

ADVOCACY

Legal Protections for Children with Viral Hepatitis

Updated 2006

Overview

In the United States, three federal laws are critical in protecting children with viral hepatitis against discrimination in schools, daycare centers, athletic programs, camps and other areas of daily life.

The Americans with Disabilities Act (ADA) is the most powerful law safeguarding the rights of children in public and private schools and daycare centers. The law also prevents any organization or business from discriminating against a person because of a real or perceived disability, such as an infectious disease.

A second law, Section 504 of the Rehabilitation Act, bars schools, colleges and other organizations receiving federal funding from discriminating against children with disabilities. Section 504 identifies chronic liver disease as a “hidden disability.”

Most advocates say hepatitis B and C are disabilities that are protected by ADA and Section 504—even though these chronic liver diseases are relatively asymptomatic in children.

A third law, the Family Educational Rights and Privacy Act (commonly called FERPA or the Buckley Amendment) prevents school officials from divulging medical information about a student to anyone beyond essential school personnel. ADA also has provisions that protect student medical records.

Many states also have civil rights laws that, similar to ADA, protect people with infectious diseases and other disabilities against discrimination.

Of all these laws, ADA extends the most far-reaching protections for families of children with chronic viral hepatitis. Its goal is to protect the privacy and integrity of people with disabilities and to integrate them fully into their communities so no child is treated differently or isolated because of viral hepatitis. ADA requires all schools, organizations and businesses to treat children with infectious diseases just as they would any other child, unless the child poses a significant health risk that cannot be eliminated by a modification of procedures or by the provision of additional aids or services. All daycare centers and schools must evaluate the chance that viral hepatitis

transmission will actually occur during normal school or daycare activities and whether reasonable modifications of their policies, practices or procedures will lessen the chance of transmission and prevent the need to treat any child differently.

The evidence is overwhelming that the risk of transmitting hepatitis B or C is extremely low in daycare and school settings when standard precautions are followed.

According to health experts, the presence of a person with hepatitis B or C poses no significant risk to others in school, daycare, or school athletic settings as long as all teachers, staff and coaches are properly trained in first aid and standard precautions.

Who Determines What Medical Condition (or Child) Poses a Health Risk?

Determining who is a significant health risk and under what circumstances is extremely important, and the ADA is very clear about who plays the role of health risk arbiter.

A medical expert using up-to-date information must make this assessment—not a teacher, principal, daycare provider or another parent.

“I’ll never forget the day my daughter entered kindergarten,” said a mother of a child with hepatitis B. “The teacher decided my child should be transferred to another class because a boy in the class was receiving chemotherapy and she thought my daughter posed a health risk. To make matters worse, the teacher asked the boy’s parent, who happened to be a doctor, whether she thought a student in the classroom with hepatitis B posed a health risk to her son. The doctor-parent, who was not a gastroenterologist, had no idea.

“I was furious,” the mother recalled. “The next morning, I was waiting for the principal when he walked into the school. I explained that they had violated the ADA by failing to consult a proper medical expert when evaluating the alleged health risk, and they violated FERPA by disclosing medical information about a student to someone who was not a school official. They hadn’t even checked the boy’s records to see if he had been vaccinated against hepatitis B. It turned out he had been.”

The school principal apologized on behalf of the school district, the child with viral hepatitis stayed in the classroom, and the school district incorporated ADA language that defined how a medical risk was to be evaluated into its own regulations. During the next teacher workshop day, school officials reviewed the right to privacy provisions under FERPA with teachers and held a standard precautions training session. Daycare centers and schools usually contract with doctors who, under ADA, could serve

as a medical expert in such health risk assessments. School nurses often lack the expertise needed to make informed assessments about health risks posed by viral hepatitis.

ADA regulations clearly state, “The determination that a person poses a direct threat to the health or safety of others may not be based on generalizations or stereotypes about the effects of a particular disability; it must be based on an individual assessment that considers the particular activity and the actual abilities and disabilities of the individual. The individual assessment must be based on reasonable judgment that relies on current medical evidence.”

It is important to remember that under ADA, schools can only treat children with infectious diseases differently from other students where there is a significant health risk that is based in science, not speculation or fears of contagion.

When Does a Child Pose a Health Risk?

When does a child with an infectious disease pose a health risk to others? Parents wrestle with this question daily whenever their child visits a friend, attends a sleepover or goes to soccer practice.

Among children and teens, hepatitis B and C viruses are spread primarily through sexual contact, sharing injecting drug equipment and exposure of open sores, cuts or mucous membranes (inside the nose and mouth and around the eyeballs) to infected blood.

Young children are unlikely to engage in sexual activity or share needles. Exposure could come from skin abrasions or nosebleeds that result in blood spills.

If the classroom or daycare center is properly supervised, and if the staff is trained in standard precautions and first aid, it is unlikely that any student will come into contact with another student’s blood, according to reports by the National Centers for Disease Control and Prevention (CDC).

CDC has recommended guidelines to prevent viral hepatitis transmission in daycare facilities and schools. These guidelines are important because they protect infected and uninfected students alike. No parent wants their child, with or without viral hepatitis, exposed to any bloodborne diseases.

- Daycare centers and schools should require students and staff to all be immunized against hepatitis B, as recommended by CDC and the American Academy of

Pediatrics (AAP). (Currently, there is no vaccine against hepatitis C.)

- Staff should be properly trained in standard precautions and first aid.
- Children should not share toothbrushes or drinking cups, to prevent any disease transmission.
- Blood spills should be cleaned up immediately by staff wearing gloves.
- Any surfaces on which blood has been spilled should be cleaned using a freshly-prepared 10-part water to 1-part bleach solution.
- Daycare teachers should wear gloves when changing diapers to prevent transmission of the hepatitis A virus.
- Children should wash their hands frequently, and always after using the toilet.
- If teachers have open sores, cuts or other abrasions on their hands, they should be sure to wear gloves when changing diapers, cleaning up blood spills or coming into contact with any body fluids.
- Students should be observed for aggressive behavior, such as violent biting or scratching that could result in bloodborne disease transmission. (This last recommendation should apply to all students, considering many children infected with viral hepatitis or other bloodborne diseases have not yet been diagnosed and are unaware of their infection.)

Biting Among Young Children

One of the big issues that confronts daycare providers and parents of young children, ages 2 to 4, is biting. From a disease-fighting perspective, biting is a two-way street.

If an uninfected child bites an infected child hard enough to produce a blood spill into the biter's mouth, there could be exposure to a bloodborne virus.

If an infected child bites another hard enough to break the skin, there may be a low chance of transmission. Saliva contains very low quantities of hepatitis viruses. In fact, even deep and vigorous kissing, which could cause abrasions and bleeding, is considered a minor risk for hepatitis virus transmission by health officials. A daycare center is required to make reasonable accommodations if a chronically

infected child (or another child in the same class) exhibits violent behavior that could result in a blood spill and bloodborne transmission of a virus.

Teachers, parents and a physician who can serve as the medical expert need to weigh whether the biting period is likely to be short-lived, or whether the child exhibits continuous violent behavior. If biting persists, CDC recommends a team made up of the child's parents or guardians, childcare provider, daycare physician and child's physician be involved in deciding whether a child poses a health risk to others in that daycare setting.

This decision, under ADA, cannot be made arbitrarily. The team must make an individualized assessment based on current medical knowledge or on the best available objective evidence to determine the nature, duration and severity of the potential health risk.

A daycare center's refusal to admit a child who has viral hepatitis, because of the fear that the child might bite and might therefore transmit the virus to other children, is a violation of ADA. It is incorrect to assume that all young children bite.

School Sports—How High a Risk?

Although participation in contact sports, such as football, softball, baseball and soccer, carries a risk of blood spills, the risk of disease transmission is so low that the AAP and CDC do not recommend players be barred from a sport because of an HIV or hepatitis B or C infection. However, it is critical that training in first aid and standard precautions be offered to students and coaches alike. Students should ideally receive some standard precautions and disease prevention education through school health classes.

The following is an excerpt from a sample school policy, used by numerous public school districts and in compliance with ADA, that addresses HIV infection, another bloodborne virus. However, it can be used as a model to address any bloodborne infectious disease.

“The privilege of participating in physical education classes, programs, competitive sports and recess is not conditional on a person's HIV status. School authorities will make reasonable accommodations to allow students living with HIV infection to participate in school-sponsored physical activities.

“All employees must consistently adhere to infection control guidelines in locker rooms and all play and athletic settings. Rulebooks will reflect these guidelines. First aid kits

and standard precautions equipment must be on hand at every athletic event.

“All physical education teachers and athletic program staff will complete an approved first aid and injury prevention course that includes implementation of infection control guidelines. Student orientation about safety on the playing field will include guidelines for avoiding HIV infection.”

Ideally, schools, daycare centers and other organizations should create policies and follow up with appropriate training in standard precautions so all students, regardless of their infectious disease status, can participate in all school, daycare or camp sporting activities. Schools and daycare centers should also remember that standard precautions are necessary because they do not know the infectious disease status of all the children in their care. Singling out children with known infectious diseases, in other words, is not an effective approach.

ADA and Section 504 Protections in Schools

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination based on disability by recipients of federal financial assistance—especially public schools.

The main difference between the two laws is that one applies to the recipients of grants from the federal government (Section 504) and the other applies only to public entities (Title II of ADA). A school or college may be both a recipient of federal funds from the U.S. Department of Education and also a public entity. In such cases, the institution would be covered by both ADA and Section 504.

Virtually all public school districts are covered by Section 504 because they receive some federal financial assistance. Most public and private colleges and universities also receive federal financial assistance.

ADA, enacted in 1990, has deep roots in Section 504. The primary difference is that while Section 504 applies only to organizations that receive federal funding, ADA applies to a much broader universe of public and private entities.

However, when it comes to education, ADA’s objectives and language are very similar to Section 504. For this reason, both laws as they relate to education are administered by the Department of Education’s Office for Civil Rights (OCR) and are considered essentially identical. Patterned after Section 504, the applicable provision of the ADA similarly states in Title II, 42 U.S.C. §12132:

“Subject to the provisions of this title, no qualified individual with a disability shall, by

reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity or be subject to discrimination by any such entity.”

Section 504 has a specific set of regulations that apply to preschool, elementary and secondary programs that receive or benefit from federal financial assistance. ADA regulations apply to daycares, preschools and private schools that do not receive federal funds.

Although ADA applies to public schools by virtue of Title II, the regulations have no specific provisions regarding education programs. Therefore, in interpreting ADA, the OCR uses the standards defined by Section 504.

In effect, virtually every violation of Section 504 is also a violation of the ADA as it applies to students; in fact, the OCR has stated that complaints alleging violations of one statute will automatically be investigated for violations of the other.

Filing Complaints Under ADA and the Rehabilitation Act

A person who believes a child is being discriminated against by either a school or daycare should first try to educate the daycare center manager or owner or school administrator about the protections mandated by ADA. There are advocacy organizations in each state that can assist families with disabilities who face discrimination. A parent can also suggest reasonable policy changes that will provide equal access to daycare or school services.

Parents may seek mediation services provided by community or private mediation programs. If the situation is not resolved satisfactorily, a complaint may be filed with the U.S. Department of Justice. The Department of Justice is authorized to investigate complaints and to bring lawsuits in cases of general public importance, or where there is a “pattern or practice” of discrimination.

Due to resource limitations, the department is unable to investigate every complaint. The department may seek injunctive relief (i.e., having the daycare center correct its discriminatory practices) or monetary damages and civil penalties.

ADA and Rehabilitation Act complaints should be sent to the Disability Rights Section, Civil Rights Division, Department of Justice, P.O. Box 66738, Washington D.C. 20035-6738 (www.ada.gov).

Individuals are also entitled to bring private lawsuits. If a person files a private lawsuit

under ADA, he or she may not seek monetary damages in most cases. However, parents may seek policy changes at the daycare or school, reinstatement of students, and reimbursement of attorney's fees and costs. If a person files a private lawsuit under the Rehabilitation Act against an entity that receives federal funding, monetary damages and changes in policy are both available.

What Schools Must Do to Prevent Harassment Based on Disability

Children have a right to an education that is free from the fear and humiliation that comes with harassment by other students or staff. In July 2000, the Department of Education's Office of Civil Rights wrote a letter to educators warning of their legal and educational duty to stop harassment of disabled students under Section 504 and ADA.

"Disability harassment can have a profound impact on students, raise safety concerns and erode efforts to ensure that students with disabilities have equal access to the myriad benefits that an education offers. Indeed, harassment can seriously interfere with the ability of students with disabilities to receive the education critical to their advancement," wrote Assistant Secretary for Civil Rights Norma V. Cantu. "Teachers and administrators must take emphatic action to ensure that these students are able to learn in an atmosphere free from harassment."

If a school fails to halt harassment, parents can initiate administrative due process procedures under Section 504 or ADA to address the basic denial of a proper and free education, which is guaranteed by federal law. Parents and organizations can also file complaints with the Department of Education's Office of Civil Rights. Harassing conduct also violates many state and local civil rights laws. If a school fails to intervene, it risks civil and criminal action, depending on the severity of harassment, and it could lose its federal funding.

The office suggests schools and colleges take the following steps to prevent and eliminate harassment:

- Create a campus environment that is aware of disability concerns and sensitive to disability harassment, weaving these issues into the curriculum or programs outside the classroom.
- Encourage parents, students, employees and community members to discuss disability harassment and to report it when they become aware of it.
- Widely publicize anti-harassment statements and procedures for handling

discrimination complaints. This information makes students and teachers aware of what constitutes harassment, that such conduct is prohibited, that the institution will not tolerate such behavior, and that effective action, including disciplinary action where appropriate, will be taken.

- Provide appropriate, up-to-date and timely training so staff and students can recognize and handle potential harassment.
- Provide counseling to victims and harassers alike.
- Implement monitoring programs to follow up on resolved issues of disability harassment.
- Regularly assess and modify existing disability harassment policies and procedures to address any new issues.

The Office of Civil Rights offers technical assistance to schools, parents and disability advocacy organizations to ensure no student is harassed. For more information, contact the office at 800-USA-LEARN or 800-437-0833 (TTY) or 202-205-5507.

FERPA Protects the Privacy of Student Medical Records

All public schools keep records and files on each student. Academic grades, teacher evaluations, disciplinary actions, I.Q. and achievement scores and medical and immunization reports are all kept in a student's file.

Until 1974, this information was made available to almost everyone—potential employers, colleges, draft boards and police—but not to students or their parents.

In 1974, the federal Family Educational Rights and Privacy Act (FERPA, also called the Buckley Amendment) became law. This law gives parents and adult or emancipated students access to student records and prevents the release of these records to third parties without written consent. All public schools and institutions that receive federal funds are subject to this law.

The only people who may have access to student records without such consent are school officials with “legitimate educational interests,” such as school officials at a school where the student is transferring to, certain state and federal educational agencies, financial aid personnel (only financial information), research organizations as long as the information remains confidential, accrediting organizations, health officials

(if such access is necessary to protect community health) and, in complying with a court order, law enforcement officials, probation officers and court personnel.

Certain records may be withheld from students and their parents, including notes from a teacher not shown to anyone except a substitute teacher, school security information, records of students' post-graduate activities, personnel records of school employees and the records of a school where a student applied but never attended.

FERPA requires that each school annually prepare a statement that explains the procedure for examining a student's records. Parents and eligible students are entitled to copies of these procedures. The law also provides a way in which parents and students can change or eliminate incorrect or misleading records.

To do this, the parent or student first requests the change in writing. If the school refuses, then a hearing is held before a neutral hearing officer in which witnesses may testify and written evidence may be introduced.

If the hearing officer decides in favor of the school, the parents have the right to include a statement in the records explaining why they believe the information is wrong. The school must include this statement every time the records are released to a third party.

Students and their parents cannot bring individual lawsuits to enforce a claim under FERPA, but they may file a complaint with the U.S. Department of Education concerning alleged failures by a school to comply with the requirements of FERPA, and the Department can investigate those complaints. Any complaint must be made within 180 days of when the claimant learned of the circumstances of the alleged violation.

Complaints can be sent to:

Family Policy Compliance Office
U.S. Department of Education
400 Maryland Avenue, SW
Washington, DC 20202-5901

Can Daycare Providers and Schools Ask About Infectious Diseases?

Given the clear laws that prohibit discrimination based on health issues, why do schools, camps and daycare centers continue to ask if a child has a "chronic or infectious health issue?"

Under ADA, employers are prohibited from asking such questions of job applicants, yet

schools and organizations routinely ask these questions of students and applicants.

According to Dr. Harold Margolis, former director of the Hepatitis Division at the Centers for Disease Control and Prevention (CDC), disclosure is not necessary to protect the safety of students and staff.

“Students infected with HIV, HBV (hepatitis B virus) or HCV (hepatitis C virus) do not need to be identified to school personnel, based on the assumption that school staff are using standard precautions when handling first-aid or emergency situations,” Dr. Margolis stated. “Since HIV-, HBV- and HCV-infected children and adolescents will not be identified, policies and procedures to manage potential exposures to blood or blood-containing materials should be established and implemented, and parents should take an active role to ensure these are in place.”

If a child has a hepatitis B virus infection and the school requires vaccination for hepatitis B, Dr. Margolis recommended, “the child’s physician might want to provide the school with a letter stating that your child is ‘immune’ or shown by testing to not be susceptible to hepatitis B virus infection.”

Disclosure to daycare centers is also not recommended, said Dr. Margolis. “However, procedures should be in place for any special health problems or medical conditions that a child might have and that might need specific action. Examples of conditions needing procedures/actions might include allergies, asthma, diabetes, epilepsy and sickle cell anemia. These conditions can cause life-threatening attacks that may require immediate action. You should know 1) what happens to the child during a crisis related to the condition, 2) how to prevent a crisis, 3) how to deal with a crisis, and 4) whether you need training in a particular emergency procedure. Again, all aid should be rendered using standard precautions.”

How Should Parents Respond to These Questions?

While CDC and the American Academy of Pediatrics oppose disclosure of children’s infectious disease status, at this time no federal rules or regulations or court decisions prevent schools, daycare centers, camps or other organizations from asking prospective students or campers about their infectious disease status.

The confusion continues because this issue is in the early stages of legal review. The Department of Justice, which administers and enforces ADA, has not issued any guidelines or “technical assistance” papers on this particular issue, nor have there been court challenges or rulings that address whether a school or daycare center can ask about

a student's infectious or chronic disease status.

Until there is more legal clarity, parents must individually decide how to handle the questions given the conflicting or the absence of clear legal directives.

Some parents say they simply do not respond to the questions. Others say they fill them in rather than risk personal liability or a charge of negligence if they do not truthfully answer the application.

"I know schools are supposed to keep this information completely private, but I think we all know that word travels fast, especially in small towns," said a mother of a child with viral hepatitis. "I look at these forms and I have to balance my child's need for confidentiality and privacy, which is supposed to be guaranteed under ADA, against truthfully putting teachers or camp counselors on alert that they should practice universal precautions. Frankly, I just don't know what to do."

The Department of Justice is, on occasion, asked for "technical assistance" to provide non-legally binding advice on implementation and adherence to ADA guidelines.

In December 1994, John L. Wodatch, chief of the DOJ's Public Access Section, responded to a question about what medical information daycare centers can legally request from families under ADA.

Wodatch wrote, "Child care providers may ask of all applicants whether a child has any diseases that are communicable through the type of incidental contact expected to occur in child care settings. Providers may also inquire about specific conditions, such as tuberculosis (an airborne infection), that in fact, pose a direct threat. Medical experts may and should be consulted if specific questions are to be asked, and care must be taken to insure that inquiries are made only about specific conditions that in fact pose a direct threat in the type of conditions present in the particular facility in question."

If the decision is made to disclose information about a child's medical status to his/her school or daycare center, it is a good idea to tell the school personnel that the information is not to be disclosed to others, and that this information may only be shared with others who have a medical need to know about the child's status. Making a request to keep a child's health information private may help prevent the school personnel from inadvertently sharing this information.