completely controlled by medication and he or she is able to participate fully in school without any difficulties, he or she may not be considered to have a disability under the definition in Section 504.⁴⁰

⁴⁰ In 1999, the United States Supreme Court issued *Sutton v. United Air Lines, Inc.* 527 U.S. 471 (1999), an employment case under the Americans with Disabilities Act (ADA), which curtailed the scope of protection under the ADA and Section 504 (which is interpreted in the same manner as the ADA) for people with so-called “correctable” conditions such as epilepsy and diabetes. In this case, the Supreme Court made it clear that, in determining whether a condition is substantially limiting, the effects, both negative and positive, of mitigating measures, such as medication, must be considered.

5.3Q: Are students with epilepsy who are protected by Section 504 automatically entitled to special education?

A: No. To receive special education under Section 504, a student with epilepsy would need special education as a reasonable accommodation for his or her disability. Special education would be the means by which the student would gain an equal opportunity to participate in education along with peers without disabilities. Many students with epilepsy do not need special education services; rather, they may need accommodations such as extra time for tests or additional time to make up work missed because of seizures or medical appointments. If students with epilepsy have other disabilities, such as learning disabilities or attention deficit hyperactivity disorder, in addition to their epilepsy, they may need special education to address those disabilities or the needs that arise from the combination of disabilities.

5.4Q: If a student takes medication that completely controls his or her seizures, does that preclude his or her eligibility for services under Section 504?

A: It depends. A student may take medication that completely controls his or epilepsy, but the medication may cause side effects that require the provision of accommodations to the student. For instance, he or she may need extra time to complete work because of frequent naps due to sleepiness from the medication. In such a case, the student may be covered under Section 504. Or, the student may need medication administered during the course of the school day, and school staff will be responsible for administering it as an accommodation under Section 504. See Question 5.5. However, if the student is not impaired in any way by his or her epilepsy or by the medication he or she takes to control the epilepsy, the epilepsy would not be considered to substantially impair a major life activity, and the student may not be protected by Section 504.⁴¹ However, if the student's situation were to change, the student might become eligible for services under Section 504. For instance, if the student began to experience breakthrough seizures that interfered with his or her ability to complete school assignments, or if she began a new medication that caused interfering side effects, or something else were to occur that substantially limited at least one of his or her major life activities such as learning, the student would come under the scope of Section 504.

⁴¹ However, schools generally do not dispute that a student has a disability within the meaning of Section 504, and only a few cases have ruled that a student is not covered because of mitigating measures used to control his or her disability.

5.5Q: Would a student whose seizures are controlled with medication but who needs school personnel to hand out or actually administer the medication during the school day, or who experiences side effects from his or her medication, qualify for services under Section 504?

A: Yes, if medication administration is needed as a reasonable accommodation, the school district must provide this service to the student. Likewise, if side effects substantially limit the child and he or she needs reasonable accommodations in order to participate in school, the child is entitled to such accommodations under Section 504. The fact that the student takes medication that controls his or her seizures does not preclude him or her from qualifying for services under Section 504. The United States Education Department's Office for Civil Rights (OCR) issued a Guidance memorandum to its staff addressing this issue after the United States Supreme court issued *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999). The memorandum explains that when a measure is effectively unavailable to a student unless the school takes action or grants permission, then the measure is not considered mitigating. For example, if a school must administer the student's medication or give the medication to the student to take, or if the school must accommodate the student because of the medication's side effects, the fact that the school must do something for the child precludes it from viewing the student's medication as a mitigating measure. See: *Sutton* Investigative Guidance: Consideration of "Mitigating Measures" in OCR Disability Cases, U.S. Department of Education Office for Civil Rights (September 29, 2000).⁴² (Mitigating measures are medications and assistive

⁴² This Guidance is important to advocates because *Sutton* is sometimes erroneously used as a justification for denying accommodations to students. In the Guidance, OCR noted the difference between mitigating measures which the student may use without any action or assistance by the school, on the one hand, and those reasonable modifications, academic adjustments, auxiliary aids and services, or related aids and services that schools are required to provide, on the other.

OCR explains:

Mitigating measures should not be confused with reasonable modifications, academic adjustments, auxiliary aids and services, or related aids and services, all of which are provided by, or are under the control of, the educational institution. Examples of these are computers adapted for use by blind students, sign language interpreters, and permission to monitor diabetes or inject insulin. When some action or permission on the part of the school would be required before a student could use a measure, the effects of the measure will not be considered as "mitigating" because the measure is effectively unavailable to the student unless the school takes some action. Therefore, OCR will not consider the impact of reasonable modifications, academic adjustments, auxiliary aids and services, or related aids and services when evaluating whether a student's impairment substantially limits a major life activity.

OCR further explains:

If there is a mitigating measure involved, determine if the student can use the mitigating measure independently in the school setting. Does the student need the school to take some action (such as provide a related aid or service, or modify a policy, including giving permission to use the mitigating measure during school hours, on school grounds) in order to use the mitigating measure? If the student needs the school to take some action, do not

devices used by individuals to reduce or eliminate the effects of their disabilities.)

5.6Q: What are the components of a Section 504 plan?

A: The Section 504 regulations do not require a written plan, however, it is good practice to write down the services and accommodations a student will receive from the school district. A Section 504 plan should address everything the student needs because of his or her epilepsy. A model Section 504 Plan is included in this Manual at Appendix B. It is unlikely that any one student would need all of the services and accommodations discussed in the plan, but it is meant as a comprehensive guide from which to draw the relevant services and accommodations possibly needed in designing an individualized Section 504 for a particular student with epilepsy.

5.7Q: What kinds of services might a student with epilepsy receive under Section 504?

A: The services a student with epilepsy receives under Section 504 will depend on the student's individual needs. Examples include accommodations such as extra time for tests if a student has impaired concentration due to seizures or side effects from medication; additional time to complete school assignments or homework if the student loses time because of seizures or medical appointments; or adapted physical education activities for some of the physical education curriculum if a student has frequent seizures and safety would be an issue if the student were to participate in a regular physical education class for all activities. Another possible accommodation might be an adjusted school start time if the student needs to sleep later in the morning because waking up early triggers seizures. Depending on the age of the student, education or training of the

consider the effect of the measure (positive or negative) in determining if the student has an impairment that substantially limits him or her in any major life activity.

OCR notes other relevant considerations to be evaluated. For example, there may be side effects to mitigating measures used by a student. Additionally, mitigating measures may not fully correct the effects of the disability. Both of these factors affect the determination of whether a person has a disability for purposes of coverage under Section 504 or the ADA.

OCR's Guidance specifically recognizes the need to provide emergency medication:

Determine if the mitigating measure is effective all of the time for this student. If there is a risk of failure of the mitigating measure(s), or a risk that the effect of the mitigating measure(s) may not be consistent, then the student may still be substantially limited in a major life activity, despite the use of the measure(s). If that is the case, the school should be prepared to deal with emergency situations that might arise if the mitigating measure fails. For instance, a student with diabetes who injects insulin at home may still need an insulin injection, on an emergency basis, at school.

student's classmates about epilepsy might be warranted; this is another service that could be included in a Section 504 plan, as it would promote the social inclusion of the student with his or her peers.

Additionally, the services outlined in a student's seizure action plan would be covered by Section 504; these services might include routine and emergency medication administration, staff training, and communication with family and any necessary medical personnel. The seizure action plan could be attached to and incorporated into the Section 504 plan. A sample seizure action plan is included as Appendix C.

5.8Q: Who makes the decision about whether a student is entitled to services under Section 504?

A: The Section 504 education regulations, 34. C.F.R. 104.31-39, do not specify who decides if a student is entitled to services under Section 504. However, generally schools designate a team of school personnel similar to, or in some cases the same as, the IEP team. Along with the parent, this team discusses the student's situation and makes the decision about whether or not a student is entitled to services under Section 504. The team may be known as a Section 504 team.

5.9Q: When would a student need a Section 504 plan rather than an IEP?

A: A student would qualify for a Section 504 plan if he or she has an impairment that substantially limits a major life activity, such as learning. A student would qualify for a Section 504 plan rather than an IEP when he or she does not need individually designed special education services in order to make meaningful educational progress, the standard under the IDEA, but instead needs accommodations for his or her disability in order to have an equal opportunity to participate in activities and services offered to students without disabilities.

5.10Q: Are there timelines for making decisions about education services under Section 504?

A: No. Unlike the IDEA, Section 504 does not impose timelines on any part of the decision-making process for education services.

5.11Q: Does Section 504 impose evaluation requirements on school districts?

A: Yes. If the student needs, or is believed to need, special education or related services, he or she must be evaluated. Tests and other evaluations must be validated for the specific purpose for which they are used and must be administered by trained personnel in conformance with the instructions provided by the tests' producers. The tests and other evaluation materials must include those meant to assess specific areas of educational need and cannot simply result in a single general intelligence quotient. Additionally, for a student with

impaired sensory, manual or speaking skills, tests must be selected and administered so they accurately reflect the student's aptitude rather than his or her impaired sensory, manual or speaking skills, unless those are the skills the tests are designed to measure. 34 C.F.R. 104.35. Section 504 also requires periodic reevaluation of students who are receiving special education and related services under Section 504. 34 C.F.R.104.35(d).

5.12Q: If a student with epilepsy is identified as needing services under Section 504, what happens next?

A: A Section 504 plan that includes the services and accommodations needed by the student should be developed. This generally occurs at a meeting with a team of school staff and the student's parents.

5.13Q: What is the difference between a Section 504 plan and an IEP?

A: As discussed in Chapter 4 (see Question 4.18), the IDEA is quite specific about what needs to be included in an IEP. Section 504, however, does not discuss student plans and contains no details about what such a plan ought to look like if one is drafted. This is likely in large part because the IDEA is specifically an education law, but Section 504 is a general anti-discrimination law. The IDEA gives states money to comply with its requirements; failure to comply with Section 504 could result in loss of federal funds.

Typically, Section 504 plans are not as detailed as IEPs, but there is no inherent reason this should be the case. A Section 504 plan should be as detailed as it needs to be to outline clearly each service and accommodation a student with epilepsy needs during the school day and during any extracurricular or nonacademic activities, including school trips, sports activities, club meetings or other events.

5.14Q: What are some of the typical services that might be included in a Section 504 plan?

A: Although services will vary depending on the needs of the individual student, a Section 504 plan typically might include provisions regarding routine and emergency medication administration, including identification of staff who will perform this task; storage of medication; accommodations for class assignments, homework, and tests; any special arrangements that might need to be made for physical education curriculum units; who will administer necessary medications during extracurricular and nonacademic activities and events; and any other services or accommodations necessary to meet the student's needs at school and school-related activities and events.

5.15Q: What should a good Section 504 plan look like for a student with epilepsy?

A: A good Section 504 plan should include a statement of the child's needs and all of the services and accommodations the child will receive. See the model Section 504 plan in Appendix B for an example. As noted in Question 5.6, it is unlikely that one student will require all of the services and accommodations discussed in the model plan, but the model is a comprehensive guide that can be used in designing an individualized Section 504 plan for a student with epilepsy based on his or her particular needs.

5.16Q: Who participates in the development of a Section 504 plan?

A: Typically, a team of staff at the student's school develops a Section 504 plan, along with the student's parent. If evaluations are being reviewed or placement is being discussed, a group of people who are knowledgeable about the student, the meaning of the evaluation data, and placement options must make the placement decision. 34 C.F.R. 104.35(c).

5.17Q: Are there any requirements regarding meeting attendance?

A: No. Unlike the IDEA, Section 504 does not require the presence of particular types of people at meetings, nor does it contain provisions for excusing the presence of team members.

5.18Q: What are the placement requirements for students under Section 504?

A: Section 504 mandates that students with disabilities be educated with students who do not have disabilities to the "maximum extent appropriate" to the needs of the person with the disability. 34 C.F.R. 104.34(a). A student must be placed in the regular educational environment unless the school district can demonstrate that education in the regular environment cannot be achieved satisfactorily with the use of supplementary aids and services. If the student is not placed in the regular education environment, the school district must consider how close the alternate setting is to the student's home. 34 C.F.R. 104.34(a).

5.19Q: Is this similar to the IDEA's requirement that students be placed in the least restrictive environment?

A: Yes. Under the IDEA, students with disabilities must be educated in the least restrictive environment in which their IEPs can be implemented; the IEP must be based on the unique needs of the student. Only if the IEP cannot be implemented in a general education setting, even with the use of supplementary aids and services and programmatic supports and modifications, can the district move a student to a more restrictive education setting. Similarly, under Section 504, school districts must educate students with disabilities in the regular education setting alongside students without disabilities to the maximum extent

appropriate to the needs of the student with the disability, and school districts must provide necessary supplementary aids and services to enable the student to be appropriately placed in the regular education setting. Similarly, the IDEA expresses a preference for a student's attendance at the school he or she would attend if not disabled and for placement as close as home as possible, just as Section 504 mandates consideration of distance of the alternate setting to the student's home. 34 C.F.R. 104.34(a).

5.20Q: Does a school district have any responsibility to students to help them be placed successfully in general education?

A: Yes, as noted above, the school district must provide supplementary aids and services. In general, Section 504 requires reasonable accommodation of a person's disability. A school district must provide the accommodations necessary to enable a student to participate in general education to the maximum extent appropriate to the student's needs. For a student with epilepsy, the services may be as simple as providing a staff person to administer needed medication at specified times of the day or to administer emergency medication in the event of a prolonged seizure or cluster of seizures. Alternatively, a student may need a variety of other accommodations, such as a delayed school start time and extra time for tests. For a student with epilepsy and other disabilities, services may include special education as well as medication administration and other accommodations, but the student may be more appropriately served under the IDEA, which has more specific programmatic requirements, timelines and procedural safeguards.

5.21Q: What if state law requires a licensed health care professional to administer an emergency antiepileptic medication such as Diastat AcuDial (rectally administered diazepam gel) and other health care services to a student with epilepsy at school, and the school district tells the parent that the student must go to a school ten miles away to have access to the person and the service?

A: Unless the school district can establish that provision of a trained person to administer emergency antiepileptic medication at the student's school is an accommodation that would cause a fundamental alteration to its program or that it is not appropriate to meet the student's needs, it would be a violation of Section 504 to move the student to another school in order to receive this service. The proposed removal of the student from his or her neighborhood school because of the refusal to provide a needed supplementary service—as well as the distance of the proposed placement—would raise serious compliance concerns under Section 504.

5.22Q: Does Section 504 impose any requirements regarding nonacademic services?

A: Yes. School districts must provide students with disabilities an equal opportunity to participate in nonacademic and extracurricular activities. According to the Section 504 regulations, these activities may include counseling services, athletics, transportation, health services, recreational activities, special interest groups or clubs sponsored by the school or district, referrals to agencies that provide assistance to people with disabilities, and employment of students. 34 C.F.R. 104.37.

5.23Q: Is there a timeline for implementation of a Section 504 plan?

A: No. Since the regulations do not mandate the development of a plan, they do not contain a timeline for its development.

5.24Q: What happens if a parent disagrees with a decision about a student's eligibility for services under Section 504, the content or number of services, or the recommended placement?

A: Section 504 regulations require school districts to establish and implement procedural safeguards that include notice, an opportunity for parents or guardians to examine relevant records, an impartial hearing with an opportunity for participation by the student's parents and representation by counsel, and a review procedure. One way of complying with these requirements is by complying with the IDEA's due process procedures. 34 C.F.R. 104.36.

5.25Q: What happens if a parent has concerns about the implementation of a Section 504 plan?

A: School districts must identify a person to coordinate efforts to comply with Section 504. Parents or their advocate can contact the school district's Section 504 coordinator to try to resolve their concern informally. If that effort is unsuccessful, they can contact the state department of education's Section 504 coordinator. They can seek an administrative hearing or they can file a complaint with the U.S. Education Department's Office for Civil Rights, which has regional offices throughout the country. See Chapter 8 for a full discussion of available dispute resolution procedures and legal remedies under Section 504 and the IDEA.

5.26Q: If a parent places his or her child in a private school, is the child still protected by Section 504?

A: Whether a student in a private school is protected by Section 504 depends on whether the school receives any federal funds. If the school receives federal funds, even if only for its library or for milk, the school is subject to Section 504

and must comply with its requirements. If the school does not receive any federal funding, it is not subject to Section 504. However, private schools must comply with Title III of the ADA unless they are run or controlled by religious entities. See Chapter 2, Question 2.30 for additional information.

5.27Q: Is a student with epilepsy protected by Section 504 if he or she faces disciplinary proceedings?

- A:** Yes, to the extent that it is illegal to discriminate against a student with a disability on the basis of his or her disability. Therefore, if the behavior that led to the disciplinary action is a manifestation of the student's epilepsy, he or she cannot be disciplined for it; to do so would be to punish him or her for behavior that is part of his or her disability. The school staff must look at the situation and the student to see if there is a relationship between the behavior and the disability. For example, if a student has a seizure in class and involuntarily yells out during the seizure, he or she cannot be suspended for disrupting the class; the yelling was part of the seizure. Or if a student has a seizure and is somewhat dazed or confused for a period of time following the seizure as he or she recovers, it would be a violation of Section 504 to discipline the student for failing to follow directions, for example, as the student is not fully able to process what is going on in this immediate post-seizure state. However, if a student with epilepsy who is stable on his or her medications and has not had a recent seizure gets into a fight and hits the assistant principal, the staff should look at whether anything has changed with the student to indicate that the behavior is a manifestation of the epilepsy and, if not, the student can be disciplined in the same way as a student without disabilities.

5.28Q: What steps can attorneys and advocates take to prepare for a Section 504 meeting?

- A:** An attorney or advocate can help the family prioritize their goals for the meeting. Does the family want a Section 504 plan for the student? The attorney or advocate can use the model Section 504 plan contained in this manual (see Appendix B) with the family to identify the areas in which services and accommodations will be requested. Then the attorney or advocate can identify the evidence that is necessary to support the family's position. What evidence supports the need for each of the services or accommodations the family is requesting? Are there medical evaluations? Teacher reports? Other information? Who will be at the meeting? Are there other people who *should* be invited? The attorney or advocate should make sure the district knows that the attorney or advocate will be in attendance; many, but not all, districts send their own attorney to meetings if parents bring a representative.

Case Scenarios

Case Scenario 1 — Eligibility for Section 504 Plan

William is a ten-year-old child who has fully controlled epilepsy and has not had a seizure in eight years. He has no academic difficulties and does not need medication during school hours. He has no overt side effects from his medication, has lots of friends and is able to participate fully in school activities. His parents contact a lawyer because a friend has told them about Section 504 and they want to know how the law may help William.

Discussion and Advocacy Strategy: As it stands, William will not qualify for protection under Section 504 because his epilepsy does not significantly impair a major life activity. He is able to participate in all activities without the need for any accommodations. However, it is possible that his situation will change at some point, and the attorney should explain Section 504 to William's parents and describe the types of situations in which Section 504 might be helpful in the future. The following information may be useful to William's parents:

- 1) If William begins to have breakthrough seizures and needs medication during the school day, school staff would be required to administer the medication.
- 2) If William begins to have seizures that interfere with his ability to concentrate or to complete his work in a timely way or if his medication begins to cause side effects that cause this result, he may need accommodations such as, but not limited to, additional time to complete his work, reduced amount of work, or a quiet room in which to take tests. It is likely that if, after a long period with no seizures, William suddenly begins to have seizures again, he will be spending a good deal of time at physician appointments and trying various dosages of medications. The school will need to be prepared to accommodate absences and the potential medication side effects that are likely to ensue.
- 3) If William begins to have seizures that are caused by lack of sufficient sleep, he may need an adjusted school start time as a reasonable accommodation, so that he does not have to be awakened early in the morning, since that might trigger a seizure.
- 4) It is important to remind William's parents that William's protection under Section 504 is conditional on something changing. At the moment, his epilepsy is so well controlled that he does not need the protection offered by Section 504 because his epilepsy does not impair him in any way that warrants the protection of the law. But that could change at any time and, at that point, Section 504 is available to protect him from discrimination and to ensure that he receives whatever reasonable accommodations he needs.

Case Scenario 2 — Application of School-Wide Policy to Student with Seizures

Abby is a seven-year-old child with epilepsy who attends Lincoln Park Elementary School. She sometimes falls asleep after seizures and may sleep anywhere from half an hour to three hours. Under the school district's policy, if a child is asleep for one hour for any reason, the parent will be asked to pick up the child and take him or her home. Lincoln Park has applied this policy to Abby and will not make an exception for her on the basis of her seizure disorder. Lincoln Park says that Abby must sleep in the nurse's office, but the nurse needs the space for other students. Abby's parents have asked that she be allowed to sleep elsewhere, but Lincoln Park has refused, saying that she must be monitored by the nurse, even though Abby is sleeping, and that the nurse has too many other things to do. Abby's parents point out that Abby has a one-to-one aide who can monitor her; Lincoln Park's first response is that the monitoring must be done by a nurse. Lincoln Park then says that even if the aide could monitor Abby, it does not matter, because she must be treated the same way as all other students who sleep for more than an hour, since that is the district policy. When Abby wakes up, she is alert and ready to learn. Often, however, she is at home instead of at school, because Lincoln Park has made her leave to "sleep off" the seizure, and it would take too long to drive her back to school. Abby's parents contact an attorney because they feel that lately, Abby has spent more time out of school than in school.

Discussion and Advocacy Strategy: This application of the policy clearly violates Section 504. When a school district applies a general policy in a rigid way without looking at the individual situation presented by a child with disabilities, the likelihood of a violation of Section 504 grows greater. The following advocacy strategy may be helpful to Abby's parents:

- 1) Obtain a copy of the school district's policy regarding the one-hour sleep rule and confirm that there are no exceptions for students with disabilities.
- 2) Contact the Section 504 coordinator for the school district to discuss the matter. Explain that when Abby falls asleep in school after a seizure, it is a direct result of her disability, and that by failing to accommodate her by making an exception to the district's policy, Lincoln Park and the district are violating Section 504.
- 3) If the Section 504 coordinator cannot resolve the matter, contact the attorney for the district and attempt to resolve the matter informally through a telephone call or meeting.
- 4) If necessary, file a complaint with the Office for Civil Rights for the region in which Abby's family lives.

- 5) Alternatively, consider filing a request for a due process hearing. Although due process hearings are not required under Section 504, school districts are required to have a hearing process in place if parents wish to use an administrative hearing process for resolution of disputes.

CHAPTER SIX

Special Education and Students with Epilepsy: Specific Issues

6.1Q: May school staff require that a student with epilepsy wear a helmet to keep him or her safe in case of a seizure?

A: No. School staff may not simply force a student with epilepsy to wear a helmet for safety reasons without going through the IEP process. If school staff believe a helmet is necessary, the IEP team can discuss the issue and propose to add the helmet to the student's IEP. There should be medical justification for the helmet, based on an individualized evaluation of the student. If the student's parents disagree with the use of the helmet, they can appeal. It is important to note that use of a helmet does not have to be an all-or-nothing endeavor, however. It may be that narrow and judicious use of a helmet in certain circumstances, such as outdoors for a student with unpredictable drop seizures, is appropriate, but indoors, use of the helmet is not necessary. If a helmet is used, the specific circumstances when it may be used should be clearly specified on the student's IEP. The helmet should be used only when necessary so that the student is able to participate in educational activities safely.⁴³

6.2Q: May school staff require that a student with epilepsy be strapped into his or her classroom chair for safety or any other reasons?

A: No. Strapping a student into a chair is a restraint, and parents should be wary of a request by school staff for permission to do so, even if it is couched in language about the student's safety. The regulations implementing the IDEA at 34 C.F.R. 300.320(a)(4) require IEPs to include a statement of the special education and related services, including supplementary aids and services "based on peer-reviewed research to the extent practicable," that will be provided to a student. Parents can ask for the peer-reviewed research that supports strapping a child with epilepsy into a chair for safety or other reasons; it is unlikely that school staff will be able to produce any research to support their position. Additionally, parents can seek to ensure that equipment such as special positioning chairs or other devices that may be used with their children be used only for the purpose intended by the manufacturer, and that use of such equipment and the purpose for which it will be used be specified in the IEP. If a parent is willing to agree to a restraint or to the use of a safety device, it should be included on the student's IEP.

⁴³ See, e.g., *South Vermillion Community School Corporation*, Indiana State Educational Agency, 1262.01 (October 2, 2002), 37 IDELR 270 (upholding helmet for child with epilepsy because it was part of an agreed upon IEP, even though parents sought to challenge its use.)

Many states have statutes, regulations, or policies governing the use of restraints and seclusion in schools. Attorneys and advocates should familiarize themselves with any available law. Additionally, many states prohibit the use of corporal punishment. Arguably, the use of restraint with a student, particularly a student with a disability, might constitute corporal punishment.

6.3Q: May school staff use a leash with a child with epilepsy on community outings for safety or for any other reason?⁴⁴

A: The IDEA does not prohibit the use of a leash, but it is a degrading practice, and it is difficult to imagine how it could possibly help keep a student with epilepsy safe. Presumably, staff believe that somehow they can prevent a student from falling to the ground during a seizure if the student is leashed, but unless staff can produce peer-reviewed research to support this assertion, parents should not agree to the use of a leash. School staff should consult with the student's parents and his or her physicians to determine the most appropriate and least intrusive means of ensuring the student's safety in the community.

6.4Q: Must a school administer antiepileptic medication to a student with epilepsy during the school day?

A: Yes, a school must administer antiepileptic medication to a student with epilepsy during the school day if he or she has a doctor's order and needs the medication during the school day in order to be able to attend school and benefit from his or her education. Medication administration is a "school health service," a related service under the IDEA. 34 C.F.R. 300.34(c)(13). School health services are provided by a "qualified school nurse or other qualified person" and are health services that are designed to enable a student with a disability to receive a free appropriate public education as described in his or her IEP. See Chapters 4 and 7 for a full discussion of these issues.

6.5Q: What are a school district's obligations regarding maintenance of the ketogenic diet for a student with epilepsy?

A: It is useful to analogize the diet to administration of medication: Schools are required to administer medication when a student needs physician-prescribed medication in order to attend and remain in school, but the school is not required to purchase or provide the medication. Similarly, schools must maintain the diet as ordered by the student's physician, but are not required to purchase or provide the student's food. A student on the ketogenic diet should have a physician's order explaining the diet and its requirements during school hours. The school district must maintain the diet during school hours by ensuring that a student eats food and liquids brought from home and does not eat or drink anything not permitted by the diet.

⁴⁴ As inconceivable as this situation may seem, it has arisen in at least one situation involving a student with drop seizures; therefore, the question is included in this chapter.

6.6Q: What are the obligations of a school district with respect to a student who has a vagus nerve stimulator (VNS)?

- A:** The definition of “related services” excludes a medical device that is “surgically implanted, the optimization of that device’s functioning (e.g., mapping), maintenance of that device, or the replacement of that device.” 34 C.F.R. 300.34 (b)(1). While this provision is primarily geared to cochlear implants, it is also applicable to VNS units, which are surgically implanted. What this provision means is that school districts are not responsible for the implantation of a VNS device, the programming or maintenance of the VNS, or the replacement of the VNS if it needs replacement.

However, the regulations also contain a provision that makes clear that a school district has the responsibility to monitor and maintain medical devices that are needed to “maintain the health and safety of the child, including breathing, nutrition, or operation of other bodily functions....” 34 C.F.R. 300.34(b)(2)(ii). The magnet swiping that may shorten or abort a seizure might be considered part of the monitoring function or it may be analogized to medication administration. However it is characterized, it is a service that must be performed by school district personnel.

6.7Q: Must a school district ensure that a person is available who can administer emergency medication to a student with epilepsy during the school day?

- A:** Yes. See Chapter 7 for information about this topic.

6.8Q: Must school staff call 911 whenever a student with epilepsy has a seizure?

- A:** No. The IDEA does not contain any provisions regarding 911 contact for students with any type of disability. Many state departments of education or local school systems have a policy requiring that 911 be contacted if a student has a seizure or if he or she receives emergency medication. However, these policies do not necessarily distinguish between students who have seizure disorders and have seizures frequently, and those who experience seizures only rarely. For a student with epilepsy, a policy of contacting 911 whenever he or she has a seizure makes little sense, and it can be disruptive and detrimental to the student for a variety of reasons. For instance, it frequently may result in unnecessary trips to the emergency room, which can be traumatic and can expose the student to illnesses suffered by other people in the emergency room. Emergency room visits can also result in missed time from school and significant expense to the parents for the cost of paramedics and transport. It is helpful to the student if his or her parents and the IEP team or Section 504 team are able to discuss this issue and work out a common-sense resolution that sets out the parameters under which 911 needs to be called, so that calls are made only when truly necessary.

6.9Q: Does a school have an obligation to inform the parent of a student with epilepsy if the student has a seizure at school?

A: No. The IDEA does not explicitly address this level of communication between school staff and parents. However, during the IEP or Section 504 process and in the development of a health plan for a student with epilepsy, parents should make sure to discuss communication between home and school regarding seizures and other issues regarding their child's education. The communication plan can be incorporated into the IEP or Section 504 plan, or it can be included in the health plan if the health plan is incorporated into the IEP or Section 504 plan.

6.10Q: How can effective communication between parents and school staff be established?

A: It is important to balance the need to share information between parents and school staff with the potential burden on parents and school staff of additional paperwork. Parents and teachers can work together to develop a home-to-school form and a school-to-home form or checklist that captures the information teachers should have about a student when he or she arrives at school in the morning and the information parents should have when the student arrives home each afternoon. Depending on the student's age and what disabilities he or she has in addition to epilepsy, the form might include a list of options regarding the student's demeanor during the day (e.g., alert, tired, happy, quiet); whether the student had any seizures and, if so, what type, how long they lasted, and what interventions, if any, occurred; what therapies or other related services the student received; what the parents can work on at home or what homework the student needs to complete; how and what the student ate; and any other information the parents and school feel is necessary. Most of the information can be provided by checking off or circling the appropriate item.

For a home-to-school form, it is helpful for parents to report to school staff any health concerns that arose after the end of the previous school day. This form could address issues about seizures, medication use and side effects, and it could provide contact information for the parents during school hours, as well as any other pertinent information. Particularly for parents of young children who will be dealing with the school system for many years, it is important to establish a good working relationship with school personnel at the outset. Communication is a key element of this relationship. Sample communication forms are included in Appendix D.

6.11Q: Must parents permit school staff to speak with their child's physicians?

A: No, parents do not have to allow school staff to speak with their child's physicians, but such communication can be helpful in ensuring that the student is served effectively and appropriately at school. Permitting such direct contact is part of the process of establishing a good working relationship between school and home, and it should work to the benefit of the student. If the relationship between parents and school staff is strained, however, parents may wish to be the intermediary between school and physicians and filter all contacts. This can be time consuming and somewhat difficult, and if possible, parents should consider permitting school staff to speak with their child's physicians, even if they specify the particular physicians, limit the topics, request that they be notified when contacts are made, or otherwise set boundaries for these contacts.⁴⁵

6.12Q: Should students with epilepsy have a health plan at school?

A: Yes. Students with epilepsy should have a health plan that addresses routine care and a health plan that addresses emergency care. The routine care plan should discuss:

- 1) the types of seizures the student has, along with their frequency and any needed interventions
- 2) the medication the student takes, including any medication to be administered at school with all details, including side effects
- 3) whether the student needs to comply with the ketogenic diet or other dietary requirements
- 4) whether he or she has a VNS, and the assistance needed with that device
- 5) the role of health care personnel and school staff
- 6) how communication on a daily basis about the student's status will occur

The emergency care plan should address what will happen if there is a non-routine event. Administration of emergency antiepileptic medication and who will administer it, possible contact with 911, and communication with the family are all issues that should be addressed in the emergency health plan. See Appendix C for a sample seizure action plan that can be incorporated into an IEP or a Section 504 plan.

⁴⁵ See *John A. v. Board of Education for Howard County*, 929 A.2d 136 (Md. Ct. App. 2007), in which Maryland's highest court found that a school district was justified in refusing to administer a student's medications, which were clearly an IEP-related service, in light of the parents' refusal to permit school district personnel to speak with the student's physician to obtain clarification regarding his orders. The school district was concerned about the dosages in light of the student's lethargy in school and wanted to speak with the physician prior to continuing to administer the medications as prescribed.

6.13Q: If a student with epilepsy has a health plan at school, does it replace the IEP or Section 504 plan?

A: No, the health plan does not replace the IEP or Section 504 plan, but the health plan should be attached to the IEP or Section 504 plan and become part of it.

6.14Q: Is a student with epilepsy entitled to participate in extracurricular or nonacademic activities?

A: Yes. A student with epilepsy has the same right that other students with disabilities do to participate in extracurricular and nonacademic services “to the maximum extent appropriate.” 34 C.F.R. 300.117. School districts must provide supplementary aids and services and programmatic modifications and supports to staff that will enable the student to participate in these activities with other students with and without disabilities. Section 504 also mandates an entitlement for participation in nonacademic and extracurricular activities for students with disabilities along with people without disabilities to the maximum extent appropriate. 34 C.F.R. 104.34(b).

6.15Q: What happens if the student with epilepsy needs extra supports or services in order to participate in extracurricular or nonacademic activities?

A: If a student with epilepsy needs extra supports or services in order to participate in extracurricular or nonacademic activities, the school district has an obligation to provide these supports and services. 34 C.F.R. 300.320. Such services or supports might include, for example, late transportation home, a one-to-one assistant, administration of medication after school, or attendance by health personnel with a student on a field trip. The activity and the supports necessary for the student’s participation should be reflected in the student’s IEP or Section 504 plan.

6.16Q: Can a school district charge parents extra money to cover the additional costs that may be associated with the extra supports or services provided to enable a student with epilepsy to participate in extracurricular or nonacademic activities, field trips or similar activities?

A: No. Charging parents extra money for supports and services would be a violation of the IDEA’s requirement that students be provided a free appropriate public education. It would also be a violation of Section 504’s mandate that students with disabilities have equal access to the programs and activities available to students without disabilities.

6.17Q: What happens if a student with epilepsy needs extra time to complete schoolwork or a test because of seizures or side effects from medication?

A: If needed, extra time must be provided to a student with epilepsy to complete schoolwork or a test because of seizures or side effects from medication. This is a reasonable modification under Section 504 that should be included on the student's Section 504 plan. Under the IDEA it is an accommodation that would need to be reflected on the student's IEP.

6.18Q: Must a school modify requirements for academic honors or other recognition programs to take a student's epilepsy into account?

A: Yes and no. A school is not required to modify fundamental requirements for academic honors for students with epilepsy or other disabilities, although certain requirements—such as those regarding attendance—may be modified or waived for students with epilepsy or other disabilities if disability-related absences make them unable to meet an attendance requirement. But the student would have to meet the other requirements of the program—such as academic achievement, citizenship, or whatever the program is recognizing—unless prevented from doing so by his or her disability. If a student with epilepsy receives modifications—such as extra time to complete work because of epilepsy-related issues such as medication side effects, and is still unable to meet the academic requirements of an honors program—the honors program does not have to lower its academic standards to include the student.

In *Hornstine v. Moorestown Board of Educ.*, 263 F. Supp.2d 887 (D. N.J. 2003), the court held that schools may not discriminate against people with disabilities in the application of criteria for honors or other recognition programs. The school district at issue attempted to change its valedictorian policy just prior to graduation to prevent a student with chronic fatigue syndrome from becoming valedictorian because of concerns about the fairness of her grades, since she had received much of her education in a home-based program. The court issued a restraining order preventing the district from changing its policy. It seems clear though, that at some point if too many modifications are sought, the person with a disability will not be considered "otherwise qualified" or the modifications will be considered a fundamental alteration of the program and will not be upheld.

6.19Q: Must a school modify its requirements to permit a student with epilepsy to participate on sports teams?

A: Yes, a school must modify its eligibility requirements to permit a student with epilepsy to participate on a sports team to the extent that such modifications do not fundamentally alter the sports program and to the extent that the student can participate safely. For example, attendance requirements may need to be modified to permit the student to participate and, depending on the student's

seizure status, his or her participation in practice sessions and games or meets might need to be adjusted. A school cannot simply deny a student with epilepsy the opportunity to participate on a sports team on the basis of his or her epilepsy. The IEP team or family and coach will need to conduct an individualized examination of the student's situation and the requirements of the team, and make a decision about the ability of the student to participate and at what level he or she can do so.

Case Scenarios

Case Scenario 1 — Restraint/Behavior Intervention/Safety Issues

Amalie is a seventeen-year-old nonverbal young woman with an intractable seizure disorder, mental retardation and aggressive behaviors due to a chromosomal disorder. She attends Edgeview Falls, a public separate special education school. She has drop seizures, absence seizures and tonic-clonic seizures. She also engages in avoidance behavior in which she will drop to the floor to avoid demands being made on her. She has a behavior plan that includes use of a seatbelt to keep her in her chair during instructional periods. The school's behavior specialist developed the plan based on a one-hour observation of Amalie and a cursory review of her records. He did not speak with Amalie's parents, her doctors or the school nurse; nor did he review her medications or their side effects. The behavior specialist tells Amalie's parents that the seatbelt is for safety reasons so that Amalie will not fall from her chair during a seizure. On community outings, the IEP team wants to use a leash with Amalie, as well as have her be supported by two staff. The alternative they present to Amalie's parents is to have Amalie travel by wheelchair. Amalie has sustained a number of injuries in the classroom, some requiring stitches, because she fell against sharp furniture corners during seizures. Her parents seek advocacy assistance.

Discussion and Possible Advocacy Strategy: The seatbelt plan proposed by the behavior specialist is nothing more than a restraint, and Amalie's parents are correct to be concerned. The behavior specialist has made no effort to try to distinguish between Amalie's avoidance behavior, which should be addressed through a behavior plan, and her seizures, which are a medical, not a behavioral, issue. Likewise, the behavior specialist has not tried to determine the effect Amalie's medications may have on her behavior or even what effect her seizures have on her behavior. Nor has the specialist explained why, if he thinks the seat belt is important for safety reasons, it would be used only during instructional periods. Neither has he offered any explanation for his position that it is safe to restrain Amalie with a seatbelt in a chair during a seizure. Further, the behavior specialist and the team appear not to have considered the use of positive behavior supports, strategies and interventions, as required by the IDEA. 34 C.F.R. 300.324(a)(2)(i). Nor does it appear that Amalie has had an assistive technology assessment to address her communication needs, which may also have an impact on her behavior.

Likewise, the team has proposed a restrictive and degrading method of managing Amalie on school outings; the choice the parents have been given between a leash and a wheelchair is unacceptable. At the same time, as overly concerned as the school staff appear to be about Amalie (or about their liability) in the community, they have taken few, if any, steps to make the classroom area safe. The following advocacy strategy may assist Amalie:

- 1) Ask the behavior specialist for the research that supports his recommendation of a seatbelt for Amalie. Similarly, ask for the research that supports the team's recommendation that a leash be used with Amalie in the community or, if not a leash, that a wheelchair be used to move a student with epilepsy who is able to walk on his or her own. The IDEA requires that IEPs include a statement of the special education and related services and the supplementary aids and services, "based on peer-reviewed research to the extent practicable," to be provided to the student. 34 C.F.R. 300. 320(a)(4). It is unlikely that the team will be able to produce any research to support its position. Advocate against these highly restrictive recommendations.
- 2) Advocate for a meaningful functional behavior assessment and behavior intervention plan based on positive behavior interventions. As a first step, advocate for the behavior specialist, the school nurse and Amalie's neurologist to discuss the relationship between her seizures, her medications and her behavior. It is critical to try to distinguish when Amalie is having a seizure from when she is dropping to the ground to avoid engaging in a task. A revised behavior intervention plan should be included as part of Amalie's IEP.
- 3) Advocate for an assistive technology assessment to address Amalie's communication needs. The assessor should also work with the behavior specialist, as Amalie's behavior may be related to her lack of ability to communicate her needs.
- 4) Amalie should also have a health care plan that explains the types of seizures she has, the medications she takes and the side effects they cause, and the impact all of this has on her education. This health care plan should be included as part of Amalie's IEP.
- 5) Advocate for additional training for staff so they are better able to distinguish Amalie's seizures from her avoidance behavior. This training should be included on Amalie's IEP as a programmatic support.
- 6) Discuss with the IEP team steps that can be taken to make the classroom safer for Amalie. For example, sharp furniture corners could be padded with foam. If the classroom is not carpeted, inexpensive rugs or carpet could be put down to help cushion falls. Any modifications agreed upon should be included in the IEP.

- 7) Discuss with the IEP team alternative steps that can be taken to ensure Amalie's safety in the community. How often does Amalie have seizures on community outings? Is she having seizures or is she engaging in avoidance behavior? How do staff react? If she is engaging in avoidance behavior, does she get reinforced by having two staff people rush to her and hover? Would sitting in a wheelchair and being pushed around give her even more reinforcement? Would it teach her dependence? If she is actually having seizures, what does her physician recommend? The precautions necessary inside a carpeted auditorium will be different from those necessary for an outdoor trip to a place with concrete sidewalks. Consider alternatives that maintain Amalie's dignity. If an outing will mostly occur outdoors and Amalie is subject to frequent drop seizures, perhaps a soft or hard helmet might be an appropriate means of resolving the impasse. If the outing will be primarily indoors, perhaps no helmet would be necessary, and staff could simply stand by to intervene as necessary.

See Chapter 8 for an alternate scenario with the same facts.

Case Scenario 2 — Communication Regarding Seizures at School

Benjamin is a six-year-old student with epilepsy who has several seizures a week. He receives a combination of special education and general education services at Stonewall Elementary School, his neighborhood school. Benjamin's neurologist is adjusting his medication dosage, and it is particularly important that his seizure frequency be logged accurately so that his parents can report to the neurologist on a regular basis. Stonewall staff have not been reporting daily, and Benjamin is unable to tell his parents if he has had a seizure at school. When his parents have contacted the principal, she responds that her teachers have too much paperwork and too many responsibilities, and she does not want to burden them further. Benjamin's parents wish to resolve this in as cooperative a manner as possible.

Discussion and Possible Advocacy Strategy: Communication issues often lie at the heart of disputes between families and school districts. A quick resolution of this matter would be in everyone's best interest, particularly Benjamin's, both medically and educationally. The following advocacy strategy might be useful:

- 1) Obtain a letter from Benjamin's neurologist explaining the need for accurate information from the school in getting a complete picture of what is happening with Benjamin over the course of each day.
- 2) Develop a checklist for Benjamin's teacher or other classroom staff to complete on a daily basis. The form could list the date and types of seizures Benjamin has, and include a space for the time the seizure began and ended. If additional information is needed, the form could include space for that as well. Summarizing seizure information on a checklist imposes very little burden on school staff, as opposed to requiring a narrative report. A standard seizure observation record form is included in Appendix C.

- 3) Request an IEP meeting to request use of the checklist and incorporate use of the checklist onto the IEP.
- 4) If the team is still resistant and refuses to agree to this basic communication tool, consider a complaint to the district's special education director or the state department of education's special education director.

Case Scenario 3 — Ketogenic Diet

Talia is a five-year-old kindergarten student with epilepsy attending Enchanted Garden Elementary School, her neighborhood public school. She is on the ketogenic diet. Talia's mother wants Enchanted Garden to provide all of Talia's food, to train all school staff about the ketogenic diet, and to eliminate snacks and all food aspects of all party celebrations in Talia's class since she cannot eat the foods served at these celebrations. Enchanted Garden has refused to provide Talia's food and to eliminate snacks and party food, but has agreed to train her teachers regarding the diet. Talia's parents and Enchanted Garden are at a standoff, and Talia's parents have sought legal representation.

Discussion and Possible Advocacy Strategy: Talia's parents need to understand that they are not likely to obtain everything they are seeking for Talia. Although there may be some room for compromise, the school's position is not unreasonable, and an attorney or advocate will have to work through these issues with Talia's parents in a way that helps them understand what Talia's rights are under the law. The following advocacy strategy may be useful:

- 1) Provision of ketogenic diet food should be viewed similarly to provision of other supplies that students need at school, such as diapers, gastrostomy tube equipment, oxygen and medications. Although school staff must change diapers, administer g-tube feedings and oxygen, and provide prescribed medication to students during school hours, it is not the school system's responsibility to obtain and provide these personal medical supplies or equipment. It is likely that if Talia's parents were to pursue due process or go to court seeking that the school system provide the food for the ketogenic diet, they would lose. Therefore, it is important to help Talia's parents understand the responsibility they have to provide Talia's food and the corresponding responsibility school staff have to give Talia the food provided by her parents and to ensure that the diet is maintained at school.
- 2) Training of all school staff regarding the ketogenic diet is an important element of Talia's education, and this should be incorporated into Talia's IEP. At a minimum, staff need to understand what the diet is, how it works, the rigorous requirements the diet imposes, and the consequences if there is any deviance from the diet.
- 3) There is, perhaps, some room for compromise on the issue of snacks and party food. Talia's parents are not likely to prevail on their request to eliminate all

snacks and party food from Talia's classroom; this is a fairly drastic modification to classroom routine for young children and, based on cases involving children with peanut and tree nut allergies, it is not a winning position. However, perhaps Talia's parents can consult with her neurologist about having some of her daily calories be in the form of a snack that she could have at the same time that her classmates have their snack, and perhaps her teacher can notify her parents ahead of time when there will be a celebration, so that arrangements can be made to permit Talia to eat something along with her classmates, even though it will not be the same food. If this is not possible, perhaps Talia's teacher can identify a special job or activity that Talia can perform during snack time or celebrations so that she does not feel quite as left out while other children are eating. At the same time, in addition to training school staff about the ketogenic diet, it may be helpful to train Talia's classmates as well. It is possible that out of loyalty and compassion to Talia, her classmates will choose to forego a snack or choose to celebrate birthdays in a different way, but the choice should be theirs, it cannot be imposed by Talia's parents.

Case Scenario 4 — Vagus Nerve Stimulator (VNS) and Attendance at School

Sam is a fifteen-year-old young man with epilepsy and other developmental disabilities who attends Hillside High School, a separate special education school. He recently had a VNS implanted and has been cleared by his neurologist to return to school. Although he has always had a variety of types of seizures at school, he has had several intense tonic-clonic seizures since he has returned, although none has lasted long enough to require emergency medication. However, the principal of the school has contacted Sam's mother and asked her to keep Sam home until his seizures are under control. Sam's mother seeks legal assistance to get Sam back into school.

Discussion and Possible Advocacy Strategy: As a school that exclusively serves students with developmental disabilities, Hillside should be accustomed to students with seizures and, in fact, Sam has a history of having seizures at school. It appears that the implantation of the VNS, along with the fact that Sam has had several seizures that are perhaps more intense than his usual seizures, have made school staff, or at least the principal, nervous. This situation needs to be addressed quickly before Sam misses many days of school. The following advocacy strategy may be helpful:

- 1) Contact the principal and offer training to school staff from the local Epilepsy Foundation affiliate (or another organization) regarding the VNS and its use. Explain to the principal that the VNS may take some time to program to the optimal level.
- 2) Obtain a letter from Sam's neurologist explaining the VNS and how it affects Sam. The letter should make clear that Sam can safely attend school, and should explain any responsibility the school needs to exercise with respect to the VNS, such as swiping a magnet over the implant if Sam has a seizure.

- 3) Inform the principal that excluding Sam from school without a valid reason is equivalent to a suspension and tell her that if her intent is to suspend Sam, she needs to provide the required written notice. Often, pressing the issue is enough to get a student back in school immediately.
- 4) If necessary, make a complaint to the special education director for the district, or an IDEA complaint to the state department of education.

See Chapter 8 for discussion of an alternate advocacy strategy regarding this same scenario.

CHAPTER SEVEN

Administration of Emergency Antiepileptic Medication in Schools

7.1Q: When should emergency antiepileptic medications be administered and which ones are appropriate?

- A:** Some children with epilepsy are susceptible to prolonged seizures; these seizures can cause serious brain injury and even death. An example of extremely serious seizure activity is status epilepticus. Status epilepticus is a period of prolonged seizure activity, occurring either when one seizure does not stop or when a series or cluster of seizures continues without the person returning to baseline. Current medical definitions consider 10 minutes as the amount of time after which uninterrupted seizure activity would be considered status epilepticus. The overall mortality rate of patients experiencing status is estimated to be 20 percent. Such seizures can also cause intellectual dysfunction, neurological deficits and chronic epilepsy. See Chapter 1 for additional information about status epilepticus.

The standard out-of-hospital medication for treatment of prolonged or cluster seizures is Diastat AcuDial. This is the trade name of a gel preparation of diazepam for rectal administration. Diazepam is in a class of drugs called benzodiazepines, which are central nervous system depressants (a common brand name of the oral form of this medication is Valium).⁴⁶ Caregivers are directed to administer diazepam—typically three to five minutes after a seizure begins—in order to abort the seizure and prevent status epilepticus.

Diazepam was specifically developed to be administered by people without medical training, such as parents, teachers and other caregivers. It is the only FDA-approved medication for treatment of cluster seizures by non-medically trained caregivers.

Following standard procedures, as prescribed by the treating physician, lay people can easily and safely administer diazepam when a prolonged seizure or cluster of seizures occurs, provided they are familiar with the manufacturer's instructions. The medication is contained in pre-packaged syringes that are

⁴⁶ As noted in Chapter 1, Ativan (lorazepam) and Versed (midazolam) are benzodiazepines that are often used to control seizures in emergency rooms and other hospital settings. Many doctors suggest using these medications for seizure clusters or to break a prolonged seizure prior to the development of status epilepticus *before* taking a patient to the hospital. These medications have undergone some testing in which the drug is placed or sprayed inside the cheek or under the tongue of a person who is seizing. However, since these medications have not completed the clinical trials required for FDA-approval for treatment of seizures, they are not widely available for this purpose, and their use has been limited to physicians who feel comfortable providing this option. References to “emergency medication” in this chapter are intended to include all appropriate medications, unless otherwise specified.

already prepared with the appropriate dose, with a rectal tip that is either pediatric or universal in size. The most common side effects are drowsiness, headache, dizziness, diarrhea, flushing, unsteady gait, agitation and confusion.

A caregiver needs to call 911 after the medication is administered only in the rare event that complications occur. Typically, the child's treating physician will provide a treatment plan to the school or child care provider which spells out the monitoring that may be required, as well as the particular circumstances under which it would be necessary to call 911, and instructions about when it is necessary to administer the medication. Sample plans for child care programs and schools are provided in Appendices A and C.

7.2Q: Are school districts required to provide staff to administer emergency antiepileptic medication to students with epilepsy?

- A:** Yes. If a student with epilepsy needs such medication in order to be able to attend school safely, he or she must have access to the medication, and the school district must identify at least one person who is able to administer it. The United States Supreme Court's decision in *Cedar Rapids Community Sch. Dist. v. Garret F.*, 526 U.S. 66 (1999), makes clear that if a health service is needed in order for a student to be able to attend school and participate in his or her educational program safely—and the service can be provided by a person other than a physician—then it is a “school health service” within the meaning of “related service” under the IDEA.⁴⁷ Administration of emergency antiepileptic medication clearly fits within this definition.

There are apparently no judicial decisions directly addressing administration of emergency antiepileptic medication, but there are at least two special education hearing decisions on point: *San Francisco Unified School District*, California State Educational Agency, SN01-02331 (March 1, 2002), 37 IDELR 144 (www3.scoe.net/speced/seho/seho_search/sehoSearchDetails.cfm?ID=1742) and *Silsbee Independent School Dist.*, 25 IDELR 1023 (Tx. SEA 1997).

In the San Francisco case, the school district had refused altogether to administer diazepam and would call 911 as its only response to a prolonged seizure of five minutes or more. The hearing officer thoroughly analyzed available research on the safety of diazepam, considered the school district's concerns about respiratory depression as a possible side effect and the school district's reservations about administering the medication, reviewed the parent's history of emergency room visits with the student and the adverse effect these

⁴⁷ The *Garret F.* decision reiterated and expanded the Supreme Court's earlier holding in *Irving Independent Sch. Dist. v. Tatro*, 468 U.S. 883 (1984). In *Garret F.*, the Court made clear that even if a student requires one-to-one nursing services, as Garret did, that service is an IDEA-required related service because it can be provided by someone other than a physician.

visits had on him, and carefully analyzed the IDEA and relevant cases regarding school health services.

Concluding that the evidence indicated that use of diazepam posed no unreasonable risk of respiratory complications for the student and that, in any event, possible complications could be effectively addressed by a trained professional aide, the hearing officer ordered the school district to implement the protocol for diazepam administration developed by the student's neurologist. The hearing officer ruled that implementation of the protocol by qualified district personnel was necessary to make public education meaningfully accessible to the student and to meet his unique needs and afford him educational benefit. Implementation of the protocol was, therefore, a related service.

Similarly, in the *Silsbee* case, the hearing officer held that calling 911 was not an appropriate response when treatment for a seizure disorder was needed, as there was no guarantee that an ambulance would arrive within any particular time frame, despite the fact that a hospital was nearby. The student in this case was a seven-year-old first grader who experienced convulsive seizures and drop apnea. The school had a seizure protocol, which involved having school personnel turning the student on his side, timing the seizure, contacting the school nurse, and administering diazepam if his seizure and apnea lasted for three minutes or more.

At the time the case was heard, administration of diazepam involved drawing the medication from a glass ampule by a needle and syringe and removing the needle before inserting the syringe. The student's neurologists recommended to the school district that diazepam be administered only by a registered nurse and not by a licensed vocational nurse, and that the registered nurse be on call and available at all times. This recommendation was made because of potential complications including the possibility of puncture with the needle or perforation of the bowel with the syringe (neither of which is possible with the current form of the medication). The school district requested the due process hearing in order to determine whether the IDEA's related services provision required that the student receive the services of a registered nurse, rather than a licensed vocational nurse, and whether training of teachers and staff in seizure response was a required related service.

The hearing officer ruled that the school must ensure that a registered nurse or other equally qualified person capable of administering the medication rectally in case of prolonged seizure is in close proximity to the student at all times during the school day. The presence of such a person on the school campus, the hearing officer concluded, is a supportive service necessary to assist the student in receiving a benefit from his special education.

7.3Q: Does the Epilepsy Foundation have a position about the administration of emergency antiepileptic medication?

A: Yes. The Epilepsy Foundation's position states, in part:

Federal and state laws guarantee every child/student the right to participate in a free, appropriate public education in the least restrictive setting. Schools, camps, and day care providers are also required to provide many health-related services, including administering medicine, if needed, to students with disabilities, as either a reasonable accommodation or a related service. The purpose of these laws is to ensure that children with chronic health conditions like epilepsy can be educated in the least restrictive environment and participate in recreational activities, camp and day care programs with their peers. Because medicines, including rectally administered diazepam, can be administered by non-medical personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason to refuse to administer the medication on-site or to deny a child or student access to the program. The Epilepsy Foundation wholly supports these principles as being in the best interest of the child.

The Epilepsy Foundation urges providers of child care and educational services to work with the child, his or her parents and the child's treating physician to learn how and when to administer the appropriate treatment. Schools and service providers should, along with the child's parents and, as appropriate, the treating physician, develop a plan for ensuring that adequate measures are taken to administer the treatment and that the appropriate staff is properly trained to do so.

7.4Q: Who is allowed to administer emergency antiepileptic medication to students in schools?

A: This depends on state law. State nurse practice acts and education codes govern the tasks that are reserved for licensed nurses and the tasks that may be delegated by nurses to unlicensed assistive personal (UAPs) such as health aides. Most states do in fact authorize school nurses to delegate the authority to administer certain medications to UAPs. Louisiana is an example of a state where nurses apparently freely delegate the authority to administer diazepam, and in that state a detailed clinical protocol on diazepam administration has been developed.

However, in a number of states, it is unclear whether the authority to delegate extends to the administration of diazepam or other emergency antiepileptic medications. The reason for this lack of clarity is that many state education codes or nurse practice acts prohibit delegation of nursing duties that require the exercise of "professional nursing knowledge or judgment or complex nursing

skills”—and most of these laws do not clarify whether this restriction applies to administration of diazepam or similar medications.

Even if state law permits the delegation of authority to administer emergency antiepileptic medication, an individual nurse may choose not to delegate; nurses make their own decisions about whether to delegate a task that the law permits them to delegate. If a nurse chooses not to delegate when delegation is permitted, the school district is obligated to provide a nurse to administer the medication.

However, many states' laws expressly permit UAPs to administer medications in the case of an emergency with or without delegation of that authority by a nurse. Arguably, such emergency exceptions would authorize UAPs to administer diazepam and other similar medications (with or without authorization by a nurse), but, again, there is a lack of clarity on this issue as well.

Currently, it appears that only Kentucky requires that schools ensure that UAPs are available to administer diazepam. Kentucky law mandates each school to have a staff member, who has consented to provide health services generally, available to administer the medication. Further, a handful of states, including Texas, expressly or implicitly permit school officials other than RNs (such as the principal) to authorize UAPs to administer diazepam or similar medications.

Appendix E contains a chart summarizing selected state laws pertaining to the administration of medication in school. The chart addresses the extent to which state law permits nurses to delegate to UAPs the authority to administer medication, and highlights laws specifically addressing emergency antiepileptic medication. A comprehensive chart summarizing all state laws on this subject is available at www.epilepsylegal.org.

7.5Q: What happens if the school district says that only a nurse can administer emergency antiepileptic medication but there is no nurse available to do so at the student's school or at a nearby school?

- A:** It is important to determine if the school district's position is based on the state's nurse practice act, its education code or its own rules. Sometimes, a state law may permit delegation but the nurse for the school or the district's health department does not wish to delegate. If the nurse practice act requires administration of the medication by a nurse, the district must obtain a nurse if there is no nurse at the student's school or a nearby school. Possible options for the school district include contracting with a private nursing agency, hiring a nurse or looking to the local health department.

7.6Q: What if the only person available to administer this medication is located at a separate special education school, but the student with epilepsy can be educated appropriately in a less restrictive setting?

A: Although courts have held that cost can be a consideration when addressing inclusion of students with disabilities into regular education, the Department of Education has made clear that students must be placed on the basis of their abilities, needs and individual IEPs, not solely on factors such as category of disability, severity of disability, availability of space or administrative convenience. *See* Comments to IDEA Regulations, Federal Register, Vol. 71, No. 156, August 14, 2006, p. 46588. Placement of a student with epilepsy into a separate special education school simply to have access to a licensed health care professional who is authorized under state law to administer emergency antiepileptic medication would constitute placement for administrative convenience or placement made because of the way the service delivery system is set up. It would be unlikely to withstand a challenge. However, if a district proposes moving a student to another school which has a person who can administer the medication, and also allows the student access to general education services with students without disabilities, such placement would likely be found acceptable by a court.⁴⁸

7.7Q: What if school staff insist on calling 911 whenever a student with epilepsy has a seizure?

A: It is important to determine if the school staff are relying on a district policy that applies to all students or on a policy that applies to students with epilepsy. If the policy is one that applies to all students, then it may be helpful to hold a meeting with district administrators and their legal counsel to discuss modifying the policy for students with epilepsy. There is a difference between a student who has a first-time seizure and a student who has chronic seizures because he or she has epilepsy. In the first case, it would be entirely reasonable to call 911; in the second, there would be no reason to call 911 unless the student experienced complications during or just after the seizure, e.g., if he or she stopped breathing, turned blue, went into status epilepticus or took longer than usual to come out of the seizure.

For students with epilepsy, seizures may be a way of life. Repeated 911 calls, with their resultant paramedics and emergency room visits, may cause anxiety

⁴⁸ *See, e.g., Barnett v. Fairfax County Public Schools*, 927 F.2d 146 (4th Cir. 1991) (Court denied home school placement to student who used cued speech interpreting, finding that whether a particular service or method can be feasibly provided in a specific special education setting is an administrative determination; it was acceptable for school district to centralize its cued speech interpreting program at a different regular school and to consider cost as a factor); *White v. Ascension Parish Sch. Bd.*, 343 F.3d 373 (5th Cir. 2003) (School boards have significant authority to determine school sites for the provision of IDEA services; proximity factor is a preference, not a presumption that the child attend his or her neighborhood school).

for the student and his or her family, friends and classmates; they may also result in treatment confusion or errors if emergency room staff do not have access to the student's medication regimen, illness if the student is exposed to sick people in the emergency room, and lost time from school. Additionally, 911 calls can turn a chronic, manageable, everyday part of life into an emergency, resulting in expensive and unnecessary intervention. If families do not want 911 to be contacted whenever their child has a seizure, they and their advocates should try to work with school district personnel to educate them and develop an individualized approach that makes sense for their child.

7.8Q: What if school staff administer emergency antiepileptic medication but insist on also calling 911 when the student has a seizure?

A: One reason emergency medications were developed was to avoid the need to take people to the emergency room because of lengthy seizures or clusters of seizures. Some school districts insist, however, on calling 911 whenever they administer emergency medications. As discussed in Answer 7.7, families and their advocates can try to work with school staff to change this policy if they do not want 911 to be called; otherwise, it will be necessary for a parent to come to school to release the emergency response staff so that they do not transport the student to the emergency room.⁴⁹

7.9Q: Are staff required to administer emergency antiepileptic medication to a student with epilepsy who experiences status epilepticus on the school bus?

A: Yes, school staff must administer emergency antiepileptic medication if the administration of the medication is part of the student's IEP and transportation is included in his or her IEP as a related service. This means that someone qualified to administer the medication needs to be on the bus with the student. In practical terms, it may be difficult to administer a medication such as diazepam on a school bus, since there is not a lot of space, the floor of the bus is dirty, there is no privacy, and the bus may not be able to pull over anywhere to stop moving. However, at least one school district has found an effective means of addressing this situation. See *Forest Area Community Schools*, 2005-115b, Michigan State Educational Agency (May 23, 2006). In this hearing decision, the parents sought an aide to travel with the student on the bus. The hearing officer found that an aide was unnecessary because the district had taken steps to ensure the student's safety and privacy. The bus route between home and school was short, and the district had a bus driver who was trained to administer the

⁴⁹ Although it has no precedential value, a Minnesota state department of education administrative complaint letter has addressed this issue in the case of a medically fragile child with epilepsy who gets sick easily and whose parent was concerned about the cost of repeated visits to the emergency room. The department found that although the district might want to include calls to 911 in the student's individualized health plan, failing to do so would not bar the district from calling 911 if it believed the situation were an emergency. *Anoka-Hennepin Independent School District #011*, Minnesota State Educational Agency, 1828 (March 17, 2003), 106 LRP 19152 (online only).

rectal injection the student would need in the event of a seizure. Additionally, the district's plan called for a privacy drape to be used to shield the student from the view of others while the medication was being administered.

In school districts that may not be so accommodating, it may be preferable to explore the possibility of shortening travel time as much as possible, including by using alternate forms of transportation such as paratransit or taxi. If necessary, however, the district must ensure that emergency antiepileptic medication is administered on the bus, as it is a necessary school health service that makes the related service of transportation safe for the student and enables him or her to get to and from school and participate in his or her education services.

7.10Q: Are school staff required to administer emergency antiepileptic medication to a student with epilepsy who experiences status epilepticus on a school field trip?

A: Yes. Students with disabilities have a right under both the IDEA and Section 504 to participate in nonacademic and extracurricular activities, in addition to academic activities, thus the school district is obligated to provide the related services and the accommodations necessary to ensure that students with disabilities are able to participate in these activities to the same extent as students without disabilities. For a student with epilepsy who needs access to emergency antiepileptic medication in order to be able to attend a school field trip, the school district must designate a person to attend the trip with the student who is able to administer the medication if needed.

7.11Q: Are school staff required to administer emergency antiepileptic medication to a student with epilepsy on a school field trip if the trip occurs on a weekend?

A: Yes. If the field trip is sponsored by the school district, the district must make staff available who can administer the medication to the student. The school district cannot argue that it does not have health care staff available to work on weekends or that it is too expensive to provide staff, nor can the district charge the student extra money for the cost of the staff. The district can contract with a private health services agency if necessary to obtain staff, or it can make arrangements with its own staff, but if the student wishes to attend the trip, the district must ensure that the student is able to do so with the necessary services in place. Although field trips are covered by Section 504, it may also be helpful to address known trips, e.g., an annual weekend class camping trip or an annual club trip, in a student's IEP. This will ensure that there is a clear understanding that the student will participate, planning will need to occur, and staff will need to be provided.

Case Scenarios

Case Scenario 1 — No Nurse at School/Delegation Not Permitted

Shanika is a thirteen-year-old student with epilepsy who needs emergency antiepileptic medication approximately once every two or three weeks at school. She attends a regular middle school where she receives a combination of regular and special education services because of learning disabilities and the impact of epilepsy on her educational progress. This combination of regular and special education services is working well for her and she is making good educational progress, as reflected by her grades and test scores. She lives in a rural area and it frequently takes up to fifteen or twenty minutes for an emergency vehicle to reach her school. Shanika lives in a state in which emergency rectal administration of medication may not be delegated by a licensed nurse to an unlicensed health aide. Shanika's school has had a nurse on staff who has been administering emergency medication to Shanika, but the nurse is nine months pregnant and is about to go out on extended leave. The district does not have a replacement nurse to assign to the school, as it is the middle of the year, and all staff are allocated for the remainder of the year. The district has offered Shanika's family two options: Shanika can transfer to a separate special education school eight miles away from the current school and twelve miles farther from her home, where there is a nurse on staff, or she can remain where she is, and the school will call 911 when she has a seizure. Shanika's parents do not believe either of these options meets her needs appropriately and they seek legal assistance.

Discussion and Possible Advocacy Strategy: It is unfortunate that the school district apparently did not plan for a replacement for the nurse at Shanika's school; it would have been clear early in the school year that the nurse would be available for only part of the year. That said, it is unequivocally the district's responsibility to ensure that Shanika's needs are met appropriately. A possible strategy to resolve this situation might include the following steps:

- 1) Convene an IEP meeting to discuss the district's proposed options and nursing services. Request that the school district's compliance officer or attorney attend the meeting.

- 2) At the meeting, present progress reports, report cards, tests and other documents that reflect the educational progress Shanika is making in her current placement. This supports an argument in favor of continued placement of Shanika at her current school; placement at a separate special education school would simply be too restrictive for her educational needs.

- 3) If necessary, distribute copies of the comments to the IDEA regulations (Federal Register, Vol. 71, No. 156, August 14, 2006, p. 46588). In this guidance, the Education Department makes clear that placement of a student cannot be based on the configuration of the service delivery system, administrative convenience or on other factors, such as the category or severity of the disability, the availability of special education and related services or the availability of space. To move Shanika to a separate special education

school because a nurse is located there would clearly be a decision based on administrative convenience, the configuration of the service delivery system or the availability of the related service she needs.

4) Educate the IEP team about why keeping Shanika at her current school without a nurse is also inappropriate. Waiting 15 or 20 minutes for paramedics to arrive is too long a delay; failing to administer the medication during that time may put her health at risk, and the point of providing the medication at school is to obviate the need for the paramedics to come in the first place. Obtain letters from Shanika's physicians, and obtain and share any information from the Epilepsy Foundation or its local affiliate about the medication that may be helpful.

5) Advocate for the school district to contract for a nurse for the remainder of the school year while it makes efforts to hire a nurse for the following school year if Shanika's nurse will not be returning to school. The district should contact the county health department, the state department of education, private nursing agencies and all local hospitals to find an appropriate replacement, if only for the rest of the school year. Other sources of possible assistance might be universities with nursing schools and community colleges with nursing assistant programs, since courses will likely be taught by registered nurses. Additionally, the district could advertise in all local and statewide newspapers and offer pay incentives.

6) If these efforts do not yield a nurse quickly, then the district should communicate with the state board of nursing to try to obtain a waiver of the delegation rule so that an unlicensed person can be trained to administer Shanika's medication. The goal is to ensure that Shanika does not miss school when her nurse leaves if the district has been unable to secure a replacement nurse.

7) If the district is unwilling to take these steps, Shanika's family should pursue a due process hearing request.

Case Scenario 2 — Weekend Field Trip

Marcus is an eleven-year-old student with epilepsy who has recently joined the school choir. Marcus is in general education classes, but has a Section 504 plan that includes accommodations such as extra time for tests and school assignments because of the side effects he experiences from his antiepileptic medications and the impact of his seizures on his cognitive abilities. The choir takes a weekend overnight trip every spring to perform at a local amusement park and then spends the next day at the park. Marcus needs emergency medication about once a month, and he lives in a state in which administration of emergency antiepileptic medication may be delegated by a nurse to an unlicensed health aide. Marcus's Section 504 plan includes emergency antiepileptic medication administration by a nurse or other qualified person. However, the school has always provided a nurse, as the nurse at Marcus's school has refused to delegate emergency antiepileptic medication administration because she is concerned about liability if the health aide at the school were to make an error. The school principal and

district special education director have told Marcus's mother that they will not provide a nurse or health aide to accompany Marcus on the trip because school district nurses do not work on weekends and it would be too expensive to contract with a private duty nurse to work on the weekend. They will not provide a health aide out of deference to the school nurse. They have told Marcus's mother that he may attend the trip only if she accompanies him so that she may administer Marcus's medication if he needs it. Marcus does not want his mother to go on the trip with him, nor does his mother think it is appropriate for the school to require her to attend as a condition of his attendance. She seeks legal assistance.

Discussion and Possible Legal Strategy: This is a school-sponsored trip. Section 504 requires the district to have a person attend the trip with Marcus and administer his emergency medication if necessary. Since Marcus's Section 504 plan permits the person to be a nurse or other qualified person, the district could choose to send an unlicensed health aide; the fact that he has a nurse rather than a health aide is only because the nurse refuses to delegate the task, not because he needs a nurse. The district has chosen to incur the added expense of a nurse and cannot rely on this decision as the basis of its refusal to assign a nurse to go on a weekend school-sponsored field trip with him. The following strategy may be helpful:

- 1) Contact the special education director directly. Explain how refusing to provide a nurse or health aide is a Section 504 violation.
- 2) If unsuccessful, contact the Section 504 coordinator for the school district.
- 3) If unsuccessful, contact the Section 504 coordinator for the state department of education.
- 4) If unsuccessful, depending on the timeframe, file a complaint with the Office for Civil Rights or file a complaint for a temporary restraining order in court.

Case Scenario 3 — 911 Call

Deena is a nine-year-old student with epilepsy and multiple developmental disabilities. She attends Harmony Heights Center, a separate school for students with disabilities. Harmony Heights has two nurses on staff, and many of the students at the school have epilepsy and experience seizures at school. Deena's IEP contains a number of health services, including gastrostomy tube feeds, suctioning, positioning changes, medication administration, and administration of emergency antiepileptic medication for prolonged seizures or clusters of seizures. Deena tends to have seizures every day and requires this medication about once a week. Harmony Heights insists on calling 911 every time the medication is administered, saying that this is school district policy. In order to avoid unnecessary trips to the emergency room, Deena's mother, who is a single parent, must immediately rush to the school to meet the paramedics and sign paperwork refusing transport of Deena from school to the emergency room. Past visits to the emergency room have been traumatic for Deena, as she does not respond well to loud sounds and

people she doesn't recognize, and she has been administered medications other than those she usually takes, which have left her sedated. Deena's mother has been unable to negotiate an exception to the school district policy, and she seeks legal assistance. The issue is particularly pressing, as she is facing the loss of her job because she has missed so much work as a result of her many trips to the school. Her supervisor has told her that if she leaves work one more time, she will be fired. Deena's mother seeks legal assistance; she is desperate and cannot even take time off from work for meetings with school personnel or her legal representative without risking her job.

Discussion and Possible Advocacy Strategy: This is clearly an urgent case; even if Deena were to be transported to the emergency room, her mother would have to leave work to go to the hospital and would likely lose her job, so the issue has to be resolved in a way that allows Deena to receive the medication and remain at school without 911 being called and without emergency room transport. The following strategy might prove helpful in approaching Deena's case:

1) Confirm that the medication/911 policy is a district policy, rather than a school policy. Obtain a copy in writing and review it carefully. If it is not in writing, it will be easily challengeable. If it is in writing, when was it written? What is the basis for calling 911? Does it explicitly address students with chronic seizures? Does it permit any exceptions?

2) Contact the school district's special education director, health services supervisor, and attorney and set up a meeting as soon as possible. Before the meeting, share a summary of Deena's case as well as information about the safety of the medication.

3) At the meeting, offer additional training for the staff at Harmony Heights, which, as a separate special education school serving children with multiple developmental disabilities, should already be well trained in seizure management. Reiterate the information concerning the safety of the medication. Make clear how harmful emergency room visits are for Deena. Discuss the impact on Deena's mother of her frequent visits to the school to decline transport to the emergency room for Deena. If the district staff are still not convinced, make it clear that applying this policy on a blanket basis is counter to the individualized consideration required by the IDEA and Section 504, and that, as such, it will be challenged.

4) If necessary, contact the state department of education and seek assistance in trying to resolve this matter.

5) Depending on the jurisdiction, it may be necessary to exhaust administrative remedies before going to court; therefore, you might need to file a due process hearing request before you can turn to court for recourse.

CHAPTER EIGHT

Dispute Resolution and Legal Remedies

8.1Q: What is a parent's recourse if he or she disagrees with a recommendation made by an IEP team or with some other aspect of his or her child's special education program or services?

A: The IDEA includes several methods of dispute resolution including IDEA complaints to the state department of education, mediation, due process hearings and appeals to federal or state court. In addition, families may attempt to resolve disputes in a more informal way with local school district administrators.

8.2Q: In what types of situations might a parent try to resolve a situation informally, and what steps would he or she take to do so?

A: Sometimes a situation arises in which a student's safety is at stake, in which the IEP team is being extremely recalcitrant in the face of factual evidence, or the student's parents and the IEP team are at an impasse because the team is misinterpreting a school district policy. In these situations, it can be helpful for parents or their attorney or advocate to call or write to the compliance representative for the district, an area supervisor, or the special education director, depending on the situation, and ask for intervention to try to resolve the matter. Particularly if an attorney or advocate has a working relationship with the district's administrators, many such issues can be resolved informally, either at the IEP meeting level or by working directly with administrators.

For example, if a student with epilepsy needs routine administration of medication every day, and the IEP team refuses to include medication administration on the IEP because the team says it cannot guarantee that there will always be a staff person available to administer the medication to the student, the parents could immediately challenge this refusal by seeking a due process hearing. However, this is such an obvious violation of the IDEA that a quick telephone call to the compliance officer or the special education director for the district might resolve the situation much more quickly, inexpensively and effortlessly. On the other hand, if the dispute centers around the types of accommodations the student needs for academic school work and whether the student needs extra time for tests because of the side effects from seizure medications, this is a more substantive dispute that turns on factual evidence, and if the family and district cannot come to an agreement, the parents may wish to seek mediation or a due process hearing.

8.3Q: What is an IDEA complaint?

- A:** An IDEA complaint is an administrative complaint filed with the state department of education. A complaint can address any alleged violation of the IDEA for an individual student or a group of students. The state department of education must investigate the complaint and, in accord with its general supervisory responsibility under the IDEA, order corrective action as appropriate. Corrective actions might include compensatory services or monetary reimbursement; the state department of education might also provide technical assistance or attempt to negotiate a resolution between the parent and the local school district. 34 C.F.R. 300.151 and 152. The state department of education must have a process in place to give the school district an opportunity to respond to the complaint. The school district might choose to resolve the complaint or engage in mediation. If the state department of education determines that an investigation is necessary, the department must carry out an independent investigation; this investigation can be on-site.

The state department of education must review all information and make an independent determination as to whether the school district is violating the IDEA, then issue a written decision to the complainant that addresses each allegation and contains findings of fact and conclusions, as well as the reasons for the state department of education's decision. The state department of education has 60 days to complete its investigation unless it determines that exceptional circumstances warrant an extension. 34 C.F.R. 300.152.

It is important that the written complaint contain as much information as possible to support the allegation. If a conversation would be helpful, parents or their representatives may want to request that the state department of education interview them; however, this is not necessarily a routine part of the investigation process.

8.4Q: For what types of issues would it be appropriate to file an IDEA complaint?

- A:** Although an IDEA complaint can be filed for any type of violation of the IDEA, such complaints are most effective for procedural violations such as the failure to provide a service that is required by a student's IEP. Disputes about the appropriateness of a service or the amount of a service received by a student do not readily lend themselves to resolution through the complaint process because they depend on information that has been analyzed by the IEP team, and the state department of education will generally refuse to second-guess a decision made by an IEP team. However, for a student with epilepsy, if an IEP team refuses to take an action when there is a clear requirement to do so, such as including administration of routine medication on an IEP or designating a person to administer emergency antiepileptic medication, the IDEA complaint process might be a quick and effective way of addressing the issue, rather than proceeding to due process. In these examples, the law is quite clear — students

are entitled to the health services they need in order to attend school and benefit from the educational services provided to them.

8.5Q: How can a parent make a complaint?

A: The complaint must be in writing and must be copied to the school district serving the student at the same time that it is filed with the state department of education. The complaint cannot allege a violation that occurred more than one year before the date the complaint is received. Either a parent or an organization can file a complaint. 34 C.F.R. 300.153.

8.6Q: Does the complaint require any information in particular?

A: Yes. The complaint must contain a statement that the school district (or other public agency) has violated the IDEA. The complaint must contain the facts upon which the statement is based, and the signature and contact information for the person making the complaint. If the complaint is made on behalf of a specific student, it must contain the name and address of residence of the student, the name of the school the student is attending, a description of the student's problem—including the facts relating to the problem—and a proposed resolution of the problem, as far as the problem is understood and on the basis of all information known to the person making the complaint at the time the complaint is made. 34 C.F.R. 153(b).

8.7Q: What are the benefits and drawbacks of the complaint process?

A: The complaint process is relatively quick, easy for parents to use, and much less formal than a due process hearing, which can be very stressful and costly. Additionally, unlike due process hearings, which can be filed only on behalf of an individual student, an IDEA complaint can be filed on behalf of one or multiple students and might address a student-specific issue or a systemic issue. However, the strength of the complaint process depends on the quality of the investigations conducted by the state department of education, the extent to which the state department of education complies with the mandated timelines, the willingness of the department to order corrective actions, and the willingness and ability of the department to enforce its decisions if required corrective actions are not taken by the school district.

8.8Q: What is mediation?

A: Mediation is a form of dispute resolution in which a qualified, trained, impartial person assists the parties in attempting to resolve their dispute. The IDEA encourages the use of mediation as an alternative to due process, and parties may request mediation at any time. Mediation cannot be used to deny or delay a due process hearing. Mediation is voluntary. If one party wishes to mediate but the other does not, mediation cannot go forward. Mediation discussions are

confidential; any agreement reached at mediation must be in writing and can be enforced in court. 34 C.F. R. 300.506.

8.9Q: When would mediation be appropriate?

A: As noted above, mediation can be requested at any time, and is often requested at the same time as, or instead of, a due process hearing. However, there are some issues that lend themselves to mediation more than others. For example, an issue for which there is a clear compromise position is one for which mediation may be particularly successful. On the other hand, an issue that turns on a purely legal interpretation may not successfully resolve at mediation because the parties may not have an incentive to compromise or to shift their position on the issue. If, for instance, a student with epilepsy needs administration of emergency antiepileptic medication and the school refuses to designate a trained person to administer the medication and relies on calling 911 instead, the issue of whether the school must administer the medication is not one the parents will be willing to compromise about. In contrast, disputed secondary issues related to medication administration may very well lend themselves to negotiation with a trained mediator. Such issues might relate to who administers medication, where in the school the medication is administered, whether 911 is called every time the student has a prolonged seizure, how the seizures are documented and how the parents are notified of seizures. Sometimes, compliance representatives or school district counsel might need the incentive of a mediation request or a due process hearing because resolution of the matter requires a commitment of resources that cannot be obtained through the IEP process alone.

8.10Q: How would a parent request mediation?

A: States may have different procedures but, generally, a parent would request mediation by making a written request to the school district and to the office that conducts mediation sessions, which may be the same office that conducts due process hearings. This may be the state department of education or a separate office of administrative hearings or office of administrative law. A parent can request mediation at the same time he or she requests a due process hearing or he or she can request mediation by itself.

8.11Q: What happens at mediation?

A: Generally, the mediator will begin with introductions and an explanation of the ground rules. The mediator will probably explain that mediation is confidential and may ask the parties to sign a confidentiality document in which they agree that whatever is discussed during the mediation session will remain confidential. The mediator will hear from each party regarding its position and will attempt to help the parties negotiate an agreement. The mediator might meet with the parties together, then meet with each party separately, then bring the parties together again. If the parties come to an agreement, the agreement will be

written up and each party will get a copy. If there is no agreement, the parties will leave and, if a due process hearing is pending, the parties will then move forward with the hearing.

8.12Q: What are the benefits and drawbacks of mediation?

A: If mediation has been requested at the same time as a due process hearing, the mediation session is held while the hearing timeline is pending, so mediation does not cause any delays. If mediation is scheduled outside of the hearing timeline, it will take longer to get to a due process hearing if that is the ultimate dispute resolution action needed. Mediation can be a quicker and easier way of resolving a dispute than a due process hearing and, because mediation agreements are enforceable in court, mediation may well be worth a try, especially if the family lives in a state in which families lose due process hearings at a high rate. Even if the issue does not seem to lend itself to compromise, mediation may be worth trying, since different school system personnel may attend mediation than have been present at IEP meetings, and the change in people—along with the presence of the mediator—may change the dynamics enough to allow the issue to be resolved. However, because mediation is voluntary, it is possible that parents might wish to engage in mediation but the school system does not; in that instance, mediation will not be possible. It is also possible that despite the IDEA’s requirement that the mediator be qualified and trained, he or she will not be skilled at working with the parties, and that the opportunity to negotiate a resolution will be lost.

8.13Q: What is a due process hearing?

A: A due process hearing is an administrative remedy under the IDEA. During a due process hearing, the parents and the school district each present evidence to an impartial hearing officer or administrative law judge, who then issues a written decision with findings of fact and conclusions of law. A due process hearing is like a trial, with each party presenting direct evidence and having an opportunity to cross-examine the witnesses of the other party. The hearing officer, who is in the role of the judge, must have knowledge of—and the ability to understand—the provisions of the IDEA, federal and state regulations that implement the IDEA, and federal and state court decisions that interpret the IDEA. Additionally, the hearing officer must know how and be able to conduct hearings and render and write decisions in accordance with appropriate and standard legal practice. 34 C.F.R. 300.511.

A party can only raise issues at the hearing that were raised in the hearing request unless the other party agrees otherwise. 34 C.F.R. 300.511. If a hearing officer addresses the issue of whether a student received a free appropriate public education, the decision must be based on substantive, rather than procedural, grounds. However, procedural violations could result in a substantive denial of a free appropriate public education if the procedural

violations themselves impeded the student's right to a free appropriate public education, significantly impeded the parent's opportunity to participate in the decision-making process regarding the provision of a free appropriate public education to the student, or caused the student to be deprived of educational benefit. 34 C.F.R. 513. A student can raise the procedural violations at a due process hearing, but under the IDEA, the procedural violations will not be meaningful in the hearing officer's determination of whether or not the student received a free appropriate public education unless the procedural violations were significant enough to meet one of the three criteria listed above.

8:14Q: When would a due process hearing request be appropriate?

A: A due process hearing request would be appropriate when a student's parents and the school district have been unable to reach an agreement about some aspect of the student's special education program or the identification or evaluation of the student. Because of the IDEA's emphasis on voluntary dispute resolution and the availability of other less burdensome resolution options, including mediation, a due process hearing generally should occur only after other efforts to resolve the issue have failed.

8.15Q: How would a parent request a due process hearing?

A: Either a parent or a school district may file a request for a due process hearing. There is a two-year statute of limitations, meaning that the hearing request must allege an IDEA violation that occurred not more than two years before the date the parent or public agency knew or should have known about the alleged action that forms the basis of the due process complaint. If the state has a different statute of limitations, that timeline would apply. 34 C.F.R. 300.507.

The party filing for a due process hearing must send a copy of the request to the state education agency. If a parent files a due process complaint, the school district must file a response unless the district has already met the requirements of prior written notice with respect to the issues. 34 C.F.R. 300.508(e). Prior written notice is the notice that a school district must provide to parents when the district proposes or refuses to initiate or change the identification, evaluation, or educational placement of the student or the provision of a free appropriate public education to him or her. 34 C.F.R. 300.503. If the district files the hearing request, the parent must file an answer. 34 C.F.R. 300.508(f).

8.16Q: Does the due process hearing request have to include specific information?

A: Yes. The due process hearing request must include the student's name, his or her address of residence, the name of the school the student is attending, a description of the nature of the problem relating to the proposed initiation or

change in services, and a proposed resolution of the problem to the extent known and available to the party at the time. 34 C.F.R. 300.508.

8.17Q: Do parents have rights in the due process hearing process?

A: Yes. Parents and school districts have the right to bring an attorney to the hearing and to bring other individuals “with special knowledge or training with respect to the problems of children with disabilities.” 34 C.F.R. 300.512(a). Parties also have the right to present evidence; confront, cross-examine, and compel the attendance of witnesses; prohibit the introduction of evidence not disclosed to the party at least five business days before the hearing; and obtain a record of the hearing. Additionally, parents have the right to have their child present at the hearing and to open the hearing to the public if they wish to. Parents also have the right to have a record of the hearing and the findings of fact and decisions made available to them at no cost. 34 C.F.R. 300.512.

8.18Q: Are there any prerequisites to a due process hearing?

A: Yes. If the parties have not gone to mediation and have not waived a resolution meeting, there will be a resolution meeting before the due process hearing timeline begins to run. This is an opportunity for the parties to attempt to resolve their issues. Within fifteen days of receiving the hearing request, the school district will convene a meeting with the parent and relevant members of the IEP team who have knowledge of the facts identified in the due process hearing request; the meeting participants must include school district personnel who have decision-making authority. The school district attorney may not attend the meeting unless the parents bring an attorney. At the meeting, the parents can discuss their complaint and the school district has an opportunity to try to resolve the issue. If the parties reach an agreement, it will be put in writing. Either party may void the agreement within three days. Otherwise, it will become an enforceable agreement. If the parties do not reach an agreement, they will move forward with scheduling the due process hearing. 34 C.F.R. 300.510.

8.19Q: What happens at a due process hearing?

A: A due process hearing generally begins with opening statements. Each party makes a general statement about what the case is about and what the evidence will show. If the parent has requested the hearing, the parent then presents his or her witnesses. Parents and the school district will need to trade names of witnesses and copies of documents at least five business days before the hearing; if either party fails to do so, the other party will be able to bar the witnesses from testifying or keep the documents from being entered into evidence. After each witness testifies in direct testimony, the school district has the opportunity to cross-examine the witness, and the hearing officer may ask the witness questions as well. The school district then presents its witnesses, and the parent has an opportunity to cross-examine the witnesses, with the hearing officer asking questions as well. The parties then offer closing arguments. Most hearings are closed, meaning that they are confidential proceedings to which the public is not

allowed to attend. If parents choose to pen the proceedings, they may do so. If parents prevail in a due process case or in court, they may be entitled to attorney's fees. 34 C.F.R. 300.517. There are certain circumstances under which parents or their attorneys may be liable for the school district's attorney's fees, such as if the parents bring a case for an improper purpose. 34 C.F.R. 300.517.

8.20Q: May a party appeal a due process hearing decision?

A: Yes. Either parents or the school district may appeal a due process hearing decision to court. Decisions can be appealed to state or federal court. The IDEA sets a 90-day timeline for appeal unless states set a different appeal timeline.

8.21Q: What are the benefits and drawbacks of the due process hearing system?

A: For parents who wish to have their day in court, a due process hearing offers an administrative trial in front of an impartial decision maker. Due process hearings have become relatively formal proceedings, and parents generally must go through the administrative process in order to proceed to court. In very rare circumstances, parents can go to court without exhausting administrative remedies, but generally only if exhausting administrative remedies would be futile. The benefit of a hearing is that parents can let an impartial decision maker hear evidence and make a decision, instead of continuing to work with a school district they find difficult. This is also a drawback, however, especially for parents of young children. Due process hearings by their nature are adversarial. Children may be in the special education system for many years, and it is helpful if parents can forge working relationships with school district staff. A due process hearing will resolve a dispute, but it is generally not the best way to do so. It is helpful for parents and advocates to look to the alternative methods of dispute resolution discussed earlier in this chapter in an effort to resolve issues in the least adversarial way possible, and to save due process for the rare instances when it is truly impossible to resolve an issue any other way.

8.22Q: What can a parent do if he or she believes that the school has discriminated against his or her child?

A: One option is for a parent to file a complaint. If the parent believes that the school district has violated Section 504, he or she can file a complaint with the U.S. Education Department's Office for Civil Rights (OCR) or, in some states, as discussed below, may file a request for a hearing. There is a 180-day timeline for filing complaints; OCR will not investigate an alleged act of discrimination raised in a complaint that took place more than 180 days previously, unless the complaint meets one of the limited reasons for a waiver of the rule. Prior to

filing a complaint, the parent may wish to contact the Section 504 coordinator for the district in an effort to try to resolve the matter informally.

8.23Q: What information should be included in a Section 504 complaint to OCR?

A: An OCR complaint should include the name and contact information for the person filing the complaint, the name and contact information for the lawyer or advocate for the person filing the complaint, the name of the person and organization who engaged in the discrimination, a description of the discrimination with supporting facts, copies of any information or documents that support the claim, and the date(s) the discrimination took place. The complaint should also include a description of the remedy being requested.

8.24Q: What does OCR do after a complaint is filed?

A: OCR will investigate the complaint by getting additional information from both parties. If it appears that the school district may have violated Section 504, OCR will try to work with the school district to get the district to resolve the complaint voluntarily with a resolution agreement. Many times, OCR issues a decision finding that discrimination has or has not occurred. On rare occasions, OCR may initiate proceedings to cut off federal funding. Sometimes, OCR does not pursue a complaint because the person who filed the complaint does not cooperate in the investigation or because the complaint is more appropriately filed with another agency, such as the Office for Special Education Programs, since it concerns the IDEA, for instance, rather than Section 504.

8.25Q: Can a parent ask for a hearing under Section 504 instead of filing a complaint with OCR, and is a hearing under Section 504 similar to a due process hearing under the IDEA?

A: Yes. Because OCR has no timelines for its complaint investigation, some parents might wish to resolve their dispute by proceeding to a hearing. Some states have the same hearing system with the same hearing officers; others do not. The hearing itself is substantively similar; however, it is important to note that Section 504 does not have the same exhaustion requirement that the IDEA does; it is not necessary to go through an administrative hearing under Section 504 before going to court. If, however, the issue under Section 504 is one that could be addressed under the IDEA, the administrative process must be exhausted. For example, if a student with a seizure disorder receives services under the IDEA, his or her parents may not go to court under Section 504 to challenge the school district's failure to provide medication and other services. To do so would be viewed as an effort to avoid the administrative process. Rather, they would have to go through an administrative hearing, then proceed to court if necessary. On the other hand, if a student with a seizure disorder does not receive any special education, parents should be able to proceed directly to court under Section 504 if they wish to bypass the administrative hearing process. Some courts, however, have taken a very expansive view of exhaustion requirements, and attorneys should review the relevant law in their circuit before

proceeding. See the Selected Cases section at the end of this chapter for additional information.

8.26Q: Does a parent need a lawyer to file a complaint or to go to mediation or a due process hearing?

A: No. A parent does not need an attorney to file a complaint, go to mediation or go to a due process hearing. However, many parents feel more comfortable being represented by counsel at due process hearings because they are complex, school districts are usually represented by counsel, and because parents may, in certain circumstances, be liable for the attorney's fees of the district. Especially in a state in which there is only one level of due process hearing before an appeal to court, parents may be particularly concerned about ensuring that they present the strongest case possible at the due process hearing and may not feel that they can do so without representation.

8.27Q: What can a parent do if he or she wants a lawyer but cannot afford one?

A: The school district must inform a parent about any free or low-cost legal or other relevant services that are available in the area if the parent requests the information or if the parent or the school district requests a due process hearing. 34 C.F.R. 300.507(b). The parent may also contact the Epilepsy Foundation for a referral to an attorney that may be able to provide some level of free legal services. For more information, see the introduction to this manual.

8.28Q: Can a parent sue a school district based on a claim of personal injury seeking monetary damages for its failure to provide required medication or care to a student with epilepsy?

A: Yes. A school district or its employees may have tort liability under state law if there is a failure to take steps to prevent avoidable harm, or if the school district has a policy that prohibits a student from carrying medication when that medication is necessary for the student's medical care—but the district is not required to provide all care that could conceivably be required.⁵⁰ See, e.g. *Taylor v. Altoona Area School District*, 05-350J (W.D. Pa. 2007), 48 IDELR 185 (court upheld the parent's claim against her child's teacher, who had refused to allow the student, who had asthma, to call his parent, or to seek help in the nurse's or principal's office during an asthma attack; the student died); *Gonzalez v.*

Hanford Elementary School District, 2002 Cal. App. Unpub. LEXIS 1341 (2002) (school policy required student medication to be stored in a place that

⁵⁰ State tort remedies may be available when school officials had a duty to act and breached that duty, provided that school officials do not have immunity from tort suits and other requirements for bringing a claim are met. Tort law varies from state to state, especially with respect to whether a public or private school or its employees are immune from liability. Negligence claims may be asserted when schools fail to provide care and treatment for students. Unlike anti-discrimination law, tort claims are only available after a student has suffered actual harm, such as physical injury.

was inaccessible to students; student's nebulizer was kept in the school office and the student required staff assistance when he needed to use it. The student had an asthma attack but collapsed before effective help could be provided, and died later that afternoon; application of the school's policy was found negligent); *see also, Salte v. YMCA of Metropolitan Chicago Foundation*, 814 N.E.2d 610 (Ill. Ct. App. 2004) (YMCA not required to have a defibrillator on premises).

Such a situation might easily arise for a student with epilepsy. For example, one possibility is a situation in which a school district deliberately fails to administer emergency antiepileptic medication when it knows circumstances warrant administration of the medication; another relates to the situation in which the district fails to take steps to develop an effective health plan for a student who has frequent seizures at school. In that situation, if the student has a seizure at school and suffers adverse consequences, the district may face tort liability and be obligated to pay monetary damages because it did not take steps to prevent avoidable harm. On the other hand, if the district has a health plan in place that is based on the recommendations of the student's physician and the parents, the student has received medication in accordance with the physician orders on file with the school, and the school staff has acted responsibly and professionally, the district likely will not face liability if something adverse happens to the student during a seizure.

Case Scenarios

Case Scenario 1 — Emergency Antiepileptic Medication Administration and Placement in the Least Restrictive Environment

Lizzie is a four-year-old student with epilepsy, cerebral palsy and mild mental retardation who has been fully included in a private preschool program. She has made friends in this program and has made significant gains educationally, as well. At the IEP team meeting to determine a kindergarten placement for her, Lizzie's parents seek placement in their neighborhood school with the assistance of a licensed practical nurse (LPN) who can administer emergency antiepileptic medication as necessary, and provide other supports and services. The team recommends placement in the district's separate special education school because there is a nurse assigned full time to the school who would be able to administer Lizzie's emergency medication if necessary. Lizzie's parents are strongly opposed to this recommendation and seek assistance in obtaining their neighborhood school placement, although they are willing to have their daughter placed at another elementary school nearby, even though it is not their zoned school. Their zoned school has a health aide assigned five days per week; the other elementary school has a school nurse on-site five days per week.

Discussion and Possible Advocacy Strategy: Lizzie's parents and their advocate have met with the IEP team several times in an effort to resolve this matter and have followed the advocacy strategy set out in Chapter 4 of this manual. However, the IEP team has continued to refuse to consider any alternatives to the separate special education school. Reluctantly, Lizzie's parents decide that they must pursue formal dispute resolution. The following advocacy strategy may be helpful:

- 1) If Lizzie's parents have been working with an advocate, they and their advocate may wish to consult with an attorney regarding the best way to proceed. If the decision is to proceed to mediation, Lizzie's parents and their advocate may wish to do that on their own. If, however, the decision is to proceed to due process, Lizzie's parents may wish to be represented by counsel, as the hearing process is complex and school districts are generally represented by attorneys.
- 2) Lizzie's representative (advocate or attorney) may wish to file a request for mediation and a due process hearing. Because Lizzie's parents are willing to be flexible about placement, this is a case that could resolve at mediation if the school district administrators are inclined to avoid a hearing. This will depend on how strong a case Lizzie's parents have, and how involved the administrators and their counsel have been in making the decision that Lizzie should be placed in the separate special education school.
- 3) If the case does not resolve at mediation, Lizzie's parents will need to go forward with a due process hearing unless they change their minds about placement. Their advocate/attorney will have had to have been preparing for the hearing all along; once mediation fails, there will be very little time left before the hearing occurs. Lizzie's parents will bear the burden of establishing that the proposed separate placement is inappropriate for her and that she can be educated appropriately in a less restrictive setting. To do this, they will need experts who can discuss the benefits she gains by being educated with peers who do not have disabilities. They can use teachers and administrators from Lizzie's preschool. It also may be helpful to obtain a college or university professor with expertise in inclusive education who can review Lizzie's records, observe her in her preschool setting, observe the proposed placement, the neighborhood school kindergarten, and the nearby regular elementary school kindergarten, and discuss what would be appropriate for Lizzie and why. This professor could also talk about the least restrictive environment provisions of the IDEA in general, how schools can implement them effectively and how they can be specifically implemented in a way that meets Lizzie's needs. Lizzie's parents should also use their witnesses as well as the school witnesses on cross examination to show how the district's decision is based on administrative convenience and the configuration of the service delivery system.
- 4) Lizzie's parents will also need to present evidence regarding the administration of the emergency antiepileptic medication and who may administer it. They will need a witness who can testify about the Nurse Practice Act in their state and the

delegability or non-delegability of the medication administration and what the implications are for staffing in the school Lizzie attends.

Case Scenario 2 — Restraint/Behavior Intervention/Safety Issues

Amalie is a seventeen-year-old nonverbal young woman with an intractable seizure disorder, mental retardation and aggressive behaviors (due to a chromosomal disorder). She attends Edgeview Falls, a public separate special education school. She has drop seizures, absence seizures and tonic-clonic seizures. She also engages in avoidance behavior in which she will drop to the floor to avoid demands being made on her. The school's behavior specialist has developed the plan based on a one-hour observation of Amalie and a cursory review of her records. He did not speak with Amalie's parents, the school nurse or Amalie's doctors; nor did he review her medications or their side effects. He designed a behavior intervention plan that includes keeping Amalie in her classroom chair by using a seatbelt during instructional periods. He tells Amalie's parents that the seatbelt is for safety reasons so that Amalie will not fall from her chair during a seizure. On community outings, the IEP team wants to use a leash with Amalie, as well as have her be supported by two staff. The alternative they present to Amalie's parents is to have Amalie travel by wheelchair. Amalie has sustained a number of injuries in the classroom, some requiring stitches, by falling against sharp furniture corners during seizures. Her parents sought advocacy assistance, and efforts were made to follow the strategy outlined in Chapter 6. After a series of IEP meetings, some improvements were made in Amalie's situation; no leash or wheelchair is being used on community outings, and the classroom furniture has been padded, but little else has been done to improve the quality of her program, despite repeated promises from school staff and area administrators, and her parents are feeling desperate.

Discussion and Advocacy Strategy: Amalie does not have a lot of time left in the education system. The use of restraint and her lack of meaningful communication add more urgency to her situation. This is a case in which parents may wish to proceed to due process without asking for mediation. They can choose to attend a resolution session or try to waive it if the school system agrees; whether a resolution session has a chance of being successful depends on who is in attendance and how serious the parties are about resolving the matter. The following advocacy strategy may be helpful to Amalie's parents and their attorney:

- 1) Identify the issues for the due process hearing. There are a number of issues in this case. Prioritize the issues to be addressed. Issues of significance may be the use of restraint, the failure to conduct an appropriate functional behavioral assessment and develop an appropriate behavioral intervention plan, the failure to conduct an assistive technology assessment and provide appropriate augmentative communication devices and services, and the failure to develop an appropriate health care plan addressing seizures, medications, side effects, impact on education, and needed services and accommodations. Any other issues probably fall within these bigger categories.

- 2) Obtain experts in education, assistive technology and communication, and if necessary, seizures and medications.
- 3) If a resolution session is scheduled, be prepared to identify what a successful resolution of the case would look like. The hearing request will have identified the proposed solution sought by the family, but if they would accept anything less than that, be prepared to negotiate. If not, be prepared to stand firm.
- 4) Proceed to due process if necessary.

Case Scenario 3 — Seizures and Attendance at School

Sam is a fifteen-year-old young man with epilepsy and other developmental disabilities who attends Hillside High School, a separate special education school. He recently had a vagus nerve stimulator (VNS) implanted and has been cleared by his neurologist to return to school. Although he has always had a variety of types of seizures at school, he has had several intense tonic-clonic seizures since he has returned, although none has lasted long enough to require emergency antiepileptic medication. However, the principal of the school has contacted Sam's mother and asked her to keep Sam home until his seizures "are under control." Sam's mother sought legal assistance to get Sam back into school and was able to do so, but the principal mentioned during the course of a meeting that she has begun routinely to send students home when they have "big" seizures and tells parents not to send them back until they are "better" because she doesn't like students having seizures in her school, and that she will send Sam home again if this recurs.

Discussion and Advocacy Strategy: Sam is, of course, attending a separate day school designed to serve students with special needs, and the principal is supposed to be able to cope with the needs of the students in her school. Because the principal is illegally sending students home from school, this is a situation that lends itself to a class IDEA complaint on behalf of Sam and all other similarly situated students. Although Sam is currently in school, he may be affected by this practice in the future, and other students are affected by it on a daily basis. In addition to asking that the practice stop, Sam's parents may wish to ask for a significant amount of training for the principal and school staff regarding seizures. They may also wish to make a complaint about the principal to her supervisor and the superintendent's office.

Selected Cases

Attorney's Fees:

Buckhannon Board and Care Home, Inc. v. West Virginia Department of Health and Human Resources, 532 U.S. 598 (U.S. 2001)

In order for a party to be a "prevailing party" under the Fair Housing Amendments Act and the ADA, there must be a "material alteration of the legal relationship of the parties,"

532 U.S. at 604 (quotation omitted), and there must be “judicial *imprimatur*” on the change.” *Id.* at 605 (emphasis in original). It is not clear if the Supreme Court’s examples of judicial action (securing a judgment on the merits or the obtaining of a court-ordered consent decree) are the only acceptable options, or whether other forms of relief are sufficient to confer prevailing party status.

The following circuits follow *Buckhannon* in the context of the IDEA:

First Circuit

Smith v. Fitchburg Public Schools, 282 F.3d 268 (1st Cir. 2005)

Doe v. Boston Public Schools, 358 F.3d 20 (1st Cir. 2004)

Second Circuit

A.R. v. New York City Department of Education, 03-7258 (2d Cir. June 3, 2005 amended decision)

J.C. v. Regional School District 10, Board of Education, 278 F.3d 119 (2d Cir. 2002)

Third Circuit

John T. v. Del. County Intermediate Unit, 318 F.3d 545 (3d Cir. 2003)

Fourth Circuit

G. v. Fort Bragg Dependent Schools, 324 F.3d 240 (4th Cir. 2003)

Smyth v. Rivero, 282 F.3d 268 (4th Cir. 2002) (not an IDEA case; *Buckhannon* applies to all prevailing party fee-shifting statutes)

Fifth Circuit

No circuit court cases, but see: *Matthew V. v. DeKalb County*, 245 F. Supp.2d 1331, 1341-2 (N.D. Ga. 2003)

Seventh Circuit

T.D. v. LaGrange School District No. 102, 349 F.3d 469 (7th Cir. 2003)

Eighth Circuit

Christina A. v. Bloomberg, 315 F.3d 990 (8th Cir. 2003)

Ninth Circuit

Shapiro v. Paradise Valley Unified School District No. 69, 374 F.3d 857 (9th Cir. 2004)

District of Columbia Circuit

Alegria v. District of Columbia, 391 F.3d 262 (D.C. Cir. 2004)

Burden of Proof:

Schaeffer v. Weast, 546 U.S. 49 (2005)

The burden of persuasion in an administrative hearing challenging an IEP is on the party seeking relief.

Damages:

A.W. v. Jersey City Public Schools, Case No. 05-2553 (3rd Cir. 2007)

Damages action cannot be maintained under Section 1983 for violation of the IDEA (reversing *W.B. v. Matula*, 67 F.3d 484 (3^d Cir. 1995) (damages available under Section 504 and under 1983 claim predicated on Section 504 or the IDEA)).

Charlie F. v. Bd. of Educ. of Skokie School District, 98 F.3d 989 (7th Cir. 1996)

The court required exhaustion of IDEA administrative remedies in a damages case that had not been brought under the IDEA, finding that, in principle, the relief the parents sought was available under the IDEA.

Crocker v. Tennessee Secondary School Athletic Association, 980 F.2d 382 (6th Cir. 1992)

Damages are not available under the IDEA or pursuant to a Section 1983 claim to enforce the IDEA.

Heidemann v. Rother, 84 F.3d 1021 (8th Cir. 1996)

Damages are not available pursuant to a Section 1983 claim to enforce the IDEA; the court relied on *Crocker*.

Sellers v. School Board of the City of Manassas, 141 F.3d 524 (4th Cir. 1998)

Damages are not available under the IDEA or pursuant to a Section 1983 claim to enforce the IDEA. Damages are available under Section 504 but the plaintiff must show bad faith or intentional discrimination.

Baird v. Rose, 192 F.3d 462 (4th Cir. 1999)

Damages may be available under the ADA.

Witte v. Clark, 197 F.3d 1271 (9th Cir. 1999)

Damages are not available under the IDEA; exhaustion of IDEA administrative remedies is not necessary.

Covington v. Knox County School System, 205 F.3d 912 (6th Cir. 2000)

A claim for money damages does not create an automatic exception to the IDEA's exhaustion requirement, but in the case at hand, money damages, which were the only remedy that could redress plaintiff's injuries, were not available in the administrative process and exhaustion would have been futile.

Padilla v. School District No. 1, City and County of Denver, Colorado, 233 F.3d 1268 (10th Cir. 2000)

The court did not address whether the IDEA permits damage awards in this case, which involved a child whose injuries during a restraint incident exacerbated her seizure disorder; the court found that exhaustion of administrative remedies was unnecessary because the relief she sought was unavailable in the IDEA's administrative remedy process.

Polera v. Board of Educ. of Newburgh Enlarged City School District, 288 F.3d 478 (2d Cir. 2002)

The court held that damages are not available under the IDEA, but plaintiffs cannot avoid the IDEA's exhaustion requirement simply because they seek relief that is not available under the IDEA. But earlier precedent allowing damages pursuant to a Section 1983 claim for denial of access to administrative remedies under the IDEA's predecessor statute remains valid law, and district courts within the circuit have relied on the decision to hold that damages are available on claims brought under Section 1983 for violations of the IDEA. See *Quackenbush v. Johnson City Sch. Dist.*, 716 F.2d 141, 148 (2d Cir. 1983), cert. denied 465 U.S. 1071 (1984).

Nieves-Marquez v. Commonwealth of Puerto Rico, 353 F.3d 108 (1st Cir. 2003)

Money damages are not available under the IDEA, but the court left open the possibility of damages under Section 504 or the ADA for intentional conduct causing harm and possibly, but not clearly, for other claims.

Barnes v. Gorman, 536 U.S. 181 (2002)

Punitive damages are not available under Title II of the ADA or under Section 504.

Exhaustion of Administrative Remedies:

Frazier v. Fairhaven School Committee, 276 F.3d 52, 60-61 (1st Cir. 2002)

A party must exhaust all avenues of administrative review regardless of whether the administrative process offers the particular type of relief that is being sought. There are a number of benefits to exhaustion: the educational agency can develop a factual record, apply its expertise to the problem, and exercise its discretion and correct its own mistakes, and the process puts educational professionals with specialized knowledge at the center of the decision-making process. Additionally, the administrative hearing process results in the development of a detailed evidentiary record.

Polera v. Bd. of Educ., 288 F.3d 478, 488, n. 8 (2d Cir. 2002)

The burden is on the party seeking an exception to the exhaustion requirement to show the applicability of the exception.

Hope v. Cortinez, 69 F.3d 687 (2d Cir. 1995)

Plaintiffs must exhaust the IDEA's administrative procedures before bringing suit under the ADA to obtain relief that is available under the IDEA.

Heldman v. Sobol, 962 F.2d 148 (2d Cir. 1992)

Exhaustion may be excused as futile when the agency is either acting in violation of the law or is unable to remedy the alleged injury.

Mrs. W. v. Tirozzi, 832 F.2d 748, 756 (2d Cir. 1987)

Exhaustion is not an inflexible rule. Exceptions may be made to the exhaustion rule if:

- 1) Exhaustion would be futile
- 2) The agency has adopted a policy or has a generally applicable practice that is contrary to law
- 3) Adequate relief is improbable through administrative remedies

J.G. v. Board of Educ. of Rochester City School Dist., 830 F.2d 444, 446-7 (2d Cir. 1987)

Administrative remedies are generally inadequate when structural, systemic reforms are sought.

Lester H. v. Gilhool, 916 F.2d 865 (3rd Cir. 1990), *cert denied* 499 U.S. 923 (3rd Cir. 1991)

The IDEA requires exhaustion of administrative relief unless recourse to the administrative process would be futile or inadequate, such as when the relief sought is not available under the IDEA. In this case, exhaustion would have been futile because the issues involved were purely legal, the record was fully developed, and the administrative process was powerless to address the issue of whether compensatory education was appropriate.

M.M. v. Sch. Dist. of Greenville Co., 303 F.3d 523, 536 (4th Cir. 2002)

Parents must exhaust administrative remedies under the IDEA. There are three exceptions to the exhaustion rule:

- 1) Exhaustion would be futile
- 2) The school board failed to give parents proper notice of their administrative rights
- 3) Administrative exhaustion would have worked severe harm upon a child with disabilities

Pace v. Bogalusa City School Board, 325 F.3d 609, 622, fn. 20 (5th Cir. 2003)

Although IDEA plaintiffs may bring claims under other statutes, such as the ADA, they must first exhaust administrative remedies if they are seeking relief that is available under the IDEA.

Gardner v. School Board of Caddo Parish, 958 F.2d 108 (5th Cir. 1992)

Plaintiffs must exhaust state administrative remedies before bringing suit in federal court under the IDEA unless exhaustion would be futile. The plaintiffs bear the burden of demonstrating futility.

Crocker v. Tennessee Secondary Sch. Athletic Ass'n, 873 F.2d 933, 935-37 (6th Cir. 1989) (*Crocker I*)

Plaintiffs must exhaust their administrative remedies before bringing a civil action to enforce their rights under the IDEA. Exhaustion is not required if the plaintiffs were not given full notice of their procedural rights under the IDEA. The party seeking to avoid the administrative procedures bears the burden of demonstrating that exhaustion would be futile. This holding was also adopted by the court in *Covington v. Knox County School System*, 205 F.3d 912, 917 (6th Cir. 2000). *See also: Doe v. Smith*, 879 F.2d 1340, 1343-33 (6th Cir. 1989), *cert denied* 493 U.S. 1025 (1990) (plaintiffs must exhaust administrative remedies before bringing suit in federal court to obtain relief that is also available under the IDEA)

C.T. v. Necedah Area School District, 39 Fed. Appx. 420 (7th Cir. 2002)

Judicial review is generally unavailable under the IDEA unless all administrative procedures have been exhausted. The IDEA's exhaustion requirement serves several policy objectives. First, it permits deference to the education agency's expertise in resolving education matters. Second, it gives the agency an initial opportunity to correct mistakes. Third, it gives courts a more fully developed record, often involving technical issues. Finally, it prevents parties from deliberately disregarding the IDEA's comprehensive procedures and remedies.

Charlie F. v. Bd. of Educ., 98 F.3d 989, 992-93 (7th Cir. 1996)

If relief is available in principle under the IDEA, parties must exhaust administrative remedies under the IDEA even if they invoke different statutes or seek monetary damages which are unavailable under the IDEA.

M.P. v. Independent School District No. 721, 326 F.3d 975, 980 (8th Cir. 2003)

Exhaustion is required unless it would be futile or inadequate. Exhaustion is the general rule, regardless of whether the administrative process offers the particular type of relief being sought. *See also: M.P. v. Independent School District No. 721*, 439 F.3d 865 (8th Cir. 2006) (*M.P. II*) (parents could proceed with Section 504 claim even though they did not exhaust administrative remedies under the IDEA. Section 504 is a proscriptive, anti-discrimination statute with different remedies from those under the IDEA).

Porter v. Board of Trustees of Manhattan Beach Unified School District, 307 F.3d 1064 (9th Cir. 2002), *cert denied* 537 U.S. 1194 (2003)

Plaintiffs must usually exhaust due process hearing procedures prior to bringing suit under the IDEA or other federal laws when relief is available under the IDEA. However, the exhaustion requirement is not rigid, and there are exceptions when exhaustion would be futile or inadequate. The IDEA did not intend that plaintiffs exhaust both the IDEA's due process hearing procedures and the complaint resolution process prior to initiating court action. Rather, in some instances, the complaint resolution process may be a substitute for a due process hearing. *See also: Hoeft v. Tucson Unified School District*, 967 F.2d 1298 (9th Cir. 1992) (exhaustion will be excused when questions of law are involved in determining the validity of a policy; the question is whether the administrative process is adequately equipped to address and resolve the issues presented).

Padilla v. School District No. 1, City and County of Denver, Colorado, 233 F.3d 1268 (10th Cir. 2000)

Plaintiffs must exhaust administrative remedies under the IDEA before bringing suit pursuant to the ADA when seeking relief that is available under the IDEA.

Urban v. Jefferson County School District R-1, 89 F.3d 720 (10th Cir. 1996)

The purpose of the exhaustion rule is to permit agencies to exercise discretion and apply their expertise, to develop the record before judicial review, to prevent parties from avoiding the process established by Congress and to give the agency an opportunity to correct errors and, therefore, avoid unnecessary judicial decisions. Exhaustion is excused when administrative remedies would be futile, when they would fail to provide relief or when an agency has adopted a policy or practice of general applicability that is contrary to the law.

M.T.V. v. DeKalb County Sch. Dist., Case. No. 05-15258 (11th Cir. 2006)

Failure to exhaust administrative remedies defeats a claim of retaliation, which could have been raised under the IDEA.

Association for Retard Citizens of Alabama, Inc. v. Teague, 830 F.2d 158 (11th Cir. 1987)

Class action nature of lawsuit does not excuse exhaustion of administrative remedies.

Cox v. Jenkins, 878 F.2d 414, 419 (D.C. Cir. 1989)

Plaintiffs must first exhaust the state administrative remedies provided under the statute before bringing an action in federal court, unless exhaustion would be futile or inadequate.

Expert Fees:

Arlington Central School District Board of Education v. Murphy, 548 U.S. ___ (2006)

The IDEA does not permit parents who prevail in a case to recover the costs of their experts.

Statute of Limitations

Draper v. Atlanta Indep. Sch. System, 518 F.3d 1275 (11th Cir. 2008)

The school system failed to evaluate the student for five years, then identified him as having an intellectual disability when, in fact, he had a specific learning disability. The district placed him in a self-contained functional life skills class, but the family did not file for a due process hearing until several years later. The court held that the family did not know enough to realize that the student had been harmed by his misdiagnosis and held that their claim was not barred by the two year statute of limitations.

**APPENDIX A: CHILD CARE SEIZURE DISORDER
EMERGENCY TREATMENT PLAN**

CHILD CARE SEIZURE DISORDER EMERGENCY TREATMENT PLAN

Center # _____

Directions: Whenever a child with a seizure disorder is enrolled we require that the following information be provided so that the best possible care can be obtained for your child. The first section is to be completed by the parent or guardian. The next is to be completed by the physician treating the child for the disorder. The Center Director completes the third section. Your child can start attending when all sections are completed and the form returned.

Student's Name _____ Date of Birth _____

Emergency Contacts – Please list three emergency contact numbers in the order you would like to have them called. Parent or guardian must provide valid contacts and keep them updated as needed. Failure to do so may result in disenrollment.

Parent _____	Phone # _____	Phone# _____
Parent _____	Phone# _____	Phone # _____
Name _____	Relationship _____	Phone # _____
Name _____	Relationship _____	Phone # _____
Name _____	Relationship _____	Phone # _____

History of Seizure Disorder _____

Describe "typical" seizure behavior _____

Triggering Stimuli

- heat/cold
- low BS
- fatigue
- fever
- unknown
- injury
- psychosocial issues
- light
- hyperventilation

Other Comments _____

Warning Signals

- none
- cold
- numbness
- tingling
- headache
- nausea/vomiting
- tremor
- auditory aura
- visual aura
- smell/taste aura

Other Comments _____

Current Medications – Please list all medications, including prescription, over the counter and herbal preparations, and indicate the dosage that your child is currently taking.

Dietary Restrictions _____

Activity Restrictions _____

Emergency Care to be followed in all instances of a seizure

Seizure Care Guidelines/ Protocol

1. Gently protect the child from injury. Turn the child onto his or her side, place something soft under his/her head, loosen tight clothing, and clear the area of sharp or harmful objects.
 2. Do not place anything in the mouth of the child.
 3. Do not restrain or try to stop purposeless behavior.
 4. Observe and record seizure behavior (before/during/after) on seizure observation record (see page 3).
 5. Encourage onlookers to leave.
 6. Stay with the student until full recovery has occurred. Allow child to rest if he or she needs it.
 7. Be reassuring and supportive when consciousness occurs.
 8. In addition to the basic emergency care, staff should follow the specific instructions of the physician outlined below, paying special attention to the administration of emergency medication, including diazepam rectal gel.
 9. Follow the physician's instructions (page 4) regarding administration of emergency medication and other steps.
 10. Other first aid steps: _____
-

Center Staff Should Call 911 if:

- Seizure continues _____ minutes after the administration of diazepam rectal gel or another medication
- Child has one seizure after another and seizure activity continues for ___ minutes or more
- Child is having difficulty breathing
- Absence of breathing or pulse
- Continued unusually pale or bluish skin/lips or noisy breath after the seizure has stopped
- Other:

Indicate the person(s) who is/are authorized to monitor and provide care.

Check all that apply:

Center Personnel

Parent(s) or Guardian(s)

Other Name(s): _____; _____; _____

I understand that it is my responsibility to keep center management informed of changes in my child's condition and to immediately notify them and complete a new form if treatment for the condition is changed or modified in any way.

In the event that my child has a seizure requiring that 911 be called, I authorize emergency medical technicians to transport my child to the nearest hospital emergency room.

Date Signed _____

Parent/Guardian _____

Seizure Observation Record

Name of student _____
 Baseline Weight _____

DATE					
PRESEIZURE OBSERVATION Note: activity, behaviors, triggering events					
SEIZURE OBSERVATION					
Start time					
End time					
Conscious (yes/no)					
Facial movements-twitching, chewing, smacking lips					
Head movement to the left or right					
Fell					
Incontinent – urine, bowel movement					
Eye movements to the left or right, up/down, blank stare, rolled back, rapid blinking, closed					
Verbal sounds (describe) – gagging, throat clearing, drooling					
Breathing changes- noisy, slowing or other					
Extremity movement -- right arm and/or leg, left arm and/or left leg, stiffening, jerking, limp, clenching					
Skin color -- normal, red, pale, blue (facial, lips, nails)					
POST SEIZURE OBSERVATIONS					
Confused					
Sleepy, tired					
Alert					
Headache					
Speech slurring					
Other					
Length of time for reorientation, wakefulness					
ADDITIONAL COMMENTS					
Parents notified (note time)					
EMS/MERT activated, note time of call, time of arrival					
Staff initials					

Initials/Signatures _____

The following form is to be completed by the physician who is actively treating the child for the seizure disorder.

Limitations of the child: _____

Emergency Medical Services should be called when: _____

Medications to be given at Day Care

Name of Medication	Dose/Route	Time	Possible Side Effects

Emergency Medication – If child receives diazepam rectal gel or another emergency medication, please list the appropriate procedures to follow prior to, during and after administration.

Physician's Directives to EMTs: Transportation to the hospital should be provided under the following conditions.
Staff will not prevent EMTs from transporting a child that they believe requires emergency hospital care.

Physician Name (printed) _____

Physician's Signature _____ Date Signed _____

Physician's Phone # _____

By signing below I am agreeing that the center staff will follow the steps laid out in the Seizure Disorder Emergency Treatment Plan to ensure the child's safety prior to the arrival of the EMT's. The staff will also provide this information sheet, including the physician's directives and the seizure observation record to the EMT's.

Date Signed _____ Center Management _____

**APPENDIX B: MODEL SECTION 504 PLAN FOR A
STUDENT WITH EPILEPSY**

MODEL SECTION 504 PLAN FOR A STUDENT WITH EPILEPSY

[NOTE: This Model Section 504 Plan lists a broad range of services and accommodations that might be needed by a student with epilepsy in the school setting and on school-related trips. The plan must be individualized to meet the specific needs of the particular child for whom the plan is being developed and should include only those items that are relevant to the child. Some students may need additional services and accommodations that have not been included in this Model Plan, and those services and accommodations should be included by those who develop the plan. The plan should be a comprehensive and complete document that includes all of the services and accommodations needed by the student.]

Section 504 Plan for _____
(Name of Student)

Student I.D. Number _____

School _____

School Year _____

_____ _____ Epilepsy
Birth Date Grade Disability

Homeroom Teacher _____ Bus Number _____

OBJECTIVES/GOALS OF THIS PLAN:

Epilepsy, also referred to as a seizure disorder, is generally defined by a tendency for recurrent seizures, unprovoked by any known cause such as hypoglycemia. A seizure is an event in the brain which is characterized by excessive electrical discharges. Seizures may cause a myriad of clinical changes. A few of the possibilities may include unusual mental disturbances such as hallucinations, abnormal movements, such as rhythmic jerking of limbs or the body, or loss of consciousness. In addition to abnormalities during the seizure itself, individuals may have abnormal mental experiences immediately before or after the seizure, or even in between seizures.

The goal of this Section 504 plan is to outline the special education and/or related services and/or accommodations and/or aids necessary to maintain (Name of Student) at school so that s/he may participate in and benefit from school services, programs, and activities. These services and accommodations must be provided in accordance with this

plan and with the student's seizure action plan, which is attached to this Section 504 Plan and incorporated into it.

REFERENCES:

School accommodations, epilepsy care, and other services outlined in this plan will be consistent with the prescriptions and other orders provided by (Name of Student's) physician, the attached seizure action plan and with the information and protocols contained in The Epilepsy Foundation's "Managing Students with Seizures: A Quick Reference Guide for School Nurses" (2006).

DEFINITIONS OF TERMS USED IN THIS PLAN:

Absence seizures: Seizures (sometimes called petit mal seizures) that are usually just a few seconds long. They happen suddenly and the person will stop what he or she is doing, and then resume it as soon as the seizure is over. They may happen many times in a day or in clusters during the day. Type of generalized seizure.

AED: Antiepileptic drug. Medication used to treat seizures. Common medications include Dilantin, Keppra, Topamax, Depakote, Depakene, Lamictal, Zonegran, and Clonapin, among others.

Atonic seizures: Also called drop seizures, these seizures produce a sudden loss in muscle tone. A person's head will drop or the person will drop to the ground. Injury can occur; these seizures occur without warning. Type of generalized seizure.

Clonic seizure: Seizures in which a person's arms and legs jerk rhythmically. Clonic seizures by themselves are uncommon. Generalized seizure type.

Complex partial seizures: Seizures begin in one part of the brain and involve a loss of consciousness or impaired consciousness. May cause automatic behaviors such as lip smacking, chewing, swallowing, fidgeting, or other repetitious, stereotypic behavior.

Diastat Acudial: Rectal diazepam (class of drugs to which valium belongs). One type of emergency antiepileptic medication, Diastat Acudial is an effective means of aborting a lengthy seizure or a cluster of seizures and was designed to avoid trips to the emergency room.

Generalized seizures: Seizures that affect both sides of the brain and produce loss of consciousness for either a brief or longer period of time. Generalized seizures include absence seizures, atonic or drop seizures, and tonic, clonic, myoclonic, and tonic-clonic seizures.

Ketogenic diet: A special low-calorie, high-fat diet in which the body is placed in a state of ketosis so that it burns fat for energy instead of carbohydrates. Ketosis has been effective in providing seizure control or partial seizure control for many children.

Myoclonic seizures: Seizures in which the person experiences quick muscle contractions that usually occur on both sides of the body at the same time. They look like quick muscle jerks. Generalized seizure.

Partial seizures: Seizures in which the electrical firings of the neurons are limited to a specific area of one side of the brain.

Simple partial seizures: During these seizures a person remains aware of what is going on but may be limited in how he or she can react. The person may not be able to speak, or may experience tingling or pain, visual distortions, or other symptoms that may warn of more severe seizures to come.

Seizure action plan: A plan that is designed to provide basic information about the student's seizures and treatments. A completed plan should be provided to all relevant school personnel at the beginning of the school year, when a diagnosis of epilepsy is made or when a change in health status occurs. The plan should be signed and approved by the student's treating physician.

Status epilepticus: A period of prolonged seizure activity either because of one prolonged seizure or because of a series of seizures without the person returning to baseline. Current medical definitions consider 10 minutes as the amount of time after which uninterrupted seizure activity would be considered status epilepticus. It is possible that brain damage or death can result from status seizures. During status seizures, problems can arise if there is pulmonary or cardiac arrest that is not promptly treated. More often, however, serious negative consequences occur hours or days after the onset of status as a result of prolonged stress, oxygen deprivation and systemic complications such as organ failure.

Tonic-clonic seizures: The most common type of seizure (sometimes called "grand mal" seizures). They begin with a tonic phase, in which the arms and legs stiffen, and then continue with a clonic phase, in which the limbs and face jerk. During the tonic portion of a seizure, a person may have an initial vocalization followed by their breathing slowing or stopping; during the clonic portion, breathing usually returns, but may be irregular, noisy or seem labored. The person may be incontinent and may bite his or her tongue or the inside of his or her mouth during the seizure. Generalized seizure.

Tonic seizures: Seizures in which the person's leg, arm, or body muscles stiffen. The person's legs may extend. The person usually remains conscious. Generalized seizure.

Vagus nerve stimulator (VNS): The VNS is similar to a pacemaker, but it stimulates the vagus nerve in the neck, instead of the heart. The VNS is usually implanted in the upper left chest or under the arm; it stimulates, on an ongoing basis, the vagus nerve, which then sends electrical impulses to the parts of the brain that affect seizures. If a person has a seizure aura or begins to have a seizure, the VNS can be swiped with a magnet to send additional electrical current to abort or minimize the seizure.

1. PROVISION OF EPILEPSY CARE

All staff members at the school shall receive general training regarding epilepsy and first aid for a person who is having a seizure.

All staff members at the school who will be serving (student's name) shall receive general training regarding the protocol to be followed if s/he has a seizure at school or a school-related event.

Any staff member who has primary care for (student's name) at any time during school hours, extracurricular activities, or during field trips or other school-related events or activities shall receive training that includes a general overview of epilepsy and the typical health care needs of a student with epilepsy, types of seizures and how to recognize each type, the type(s) of seizures (student's name) has, what medication(s) the student takes and how and when to administer the medications if the staff member will be responsible for medication administration, and how and when to contact a school nurse if medication will be administered by the nurse or if (student's name) health status warrants attention from the nurse.

Any bus driver or other person who transports the student to and from school must be able to recognize and respond to a seizure if (student's name) has a seizure while on the way to or from school or a school-related event.

The following staff member(s) will be identified as the staff responsible for providing care to (student's name) in the event of a seizure:

All students in (student's name's) class(es) and other students in the school, as deemed appropriate by school staff and (student's name's) parent/guardian, shall be educated about epilepsy in general and, as deemed appropriate by school staff and (student name's) parent/guardian, about what to expect regarding (student name's) seizures specifically.

2. STUDENT'S LEVEL OF SELF-CARE AND LOCATION OF SUPPLIES AND EQUIPMENT

(Student's name) is able to walk to the nurse's office independently to take routine AEDs.

(Student's name) needs assistance or supervision to take his or her routine medication. S/he needs assistance with the following care tasks:

- (a) _____
- (b) _____
- (c) _____
- (d) _____

(Student's name) needs a person to perform the following care tasks during a seizure:

- (a) _____
- (b) _____
- (c) _____
- (d) Administration of Diastat Acudial

Medication and supplies shall be stored at:

3. EXERCISE, PHYSICAL ACTIVITY, AND REST PERIODS:

(Student's name) shall be permitted to participate fully in physical education classes and team sports except as set out below in accord with physician orders:

Physical education instructors and sports coaches must be able to recognize the student's seizures and assist with first aid.

Responsible school staff members will make sure that any needed emergency AEDs such as Diastat Acudial are available for (student's name) at the site of his/her physical education class and team sports practices/games.

School staff shall ensure that if (student's name) has a seizure and needs to sleep or rest afterwards or otherwise needs to rest during the school day, he or she will have the opportunity to do so in a safe, supervised, comfortable setting. The setting does not have

to be the school nurse's office, and supervision does not have to be provided by the school nurse, unless physician orders so require.

4. KETOGENIC DIET

- 4.1 (Student's name) shall have access to needed food and liquids as required during the school day in order to maintain the protocol of the ketogenic diet. (Student's name) parent/guardian shall provide pre-measured supplies of food and liquid to the school on a daily basis.
- 4.2 School staff who work with (student's name) shall be trained regarding the ketogenic diet so that violations of the diet do not occur at school.
- 4.3 As appropriate, classmates of (student's name) shall be given information about the ketogenic diet so that they do not share food with him/her.
- 4.4 As appropriate, during class parties or celebrations with food, alternatives shall be arranged for (student's name) that enable him/her to partake in the celebration if s/he will be unable to eat or drink during the party time. Such alternatives may include, but are not limited to, playing a special role in the celebration, choosing music for the party, or being the "emcee."

5. VAGUS NERVE STIMULATOR

- 5.1 School staff who work with (student's name) shall be trained regarding the vagus nerve stimulator (VNS) and how it works.
- 5.2 A staff person shall be identified who shall be trained to swipe the magnet over the VNS in the event that (student's name) has a seizure, as stated in the attached Seizure Action Plan.
- 5.3 A log shall be kept of each instance in which the VNS is swiped and the parents shall be notified at the end of each school day in which a swipe occurred.

6. ROUTINE AND EMERGENCY ANTIEPILEPTIC DRUGS

- 6.1 As stated in the attached Seizure Action Plan, (Student's name) shall be given his/her prescribed doses of AEDs in accordance with physician orders.
- 6.2 School staff shall identify a person and a back-up person to be trained to administer appropriate emergency AEDs to (student's name) in accordance with physician orders, as stated in the attached Seizure Action Plan. A trained staff member shall be available to perform this task all times during which (student's name) is at school or attending a school-related activity or event.

7. FIELD TRIPS AND EXTRACURRICULAR ACTIVITIES

- 7.1 (Student's name) will participate in all field trips, extracurricular activities, and school-related activities and events (such as sports, clubs, enrichment programs, and overnight trips) without restriction and with all of the accommodations and modifications, including necessary assistance and supervision by identified school or contract personnel, set out in this Plan. (Student's name's) parent/guardian will not be required to accompany him/her on field trips or any of these other listed events or activities.
- 7.2 A trained person shall be designated to be available on site at all field trips, extracurricular activities, and other school-related activities and events to provide administration of any necessary medication in the event of a seizure, or any other seizure first aid as needed.
- 7.3 The student's AEDs will travel with the student to any field trip or extracurricular activity on or away from the school premises.

8. CLASSROOM WORK AND TESTS

- 8.1 If (student's name) has a seizure during a test, he or she will be allowed to take the test at another time without any penalty.
- 8.2 If (student's name) has side effects from AEDs that affect his/her ability to concentrate on schoolwork or tests, s/he may have extra time to complete assignments and tests without any penalty.
- 8.3 If (Student's name) arrives to school late because of an adjusted start time due to the need to wake up later to avoid morning seizures, s/he will not be penalized for work missed and will be given an opportunity to make up the work.
- 8.4 (Student's name) shall be given instruction without penalty to help him/her make up any classroom instruction missed due to epilepsy care.
- 8.5 (Student's name) shall not be penalized for absences required for medical appointments and/or for illness related to his/her epilepsy.

9.0 DAILY INSTRUCTIONS AND COMMUNICATION

- 9.1 Every substitute teacher and substitute school nurse shall be provided with written instructions regarding (student's name) seizure care and a list of all school nurses and staff involved in his/her care at the school.
- 9.2 (Student's name's) parents shall be informed each day of any seizures that occurred at school or at any school-related activity or event. The information

given to the parents shall be in writing and shall include information about the type(s) of seizures that occurred, any first aid or other treatment provided, and any other relevant information.

9.3 As stated in the attached Seizure Action Plan, in the event of an emergency such as a seizure that results in an unusual response, school staff shall contact 911 and notify (student's name's) parents.

10. EMERGENCY EVACUATION AND SHELTER-IN-PLACE

10.1 In the event of an emergency evacuation or shelter-in-place situation, (student's name's) Section 504 Plan shall remain in full force and effect.

10.2 The school nurse or other person identified by school staff and named in this Plan, shall provide seizure care as outlined in this Plan and will be responsible for transporting (student's name's) medication. He or she shall remain in contact with (student's name's) parents/guardians, and shall receive information, guidance, and necessary orders from the parents regarding seizure care.

11. EMERGENCY CONTACTS:

_____ Parent/Guardian Name	_____ Home Phone	_____ Work Phone	_____ Cell Phone
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_____ Parent/Guardian Name	_____ Home Phone	_____ Work Phone	_____ Cell Phone
-------------------------------	---------------------	---------------------	---------------------

Other Emergency Contacts:

_____ Name	_____ Home Phone	_____ Work Phone
---------------	---------------------	---------------------

_____ Name	_____ Home Phone	_____ Work Phone
---------------	---------------------	---------------------

Physician(s):

_____ Name	_____ Phone
---------------	----------------

_____ Name	_____ Phone
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**APPENDIX C: SCHOOL SEIZURE ACTION PLAN AND
OBSERVATION RECORD**



Seizure Action Plan

Effective Date _____

This student is being treated for a seizure disorder. The information below should assist you if a seizure occurs during school hours.

Student's Name	Date of Birth	
Parent/Guardian	Phone	Cell
Other Emergency Contact	Phone	Cell
Treating Physician	Phone	
Significant Medical History		

Seizure Information

Seizure Type	Length	Frequency	Description

Seizure triggers or warning signs: _____

Student's response after a seizure: _____

Basic First Aid: Care & Comfort

Please describe basic first aid procedures: _____

Does student need to leave the classroom after a seizure? Yes No

If YES, describe process for returning student to classroom: _____

Basic Seizure First Aid

- Stay calm & track time
- Keep child safe
- Do not restrain
- Do not put anything in mouth
- Stay with child until fully conscious
- Record seizure in log

For tonic-clonic seizure:

- Protect head
- Keep airway open/watch breathing
- Turn child on side

A seizure is generally considered an emergency when:

- Convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- Student has repeated seizures without regaining consciousness
- Student is injured or has diabetes
- Student has a first-time seizure
- Student has breathing difficulties
- Student has a seizure in water

Emergency Response

A "seizure emergency" for this student is defined as: _____

Seizure Emergency Protocol

(Check all that apply and clarify below)

- Contact school nurse at _____
- Call 911 for transport to _____
- Notify parent or emergency contact
- Administer emergency medications as indicated below
- Notify doctor
- Other _____

Treatment Protocol During School Hours (include daily and emergency medications)

Emerg. Med. ✓	Medication	Dosage & Time of Day Given	Common Side Effects & Special Instructions

Does student have a Vagus Nerve Stimulator? Yes No If YES, describe magnet use: _____

Special Considerations and Precautions (regarding school activities, sports, trips, etc.)

Describe any special considerations or precautions: _____

Physician Signature _____ Date _____

Parent/Guardian Signature _____ Date _____

Student Name:			
Date & Time			
Seizure Length			
Pre-Seizure Observation (Briefly list behaviors, triggering events, activities)			
Conscious (yes/no/altered)			
Injuries? (briefly describe)			
Muscle Tone/Body Movements	Rigid/clenching		
	Limp		
	Fell down		
	Rocking		
	Wandering around		
	Whole body jerking		
Extremity Movements	(R) arm jerking		
	(L) arm jerking		
	(R) leg jerking		
	(L) leg jerking		
	Random Movement		
Color	Bluish		
	Pale		
	Flushed		
Eyes	Pupils dilated		
	Turned (R or L)		
	Rolled up		
	Staring or blinking (clarify)		
	Closed		
Mouth	Salivating		
	Chewing		
	Lip smacking		
Verbal Sounds (gagging, talking, throat clearing, etc.)			
Breathing (normal, labored, stopped, noisy, etc.)			
Incontinent (urine or feces)			
Post-Seizure Observation	Confused		
	Sleepy/tired		
	Headache		
	Speech slurring		
	Other		
Length to Orientation			
Parents Notified? (time of call)			
EMS Called? (call time & arrival time)			
Observer's Name			

Please put additional notes on back as necessary.

APPENDIX D: SAMPLE SCHOOL COMMUNICATION FORMS

SAMPLE COMMUNICATION FORM FOR STUDENT WITH EPILEPSY

(STUDENT'S NAME): REPORT FROM SCHOOL

DATE:

Physical:

Seizures: Yes ___ No ___

If yes, # of seizure episodes _____

Time seizure(s) occurred _____

Length of seizure episode(s) _____

Type(s) of seizure(s) _____

Sleep afterwards? Yes ___ No ___

Emergency Medication used: Yes/Type _____ No ___

Other care provided: _____

Additional information: _____

Academic:

Achievement(s) during day:

Any concerns about school day:

Issues to address before tomorrow:

Other:

(STUDENT'S NAME)

REPORT FROM HOME

DATE

Physical:

Seizures: Yes___ No___

If yes, # of seizure episodes _____

Time seizure(s) occurred _____

Length of seizure episode(s) _____

Type(s) of seizure(s) _____

Sleep afterwards? Yes___ No___

Emergency medication used: Yes/Type _____ No _____

Other care provided _____

Additional information:

Concerns/Questions:

Contact Information for Today: _____
Name Telephone Number

Back-up Contact Person for Today: _____
Name Telephone Number

**SAMPLE COMMUNICATION FORM FOR STUDENT WITH EPILEPSY AND
OTHER DISABILITIES**

(NAME OF STUDENT): REPORT FROM SCHOOL DATE:

General: Circle appropriate mood:

Today, (Student's name) was: happy vocal quiet tired cranky other _____

Positioning: Check all appropriate equipment:

Today, (Student's name) used his/her wheelchair ___ mat ___ stander ___ walker ___
gait trainer ___ other ___

Physical:

Seizures: Yes ___ No ___

If yes, # of seizure episodes _____

Length of seizure episode(s) _____

Type(s) of seizure(s) _____

Time seizure(s) occurred _____

Sleep afterwards? Yes No

Emergency medication used: Yes/Type _____ No ___

Other care provided _____

Additional information _____

Diapers: #wet _____ #soiled _____

Nap: Yes ___ No ___

Appetite at lunch: excellent good okay poor

Liquids: oz. by mouth by g-tube

Classroom activities: Today, (Student's name) worked on:

Activities to work on at home:

Special activities: music adapted P.E. library art computer other

Related services: PT OT Speech Assistive Technology

General comments:

(STUDENT'S NAME): REPORT FROM HOME

Date:

After school/evening activities yesterday:

Seizures: Yes ___ No ___

If yes, # of seizure episodes _____

Length of seizure episode(s) _____

Time seizure(s) occurred _____

Type(s) of seizure(s) _____

Sleep afterwards? Yes ___ No ___

Emergency medication used? Yes/Type _____ No _____

Other care provided _____

Additional information _____

Appetite this morning:

Other news:

Contact Information for Today: _____
Name Telephone Number

Back-up Contact Person for Today: _____
Name Telephone Number

**APPENDIX E: SELECTED STATE LAWS ON SCHOOL
MEDICATION ADMINISTRATION**

**Selected State Laws on School Medication Administration including
Emergency
Antiepileptic Drugs (revised 2008)**

State	What duty does a school nurse have regarding medication in school?	Can unlicensed assistive personnel (UAP)* administer medication in school?	Extent of Nurse's Authority to Delegate Administration of Medication
Alabama	See ALA. BD. OF NURSING ADMIN. CODE 610-X-6.06.	Yes, ALA. BD. OF NURSING ADMIN. CODE 610-X-6.06 (2) and (4): Administration of specific types of prescription medications to a student may be delegated to a UAP.	RN's cannot delegate specific tasks to UAPs that require independent nursing judgment or intervention – this includes the administration of rectal or vaginal medications ALA. BD. OF NURSING ADMIN. CODE 610-X-6.06 610-X-6.06 (2) and (4) (C).
District of Columbia	D.C. CODE § 38-632 states that the school principal shall designate UAPs authorized to administer medications. No policy that specifically addresses the administration of medication by nurses in schools.	**Yes, D.C. CODE § 38-632 – any employee who has been properly trained may administer medication in compliance with the signed, written instructions of a licensed practitioner if parent/guardian hand-delivers medications to school, gives consent in writing, and employee is under the supervision of an RN or licensed practitioner.	D.C. Board of Education and the D.C. Department of Human Services jointly issue rules and regulations that establish "criteria for the selection, in consultation with the school-based licensed nurse, of employees at each public school who shall administer medication." D.C. CODE § 38-634 (a) (9).
Florida	See FLA. ADMIN. CODE r. 64 B9-14.002.	FLA. STAT. § 1006.062 (1)(b) allows each district school board to adopt policies and procedures governing the administration of prescription medication by district school board personnel. ** FLA. STAT. § 1006.062 (4) allows UAPs to perform health-related services upon successful completion of child-specific training, including (d) administering emergency injectable medication. However, under FLA. STAT. § 1006.062 (5), for all other invasive medical services not listed in (4), a licensed medical professional shall determine if UAPs shall be allowed to perform such service.	School board policies and procedures designate non-medical school personnel who will administer medication in school. FLA. STAT. § 1006.062 (1)(b). Nurses must use their nursing judgment to consider the suitability of the task or activity to be delegated. FLA. ADMIN. CODE r. 64 B9-14.002. FLA. ADMIN. CODE r. 64 B9-14.003 does not specifically include administration of medication as a task that a nurse is prohibited from delegating.
Georgia	GA. STATE EDUC. RULE 160-4-8-.01 (2000)	Administration of medication falls under the Georgia Code's definition	The Georgia NPA does not provide for delegation of licensed

* In the school context, UAPs typically include health aides, teachers, and teachers' aides.

** Signifies a law or policy explicitly or implicitly permitting administration of emergency antiepileptic medication by UAPs. These laws and policies are noted in bold text, along with laws and policies that expressly reference diazepam rectal gel or other rectally-administered medication (including those that restrict administration by UAPs).

**Selected State Laws on School Medication Administration including
Emergency
Antiepileptic Drugs (revised 2008)**

State	What duty does a school nurse have regarding medication in school?	Can unlicensed assistive personnel (UAP)* administer medication in school?	Extent of Nurse's Authority to Delegate Administration of Medication
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	requires each school system to develop a Student Services Plan that provides guidelines for its various components including school health services.	<p>of the practice of nursing. GA. CODE § 43-26-3 (6), (8)(I)-(J).</p> <p>Each public school in this state shall permit the self-administration of asthma medication by a student who has asthma. GA. CODE § 20-2-774 (2002).</p> <p>**The Georgia School Health Resource Manual (2004) states that if emergency medication (EpiPen, glucagon, diazepam) is ordered by the physician and is provided by the family, "school administration and staff should be prepared to comply with the plan, per local policy," and sets out suggested protocol for diazepam administration (pp. 178-179), see http://www.gasn.org/gasn.org/files/images/chapt03_medicationadministration.pdf</p>	activities to unlicensed individuals. See GA. CODE §§ 43-26-3 and 43-26-12.
Kentucky	As a school employee that meets the requirements of Ky. Rev. Stat. Ann. § 156.502 (a designated provider of health services), school nurses may be asked to administer diazepam to students under Ky. Rev. Stat. Ann. § 158.838.	Yes. Ky. Rev. Stat. Ann. § 156.502(2)(c) states that, under certain circumstances, health services may be provided by school employees who have had the responsibility delegated to them by a medical professional.	<p>Under Ky. Rev. Stat. Ann. § 156.502(2)(c), the nurse may delegate performance of a health service to a UAP.</p> <p>**Ky. Rev. Stat. Ann. § 158.838 (2005) mandates that each school board or district have at least one qualified school employee at each school who is on duty during the entire school day to administer diazepam rectal gel. The UAP is not required to administer the medication unless consenting to provide health services under state law.</p>

* In the school context, UAPs typically include health aides, teachers, and teachers' aides.

** Signifies a law or policy explicitly or implicitly permitting administration of emergency antiepileptic medication by UAPs. These laws and policies are noted in bold text, along with laws and policies that expressly reference diazepam rectal gel or other rectally-administered medication (including those that restrict administration by UAPs).

**Selected State Laws on School Medication Administration including
Emergency
Antiepileptic Drugs (revised 2008)**

State	What duty does a school nurse have regarding medication in school?	Can unlicensed assistive personnel (UAP)* administer medication in school?	Extent of Nurse's Authority to Delegate Administration of Medication
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Louisiana	LA. REV. STAT. ANN. § 17:436.1 (B) (1) (a)-(c) (1997) requires a written order from a physician, medication provided to the school, and clear instructions detailed in a letter from the guardian and listed on the medication container.	Yes. LA. REV. STAT. ANN. § 17:436.1 (B) allows non-medical school board employees to administer medications under certain conditions.	<p>The nurse may delegate medication administration to trained UAPs once s/he has determined that this administration can be safely performed by and delegated to that UAP. LA. REV. STAT. ANN. § 17:436.1 (B) (1) (a)-(c)</p> <p>** Regarding diazepam, the nurse must base his/her judgment on:</p> <p>1) a clinical protocol that clearly describes the responsibility and accountability of the certified school nurse delegating rectal diazepam administration to trained UAPs or LPNs;</p> <p>2) a signed agreement from the student's parents authorizing the administration of diazepam to their child by a nurse or trained UAP;</p> <p>3) the RN's assessment that the trained UAP is competent to administer the rectal diazepam.</p> <p><i>Louisiana Board of Nursing, Declaratory Statement Regarding the Registered School Nurse Delegating to Trained Unlicensed School Employees the Administration of Rectal Diastat in Certain Emergency Situations, March 15, 2005.</i></p>
Ohio	See OHIO ADMIN. CODE ANN. § 4723-13-05.	Yes, OHIO REV. CODE ANN. § 3313.713	Yes, OHIO ADMIN. CODE ANN. § 4723-13-04(A)(2) provides that nurse may delegate administration of medication in accordance with OHIO REV. CODE ANN. §

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**Selected State Laws on School Medication Administration including
Emergency
Antiepileptic Drugs (revised 2008)**

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			<p>3313.713; see OHIO ADMIN. CODE ANN. 4723-13-05 for requirements for delegating tasks.</p> <p>A state court ruled that the nurse practice act does not prohibit UAPs from administering diazepam. <u>Lancaster School District Support Association v. Board of Education, Lancaster City School District</u>, No. 03 CVH 02 02143 (Ohio Ct. of Common Pleas March 6, 2006), appeal dismissed based on mootness.</p>
Tennessee	<p>TENN. CODE ANN. § 63-7-103 (2006) states that administration of medication is a "practice of professional nursing" that "requires substantial specialized judgment and skill based on knowledge of the natural, behavioral and nursing sciences.</p>	<p>No, but see below. Administration of medications to students during the school day must be performed by appropriately licensed health care professionals. TENN. CODE ANN. § 49-5-415 (2006).</p> <p>**On May 30, 2008, the Governor signed into law a bill (HB3268) authorizing public and private schools to allow volunteer non-medical school staff to administer diazepam rectal gel pursuant to a student's individual health plan, if a school nurse is not immediately available to administer the medication. The law prohibits a school district from assigning a student with epilepsy or other seizure disorder to a school other than the school for which the student is zoned because the student has a seizure disorder. The law provides that emergency medical services must be called whenever the medication is</p>	<p>It is considered unprofessional conduct, unfitness, or incompetency by reasons of negligence, habits or other causes to "[a]ssign[] unqualified persons to perform functions of licensed persons or delegating nursing care functions and tasks and/or responsibilities to others contrary to the Nurse Practice Act or rules and regulations to the detriment of patient safety." TENN. BD. OF NURSING RULES 1000-1-.13 (1)(l) (2006).</p>

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		administered to provide necessary monitoring or transport to safeguard the health and condition of the student. The law amends the above TN Code provisions. See www.legislature.state.tn.us	
Texas	The responsibility of administering medications to students is considered an administrative task assigned by the principal, rather than a health-related service delivered or delegated by a health care professional. <i>TX School Health Guidelines, Ch. 5: Medication Administration 208 (2005).</i>	<p>Yes. Under TEX. EDUC. CODE ANN. § 22.052 (a), the task of administering medication may be assigned to a school employee by the principal as an administrative function.</p> <p>**Texas Board of Nurse Examiners Position Statement 15.13 states that “emergency administration of Epi-pens, Glucagon, and Diastat may be administered by an unlicensed person under [22 TEX. ADMIN. CODE] §224.6(4) in order to stabilize the child and prevent complications from delaying treatment.”</p> <p>Legal permission to administer medication is granted to employees of the school district, when authorized by school principals or superintendents. The law grants immunity to all school district employees. <i>TX School Health Guidelines, Ch. 5: Medication Administration 208 (2005).</i></p> <p>Students can self-administer medication for asthma or anaphylaxis. TEX. EDUC. CODE ANN. § 38.015 (2006).</p>	<p>The RN may delegate tasks in the school setting in compliance with 22 TEX. ADMIN. CODE §§ 224 and 225.</p> <p>The responsibility of administering medications to students is considered an administrative task assigned by the principal, rather than a health-related service delivered or delegated by a health care professional. <i>TX School Health Guidelines, Ch. 5: Medication Administration 208 (2005).</i></p> <p>The decision to delegate a specific task is always at the discretion of the RN in accordance with 22 TEX. ADMIN. CODE § 224.8(b)(1)(C) or §225.9(c).</p>

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Virginia	Chapter 18 of the VA Code 90-20-460 provides that administration of medications shall not be delegated unless permitted by Part 54.1-3400 of the Code of Virginia. However, the Dept of Education has established procedures indicating that UAPs may administer diazepam (see next column).	** Yes. VA Dept. of Education, School Health Services, Specialized Health Care Services, Neurological Guidance, states that "Any school personnel who has regular contact with a student who requires rectal diazepam should receive general training covering the student's specific needs, potential problems and implementation of the established emergency plan." Guidelines on who may administer shall be included in the student's individualized health plan. This report is available at: http://www.pen.k12.va.us/VDOE/Instruction/Health/SHCP6neurological.pdf	Specified nursing tasks may not be delegated. See 18VAC90-20-460.
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Epilepsy Foundations throughout the country have additional materials and offer a variety of programs to help people understand this common disorder.

*For further information about epilepsy and the name of the Epilepsy Foundation nearest you,
log on to www.epilepsyfoundation.org or call 800-332-1000.*



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