

# KEEPING KIDS WITH DIABETES SAFE AT SCHOOL



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**Friends for Life**  
Orlando, Florida  
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## Mission

**TO PREVENT AND CURE DIABETES  
AND IMPROVE THE LIVES OF ALL PEOPLE AFFECTED BY  
DIABETES**

### We deliver mission through:

- Research
- Information & Support
- Advocacy & Public Awareness



## ADA Youth Initiatives



**Safe at School Campaign**



**CAMP**



**Everyday Wisdom Kit for Newly Diagnosed**



**National Youth Advocate**



## Session Key Points

- Back-to-school considerations
- Safe at School Campaign
- School diabetes care challenges
- Federal and state laws
- Development of 504 and strategies to overcome challenges
- Resources



## Goals for School Diabetes Care

- Schools must provide a medically safe environment for students with diabetes.
- Students with diabetes must have the same access to educational opportunities and school-related activities as their peers.
- Schools must work with parent and student to support transition to independence.



## School Best Practice Components

- Blood glucose monitoring
- Recognition and treatment of hypo and hyper
- Insulin/medication administration
- Carbohydrate intake/accurate calculation
- Self-management permitted for capable students

Diabetes care should be the same at school as it is at home to ensure smooth, healthy and safe transition from home to school

## What is Needed to Achieve

- Availability of trained personnel and/or school nurse
- Access to immediate routine and emergency treatment
- Self-management and self-possession anywhere, anytime for mature and capable students
- Optimal blood glucose range for test-taking
- Full participation in all school-sponsored activities
- Blood glucose in target range for exams

These are some examples of what your child needs in place at school in order to be safe, healthy and best positioned to achieve academic success.



## **We Know That.....**

- **Diabetes care is 24/7**
- **Child with diabetes cannot take a break**
- **Smooth transition from home to school is essential**
- **Child must have access to equipment, medication, and assistance is essential**
- **Written care plans are essential, as provided for by federal and state laws**

## A Word About School Nurses....

**ADA supports goal of full time nurses.**

**However:**

- Most schools do not have a full-time school nurse.
- Even a full-time school nurse is not at all places at all times.
- The needs of students with diabetes must be met.
- ADA supports a safe model that utilizes trained school personnel in the absence of a school nurse.



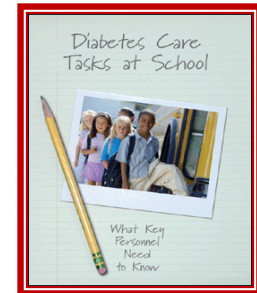
## Safe at School Campaign

**All school staff members need to have a basic knowledge of diabetes and know who to contact for help.**



**The school nurse is primary provider of diabetes care, but other school personnel must be trained to perform diabetes care tasks when the school nurse is not present.**

**Students should be permitted to provide self-care whenever they are at school or school-related activities.**



## Safe at School Principles Endorsed by:

American Academy of Pediatrics

American Association of Clinical Endocrinologists

American Association of Diabetes Educators

American Diabetes Association

Academy of Nutrition and Dietetics

Children With Diabetes

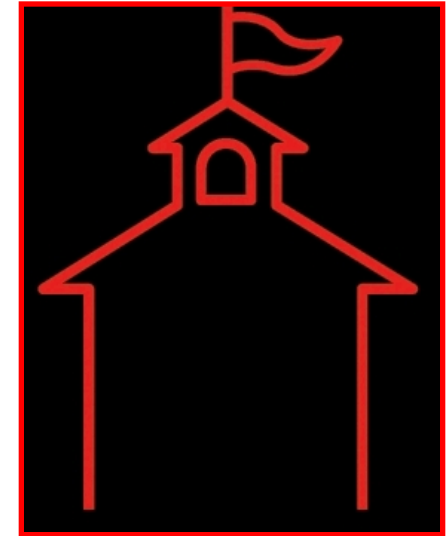
Disability Rights Education and Defense Fund

Juvenile Diabetes Research Foundation

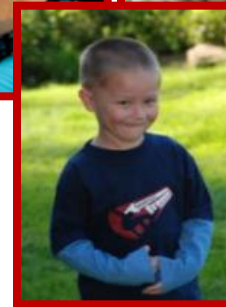
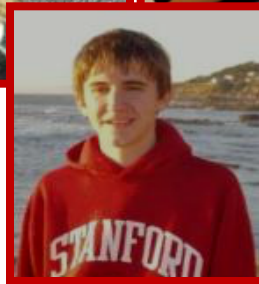
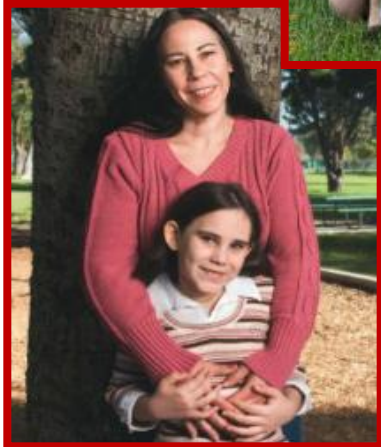
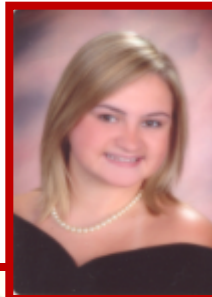
Pediatric Endocrine Society

Pediatric Endocrinology Nursing Society

Endocrine Society



# Who Is Discriminated Against Because of Diabetes?



## Challenges Facing Students with Diabetes



- Failure to have trained staff to assist student with diabetes.
- School's refusal to administer insulin.
- School's refusal to administer glucagon.
- No coverage during field trips and extracurricular activities.

## Challenges Facing Students with Diabetes



- School's refusal to permit blood glucose checks outside of the health clinic or office.
- Sending child to "diabetes school."
- School's refusal to allow a student to attend the school at all.

## Is Your CWD Being Discriminated Against?

### Discrimination occurs when students:

- Don't get the care they need, OR
- Only get the care they need:
  - By missing out on school activities, or
  - Only when a family member can provide assistance at school
- Learning is compromised.
- Health is compromised.
- Legal rights are compromised.



## Federal and State Laws to the Rescue

**These laws can help level the playing field and ensure a safe and fair school environment for our children**

### Federal laws

- Americans with Disabilities Act (ADA)
- Section 504 of the Rehabilitation Act of 1973 (Section 504)
- Individuals with Disabilities in Education Act (IDEA)

### State laws, regulations and guidelines

## ADA and 504 - Civil Rights Laws

- Prohibit discrimination on the basis of disability.
- Also prohibit retaliation for asserting the right not to be discriminated against.
- NOT limited to disabilities that affect learning/ academic progress.



## Definition of Disability

**To be protected by ADA/504 the student must have a disability, defined as:**

- a physical or mental impairment that substantially limits one or more of major life activities
- a record of such an impairment, or
- being regarded as having such an impairment.

**This includes children with diabetes!**

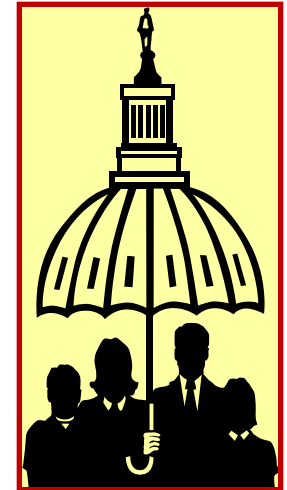
## Substantial Limitation of Major Life Activities (ADA & 504)

- Endocrine function
- Caring for one's self
- Performing manual tasks
- Eating
- Walking
- Breathing
- Learning
- Working
- Speaking

**NEED NOT BE LEARNING!**

## Americans with Disabilities Act (ADA)

- **Covered schools:** public, private, schools and day care centers –
- **Not covered:** religious institutions
- **Requirements** – Schools must: make reasonable changes in practices and policies to:
  - avoid discrimination
  - afford equal opportunity, unless doing so imposes an undue burden.



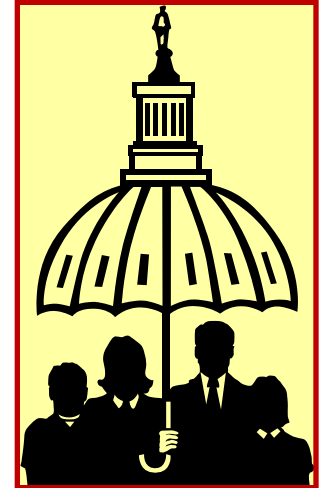
## Section 504

- **Covered schools:** All public schools and private schools (including religious schools) that receive federal financial assistance.
- **Requirements – Schools must:**
  - Identify children with disabilities.
  - Provide free and appropriate public education (FAPE).



## Section 504

- **Requirements – Schools must:**
  - Educate children with disabilities with other students as much as possible.
  - Allow parental participation in decisions.
  - Provide equal opportunity to participate in nonacademic and extracurricular activities.



## Individuals with Disabilities Education Act (IDEA)

- A child with diabetes is covered if he or she needs special education and related services in order to benefit from an education. Diabetes must adversely interfere with academic performance.
- School must provide special education program and related services. Children must be educated in the least restrictive environment.
- Team that includes parents, special education experts, and school staff develop Individualized Education Program (IEP) which outlines plan to achieve specific educational goals.



## Diabetes and IDEA

- May be eligible if another disability – other than diabetes - that limits learning/academic progress
- Frequent swings in blood glucose adversely impact learning
- Students who qualify under IDEA are also covered by ADA/504, but do not need a separate 504 plan

## Religious Schools

- Must comply with federal law if federal funds are received.
- May develop 504 Plans/IEPs for students.
- Sources of federal funds may include free or reduced breakfast and lunch programs, technology assistance or program grants, funding for textbooks and supplies.



## Navigating the 504/IEP Process

- Parents/guardians should contact school's 504/IEP coordinator
- School may initiate if suspects a need for special education or related services
- An evaluation for eligibility under 504 or IDEA will be conducted by school staff knowledgeable about your child
- Once an eligibility determination has been made, the 504/IEP team will convene to develop a written plan

## Establishing Eligibility

### Parent/Guardian Must Do More than Simply State Child has Diabetes

- **Note from clinician stating that your child has a disability because he is substantially limited in endocrine function**
- **Note can also explain other major life activities that are limited when your child is experiencing hypo- or hyperglycemia**

## Review: Comparing the Laws

### Section 504:

- Public and private school receiving federal funds.
- Major life activity substantially limited does not need to be learning.

### ADA:

- Same as 504, except covers daycares and camps.
- Does not cover religious affiliated schools/ programs unless federal funds received.

### IDEA:

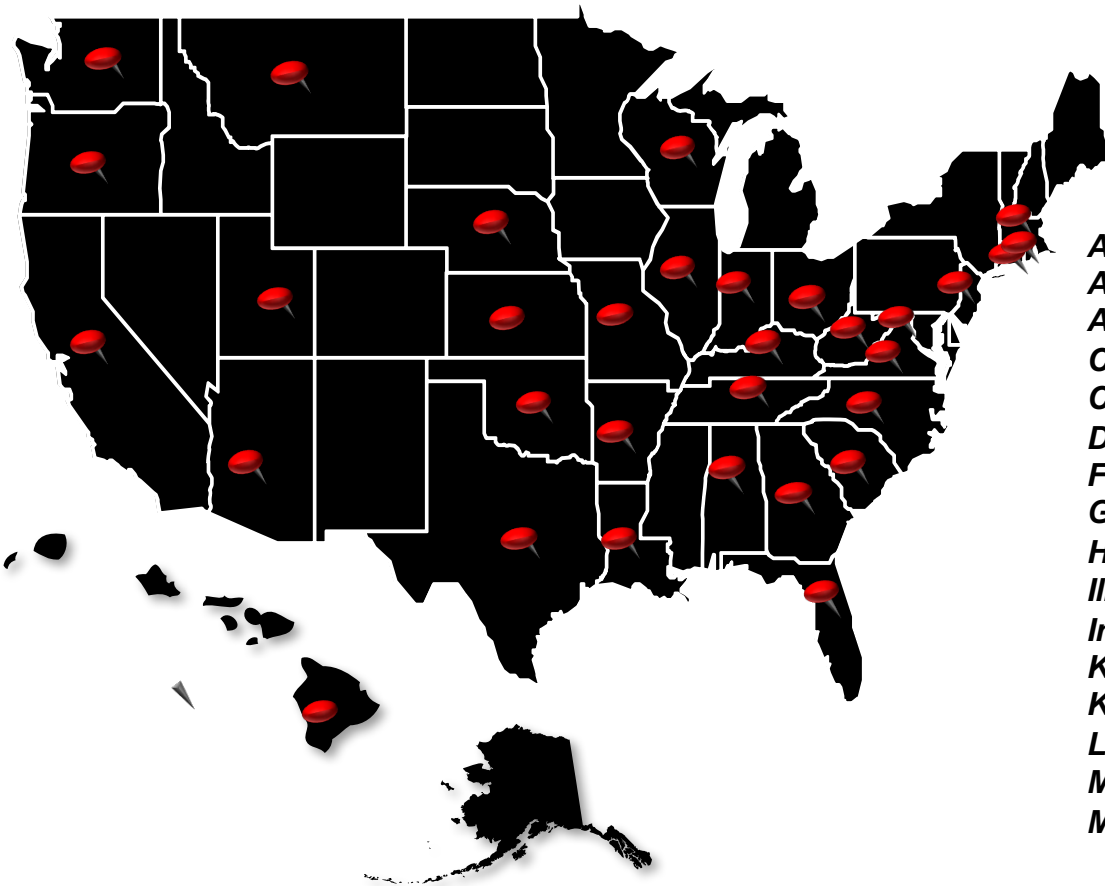
- Special education law.
- Must demonstrate that diabetes or another disability adversely impacts ability to learn and to progress academically.



## State Laws and Regulations

- State and local laws and regulations (i.e. Board of Nursing regs) vary regarding who may perform various aspects of diabetes care.
- Often there is no statewide policy. Rather, policy is determined district by district.
- Some states have developed guidelines.
- Regardless of state and local laws, requirements of federal laws must be met.
- Some states have passed school diabetes care legislation or changed Board of Nursing regulations.

## School Diabetes Care Laws



*Alabama  
Arizona  
Arkansas  
California  
Connecticut  
District of Columbia  
Florida  
Georgia  
Hawaii  
Illinois  
Indiana  
Kansas  
Kentucky  
Louisiana  
Massachusetts  
Missouri*

*Montana  
Nebraska  
New Jersey  
North Carolina  
Ohio  
Oklahoma  
Oregon  
Rhode Island  
South Carolina  
Tennessee  
Texas  
Utah  
Virginia  
Washington  
West Virginia  
Wisconsin*

*Board of Nursing Action: Nevada, Colorado, Utah, Alaska*

**Safe at School**

## What Does Your State Law Say?

- Is delegation of diabetes care tasks by the school nurse permitted, prohibited, or unclear?
- Is there a statute that addresses medication administration in the schools?
- Is there a Good Samaritan law?
- What is your state's nurse to student ratio?
- What state specific resources are available?





## Maryland, New York, Pennsylvania

Please contact Crystal Jackson [CJackson@diabetes.org](mailto:CJackson@diabetes.org) if you live in one of these states and are willing to share your child's school diabetes management challenge and willing to get involved with the Association's advocacy efforts in these states.

## Other Considerations

- **School Menu**
- **Standardized Testing – College Boards**
- **Post-Secondary Rights**



## School Menu

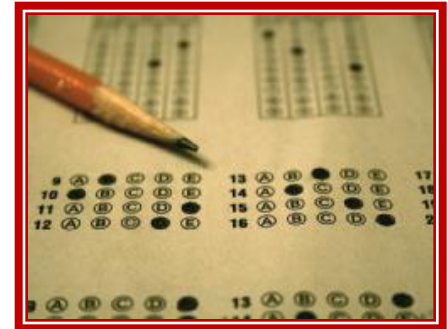
- Refer to USDA Guidance
- Schools must make food substitutions or modifications for students with disabilities



- Address menu and carb counts in your child's 504 Plan or IEP
- Work with your school nurse and a dietician to calculate carb counts if not already provided

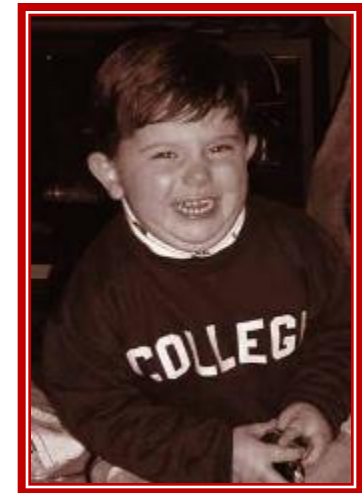
## College Boards

- PSAT, SAT, AP Tests
- Complete Student Eligibility Form
- Must provide documentation which may be your child's high school 504 plan
- Typical accommodations for students with diabetes include frequent breaks, longer breaks, access to food or supplies



## Post-Secondary Rights

- Compliance with Section 504 and ADA
- FAPE not required
- No identification requirement
- Must provide academic adjustments so that it does not discriminate because of student's diabetes
- Documentation required – high school 504 plan is not enough



## Written Plans Are Implementation Tools

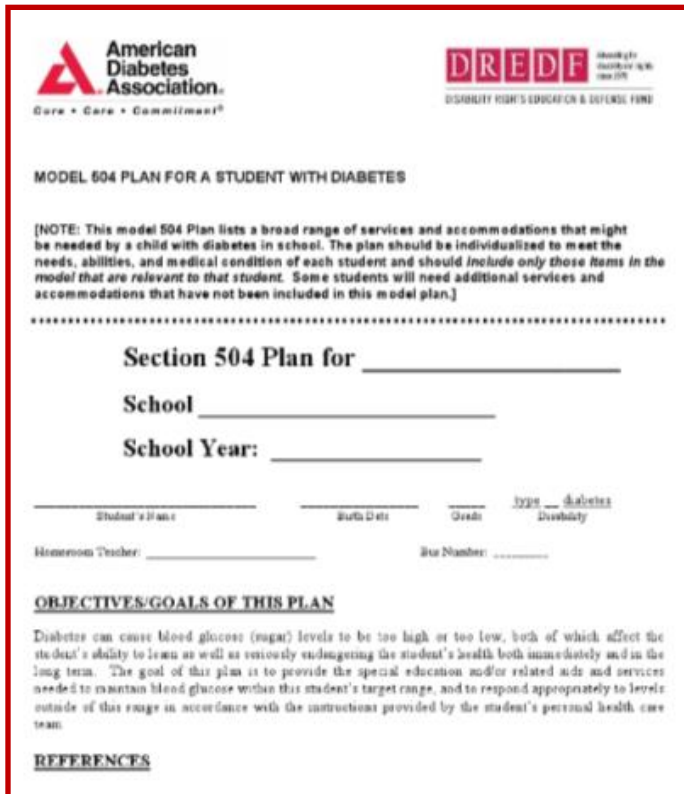
- Diabetes Medical Management Plan (DMMP)
- Individual Health Plan (IHP)
- Section 504 Plan (504)
- Individualized Education Program (IEP)





## DMMP – Diabetes Medical Management Plan

- Document developed and signed by your child’s health care provider.
- This can also be a health care plan, diabetes care plan or physician’s orders
- Sets out your child’s school diabetes care regimen.
- Used as a basis for development of Section 504 Plan or other written education plan.
- Should be updated annually or if your child’s regimen, level of self-management, or school circumstances change.
- Template in NDEP Guide

## What Is a Section 504 Plan?



 American Diabetes Association.  
Care • Cure • Commitment®

 DREDF  
Disability Rights Education & Defense Fund

MODEL 504 PLAN FOR A STUDENT WITH DIABETES

[NOTE: This model 504 Plan lists a broad range of services and accommodations that might be needed by a child with diabetes in school. The plan should be individualized to meet the needs, abilities, and medical condition of each student and should include only those items in the model that are relevant to that student. Some students will need additional services and accommodations that have not been included in this model plan.]

.....

Section 504 Plan for \_\_\_\_\_

School \_\_\_\_\_

School Year: \_\_\_\_\_

Student's Name \_\_\_\_\_ Birth Date \_\_\_\_\_ Grade \_\_\_\_\_ type of diabetes \_\_\_\_\_ Disability \_\_\_\_\_

Homeroom Teacher: \_\_\_\_\_ Site Number: \_\_\_\_\_

**OBJECTIVES/GOALS OF THIS PLAN**

Diabetes can cause blood glucose (sugar) levels to be too high or too low, both of which affect the student's ability to learn as well as seriously endangering the student's health both immediately and in the long term. The goal of this plan is to provide the special education and/or related aids and services needed to maintain blood glucose within this student's target range, and to respond appropriately to levels outside of this range in accordance with the instructions provided by the student's personal health care team.

**REFERENCES**

A written document where the parents and school agree on the services & modifications that the student needs.

Each child with diabetes has individual needs.

A Section 504 Plan must be individually developed.

Template online.



## 504/IEP Plan: Possible Contents



- Recognition and prompt treatment of hypoglycemia and hyperglycemia by trained school personnel during school day, field trips, and extracurricular activities.
- Immediate access to diabetes supplies and equipment.
- Unrestricted access to snacks, water and bathroom.
- Classroom blood glucose monitoring.

## 504/IEP Plan: Possible Contents



- Adherence to care schedule (routine blood glucose testing, insulin administration, meals and snacks eaten on time).
- Reasonable time/instruction to make up assignments and tests missed due to diabetes.
- No penalties for absences due to diabetes (illness/doctor's appointments).
- Identify trained school personnel.

## School Plans for Diabetes Management

Plan	What it covers	Who writes it
<b>DMMP</b>	<i>“Doctor’s Orders”</i> – details all aspects of routine and emergency diabetes care.	Health care team.
<b>504 Plan</b> <b>IEP Team</b>	<i>Education plans</i> - details both health care and educated related aids, services, accommodations, and special education services the student may need.	504 team IEP team
<b>IHP</b>	<i>School nursing care plan</i> - specifies how diabetes care as prescribed in the DMMP will be delivered in the school	School nurse
<b>Quick Reference</b>	<i>Resource/Tool for school staff</i> - how to recognize and treat hypo or hyperglycemia	School nurse

## Back-To-School Strategies

- Approach in spirit of cooperation and work with the school team.
- Be realistic and reasonable!
- Communication is paramount.
- Provide supplies, snacks, quick-acting form of glucose.
- Encourage your child to wear a medical ID jewelry.



## Working through disagreement: ADA Legal Advocacy Strategies

### EDUCATION. Negotiation. Litigation. Legislation.



- **Educate** school personnel about diabetes and legal obligations.
- **Negotiate** using resources such as NDEP school guide, ADA resources, and medical device trainers.
- **Litigate** if necessary – OCR, due process, state court, federal court.
- **Legislate** if all else fails and clear legal barriers exist.

## Education Resources



[www.diabetes.org/safeatschool](http://www.diabetes.org/safeatschool)

- American Diabetes Association Position Statement: Care of Children with Diabetes in the School and Day Care Setting
- ADA School Discrimination Packet
- Training modules for school personnel
- 1-800-DIABETES



# Education & Training Resources:

Diabetes Care Volume 37, Supplement 1, January 2014

## Diabetes Care in the School and Day Care Setting

American Diabetes Association

Diabetes is one of the most common chronic diseases of childhood (1). There are ~215,000 individuals <20 years of age with diabetes in the U.S. (2). The majority of these young people attend school and/or some type of day care and need knowledgeable staff to provide a safe school environment. Both parents and the health care team should work together to provide school systems and day care providers with the information necessary to allow children with diabetes to participate fully and safely in the school experience (3,4).

### DIABETES AND THE LAW

Federal laws that protect children with diabetes include Section 504 of the Rehabilitation Act of 1973 (5), the Individuals with Disabilities Education Act (originally the Education for All Handicapped Children Act of 1975) (6), and the Americans with Disabilities Act (7). Under these laws, diabetes has been considered to be a disability, and it is illegal for schools and/or day care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with diabetes. Indeed, federal law requires an individualized assessment of any child with diabetes. The required accommodations should be documented in a written plan developed under the applicable federal law such as a Section 504 Plan or Individualized Education Program (IEP). The needs of a student with diabetes should be provided for within the child's usual school setting with as little disruption to the school's and the child's routine as possible and allowing the child full participation in all school activities (8,9).

Despite these protections, children in the school and day care setting still face discrimination. For example, some day care centers may refuse admission to children with diabetes, and children in the classroom may not be provided the assistance necessary to monitor blood glucose and administer insulin and may be prohibited from eating needed snacks. The American Diabetes Association wants to ensure the safe and fair treatment of children with diabetes in the school and day care setting (10–15) ([www.diabetes.org/schools/discrimination/](http://www.diabetes.org/schools/discrimination/)).

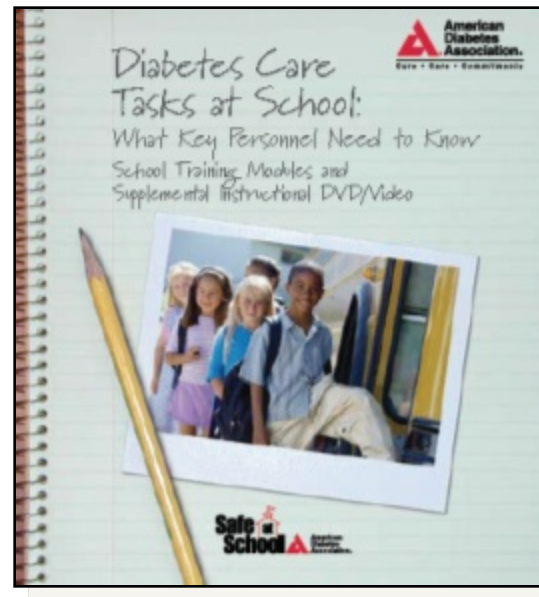
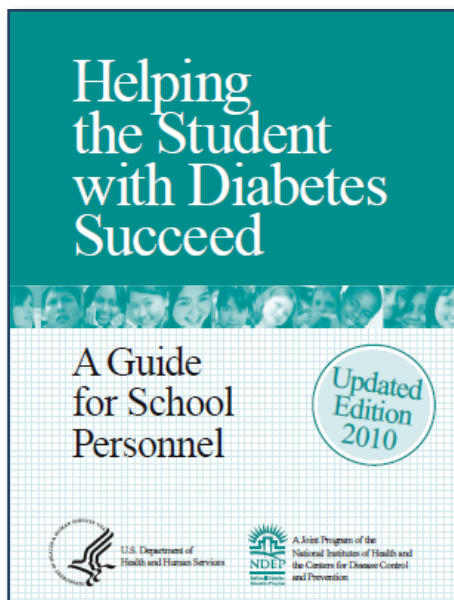
### Diabetes Care in Schools

Appropriate diabetes care in the school and day care setting is necessary for the child's immediate safety, long term well-being, and optimal academic performance. The Diabetes Control and Complications Trial showed a significant link between blood glucose control and later development of diabetes complications, with improved glycemic control decreasing the risk of these complications (16,17). To achieve glycemic control, a child must check blood glucose frequently, monitor food intake, take medications, and engage in regular physical activity. Insulin is usually taken in multiple daily injections or through an infusion pump. Crucial to achieving glycemic control is an understanding of the effects of physical activity, nutrition therapy, and insulin on blood glucose levels.

To facilitate the appropriate care of the student with diabetes, the school nurse as well as other school and day care personnel must have an understanding of diabetes and must be trained in its management and in the treatment of diabetes emergencies (1,18,19,20,24,36). Knowledgeable trained personnel are essential if the student is to avoid the immediate health risks of low blood glucose and to achieve the metabolic control required to decrease risks for later development of diabetes complications (1,20). Studies have shown that the majority of school personnel have an inadequate understanding of diabetes (21,22). Consequently,

Originally approved 1998. Revised 2008.  
DOI: 10.2337/36.14.1092  
© 2014 by the American Diabetes Association.  
See [http://care.diabetesjournals.org/for\\_much\\_more\\_info](http://care.diabetesjournals.org/for_much_more_info).

## NDEP School Guide



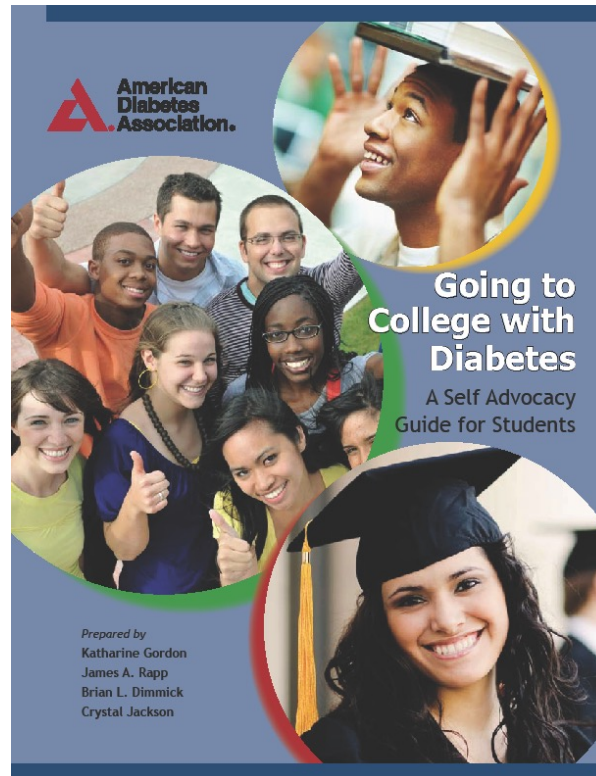
Diabetes Care Tasks at School

## ADA Position Statement

## Helping Administer to the Needs of the Student with Diabetes in School



## Post-Secondary Education



[diabetes.org/assets/pdfs/schools/going-to-college-with-diabetes.pdf](https://diabetes.org/assets/pdfs/schools/going-to-college-with-diabetes.pdf)



## Negotiate: Strategies

- Make requests and note objections  
IN WRITING – Email works!
- Obtain expert opinion letter from your  
child's health care provider.
- Gather resources to support your  
position.
- Remember:  
Push for your ideal situation,  
but focus on the absolute  
necessities and consider  
compromising on the non-necessities.



## Litigate: When and How?

### When education and negotiation fail...

- Preliminary step: School district due process or grievance proceedings
- File complaint with:
  - U.S. Department of Education, Office of Civil Rights;
  - Department of Justice;
  - or state Department of Education
- File lawsuit in state or federal court



## Legislate: When?

Legislate, if educate, negotiate, and litigate are not successful.

- Consider changing state law or policies if current laws and policies do not provide students with diabetes the protection they need
- Contact the Association first



- Legislation or regulatory change achieved in 35 states (as of June 2014).
- California Supreme Court decision (August 2013) held that trained school staff members are permitted to administer insulin to students.
- Office for Civil Rights recently issued a letter of finding making it clear that SWD must have equal access to extracurricular athletics.
- Office for Civil Rights recently issued a letter of finding making it clear that charter schools are public schools and have the same federal anti-discrimination law obligations.
- Launch of new child care initiative in 2013 to better meet the needs of very young children in the child care – [diabetes.org/childcare](http://diabetes.org/childcare).

## Next Steps.....

- Read the information on [www.diabetes.org/safeatschool](http://www.diabetes.org/safeatschool) about legal rights and written plans.
- Call us at 1-800-DIABETES if you need help or have questions.
- Work with your child's health care provider to develop or update your child's DMMP.
- Schedule a meeting with the school nurse and/or principal to review DMMP.
- Help identify training resources.
- Initiate the 504/IEP process or update your child's plan by contacting school's 504/IEP coordinator (principal, guidance counselor, teacher)

## Become a Diabetes Advocate



### Sign up at the ADA Action Center

- <http://advocacy.diabetes.org>

Receive updates on advocacy issues in:

- the U.S. Congress
- your state legislature
- ADA's Safe at School campaign

## Get Involved Locally

Call 1-888-DIABETES to connect  
with your local American Diabetes Association office

Family Link



Camp



Diabetes Expo



Step Out and help raise support for Safe at School efforts and other mission activities: [www.diabetes.org/stepout](http://www.diabetes.org/stepout)



**We're here to help you!**

**CAUTION: Keep in mind – especially if you are really frustrated:**



**1-800-DIABETES**

- Most disagreements with schools can be resolved as you educate and negotiate with school staff.
- If you get to the point that you feel litigation or legislation is the only solution, please request assistance from an American Diabetes Association Legal advocate before taking legal action:  
**1-800-DIABETES**