

1. What is this Notebook and How Should it Be Used?

This notebook is a tool designed to provide advocates with information and resources that will be helpful in working for the rights of students with diabetes. It contains sections discussing the legal rights of these students, strategies for securing these rights, and procedures to be followed when disputes cannot be resolved informally. The notebook also contains useful forms and a list of resources that can be consulted for further information. This notebook is only one component of the extensive assistance that the American Diabetes Association provides to support advocates for those with diabetes.

1.1 What is this notebook?

Legal Rights of Students with Diabetes is an authoritative and comprehensive notebook designed to assist advocates throughout the process of working with schools to secure appropriate care for students with diabetes. More detailed information about the topics covered and the organization of this notebook can be found in Question 1.4. Although the purpose of the notebook is not to steer advocates immediately toward litigation as a means of resolving disputes, it does provide the information lawyers need should legal action become necessary. Finally, the notebook provides extensive resources that advocates can use during the process of working with school personnel, including forms, web sites, and information about state laws.

1.2 Who should use this notebook?

This notebook is designed to assist advocates who need detailed information on the legal rights of students with diabetes and on how those rights can be enforced. It will be most useful to attorneys who are representing or assisting parents or guardians, since it contains many references to statutes, court opinions and administrative agency letters of finding. However, this notebook can still be useful to advocates without legal training, including parents or guardians, so long as they understand that this notebook is not legal advice and cannot substitute for the advice of a licensed attorney in situations where legal advice is needed. Advocates who are not attorneys may want to become familiar with some of the types of legal documents referenced in this notebook, which are discussed in the next question. The information in this notebook is quite detailed; advocates who need more general information about diabetes or about the legal rights of students with diabetes are encouraged to consult some of the other resources available from the Association (see Question 1.5). Schools, as well as their health care providers and attorneys, may also find this notebook useful to better understand the responsibilities they have to students with diabetes.

1.3 How should this notebook be used?

The notebook is meant to be a resource for answering specific questions during the process of advocating for the rights of a student with diabetes. Therefore, while this notebook can be read as a “textbook”, from cover to cover, individual parts can also be consulted as the need arises. The text is organized in a question and answer format; by consulting the detailed table of contents, advocates can quickly and easily find the topic they are seeking and turn directly to that part or question. For a more detailed description of the notebook’s organization, see the next question.

Many of the answers to the questions in the text are followed by a section of “Notes” which provides more detailed information on the topic. Many of these Notes contain references to statutes, regulations, court cases, or administrative decisions. While the notebook can be successfully used without consulting these references, some understanding of the differences between these sources is helpful. While the sources referenced (statutes, regulations, agency decisions, and cases) all are important parts of the legal framework governing the responsibilities of schools to students with diabetes, some types of legal sources are more persuasive and more binding on school districts 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 the schools, districts, or individuals they cover. The major federal laws relevant to students with diabetes are discussed in Question 4.1. Some relevant state statutes are listed in the Supplemental Information section. 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 what it means. Most of the regulations discussed in this notebook are issued by the U. S. Department of Education to implement the federal civil rights laws that protect students with diabetes (discussed in Question 4.1), although many states also have regulations that may need to be considered. Regulations are also binding on those to whom they apply, unless they are clearly in conflict with the laws they were issued to implement (which happens infrequently). 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 diabetes 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 each of which covers a different geographic region of the country), and district courts (trial courts) in each state. Court opinions are legally binding on courts which 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 (much of the western U.S.) but not on district courts in other regions. Even when not binding, however, often a court’s interpretation of the law will 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 notebook 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 in this question. Most of the administrative decisions cited in this notebook are issued by the U. S. Department of Education's Office for Civil Rights, but some are issued by state agencies hearing appeals from due process hearings. (For more information on OCR procedures as well as due process hearings, see Part 14). OCR agreements are only binding upon the subject school district. However, they might be used as a negotiation tool by the diabetes advocate. Many administrative decisions cited in this notebook 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 this notebook, 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: <http://www.law.cornell.edu>. Although some are available on the Internet or through the American Diabetes Association's web site, the usual source for copies of cases and administrative decisions is a local law library.

1.4 How is this notebook organized?

The notebook is divided into sections, each of which focuses on a particular topic of concern and contains specific questions and answers related to that topic. The notebook begins with general information on the medical aspects of diabetes, on the legal obligations of schools, and on the process by which needed services and accommodations are determined and documented. The middle sections address what schools are required to do in specific settings, including diabetes care at school, academics, extracurricular activities, and discipline. The final sections address the process for resolving disputes, alternative legal theories that may be available, and the rights of students in postsecondary institutions.

More specifically, the parts of this notebook are as follows:

- Part 1 (this section) describes the notebook and its organization, as well as the other services the American Diabetes Association provides to advocates.
- Part 2 provides background information on diabetes, including information about the symptoms and treatment of the condition and how it can affect students in

school. This information can be useful as background for advocates or for educating school officials.

- Part 3 contains definitions of a number of terms which are important to an understanding of diabetes care or of the legal rights of students with diabetes.
- Part 4 introduces the three main federal laws that protect students with diabetes: the Rehabilitation Act, the Americans with Disabilities Act, and the Individuals with Disabilities Education Act. The section discusses which individuals and which schools are covered by each law, and also briefly discusses state antidiscrimination laws.
- Part 5 addresses how the process for requesting accommodations and services should be initiated, including how requests should be made, what they should contain, and a school district's duty to evaluate students who may need services.
- Part 6 discusses the process by which the school district develops plans to accommodate the health and educational needs of students with diabetes. This section explains how parents or guardians participate in this process and issues surrounding the release of medical information.
- Part 7 addresses how accommodations and services should be documented, including what should be included in a written plan and when and how these plans should be revised.
- Part 8 discusses specific services and accommodations that may be needed to ensure that students get appropriate diabetes care. This section covers medication administration, emergency situations, and food in the school setting.
- Part 9 addresses the key question of who should provide diabetes care services to students. It discusses both permitting self-care and the need for trained personnel to provide care when needed.
- Part 10 addresses whether non-health care professionals can and should be trained to provide diabetes care, and emphasizes the Association's position that such personnel are a crucial part of effective diabetes care in schools.
- Part 11 discusses academic modifications that may be required for students because of their diabetes, including issues that arise on standardized and classroom tests and absences related to diabetes care.
- Part 12 discusses a school's obligation to provide services to students outside of the classroom, including coverage for field trips, extracurricular activities, athletic events and school bus rides.
- Part 13 addresses disciplinary issues that can arise when a student's conduct may be related to diabetes.
- Part 14 outlines the procedures to be followed when disputes cannot be resolved informally. The section covers procedures under the three federal laws that protect students with diabetes, including complaint procedures, deadlines, and prerequisites to litigation.
- Part 15 discusses state tort law remedies that may be available to students with diabetes for injuries suffered in the school setting.

- Part 16 explains the obligations of postsecondary institutions, including colleges, universities and vocational and trade schools, to serve students with diabetes, and how these obligations differ from those of elementary and secondary schools.
- The Supplemental Information found at the end of this notebook includes brief descriptions of state statutes, court cases and administrative decisions, as well as forms that may be useful to advocates and a list of general and state-specific resources.

1.5 How does the American Diabetes Association assist advocates?

Founded in 1940, the American Diabetes Association is the nation's premier nonprofit voluntary health organization. The Association's mission is to prevent and cure diabetes and to improve the lives of all people affected by diabetes through diabetes research, information, education, and advocacy. While maintaining its leadership in research and education, in recent years it has also become active in eliminating discrimination against people with diabetes through the use of education and negotiation, federal and state litigation, legislation and regulatory reform.

Protecting the rights of school children with diabetes is an area of special interest to the American Diabetes Association. As a result, the Association provides considerable assistance to advocates representing the interests of children, including:

- The Association maintains a website providing advocacy and legal resources. The site is at: <http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/>, and can also be accessed by going to the Association's home page at <http://www.diabetes.org> and clicking on "Living with Diabetes", then "For Parents & Kids", and then "Diabetes Care at School". The website also contains extensive information about diabetes and diabetes care that can be useful to advocates and others who need to educate school personnel about diabetes. Go to the home page and click on the "All About Diabetes" link. A school discrimination packet is also available by calling 1-800-DIABETES.
- The Association provides publications and written materials to assist advocates. Key materials in the area of diabetes care at school include:

A library of research materials for attorneys), including cases, court briefs, and administrative documents (available at <http://www.diabetes.org/living-with-diabetes/know-your-rights/for-lawyers/>).

Becoming a Diabetes Advocate in the Schools (April 2004), available at <http://www.diabetes.org/assets/pdfs/schools/becomingdiabetesadvocatesc hools.pdf>, a brochure that provides an outline of the Association's advocacy strategies for addressing the issue of diabetes care for children in school using the Association's four-step approach of educate, negotiate, litigate, and legislate.

Helping the Student with Diabetes Succeed: A Guide for School Personnel (June 2003), available at http://www.ndep.nih.gov/media/Youth_NDEPSchoolGuide.pdf, a guide by the National Diabetes Education Program (NDEP), a federally

sponsored partnership of the National Institutes of Health, the Centers for Disease Control and Prevention, and more than 200 partner organizations, including the American Diabetes Association. The purpose of the guide is to educate and inform school personnel about how diabetes is managed and how each member of the school staff can help meet the needs of students with diabetes. It is highly recommended that all diabetes school advocates obtain a copy of this guide.

Diabetes Care Tasks at School: What Key Personnel Need to Know, available at <http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/school-staff-trainings/diabetes-care-tasks.html>, a series of downloadable PowerPoint training modules developed by the Association that can be used by a school nurse or other health care professionals to train school staff members on performing diabetes care tasks.

For the latest resources available from the American Diabetes Association, advocates should check the Association's web site.

- The Association's legal advocacy staff includes attorneys and other legal professionals who are available to discuss issues important to protecting the rights of school children. Association staff regularly work with attorneys to help formulate strategy, review legal pleadings, and locate expert medical consultants.
- The Association participates in important litigation having a broad impact on the lives of people with diabetes. This participation often takes the form of submitting amicus (friend of the court) briefs. The Association's Legal Advocacy Subcommittee, whose membership includes attorneys and health care professionals, supervises these efforts.
- The Association maintains a network of attorneys interested in protecting the rights of people with diabetes. These attorneys are often willing to serve as advocates for students or assist parents in advocating for their children.

The Association has many resources available to help advocates succeed, and encourages advocates to take advantage of these resources by contacting the Association or consulting its web site.