

Coaching the parent advocate

1994 *Healthy Kids The Key to Basics*
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Advocacy is empowerment. It implies speaking up but not being adversarial or belligerent. It means developing the communication skills and strategies that build cooperative relationships and using resources and knowledge to achieve change.

The Healing Partnership

As a health care provider, you can be an important resource and ally for parents. You can provide the anticipatory guidance, moral support and information that promotes effective advocacy at school. You can reduce unnecessary risks, illness and school absences for your patients, and enhance your relationship with their families as well.

In their book, "Building the Healing Partnership," authors Patricia Taner Leff and Elaine H. Walizer emphasize that becoming a resource and ally broadens, "Both the caregiver's healing identity and sources of professional satisfaction and self-esteem...." On the other hand, when providers don't seem to respect and understand the family's comprehensive needs, "...Parents feel deprived of the support they so desperately need from their child's caregivers."

When the doctor's letter isn't enough

Many school medication policies leave no doubt that taking medication is an undesirable and illicit activity. "The use of medication in school is discouraged." "No school official or teacher will routinely dispense medication to students except in unique situations in which a child's health is dependent upon emergency medical aid." "Any staff member, may, without prejudice, decline to accept responsibility for facilitating the use of medication."

When policies or the lack of cooperation from school staff create an unfriendly environment for asthma management, parents need advocacy skills to turn anger into constructive action, to override feelings of helplessness and to overcome fears that "making waves" will make life more difficult for their children.

To overcome rejection by a school official or the lack of understanding by individual staff members, parents need to understand more than the pathophysiology of asthma and its treatment. They need examples of schools where staff are knowledgeable and children get the health supports they need.

Compare this enlightened school policy with those above: "The purpose of administering medications in school is to assist students who require medication be taken during school hours to maintain an optimal state of health, and therefore, enhancing their educational program. The intent of this procedure is to assure safe administration of medications in school for those students who require them." Examples like this can help parents frame a child's needs in positive



terms and expand an administrator's view of a school's options.

When P.G., the mother of a child with severe food allergies, wanted a nurse to be in the school at lunch time and teachers to be trained to prevent and handle emergencies, the superintendent accused the mother of frightening faculty with her safety concerns and requests for better health services. In a thank you letter to *Healthy Kids* she wrote: "Your stories of children and parents in similar circumstances and of specific examples and model policies in other schools...made it okay to envision a school system that is safe for all children. Having those examples not only encouraged me, but also helped school officials look beyond the limits of their own district..."

As a health care provider, you can be an important resource and ally for parents, providing the guidance, moral support and information that promotes effective advocacy at school and reducing unnecessary risks, illness and school absences for your patients.

Moral Support

Health care providers can follow the lead of experienced advocates who emphasize that, "First, families should believe absolutely that their children have a right to attend school and to do so in a safe and healthy environment. No school should operate in ways that are destructive to any child's health or education. Whether the problem is convincing a daycare center to ban peanuts or help with nebulizer treatments, to remove a moldy carpet or to prohibit animals in school, don't encourage parents to accept standards that disadvantage their child or to settle for a solution that doesn't meet their child's needs."

After more than a year, P.G.'s persistence in sharing her concerns and information with school nurses, school officials and school board members led to a more enlightened understanding of the school's responsibilities and the school in-

creased its nursing coverage. There were many other positive changes including the use of Individualized Health Plans for any child with special health needs. Staff training in a variety of preventative and emergency procedures ensures that a knowledgeable person will always be there for any child in a crisis.

Advocacy in Action

Urge parents to follow up when administrators pass the buck or use policies or rules to deny services or impose conditions or restrictions that discriminate against a child.

S. L. did not think to challenge the system until her twin sons were about to enter kindergarten. Then, as a full time working single parent, she realized that there would be too many days when she would have to keep one twin home if the school did not provide his nebulizer treatments. She writes: I did some investigating and found out nebulizer treatments were allowed by other neighboring school districts. After going to an asthma meeting and speaking with the district's health director, I was told about Section 504. I was appalled to think our school system was twenty years behind the times. I started with a meeting with the school principal in May. His responses were mostly negative, blaming the school board saying his hands were tied. I contacted the school board. Their response was, "No Problem," the school had been misinformed. The school principal called in August saying he would have to work on it, that the problem was with the health department which oversees the school clinics, saying their directions were that nebulizers were a medical procedure and could not be done by clinic personnel. But these same people were able to administer EpiPens, which our clinic nurse requested to have as an emergency if G. got into "trouble." ...When school started this was still not resolved, but I wasn't backing down. So for the happy ending! Today there is a nebulizer donated (by a local company) in the clinic to benefit any child needing to use it...I am finding, however, that this is still not well known by others in the community, but I am doing my best to get the word out to help others..."

No parent should have to shoulder the intimidating burden of negotiating with school officials alone. In the introduction to, "Working Toward A Balance in Our Lives," parents write about the vital role support groups play in helping parents maintain confidence in their own vision and goals. "While we must rely on the technical information that professionals can provide us, we are the only ones who truly know our children."

Health care providers working with support groups can offer parents the necessary combination of ongoing moral support, creative problem solving, specialized resources and a place to

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develop necessary communication and negotiation skills. Time spent doing role plays of meetings with teachers or school officials is time well spent. Rehearsal prepares parents to respond to hurtful or intimidating comments without becoming angry or defensive and to focus on their goals in the face of remarks that might otherwise upset or discourage them.

The individualized health plan (IHP)

States developing guidelines for serving student's with special health needs have important elements in common: the Individualized Health Plan, parent-school collaboration and staff training. The IHP is an official record of the school's commitment to educate a child in a healthy environment and a plan for removing obstacles to a child's well-being and success at school. It promotes compliance with civil rights laws, public health regulations and nursing standards that protect student's health and education. Massachusetts' new protocols for the safe delegation of medication requires that a school nurse do an individual assessment of the student and provide documentation, training, monitoring, supervision and evaluation based on the student's needs. Montana's new guidelines, the result of a statewide multidisciplinary collaboration, emphasizes that, "Parents need to be integrally involved in all aspects of the development of the Individualized Health Care Plan."

Getting Formal

Lack of cooperation in a child's health management denies children a free and appropriate public education. Section 504 regulations require that school districts and states establish a complaint process so that parents can go up the chain of command to seek resolution or remedies for problems at school. It is a complaint-driven system; a school official or an agency can't act unless it is aware of a problem. We need to document incidents so that state and federal agencies learn the extent and scope of the discrimination.

Many parents and professionals are uncomfortable with the idea of using official procedures, but procedural safeguards are the checks and balances that build accountability into the system. Don't be afraid to use them. At the state level, a complaint can trigger a variety of options including mediation and administrative hearings that offer opportunities to resolve school-parent conflicts or remedy a problem. An early resolution process helps parents and school staff work out an agreement. Where complaints have resulted in rulings, schools have been required to revise policies, provide services, train staff and make other modifications necessary for the child to attend school safely and successfully. In one OCR case, parents were reimbursed for lost work time and other expenses they incurred when a day care center did not provide nebulizer treatments.

Help families avoid frustration. Call the Department of Education in your state to obtain information on your state's complaint system. If

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a state education department is not helpful, the U. S. Department of Education, Office for Civil Rights can answer questions and provide information on Section 504 and the Americans with Disabilities Acts. OCR's role is to promote and enforce compliance with federal civil rights laws and regulations.

For more information on how to promote health and educational equity, write to Ellie Goldberg, M.Ed.,



References

Patricia Taner Leff and Elaine H. Walizer, *Building the Healing Partnership: Parents, Professionals, and Children with Chronic Illnesses and Disabilities*, Brookline Books, Cambridge, 1992.

Diamant, Anita. "Stand by Your Child." *Sesame Street Parent*, (December, 1993), p. 42.

White Bear Lake Area Schools, Minnesota.

Betsy Anderson and Janet Vohs, "Another Look at Section 504." *Coalition Quarterly*, A Publication of the Technical Assistance for Parent Programs Project, Fall-Winter, 1992-1993.

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in education and employment in any program or agency receiving federal funds. The Americans with Disabilities Act extends the protections of 504 to public accommodations.

Working Toward a Balance in Our Lives: A Booklet for Families of Children with Disabilities and Special Health Care Needs, Project School Care, Children's Hospital, Boston, MA. 1992.

No support group in your area? Start one. Contact Nancy Sanker, Support Group Services/Asthma and Allergy Foundation of America, 303/221-9165.

Ellie Goldberg, M.Ed. "He Looks Fine to Us. Why are you so Worried?" A worksheet of twenty-one statements for role plays.

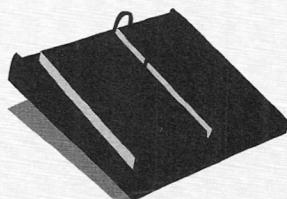
Guidelines for School Nursing Documentation: Standards, Issues, and Models, Nadine Schwab, RN, PNP, MPH, 1991 and School Nursing Practice, Roles and Standards, Susan Tonskemper Proctor, RN, MPH, 1993. Both from the National Association of School Nurses, Lamplighter Lane, PO Box 1300, Scarborough, ME 04070.

Serving Students with Special Health Care Needs, A Technical Assistance Document, Office of Public Instruction, Nancy Keenan, Superintendent, State Capital, Helena, Montana, 59620.

The person or organization filing a complaint need not be a victim of the alleged discrimination, but may complain on behalf of another person or group.

Paula J. Beckman and Gayle Beckman Boyes, *Deciphering the System: A Guide for Families of Children with Disabilities*, Brookline Books, Cambridge, MA, 1993.

Contact the U.S. Health and Human Services Department for information related to daycare centers.



PLAN AHEAD

1994 Allied Health regional course locations

September 10

Philadelphia
Adams Mark Hotel

October 1

Memphis
Adams Mark Hotel

October 22

New York City
Holiday Inn Crowne Plaza - La Guardia

April 8, 1995

Houston
Westin Oaks