



HEALTHY KIDS: THE KEY TO BASICS
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TRANSLATING RIGHTS INTO REALITIES: USING THE INDIVIDUALIZED HEALTH PLAN v. 1/96

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It is time for students with asthma and allergies to stand up and be counted.

Asthma and allergies affect more students than any other chronic health condition, but too many schools do not know who they are or understand the daily obstacles they face when they lack the health supports and cooperative planning that enable them to attend school safely and successfully.

How can we achieve the supportive policies, professional school health services and educational planning systems that prevent health and school problems?

THE INDIVIDUALIZED HEALTH PLAN (IHP)

Advocacy for children with asthma and allergies starts with an Individualized Health Plan (IHP). The IHP is a tool for documenting the extent and scope of students' needs. Health care providers should advise parents to request an IHP for any student that needs medication, monitoring, or special precautions.

Like an Individualized Education Plan (IEP), the IHP is a plan for services and modifications based on an individualized student assessment. It is created by a process of family-school collaboration and interdisciplinary planning. It gives each staff member an understanding of his or her individual contribution to and responsibility for a student's physical, educational, emotional and social well-being.

Formal documentation helps parents assert their legal rights and highlights key areas of compliance for state and federal agencies responsible for ensuring that

schools implement the enlightened laws designed to safeguard our children.

Collecting IHP information could correct the gaps and flaws in the data used by state and federal agencies to monitor schools and allocate resources.

DEVELOPING AN IHP

The manual, *Serving Students with Special Health Care Needs*,¹ offers schools a blueprint for developing a comprehensive school health agenda. It helps educators, health care professionals and parents to meet the challenge of educating students with special health needs.

"Clearly, a crucial step in meeting the special health care needs of students is the collaborative development, implementation and evaluation of standards and guidelines to ensure the provision of safe and appropriate educational and support services in school settings,"² writes Nadine Schwab, of the Division of Student Support Services, "A safe environment implies that such students will receive those health care services necessary to maintain and where ever possible to improve their health status."

TRANSLATING RIGHTS INTO REALITIES

The scenario below about Paul, a fifth grader with asthma and allergies, is based on the procedures and standards defined by federal education and civil rights law³ and is drawn from the suc-

¹ Schwab, Nadine, 1992. Connecticut Department of Education, Public Information, State Office Building, Room 304, P.O. Box 2219, Hartford, CT 06145-2219, 203/566-5677

² *Ibid.*, Page 4.

³ Guidelines, procedures and standards are defined by the Individuals with Disabilities Education Act (IDEA);

cesses and frustrations of many families and schools.

The story illustrates only some ideas for providing the variety of services and modifications to which students are entitled.⁴ But no matter what the differences in the nature, severity or variability of the child's condition, the principle is the same. Services and other supports are determined by the child's individual needs, not by disability category, administrative convenience or school custom.

IMAGINE

Imagine that you are the working parent of 10-year-old Paul. Paul has asthma and allergies to mold, dust, soy, milk and peanuts. During the winter he seems to be especially vulnerable to infections that resulting sinus problems and debilitating asthma. You understand that

Section 504 of the Rehabilitation Act of 1973; the Family Educational Rights and Privacy Act of 1974 and their implementing regulations, The Americans with Disabilities Act, and the Constitution of the United States (the equal protection and due process clauses of the 14th Amendment), and a variety of other public health laws and ethical and professional teaching and nursing practice standards. For example, school nursing standards are prescribed by the National Association of School Nurses, The National Council of State Boards of Nursing, Inc., the American Nurses' Association, and State Nursing Practice Acts.

⁴ See the references, *Serving Students with Special Health Care Needs* and *The School Nurse's Source Book of Individualized Healthcare Plans* for more detailed discussions and checklists of related services and necessary modifications and accommodations.

living with asthma and allergies is an ongoing process of educating yourself and educating others. Over the years you have gathered information and support from a wide range of people and resources. Despite the recent move to a new state, you have a reasonable sense of family balance and harmony. School starts in three weeks.

Step one: INITIATING THE IHP

You deliver a letter to the principal stating that Paul has special health needs and requesting an Individualized Health Plan. You sign a form to initiate an assessment process and a release which allows the school nurse to contact Paul's physician's directly for additional information that may become part of the student's confidential school file and medical records.

You meet the nurse. You are relieved. In the past, there was no one to talk to until the first day of school. There were years when the school refused to consider your request to develop a plan, to discuss Paul's medication, or to discuss problems such as forced exercise or poor air quality. (Many schools do not know that Section 504 of the Rehabilitation Act of 1973 entitles students with health impairments such as asthma or allergies to health services and policy and program modifications nor that a state law or school policy can not be used to deny rights guaranteed by the Constitution or other federal laws. "If a state law undermines, contradicts, or violates IDEA or Section 504 mandates, it is, of course, invalid."⁵ Schools must conform to the requirements of state laws only if the state law standard is higher.

From the school manual and parent's information packet, you learn that students who have taken a patient education course and who demonstrate an under-

⁵ For a full discussion see: *Educational Rights of Children with Disabilities: A Primer for Advocates*, 1991. Eileen L. Ordovery and Kathleen B. Boundy, The Center for Law and Education, 197 Friend St., Boston, MA 02114, 617/371-1155.

standing of their medications can carry their inhalers. You sign the standard authorizations for medication and emergency treatment.

The school nurse tells you she will check Paul's inhaler technique and will be tracking his peak flow readings for the first few weeks so she can establish base line data on his respiratory function and get to know him. A local asthma support group has recently donated a nebulizer to the school so Paul can get his neb treatments at school, too. You mentally tally up all the days Paul would have been able to attend school last year if a nebulizer had been available. (Many schools do not know that community agencies and organizations often can help schools obtain health equipment for students.)

You see that the school has supervised gym and library options for students who prefer indoor activities during recess so that Paul can play or work inside when it is too cold to go out. Obviously, some of the modifications you had to fight for in the past are not issues here.

The packet also contains information about procedures that protect parents' rights to influence or challenge school decisions and lists the state official a parent should contact if an education or civil rights law is being violated and how to file a complaint if school policies or practices disadvantage a child.

Step two: THE SCHOOL ASSESSMENT

The school system must ensure that a school nurse completes a health assessment, determines if delegation of care is appropriate, and then develops an individualized care plan. Professional nursing standards and ethical guidelines dictate that the school nurse has up-to-date knowledge and current training, and be qualified to assess, plan, delegate, and supervise staff.

Your school nurse will evaluate Paul's treatment plan in relation to the unique demands of his educational program and this particular school environment.

You tour the building with the nurse so you can point out potential asthma hot spots. She is the person who logs questions or complaints about student health and safety for action by the school health and safety committee. She will take a proactive approach to eliminating Paul's triggers or asthma aggravators. Last year the school passed a no smoking policy, prohibited pets or furry animals, and wrote guidelines that eliminates the use or purchase of hazardous, allergenic or irritating cleaning products, materials and supplies.

Her training and expertise in school health as well as knowledge of the staff give her lots of ideas about what might work for Paul. Of the two fifth-grade teachers, she suggests that Mr. Simpkins might be the best match. He is the father of a child with asthma and is very experienced and flexible.

The school assessment report will document:

- a. Paul's health status, asthma and allergy knowledge and skills, his treatment goals and treatment plans, and his need for support, education, monitoring, or direct services. (You have your doctor's file including a standard health report form, a narrative summary of Paul's health history, specific precautions and environmental control recommendations and the asthma education checklist to help the school understand Paul's knowledge and self-care skills.)
- b. Paul's educational performance, interest, and talents. (You provide a letter describing Paul, past report cards and letters from his favorite teachers.) The school may ask Paul to take achievement or aptitude tests if it wants more information.
- c. The potential challenges of various school settings. There is a checklist that includes every aspect of Paul's school day including transportation, all classrooms, academic courses and extracurricular activities, recess, lunch, physical education, art.

music, fire drills, school-sponsored events, etc.

- d. An evaluation of the staff's needs for information and training.

Step three: THE INTERDISCIPLINARY TEAM MEETING

Two days later, the IHP team meets in the principal's office. It includes you, the principal, the school nurse, the physical education teacher, the cafeteria supervisor, and Paul's fifth grade teachers.

The members of the IHP team have reviewed the assessment documentation and is now responsible for evaluating the kind and nature of all regular and extracurricular school activities, school programs and services, and the roles, responsibilities and tasks of school professionals and support personnel. They will identify student goals, define appropriate health and educational guidelines, program and policy modifications, and develop individualized emergency guidelines for responding to severe asthma episodes or anaphylaxis, and a crisis management plan in case of school fires, power failures, etc. (You know that the emergency plan "...should never be considered a substitute for a full IHP that addresses all of the student's relevant needs. In fact, if only an emergency care plan is used, it can give the false impression that a student's needs are being met when in fact there may be steps that can be taken to prevent emergencies if a more complete assessment of the student had taken place and been documented in an IHP.)⁶

A liaison is appointed to facilitate communications between home and school, to coordinate services both within the school setting and between home and school, to monitor the implementation of the plan and to advocate for Paul at school.


Step four: THE DRAFT IHP

⁶The School Nurse's Source Book of Individualized Healthcare Plans, 1993, Haas, et al., Sunrise River Press, 800/551-4754.

After reviewing the assessment, the principal translates the team's discussions into a draft IHP. Some of the specific goals and guidelines look like this:

Medication Plan:

- a. Paul's use of his bronchodilators and inhaled steroids are based on his peak flow zones (in Paul's health record). Paul will keep a written record of his peak flow measures. You and the nurse share responsibility for monitoring Paul's use of his medication and will provide guidance and support.
- b. Paul takes two puffs of bronchodilator before exertion.
- c. Paul carries his bronchodilator in his pocket or backpack to use for chest tightness or coughing.
- d. Paul's peak flow meter will be kept in the nurse's office for use as Paul requests to facilitate good decisions. If Paul uses his bronchodilator more frequently than planned he notifies the nurse for an immediate health assessment.
- e. Parent will notify the nurse when there is a change in Paul's health status or medication plan.
- f. Other medications (eye drops, nasal sprays, antihistamines, Intal) are not taken at school but Paul's full treatment needs are part of the school record.
- g. Paul's antihistamines make him intensely thirsty. Paul will keep a water bottle at his desk and will have a special hall pass so that he can use the drinking fountain whenever he wants to.

 Paul is at risk for severe allergic reactions to soy, peanuts, and milk.

Goal: To ensure that teachers have up-to-date knowledge of how to prevent exposures to allergenic foods, how to recognize reactions, and how to administer Paul's EpiPen.

Goal: To ensure that Paul gets appropriate and immediate emergency care.

Guidelines:

- a. Before school starts the school nurse will arrange for a presentation by a local specialist in food allergies to update staff on food allergies including an EpiPen training session.
- b. The school nurse will conduct an emergency drill for the teachers and lunch room staff to rehearse emergency procedures.
- c. Paul's mother will provide two EpiPens, one for the school office and one for Paul to carry at all times.
- d. The school nurse will distribute food allergy guidelines and the emergency plan to all teachers. Emergency procedures will be posted in every school area.
- e. Paul will be seated where the teacher(s) can observe him easily.
- f. Daily plan: Paul will bring all lunches and snacks from home. (Cafeteria staff have developed a list of safe menu items for students allergic only to nuts. They say that by midterm some safe items that eliminate milk and wheat will be available in the cafeteria.)
- g. A box of safe snacks and treats will be kept in Paul's homeroom for parties and in case he forgets his lunch.
- h. The teacher will avoid milk and peanuts in art or cooking projects.
- i. All students must give advance notice before bringing food into the classroom. Parents will be given guidelines on preferred foods and foods to avoid.

 Paul's tolerance for exercise varies.


Goal: to maximize Paul's participation in physical education classes, sports and recess periods.

Goal: to facilitate Paul's use of medication according to his treatment plan.

Goal: to help Paul achieve personal fitness goals (endurance, strength, etc.)

Guidelines:

- a. The adaptive gym specialist and the physical education teacher will work with Paul and his parents to develop guidelines for adjusting the pace, intensity or duration of anticipated activities. Paul's phys ed credit will be based on his performance and participation within his personal fitness goals and activity guidelines.
- b. Soccer: Paul will rotate between half back and goalie positions when he chooses moderate exertion.
- c. Gymnastics: Teacher will provide guidelines for selecting exercise and equipment options designed to match Paul's variable tolerance for exertion. On days of severely restricted activity Paul will participate as a timer and spotter.
- d. Paul premedicates before physical education class and sports activities. (2 puffs Bronchodilator) Teacher provides discreet reminders. Paul has his bronchodilator in his pocket or gym bag for use "on request" for chest tightness or shortness of breath.
- e. Safety guidelines require a buddy system in Physical Education. All students have a "buddy" who is taught how to notify the teacher of accidents, injuries or illness if a student is incapacitated.
- f. New guidelines and standards from the President's Physical Fitness Council for students with health impairments will be used during the President's Fitness Challenge week.

 **High Risk of Infection**

Paul's medication lowers his resistance making him unusually susceptible to viral and bacterial infections.


Goal: To reduce student's exposure to infection and to minimize risks of infection if exposed

Guidelines:

- a. The school nurse will review personal hygiene measures with

teachers and students including hand-washing techniques.

- b. The facilities manager will monitor fresh air intake and circulation rate in the classroom.
- c. The school nurse will notify parents by phone immediately and by letter to report an outbreak of bacterial or viral infections in Paul's or his siblings' classes. (Having this notice allows you to take necessary precautions, adjust Paul's medication, contact the doctor, and watch for early signs of illness.)

 Paul worries that using his medication may draw unwanted attention to his asthma. He worries that he will have a hard time making friends because he can't share food or buy his lunch. (He remembers third grade when his teacher made him eat alone in the hall.)

Goal: To make Paul comfortable with asthma and allergy routines at school.


Goal: To help Paul make friends.


Goal: To minimize potential for peer teasing.

Guidelines:

- a. All teachers will have individualized guidelines for Paul's asthma and allergy routines. The school will provide confidentiality guidelines for handling student's personal needs and medical information.
- b. For the first two weeks, the teachers and nurse will ask Paul at end of the day if there have been problems or dilemmas that need problem-solving help. After that they will check in on a weekly basis to make sure things are going well.
- c. Paul can take his medication privately out of the classroom in the hall or in the lavatory. Paul and his teachers will prearrange a signal if Paul needs assistance.
- d. The teachers take steps as planned to get medical assistance when Paul requests it or when teachers observe breathing problems.

- e. Teachers set a good example for students by demonstrating acceptance of Paul's needs.
- f. Teachers create classroom social climate that encourages a sense of community and a sense of belonging in the class:
- g. All students have "study buddies" who rely on each other for help with class assignments and homework.
- h. Teachers encourage the exchange of cards, calls and letters during every student's absence.
- i. Students routinely work in mixed ability groups in different topic areas and on special projects.
- j. The school administration has provided training to develop supervision guidelines and intervention strategies, use of classroom sanctions, and conflict resolution and problem solving skills to minimize verbal or physical victimization. New staff will be trained as they are hired.
- k. Teachers provide supervision during recess, lunch, before and after classes, and other unstructured times or activities.
- l. Teachers, students and parents exchange information about classroom rules which express behavioral expectations of students and cooperative values.

 Paul is at high risk for intermittent absences.

 Paul's condition or medication will occasionally affect his stamina, alertness, and ability to concentrate.

Goal: To maintain academic progress and social continuity.

Goal: To facilitate home/school/hospital transitions.

Goal: To maintain expectations for academic achievement with appropriate adaptations for variable capacity.

Guidelines:

- a. School will provide duplicate set of texts and instructional materials for Paul to keep and use at home.
- b. Paul will attend half days for main subject areas when he has limited stamina or alertness.
- c. Teachers will provide parents with monthly lesson objectives and study goals. Daily instructional objectives and study assignments will be recorded on the school's homework hotline. Paul's study buddies will call daily with classroom news and to assist with assignments.
- d. The school will provide resources and tutoring at home or in school as needed, if Paul's performance or learning is affected by absences, changes in health status, or effects of medication. (English, Social Studies, Math and Science). Instructional assistants (IAs) will be certified teachers who work at the school as classroom aides and substitutes. Home instruction plans will consider Paul's medical treatment schedule and health status so that Paul receives help when he can most benefit. Instructional assistance will include teaching materials and equipment such as VCRs, phone hook-ups, and tapes as needed. Special

events at school will be video taped for Paul.

- e. Paul's teacher and instructional assistant will develop guidelines for evaluating Paul's progress and determine grading criteria in each subject area. Paul's progress and achievement in each subject area will be evaluated every two months for mastery of course content and skills.
- f. Paul will be given the option of taking quizzes and tests in school or at home or at alternative times. Mode and length of tests will be modified.

At the end of the meeting, everyone gets a copy of the draft IHP. You look it over and make some suggestions. Paul may never need to use some of the plans and others may have to be added. The final version is typed up for everyone to sign. You know you can reconvene the team at any time.

You did not start out with the knowledge and confidence that allowed you to speak up for Paul and his needs. You are grateful that your doctor's nurse educator provided educational rights information last year when the school wanted to make Paul repeat fourth grade for missing so much school. You write a letter to your old asthma support group to tell them how easy it can be to work with a supportive school..."I can now send my

precious sweet child off to school without panicking. It takes some time and a lot of meetings but it finally works. How I wish I'd been more assertive and known about Paul's rights earlier."

AN ADVOCACY AGENDA

In a May, 1991 Senate speech about children with disabilities and the school lunch program, U.S. Senator Robert Dole pointed out that there is widespread lack of awareness and lack of enforcement of the laws designed to protect access to education for all children. In spite of the mandate obliging schools to...notify parents of the laws and how to use them, many school administrators and teachers do not know these regulations exist. "And if professionals are unaware that the regulations exist," said Senator Dole, "no wonder parents, who rely on them for information, are in the dark too."

Knowledge of their legal rights enables many parents to advocate for their children. As individual parents and health care providers, and as members of professional and lay organizations, we must protest situations that endanger and disadvantage our children. We must work together to raise awareness of the legal guidelines and resources that promote comprehensive health services and quality education.