

KEEPING KIDS WITH DIABETES SAFE AT SCHOOL



Presenter:

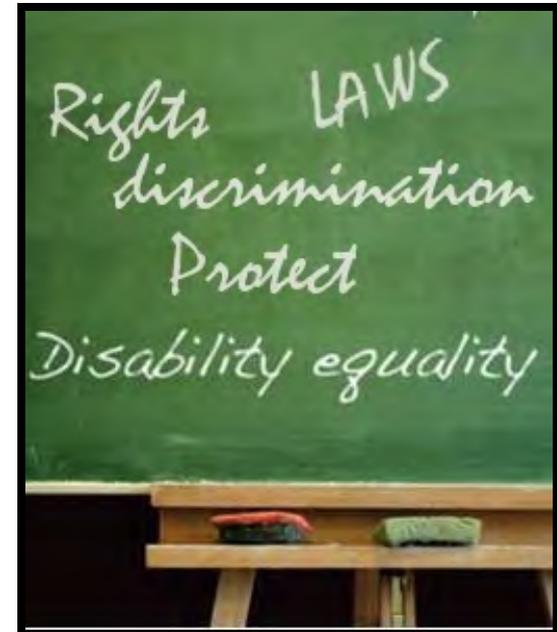
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American Diabetes Association**

The Children's Hospital of Philadelphia and JDRF
LIVING WELL WITH DIABETES: NOW AND IN THE FUTURE
Sheraton Philadelphia Downtown Hotel
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Session Key Points

- Back-to-school considerations
- Safe at School Campaign
- Strategies for overcoming school diabetes care challenges
- Federal and state laws
- Written plans
- Resources



Every Student

- Am I going to get to school on time?
- Do I have all my assignments completed?
- Who am I going to sit with at lunch?
- Am I prepared for my big exam?

Students with diabetes

- Did I give myself enough/too much insulin to cover for breakfast?
- How many times should I check my blood sugar?
- Am I going to go high or low throughout the day?
- Does my diabetes management make me weird?
- How will I feel during my exam?

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 parents and student to support transition to independence.



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.

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.



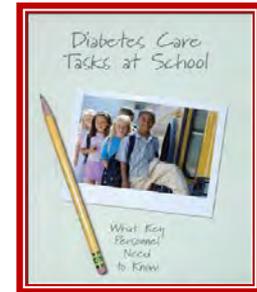
Safe at School Campaign

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



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
-
- **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

IDEA:

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

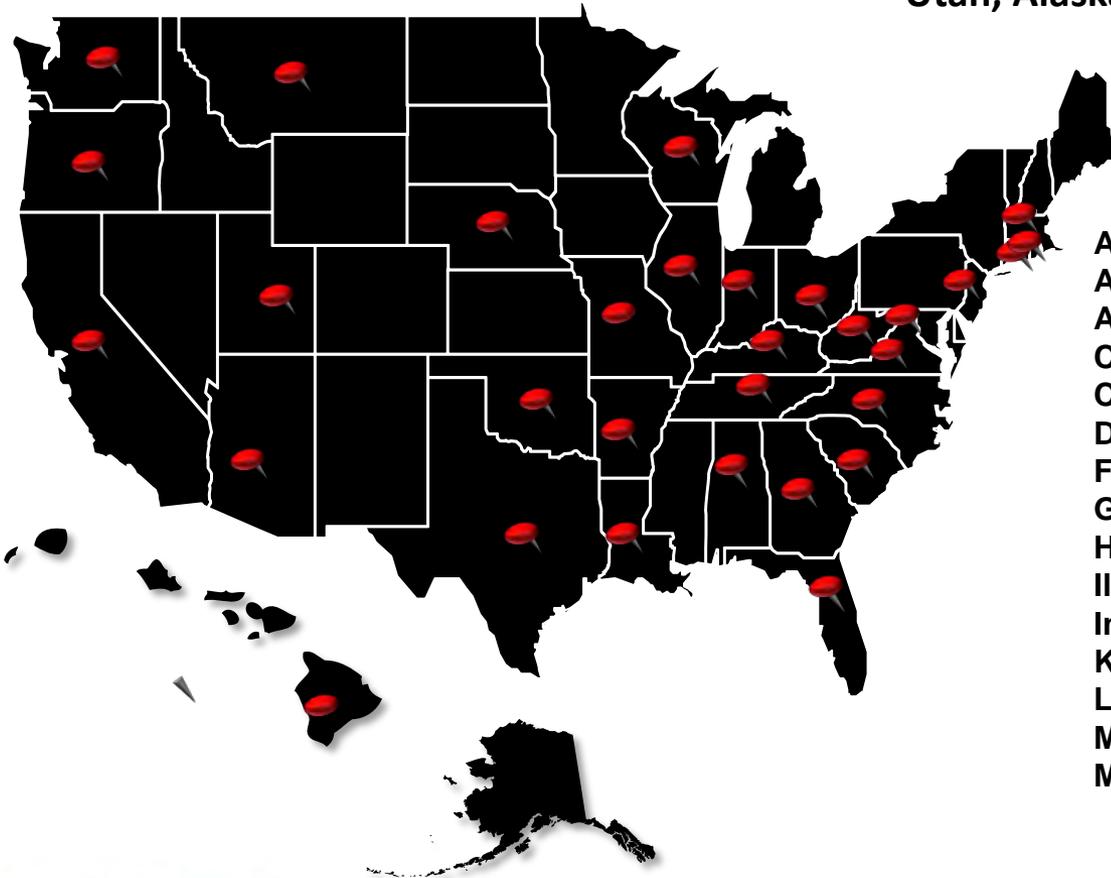


State Laws and Regulations

- 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

Board of Nursing Action: Nevada, Colorado, Utah, Alaska, North Dakota



Alabama
Arizona
Arkansas
California
Connecticut
District of Columbia
Florida
Georgia
Hawaii
Illinois
Indiana
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

School Diabetes Care in Pennsylvania Today....

- Not all students have access to needed care
- Lack of coverage for glucagon and insulin administration
- Most states allow trained school staff members to provide diabetes care
- Current PA laws are not supportive of anyone but the nurse providing care
- Change in law is needed to ensure the safety and good health of PA students with diabetes and also to make sure they are treated fairly

Status of Safe at School Legislative Efforts

- The Association has been championing legislation to allow others to provide diabetes care to students
- School nurses have been opposing this legislation arguing it is dangerous for anyone but a licensed health care professional to provide care
- School nurses no longer oppose glucagon administration
- If you've encountered problems or know someone who has or want to get involved contact Stephen Habbe, ADA's PA Advocacy Director at shabbe@diabetes.org

Written Plans

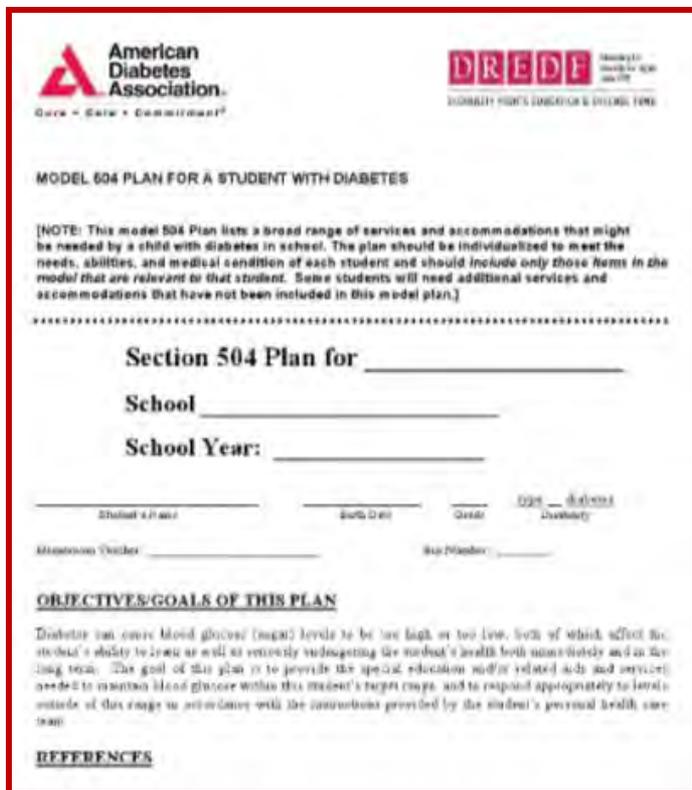
- Diabetes Medical Management Plan (DMMP)
- Individual Health Plan (IHP)
- Section 504 Plan (504)
- Individualized Education Program (IEP)



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?



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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 _____ Date _____ Grade _____ DISEASE _____ Disability _____

Mastercard Number _____ Zip 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 the 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.
- Mentoring

School Plans for Diabetes Management

Plan	What it covers	Who writes it
DMMP	<i>“Doctor’s Orders”</i> – details all aspects of routine and emergency diabetes care.	Health care team.
504 Plan IEP Team	<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
IHP	<i>School nursing care plan</i> - specifies how diabetes care as prescribed in the DMMP will be delivered in the school	School nurse
Quick Reference	<i>Resource/Tool for school staff</i> - how to recognize and treat hypo or hyperglycemia	School nurse

Extracurricular Activities:

- Sports – Interscholastic or Intramural
- Academic Teams
- Clubs
- Social events
- Detention
- Field trips

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.
- Be prepared!



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

- 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

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 most 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 diabetes. 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 works to ensure the safe and fair treatment of children with diabetes in the school and day care setting (10–13) (www.diabetes.org/schooladministration).

Diabetes Care in Schools

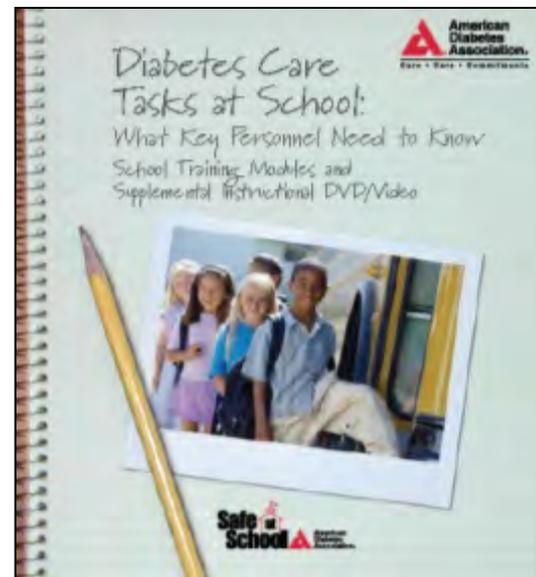
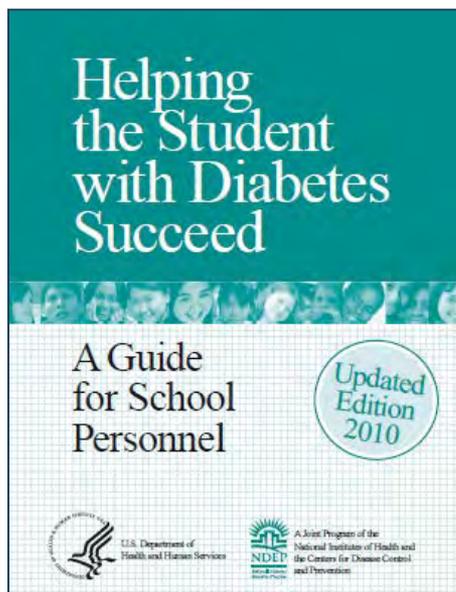
Appropriate diabetes care in the school and day care setting is necessary for the child's immediate safety, long term well-being, and optimal academic performance. The Diabetes Control and Complications Trial showed a significant link between blood glucose control and later development of diabetes complications, with improved glycemic control decreasing the risk of these complications (14,15). 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. Good self-management, 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 (13,15,20,24,36). 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,

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American Diabetes Association

NDEP School Guide



Diabetes Care Tasks at School

ADA Position Statement

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



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: Pennsylvania due process 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



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

Recent Safe at School Developments

- California Supreme Court decision (August 2013) ruled that trained school staff members are permitted to administer insulin to students.
- ANA/CSNO/ADA joint statement issued in December 2014.
- Legislation or regulatory change achieved in 35 states ; 27 states meeting the Association's 3 tenets.
- The above includes twelve states achieving favorable legislative or regulatory change within last 2 ½ years – AL, AK, AZ, CA, DC, GA, KY, LA, MO, ND, OH, TN.
- In May 2014, the Office for Civil Rights issued a “Dear Colleague” letter stating charter schools are required to comply with federal anti-discrimination laws.
- Publication of childcare position statement in October 2014 *Diabetes Care* and launch of childcare initiative.

Next Steps.....

- Contact Stephen Habbe, Shabbe@diabetes.org, if your child attends Pennsylvania schools and you'd like to become involved with ADA's Safe at School legislative efforts.
- Read the information on 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 your child's DMMP.
- Help your school to identify training resources.
- Initiate the 504/IEP process or update your child's plan by contacting school's 504/IEP coordinator.
- Sign up to become a Diabetes Advocate at <http://advocacy.diabetes.org>