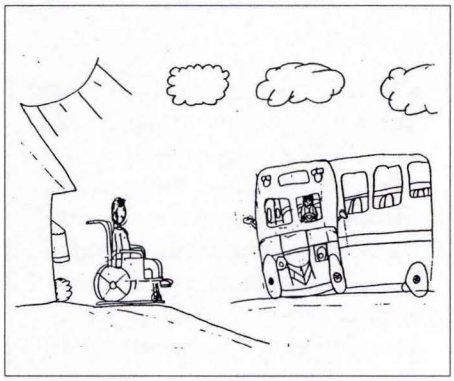
Iowa Child Health Specialty Clinics Report

CHILD HEALTH SPECIALTY CLINICS IS A STATEWIDE PROGRAM OF THE UNIVERSITY OF IOWA HOSPITALS AND CLINICS

Volume 6, No. 1 Spring 1991



A Physician's Perspective on Special Health Care in School

by Richard P. Nelson, M.D.
Director, Child Health Specialty Clinics

Children with special health care needs attend every school in Iowa and are among the students in a majority of all classrooms. Three or four of every 100 school-age children have a chronic illness or disability that affects their daily function by limiting activity. Such children may have symptoms of a health condition that persist despite the use of medication or other therapy. They may have physical incapacity that limits participation in learning tasks and even self-care, including eating and toileting. A survey conducted by the Iowa Department of Education and Child Health Specialty Clinics at the University of Iowa in 1989 found that almost 600 special health care procedures were being performed daily in Iowa schools.

There are many more children with chronic health conditions who are usually asymptomatic and do not have permanent disability, but who need regular medication or treatment and who may have sudden, unpredictable medical complications. These children have conditions such as asthma, diabetes and epilepsy.

The Need to Communicate

Physicians and other health professionals recommend that parents of these children with special health care needs share information with school staff to assure that the routine needs of their children are met while the children are at school. This requires informing the classroom teacher, principal or school nurse about the child's condition, medication which the child is receiving at home (especially if side effects might occur during school hours), and the significance of potential symptoms.

A Written Health Care Plan

Those children requiring care or procedures at school, or while being transported to and from school in a bus or van, should have a written plan agreed to by the parents and school officials. This plan may be incorporated into an Individualized Educational Plan if the child is receiving special education services. Those children not in special education should have a care plan nevertheless. The plan should specify what care, procedures and medications the child must receive while in school. The person or persons responsible for providing these services to the child should be identified. A physician in the community familiar with the child's needs should be asked by the parents to be the primary contact in the event of illness, health complications or other urgent concerns. A protocol for emergency care should be developed for those children whose conditions carry a probability of severe complications that may require rapid intervention in the classroom or transportation to the hospital.

(continued on page 2)

Reprinted from "The Connection Update," Parent-Educator Project, Iowa Department of Education, and Drake University, Des Moines, IA.

INTRODUCTION TO CHSC SPRING REPORT

The major theme of this edition of the *Report* is meeting the needs of children with special health care needs in schools. A growing number of children with long-term health conditions now attend school with their peers, and many require medications, complex health procedures or other health-related accommodations at school and while traveling to and from school. Families, educators, health professionals, transportation personnel and public policy makers are still searching for ways to assure these children safe and educationally appropriate school experiences. We hope this edition of the *Report* will provoke careful thinking and encourage action on the many concerns of these children and their families.

Thomas S. Hulme, ACSW, Assistant Director for Community Support Services

Special thanks go to Dennis Hoyt, Program Assistant with Child Health Specialty Clinics, for the researching and writing of several of the major articles contained in this issue.

PHYSICIAN'S PERSPECTIVE *(continued from page 1)*

Importance of Attending School

Physicians, educators and parents desire that every child attend school when the child can benefit from the learning and social environment of the classroom. The availability of medical treatment that preserves or restores function, while not curing the underlying disorder, permits many children to live at home and attend school. They do however require care and support in both settings. We must work together to assure the safety of these children while providing an opportunity for their optimal growth and development.

SURVEY DOCUMENTS NEED FOR SPECIALIZED SCHOOL HEALTH SERVICES

The Iowa Department of Education mailed a survey in 1989 to 1,636 building principals to assess the extent of use of special health care procedures in Iowa schools. Of surveys sent, 53% (873 of 1,636) were completed and returned. A preliminary report was prepared in February 1990 by Iowa Child Health Specialty Clinics and the Iowa Department of Education. Following are major findings:

1. Forty-two percent of the 461 students identified as needing special health procedures were in regular education classrooms. Only 30% were in self-contained classrooms.
2. Overall, the students required 598 special procedures daily for health-related conditions such as asthma, diabetes, cystic fibrosis, cerebral palsy, feeding problems, muscular dystrophy, spina bifida, scoliosis, systemic lupus, aplastic anemia, neurogenic bladder, severe bee sting allergy, and quadriplegia. Procedures included

- medications by special routes
- feeding via tube/pump
- tracheostomy care
- ventilator support
- dialysis
- cardiac pacemakers
- bronchial drainage
- high tech meds
- low tech meds
- bladder catheterization
- suctioning of mouth or airway
- oxygen administration
- monitor use
- insulin pump
- nasogastric tube care
- gastrostomy care
- ostomy care
- extraordinary physical supports

3. Forty-one percent of schools had registered nurses available 25% or less of the time. Only 14% had registered nurses available greater than 75% of the time.
4. More than half of all specialized health services were provided by individuals other than registered nurses. The study found these services were provided

- 39% by registered nurses
- 16% by teachers
- 8% by parents
- 22% by paraprofessionals
- 10% by the students themselves
- 5% by others (therapist, principal, classmate, personal aide, others)

5. A large number of schools identified a need for assistance in areas of policy and procedures, in-service training and resource materials.

WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

Children with special health care needs are a diverse group of individuals. They may have a variety of medical diagnoses, including asthma, diabetes, feeding problems, cerebral palsy, sensory deprivation, developmental disabilities, mental retardation, hemophilia, spina bifida, and health-related educational and behavioral problems.

A 1988 report, "Recommendations: Services for Children with Special Health Care Needs," developed by the Iowa Department of Education's Task Force on Children with Special Health Care Needs, describes these children as "those who require individualized health-related interventions to enable participation in the education process. Included with this population are children:

- whose medical condition is unstable or who may require emergency medical procedures;
- who require the administration of procedures during the school day which are not considered educational; or
- who are characterized by the use of a particular medical device that compensates for the loss of a body function and who require substantial, complex or frequent health care to avert death or further disability."

Overview of Issues Related to Children with Special Health Care Needs in Educational Settings

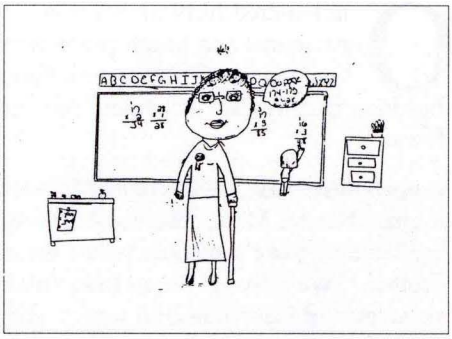
The following excerpt is from "Guidelines for the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting," May 1990, Joint Task Force for the Management of Children with Special Health Care Needs of: American Federation of Teachers, Council for Exceptional Children, National Association of School Nurses, Inc., and National Education Association. (Reprinted with permission)

In recent years advances in health care technology and procedures have increased survival rates for low birth weight infants, children with chronic illness, children with congenital anomalies, and survivors of trauma. Higher survival rates have led to increases in the number of children with temporary or long-term health care needs, including technology assistance.

Before the 1980s, children with long-term special health care needs were cared for in hospitals. Federal and state policies of deinstitutionalization, cost considerations, and pressure from advocacy groups paved the way for increased use of home health care for children with chronic health problems. Estimates of the number of children with disabilities and chronic health illness vary between 1% and 20% of the pediatric population. Specialists in the U.S. Congress' Office of Technology Assessment estimate that 47,000 or more children require technology assistance each year.

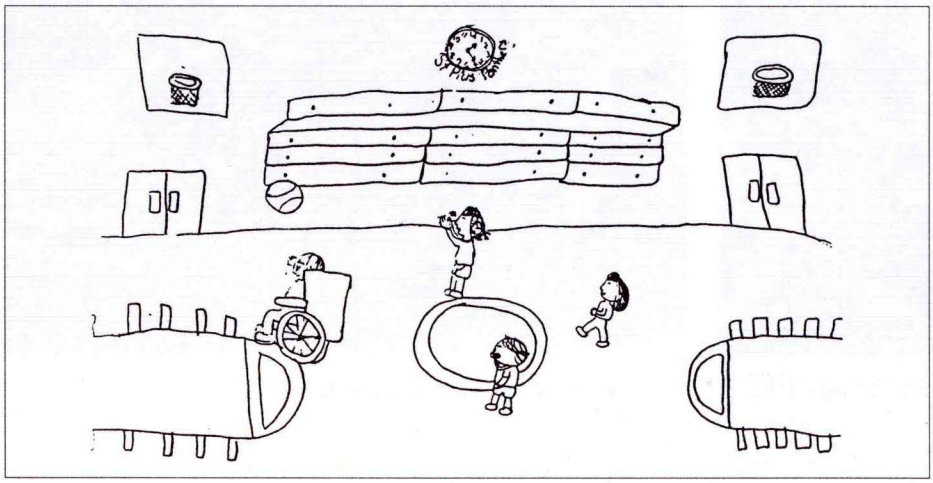
Child advocates support normalization of developmental outcomes for children with special health care needs, including school attendance in the least restrictive environment. Children with chronic health impairments are entering school systems in unprecedented numbers and have presented unique challenges and opportunities for educational policy makers.

Questions have arisen regarding responsibility for health care costs incurred during school attendance: "Public schools, pressed for funds, may often be reluctant to pay for additional full-time nurses and special transportation vehicles, and to assume legal liability for medical care during school



hours. At the time, private insurers and Medicaid will seek to minimize their costs of serving technology-dependent children at home by shifting financial responsibility to the schools" (U.S. Office of Technology Assessment, 1987).

There have also been challenges related to assignment of roles and responsibilities .... Wood, Walker, and Gardner (1986) conducted a national survey of state health and education agencies to determine the existence of guidelines for select health care procedures in schools: (1) catheterization; (2) seizure management; (3) medication administration; (4) respiratory care; (5) tube feeding; (6) positioning; (7) colostomy/ileostomy care; and (8) "others" including allergy shots. Only 6 states had written guidelines for all eight procedures, and 26 states had either no written guidelines or guidelines for medication administration only. As the number of children with special health care needs in schools increases, the need for greater clarity regarding role delineation also increases.



SPECIAL REPORT

Families, Educators, Health Professionals Urge Action to Improve Health Care in Schools

by Dennis Hoyt
Program Assistant
Child Health Specialty Clinics

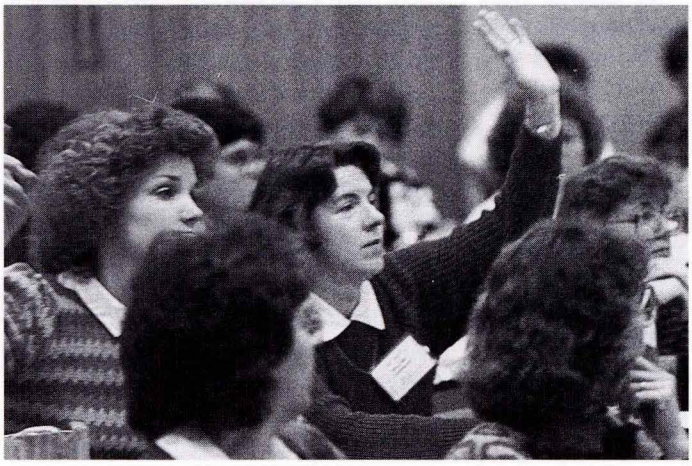
One hundred thirty-nine persons, including parents, school personnel and health professionals, participated in the conference "Children with Special Health Care Needs: Ensuring Quality Care in School," on October 20, 1990, in Ames, Iowa.

In opening remarks, the director of Child Health Specialty Clinics, Richard Nelson, M.D., observed that the quality of health services available in Iowa's schools varies greatly from one school to another. "We'd like to see all Iowa children receive roughly the same level of [school health] service and not have such tremendous differences from district to district, let alone from school building to school building."

According to Nelson, an important missing piece is a set of guidelines to promote consistency. "We really don't have the standards or protocols so that one can expect a child living in northeast Iowa will receive similar kinds of approaches and services that a child living in southwest Iowa receives."

Stephanie Porter, a registered nurse and leader in the national school health movement, emphasized the importance of good planning, teamwork, and parent participation. "Without planning, nothing is going to work," Porter observed. She said parents play a vital role in Project School Care, a Boston-based program she helped develop. "I hear the word 'partnership' a lot here in Iowa. That's really what's important, that the families are in the forefront of what's happening with their kid. Parents are included in all aspects of planning. They help to develop a health care plan. In fact, some of them have taken the health care plan and written it up themselves."

Project School Care's consultation team includes a pediatrician and registered nurse, a resource many school teams need, accord-



Attendees participate in discussion at Family Forum II, Ames, Iowa

Panel members from Family Forum II

SPECIAL REPORT

ing to Porter. "People sometimes want to have a nurse or somebody who comes from somewhere. They want to know that they're doing it right." She said the role of her consultation team has evolved over time. "We are asked to look at educational placement of the child in terms of integrating a child into the safest setting possible. We have a health care plan that we go by that outlines in detail what we want the schools to take a look at. We also work as liaison among families, schools, hospitals and community providers."

In other remarks, Nelson said Iowa can expect to see "a slow but steady increase" in the number of children in school who require special health care procedures, many of whom will be in regular education classrooms. "I think this is important, because in the minds of many, especially of some administration people, the problem with special health care procedures is sometimes associated only with issues of special education."

Over 50 recommendations for improving school care in Iowa resulted from the conference, including the following:

- Seek state legislation and funding to ensure that nurses are present in schools serving children with special health care needs.
- Define in administrative rules the roles and responsibilities of school personnel for specialized health care procedures.
- Develop a weighting system to determine the level of health services needed for individual students.
- Provide in-services on legal aspects and professional practices for educators, nurses, other school personnel, and parents.
- Establish guidelines to ensure that appropriately trained persons (aide, R.N., L.P.N.) are riding on buses when needed.
- Arrange a meeting with the chairperson of the school district board to review and discuss [school health issues].
- School principals, parent-teacher organizations, and concerned persons should work together to address these issues and to collaborate on developing solutions.
- Professional organizations for nurses, physicians, occupational therapists, physical therapists, and others should recognize the concerns of children with special health needs attending public school and the impact of professional practices on the provision of needed health care services in the school setting.
- Legislators and school board members should assure necessary funding for the safe and efficient transportation of children to and from school and appropriate school nursing services.

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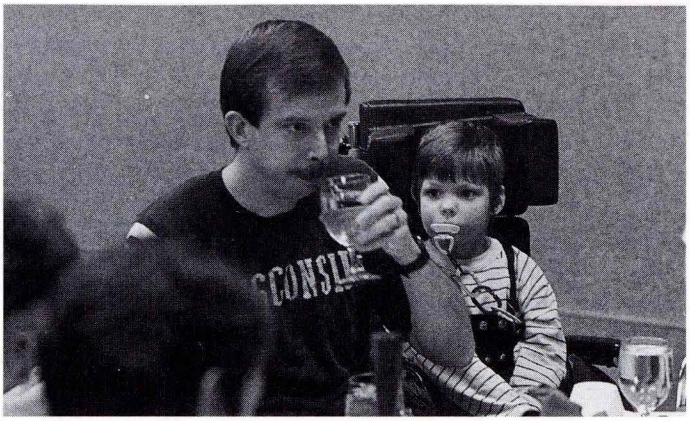


Family Forum II was sponsored by CHSC, Parent Partnership Project

SCHOOL NURSES NOT REQUIRED IN IOWA LAW

School health programs are mandated under the Iowa Administrative Code for accreditation of Iowa schools. However, the code does not require school districts to **employ nurses.** Districts now employing school nurses do so voluntarily.

The standard states

281-12.3(9) Health Services. The board shall adopt a policy for the implementation of a school health services program. The program shall be designed to help each student protect, improve, and maintain physical, emotional, and social well-being. Areas to be considered in the development of policy could include, but not necessarily be limited to: environmental health and safety; emergency health procedures and responsibility; health promotion; communicable disease prevention and control; staffing for the school health program; administering of prescription medication; acute or chronic health problems; health assessment and screening; and record keeping and program evaluation.

SPECIAL REPORT

HEALTH CARE IN SCHOOLS *(continued from page 5)*

"Ensuring Quality Care in School" was sponsored by Iowa Child Health Specialty Clinics in cooperation with the Iowa Chapter of American Academy of Pediatrics; Parent-Educator Connection Project; Iowa Nurses Association; Division of Developmental Disabilities; Iowa University Affiliated Program; Governor's Planning Council for Developmental Disabilities; Iowa Pilot Parents; Iowa Affiliate of Association for the Care of Children's Health; and Division of Family and Community Health, Iowa Department of Public Health, in cooperation with the Bureau of Special Education, Iowa Department of Education.

Family Forum II, Stephanie Porter, R.N., Project School Care, Children's Hospital, Boston, MA

STATEMENT OF PRINCIPLES
for Safe Delivery of Specialized Health Care in the Educational Setting

- Every student is entitled to a free, appropriate public education in the least restrictive environment.
- The family is the constant in the child's life and should be an integral part of decision making regarding the provision of health care in school.
- The provision of special health care procedures should promote developmentally appropriate student independence.
- A multidisciplinary meeting that includes the family, and student where appropriate, should be conducted for every child with special health care needs for the purposes of reviewing the special health needs and the delineation of roles for service delivery.
- Every child who has a special health care need requiring nursing care, intervention, or supervision should have a nursing care plan written by a nurse.
- To the degree possible, the delivery of any health care procedures should not significantly disrupt or have a negative impact on the educational process of the individual student.
- To the degree possible, the delivery of any health care procedures should not significantly disrupt or have a negative impact on the educational process of other students.
- Personnel who are responsible for the education and care of children with specialized health care needs should receive training from persons who are qualified to provide such training and certified or licensed to perform the procedure being taught.
- Specialized health care procedures should be performed by qualified personnel who have received child-specific training as defined by the child's principal health care providers and the child's family.
- Appropriate resources and environmental conditions should be available to the personnel who are providing school health procedures before the child's placement in the classroom.

From "Guidelines for the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting." May 1990.

Iowa Healthy Children Initiative

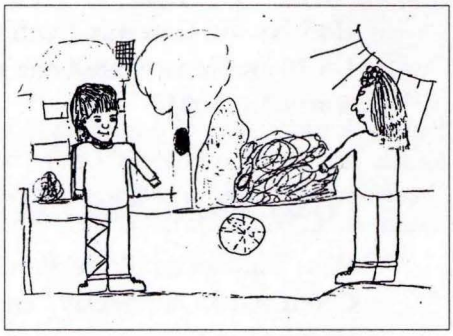
Last October, the Iowa Chapter of the American Academy of Pediatrics (AAP) and Child Health Specialty Clinics sponsored a conference to introduce an exciting new children's activity to Iowa — the Healthy Children Initiative (HCI). HCI is a nationwide effort of the AAP to provide communities with information to help them make child health care services more accessible. The initiative encourages innovation by pediatricians and leaders within Iowa communities by challenging them to use existing resources in new and imaginative ways.

An important first step in the Healthy Children process is the identification of child health service needs within the community. A simple assessment tool developed by HCI—the Community Yardstick—helps communities measure strengths and weaknesses. Community efforts can then be directed toward those needs. HCI can provide support to communities by

- identifying resource persons and materials from similar, existing community programs;
- producing promotional materials; and
- providing other technical assistance.

HCI in Iowa is directed by an 11-member steering committee, chaired by University of Iowa pediatrician, Richard P. Nelson, M.D., Director of CHSC. Dr. Nelson said that working on the Iowa Healthy Children Initiative differs from other program developments because, "It's very conceptual. . . . HCI does not organize efforts in a community. Someone in the com- munity must take a leadership role."

For further information, write to Richard P. Nelson, M.D., Iowa Healthy Children Program Facilitator, University of Iowa Hospitals and Clinics, 247 University Hospital School, Iowa City, IA 52242, or by calling 319/356-1118.



Drawings by courtesy of St. Pius X 4th grade class. Mrs. Ellen Barth, Art Teacher, Cedar Rapids, Iowa

Juvenile Rheumatoid Arthritis Program

A new service has been developed by CHSC to enable parents and communities to respond to the needs of children with arthritis. The current activities of this program are to promote learning and awareness of educational and/or other needs of these youngsters. Providing access to resource options for parents and service providers is also targeted.

The focus of this program is working with local communities to improve evaluation and treatment of this population of children.

In April, Pediatric Rheumatology Clinics staffed by UIHC pediatric rheumatologists were initiated in Davenport on a quarterly basis. It is expected that these clinical services will be extended to other areas of the state beginning in the fall of 1991.

For more information contact

Kathy Bowers, R.N., Consultant
Pediatric Rheumatology Services
University of Iowa Hospitals and Clinics
Iowa City, IA 52242
319/356-4015

OR

Dr. Mary Jones, Director
Pediatric Rheumatology Clinic
University of Iowa Hospitals and Clinics
Iowa City, IA 52242
319/356-3484

Julianne Beckett Receives National Award and Recognition

Julianne Beckett, a Program Associate with Child Health Specialty Clinics and former staff member, will receive the Lloyd M. Bentsen Award. This annual award, provided by the Kelsey-Siebolt Foundation, is a recognition for exceptional leadership in family-centered, community-based coordinated care.

Julianne serves as Coordinator for the Birth through Three Parent Network and will be serving on the Board of the Family Concerns Committee for the Virginia-based Division of Early Childhood for Exceptional Children.

ANNOUNCING
FAMILY FORUM III

October 19, 1991; 9:30 AM - 4:00 PM
Holiday Inn Gateway Center
US 30 and Iowa State Center Exit
Ames, IA 50010

FAMILY FORUM

Parent Partnership Project
Child Health Specialty Clinics
The University of Iowa

CONQUERING THE DAY CARE DILEMMA FOR CHILDREN WITH SPECIAL NEEDS

What Families and Professionals Need to Know and Do to Promote Access to Inclusive, Family-Centered, Coordinated, Quality Day Care Services for Young Children and Adolescents with Disabilities and Special Health Care Needs

PURPOSE: This forum will seek to strengthen community based family and professional leadership in promoting access to high quality day care resources for young children and adolescents with disabilities and special health care needs. Participants will have opportunities to gain information and ideas, and chart new directions for inclusive day care services. The forum will explore the relationship of community-based initiatives to implementation of recent federal legislation enacted to increase the quality, affordability and accessibility of child care.

AUDIENCE: Parents, and other family members, and professionals concerned about day care. Families are encouraged to invite their community teams—child advocates, administrators of day care programs, county policy makers, directors of resource and referral programs, public health nurses, human services workers, and others.

Registration forms and details will be available in August.

For more information, contact Darrell Bolender, Parent Coordinator, Child Health Specialty Clinics, 239 University Hospital School, Iowa City, IA 52242, 319/356-8391.

The **Iowa Child Health Specialty Clinics Report** is produced and distributed by the Iowa CHSC program as a service to Iowa children, their families, those who serve them, and all who are interested in improving the health of children and their families in Iowa. Child Health Specialty Clinics, 239 University Hospital School, University of Iowa Hospitals and Clinics, Iowa City, IA 52242, 319/356-1455.

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