



B E C O M I N G A N A D V O C A T E

In the Schools



Becoming A Diabetes Advocate... IN THE SCHOOLS

The minute a child is diagnosed with diabetes, his or her parents begin to face a series of tough decisions and difficult situations. Some of the most difficult situations may take place at school if school personnel are unfamiliar with diabetes and the need for and benefits of comprehensive diabetes management in the school setting.

Fortunately, advocacy can make a difference. With patience and tenacity, parents and other advocates can effect change within their school districts on behalf of children with diabetes. And, in the most difficult scenarios, the American Diabetes Association (ADA) may be able to help by pursuing change in school policies and state laws.

The American Diabetes Association suggests the following advocacy strategies for addressing the issue of diabetes care for children in schools:

- EDUCATE:** Educate yourself about optimal diabetes management and educational rights, then take that message to school personnel and others, including public policy makers, when appropriate.
- NEGOTIATE:** Work to understand the concerns of school personnel and negotiate toward an agreement suitable to everyone involved. Use your voice. Use the voice of others. Speak up where it matters – at the school health advisory council, school board or local media. Join forces with other individuals or groups with common concerns.
- LITIGATE:** When efforts to educate or negotiate fail, consider filing an administrative complaint or a lawsuit in court.
- LEGISLATE:** Consider legislation only when policies or laws themselves prevent good diabetes care or when other avenues have failed. A legislative response may be appropriate in states where clear legal barriers exist that affect children with diabetes statewide. Legislation may also be appropriate where policies and practices vary widely from school district to school district within a state, even if there are no apparent legal barriers.

Want to learn more about what to do? Keep reading...

Ready to Become a Diabetes Advocate?

“Laying the Cornerstone”: Relationships

Relationships — the foundation for all advocacy activities to follow, whether educating, negotiating, litigating, or legislating.

Develop relationships at school. Get involved. Now. Don't wait until there is a problem. Get to know your teachers and principal.

Your school involvement can be anything from helping with a bake-sale, to assisting with field trips to chairing the school health advisory council or PTA, or even running for the local school board.

1. Your initial involvement may not directly involve decisions about policy or practices regarding diabetes. However, you will be better positioned to learn the how, when, and who of decision-making in the school as you spend time with staff and other parents.
2. You will have greater credibility if you can approach the policy-makers as an “insider” who has an understanding of the challenges that schools face.

Most school districts have a health advisory council or comparable committee that may include parents. Find out when they meet and how to get involved.

Develop ongoing relationships with policy-makers (administrators, school board members).

1. LISTEN carefully; let them know you have heard their concerns.
2. Volunteer to work beside them at a school-wide or district-wide event.

“Maintaining a Strong Foundation”: Persistence and Vigilance

Don't give up. Stand firm in your position. Monitor what is happening.

Keep at it. Systems change slowly; inertia is an incredible force, but it can be overcome by vigilant efforts of passionate advocates in pursuit of fairness.

Pace yourself for a long journey. Change takes time. BUT don't let it take forever!

1. Persist. Do not be intimidated by apparent failure or enchanted by an instant success.
2. Follow up on both your successes and failures! Monitor what is happening.
3. Keep records. Document what is happening – both positive and negative. You want to show how doing the “right” thing leads to good outcomes, not just how doing the “wrong” thing leads to poor outcomes.
4. Do not be intimidated. Be willing to negotiate, but don't be afraid to ask for an independent mediator, or even to push toward litigation if negotiations have reached a stalemate.

Work to get optimal policy in writing. However, recognize the differences between practice and policy.

1. Helpful school personnel today may be replaced by less informed personnel next year. Signed 504 plans and Individualized Education Programs prevent problems tomorrow.
2. Be vigilant. Monitor actual practices. A written policy that supports good diabetes management will help to address your concerns, but will not guarantee that even adequate management is happening during school activities. Ask other students and parents about their experiences.

EDUCATE

Learn about the ADA Position Statement on Care of Children with Diabetes in the School and Day Care Setting.

Prepare yourself to EDUCATE local school personnel.

1. Your child's medical needs should be set out in a written plan (sometimes called a Diabetes Medical Management Plan or Health Care Plan) signed by your child's health care provider. Explain these medical needs to school personnel.
2. Point out discrepancies between local practice and the ADA School Position Statement. Do not assume that school employees are familiar enough with diabetes management to detect the differences.
3. Obtain a copy of the National Diabetes Educational Program's "Helping the Students with Diabetes Succeed: A Guide for School Personnel" and share it with school personnel.

Learn about your child's rights. Learn about the laws that protect students with diabetes in schools: Americans with Disabilities Act, Section 504, and IDEA.

Prepare yourself to EDUCATE local school personnel who may not be aware of how diabetes relates to these laws.

1. Obtain ADA's school discrimination packet by calling 1-800-DIABETES. Many of these materials are available on the ADA school advocacy page at www.diabetes.org/advocacy/school.
2. Read thoroughly and prepare to educate school employees & policy-makers.
3. Distribute printed copies of appropriate materials to school employees & policy-makers and to local and state policy makers.

Learn about state and local policies and laws.

Learn what state laws and school policies exist that address the following:

1. Where can kids test, snack, inject, etc.? What supervision is provided or required?
2. Is glucagon and a person trained to administer it available whenever the child is involved in a school activity?
3. What authority does the individual nurse have to delegate responsibility for management tasks to other school employees, or to school volunteers?
4. If authority to delegate is limited, then where do the limitations arise? With the decision of the individual school nurse? With a state-wide or district-wide policy? Who sets state-wide or district-wide policy?
5. What is the chain of supervision for health care in the schools? What is the appeal process if the school won't meet your child's needs?
6. Contact the ADA to see what is known about laws in your state that influence how diabetes management decisions are made in schools. This does not mean you must accept these policies and live within their limitations; it means you know what they are and what needs to be changed. Then educate school personnel so that they understand what is needed for good diabetes management at school.

NEGOTIATE

NEGOTIATE with local school personnel.

1. Sometimes education alone will be enough to change policy or practice. Other times, change will happen only after negotiation of mutual concerns.
2. In developing your child's education plan (such as a Section 504 plan or IEP), you may need to negotiate with school officials. You are more likely to reach an agreement if you attempt to understand and be sensitive to the concerns of school personnel and negotiate toward an agreement suitable to everyone involved.
3. Do not sign a plan unless you agree with it.

Use Your Voice! Adopt an assertive, but not aggressive style of interaction that communicates the following:

1. "I am advocating for what my child needs; I expect you to listen respectfully."
2. "I am well-informed about current recommendations for how diabetes should be optimally managed in schools."
3. "I know you have many other issues on your plate and you may not be well informed about diabetes management, and I am willing to share information with you from the American Diabetes Association and other diabetes professionals."
4. "I am willing to work with you to eliminate present barriers; I will listen to your concerns respectfully. I will work for a win-win solution that benefits all."

Organize and collaborate with other parents and concerned individuals/organizations to work for change.

1. Mobilize your known allies – those who have heard your concerns and agree with you. Encourage them to educate school personnel, contact policy-makers, and get involved to advocate for change.
2. Find and mobilize other allies. Reach them where they are already gathered: support groups, diabetes organizations' fund-raising events, camp orientation meetings, etc. Educate them about the need for change. Give them something to do to support the efforts for change.
3. Find and mobilize state and local contacts:
 - Briefly and clearly state what action you want.
 - Send an alert (mail, fax, e-mail) to spread your message far and wide. Urge recipients of the alert to send it to their networks, boards, staff, coalitions, volunteers, and media contacts.
 - Set up and activate telephone trees to get the message out.
 - Get on the agenda for community group meetings and statewide conferences (school nurse associations; professional meetings of school psychologists or social workers, medical and legal professional organizations, school boards).
 - Work with other interested individuals and organizations to raise the volume of concern.

Contact elected officials as a source of assistance.

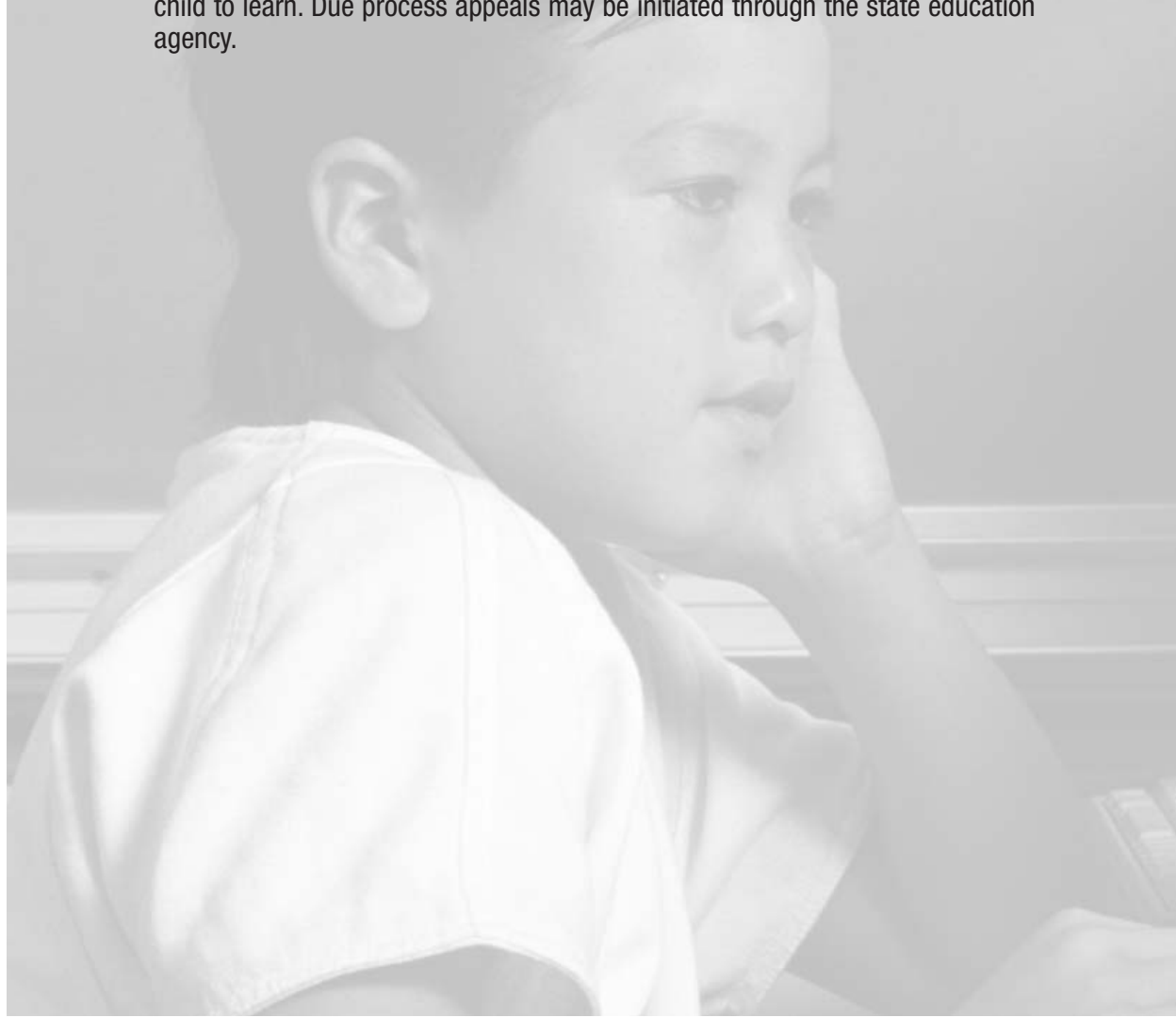
Contact the media to create community awareness and interest.

1. Alert the media to events that would provide good visuals, including meetings with your school health advisory council or school boards. Invite media representatives to your programs.
2. Write Op-eds and Letters to the Editor of your local newspaper. Time your op-eds and letters to correspond with a high visibility issue.
3. Meet with the Editorial Board or education reporter of your local newspaper.

LITIGATE

LITIGATE when necessary.

1. If your child's needs are not being met, you have the right to file an administrative complaint or a lawsuit in court. After exhausting your other options, seeking protection in the courts may be necessary to ensure that your child receives the education and medical care that he or she deserves.
2. The procedure you follow will vary depending on whether your claim is under the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act (Section 504), or the Americans with Disabilities Act (ADA).
 - The Office for Civil Rights (OCR) in the U.S. Department of Education enforces Section 504 and ADA in programs and activities that receive assistance from the federal government. Contact the U.S. Office of Civil Rights in your region when negotiation fails to secure your child's rights or adequate care.
 - The U.S. Department of Justice (DOJ) enforces ADA in schools and day care centers that do not receive federal funds, except those run by religious institutions. Parents may file a complaint with DOJ or file a lawsuit directly in court.
 - The Office of Special Education Programs (OSEP) of the U.S. Department of Education enforces IDEA and protects children whose disabilities make it more difficult for the child to learn. Due process appeals may be initiated through the state education agency.



LEGISLATIVE

LEGISLATE after attempts to educate, negotiate, and litigate have not been successful.

1. Consider changing state law if current laws and policies do not provide students with diabetes with the protection they need or when school policies and practices are inconsistent within a state.
2. Alert the American Diabetes Association about barriers encountered in education, negotiation, and litigation.
3. Work with ADA, other individuals, allies and groups to explore strategies for resolving issues. Assist ADA in assessing the need to change the rules at a local, statewide, or national level.
4. Identify legislators who may have a personal connection to diabetes, understand the concerns, and may be willing to introduce appropriate legislation.
5. Coordinate efforts with ADA to organize and energize grassroots support.
6. Realize that systems change slowly and the success of legislative efforts requires patience and perseverance.



ADA Resources

ADA has additional materials for those facing discrimination in schools and day care centers. Call 1-800-DIABETES 9342-2383) for the ADA's packet on school discrimination. You can discuss a specific school or day care problem with the ADA's Legal Advocate.

Call 1-800-DIABETES (342-2383) for general information on diabetes, or visit our website at www.diabetes.org.

Call 1-800-ADA-ORDER (232-6733) to order books or a catalog.

Call 1-800-806-7801 for subscription and membership questions.

Call 1-800-DIABETES to obtain a free Wizdom Kit.

Other Useful Telephone Numbers and Websites:

1. NDEP Guide "Helping the Student with Diabetes Succeed: A Guide for School Personnel": 301-634-0716; www.ndep.nih.gov
2. ADA's School Training Modules "Diabetes Care Tasks at School: What Key Personnel Need to Know": www.diabetes.org/schooltraining
3. U.S. Department of Education, Office of Civil Rights: 1-800-421-3481; www.ed.gov/offices/OCR
4. U.S. Department of Education, Office of Special Education Programs: 202-205-5507; www.ed.gov/office/osers/osep
5. U.S. Department of Justice: 1-800-514-0301; www.usdoj.gov
6. Disability, Rights, Education and Defense Fund, Inc.; 510-664-2555; www.dredf.org
7. TA Alliance for Parent Centers: 952-838-9000; www.taalliance.org

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1-800-DIABETES