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ABSTRACT

Federal legislation supports participation in the public schools by children who are medically fragile and technology dependent. These children require specialized technological health care procedures for life support and/or health support during the school day. Inclusion in safe school environments that facilitate effective learning requires careful planning by a coalition of educational and medical personnel. Guidelines for professionals to provide specialized health care to children who are medically fragile in school settings are generally nonexistent. Modes of service delivery vary from site to site, with paraprofessionals sometimes performing medical procedures. There is a need for national consensus regarding which professionals or paraprofessionals should implement specific procedures and what training or certification is required to ensure safe delivery of health-related services. There is also a need for the medical and education communities to collaboratively plan, develop, implement, and evaluate a comprehensive program for the safe, effective transition from hospital to school as well as the ongoing inclusion of the child in the community school. This collaboration could be accomplished by involving school health nurses on a medico-educational team. A model coalition of medical and educational personnel is the statewide Coalition for Students Who Are Medically Fragile and Technologically Dependent in Alabama. (KS)

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DEVELOPING MEDICAL AND EDUCATIONAL PARTNERSHIPS
IN SCHOOL SETTINGS TO MEET HEALTH-RELATED AND EDUCATIONAL NEEDS OF
STUDENTS WHO ARE MEDICALLY FRAGILE:
HOW CAN RURAL SCHOOLS CATCH THAT ELUSIVE RAINBOW?

The population of children with physical disabilities who are attending schools across the country is experiencing an unprecedented evolution. The needs of children with physical and health disabilities changed gradually in the initial years following passage of P. L. 94-142, the *Education for All Handicapped Children Act of 1975*. However, in the past decade the incidence of these children in the general population and the complexity of their needs have shifted dramatically (Hobbs, Perrin, & Ireys, 1985; Ireys, 1988; Lehr, 1990; Sirvis, 1988; Urbano, 1992; Office of Technology Assessment, 1987). This has resulted in a unique population of children who require the type and scope of services for which school systems had not previously been expected to anticipate, plan, or provide.

School systems have the challenge of completing the rainbow of hope that medical and rehabilitation technology have ushered in for children with special health needs. Progressive medical interventions have enabled children to survive medical crises that only a few years ago would have resulted in death (Parette, Hourcade, & Brimberry, 1990). Rapid development of innovative rehabilitation technologies has also occurred, enabling more children who are medically fragile and who remain dependent on medical technology to move from hospitals and nursing homes to home-bound care, and more recently to public school settings (Lehr & McDaid, 1993).

Definition of population. The Council for Exceptional Children (CEC) (1988) defined children who are medically fragile as children who "require specialized technological health care procedures for life support and/or health support during the school day" (p. 1). The Office of Technology Assessment (1987) defined a child who is dependent on technology as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability" (p. 3). Members of the Task Force on Technology Dependent Children (1988) clarified the concept of children who are technologically dependent for the consideration of school personnel by stating that a child who is technologically dependent is "a person from birth through 21 years of age; who has a chronic disability; requires routine use of a specific medical device to compensate for the loss of use of a life sustaining body function; and requires daily, ongoing care or monitoring by trained personnel" (p. vii-1). Although these definitions tend to suggest the nature of the health and educational needs which might exist, they fail to encompass all the unique medical conditions and educational needs of these students (Sirvis, 1988).

Inclusion of Students Who Are Medically Fragile In School Systems

Participation in the public schools by children who are medically fragile and technology dependent is supported by existing federal legislation. Section 504 of the *Rehabilitation Act of 1973* prohibits discrimination against persons with disabilities who receive services in public school settings, and mandates the opportunity to participate in federally funded programs. P. L. 101-336, the

Americans with Disabilities Act of 1990 (ADA), extended the Section 504 protection against discrimination to private and public entities. P. L. 101-476, the *Individuals with Disabilities Education Act of 1990 (IDEA)* ensures the right for all children to receive a free and appropriate *public education*. Despite these legal mandates and a shift in popular opinion regarding the inclusion of individuals with disabilities in society, practical and successful inclusion of this population of children in school settings will be difficult to achieve. School personnel are challenged to anticipate and provide for the full scope of needs of children who are medically fragile and who remain dependent on medical technology while they are in school settings. Inclusion in safe school environments that facilitate effective learning will require careful planning by a coalition of educational and medical personnel. Careful planning and the provision of appropriate learning opportunities for these children will, in turn, prepare children to become full participating members of society as adults.

The numbers of children who have complex health needs in school settings are increasing concurrently with adjustments being made by school systems in response to powerful philosophical and legal forces. Acceptance of the concept and practice of inclusion is growing in momentum (O'Brien, Snow, Forrest, & Hasbury, 1989; Stainback & Stainback, 1990). The literature is burgeoning with controversy regarding the definition of inclusion, the scope of services that should be involved in inclusionary school settings, and the appropriateness of all children being included in general education settings (see e.g., Fuchs & Fuchs, 1994). Interestingly, the literature appears to suggest that practitioners are developing inclusionary programs based on a philosophical rather than an empirical foundation. Children who are medically fragile and who remain dependent on medical technology are a new challenge to traditional general and special education programs. These children are particularly vulnerable to the newly emerging, underdeveloped inclusionary programs (Caldwell & Sirvis, 1991; Lehr, 1990a, 1990b; Viadro, 1987) which fail to consider or plan for the health-related needs of these children. Most of the literature on inclusion consistently addresses curriculum and social issues while totally dismissing considerations for children who have complex medical needs.

Opponents of inclusion have expressed concern about the dilution of special services to all children with disabilities in inclusionary settings. However, with collaborative planning by partnerships forged across medical and educational disciplines, viable means can be developed for professionals to safely and effectively meet the needs of students who are medically fragile and who remain dependent on medical technology while they are in school settings. School programs that safely and effectively include these children must be planned, developed, and implemented with the full, active collaborative participation of nursing professionals, allied health personnel, physicians, and personnel from both special and regular education. Additionally, plans for an adequate number of personnel as well as appropriate training of all personnel at each level within the educational system must be provided and continuously updated to ensure the ongoing safety of this population of children while in school settings.

Scope of Services in School Settings Needed by Children Who Are Medically Fragile

What is the scope of the services that children with special health care needs require? The Office of Technology Assessment (1987) divided the population of technology-dependent children into four subgroups. These categories provide an excellent overview of the scope of the needs of these children. Criteria for each subgroup were based on medical technology frequently needed by children with complex medical needs and include: (a) Group I children who require ventilator assistance; (b) Group II children who require parenteral nutrition and/or prolonged intravenous drugs; (c) Group III children who require other more complex device-based respiratory or nutrition support; and (d) Group IV children who require apnea monitoring, renal dialysis, and/or other device-associated nursing.

The Joint Task Force for the Management of Children with Special Health Needs of the American Federation of Teachers (AFT), The Council for Exceptional Children (CEC), National Association of School Nurses, Inc., (NASN), and National Education Association (NEA) (1990)

identified 10 categories of procedures that are typically needed by children who are medically fragile. These categories include specialized health care procedures involved in (a) activities of daily living, (b) catheterization, (c) medical support systems, (d) medications, (e) ostomies, (f) respiratory assistance, (g) screenings, (h) specimen collection/testing, (i) other health care procedures, and (j) development of protocols. Various personnel have been identified to perform these specific procedures based on specialization of training and skill level required for their performance. Personnel include the physician, registered nurse, licensed practical nurse, certified teaching personnel, nutritionist, occupational therapist, physical therapist, speech/language pathologist, teacher aides, health aides, uncertified teaching personnel, secretaries, bus drivers, cafeteria workers, and custodians (Joint Task Force for the Management of Children with Special Health Needs, 1990).

Current Modes of Service Delivery In School Systems for Children Who Are Medically Fragile

Guidelines for roles and responsibilities for professionals to provide for the safe delivery of specialized health care to children who are medically fragile in school settings have only recently been identified (cf. Caldwell, Todaro, & Gates, 1989; California State Department of Education, 1990; Haynie, Porter, & Palfrey, 1989; Joint Task Force for the Management of Children with Special Health Needs, 1990; Pennsylvania Department of Health, 1983; Viele, 1988). Despite these recent efforts to develop guidelines, school systems are unprepared for the arrival of these children in educational settings. Few educators have the requisite experience and training in the types of health care procedures required for inclusion of children who are medically fragile and who are technologically dependent (Lehr & McDaid, 1993). This presents a very serious ethical dilemma for educators. As noted by Nemeth (1993/94), "Teachers and paraprofessionals nation-wide are saying that, without formal training, often without supervision or specific information, they are being asked to make medical decisions and perform medical procedures on children with severe handicapping conditions" (p. 9). Protocols and policies which clearly establish the roles and responsibilities of personnel within the child's educational setting are typically nonexistent. Such problems, compounded with the lack of appropriate personnel training and direct experience, places school systems and students who are medically fragile and reliant on medical technology in a very precarious position (Holder-Brown, 1994).

School systems are currently attempting to address the unique needs posed by this special population of children; however, without universal policies, attempted solutions vary significantly across time, sites within each state, and across the nation. For example, Nemeth (1993/94) describes a city school system in the northwest initially was providing incentives for paraprofessionals to volunteer to receive further training to perform medical services. This practice reflects a trend toward expanding services by delegating roles, sometimes highly technical, upon paraprofessionals. Recently this same school system has developed a more expansive policy that "... determines who will be trained for what procedures..." (Nemeth, 1993/94, p.9). Their new policy states that doctors will provide written authorization for specific procedures; and additional "medical" training will be provided for teachers. Despite their acknowledgment of the need for more intensive health-related care for these children while in school settings, the role of the school health nurse was not developed to encompass meeting the needs of these children beyond providing the written Health Care Plan. Nemeth (1993/94) also describes a school district in Michigan that has specified that school nurses make all nursing judgments and decide which duties, if any, can be delegated. A southern state has addressed the issue by mandating a specific number of training hours required for paraprofessionals and for teachers before they can perform "medical" procedures. Teachers from a school system in a major northeastern city reported that they are "... performing medical procedures, but many would rather not... teachers, secretaries, paraprofessionals, and bus drivers should not be required to perform medical procedures." (Nemeth, 1994, p. 9).

Issues

Differences in philosophy, policy, and approaches within states and across the nation focus

attention on three major issues relating to serving children with special health-related needs in educational settings. The first issue is the need for a national consensus regarding which professionals and/or paraprofessionals should be implementing specific procedures. The second issue is the need for specific training and/or certification requirements designed to ensure safe delivery of health-related services to children who are medically fragile and who remain dependent on medical technology while in educational settings. Such certification requirements would be unique for each level of employee working within school settings. The third issue focuses on the need for the medical *and* educational community to collaboratively plan, develop, implement, and evaluate a comprehensive program for the safe, effective transition of children from the hospital to the school setting as well as the ongoing safe, effective inclusion of the child in his or her community school.

One possible solution that will enable the medical and educational community to successfully collaborate could be accomplished by involving more expansive use of school health nurses. Generally, school health nurses continue to provide traditional school health nursing services such as health education, first aid, screening, accident prevention, and environmental management. Frequently school systems do not have nurses on staff, or they will have one nurse who provides services for an entire school district. The use of the mutual health-related training of the nurse in the medical setting and the school nurse provides a natural bridge between the two service sectors. This partnership can be the effective connection needed to bridge the current gap between the medical environment and the educational environment. The resulting linkage is the key to the development of a medico-educational team that can ensure the success of the child's ultimate rehabilitation and maximum inclusion in society.

The Medico-Educational Team Development and Process

When the child's maximum medical recovery and physical rehabilitation has occurred in the medical setting, a shift in emphasis on service delivery begins. Rather than focusing on services provided in the hospital, attention is directed toward service delivery in the child's community. A collaborative, multidisciplinary medical team consisting of the parents, physician, nurse/health care coordinator, and appropriate allied health personnel (e.g., physical therapist, occupational therapist, speech therapist, and/or social worker) jointly review and discuss the child's health records, physician's orders for health-related procedures and equipment, and how the resulting needs can be met in the child's home, community, and school.

After this formal multidisciplinary team meeting, and before the child's hospital discharge, the nurse/health care coordinator must directly contact the school health nurse to provide information regarding the child's status and health-related needs that will continue to be required while the child is in school. This step is *imperative* to ensure appropriate maintenance of health-related procedures during the transition from the hospital to the school setting. The nurse/health care coordinator should make the initial contact with the school health nurse by telephone and follow up immediately with a letter, copy of physician's orders, and discharge plan.

Once the information has been received by the school health nurse, the nurse/health care coordinator again contacts the school health nurse by telephone to determine how the child's needs can be met within the educational setting. The nurses from the two settings collaboratively determine the need and availability of personnel, equipment, and accessibility within the school. The numbers and types of personnel, and the training they need; equipment availability; and accessibility provisions must be carefully planned to ensure that the child's health-related needs are met safely and effectively within the school setting.

The medico-educational team. This team consists of the physician, parent, the nurse/health care coordinator from the hospital, the school nurse, school counselor, and related service personnel and allied health personnel (e.g., physical therapists, occupational therapists, social worker). The team collaboratively makes determinations based on shared information gained from the medical records,

school records, concerns of the parents and child, as well as identified resources and needs of the school. A home visit may be of value, but may not always be realistic. All team members may not be able to participate and some parents may not desire a home visit from a team member. Alternatives for the first medico-educational team meeting must be flexible.

The minimum medico-educational team participants for the initial transition meeting should include the nurse/health care coordinator for the hospital or rehabilitation center, the school health nurse, the parent, and, if appropriate, the child. A meeting involving these three key people is imperative to ensure the effective bridging of the medical and educational communities.

Options for the initial meeting of the medico-educational team include the (a) hospital; (b) school; (c) child's home; or (d) a geographic site between the hospital and school when long distances are involved. An alternative to a physical meeting site could be a three-way telephone conference. During this meeting the participants will determine the family's and the medico-educational team's resources for providing health-related needs to the child during the daily transition between the home and the school setting. The team members must collaboratively address needs for training, equipment, and accessibility for home, community, and school to safely and effectively provide for child's health-related needs within each setting as it relates to the child's educational development. It is important that the findings be recorded by the nurse/health care coordinator and be sent to all members of the medico-educational team. Also, this report can become part of the school nurse's assessment and must be used as a foundation for the child's Health Care Plan; thus, it should become a permanent part of the child's school records.

It is imperative that the medico-educational team collaboratively determine what is needed to ensure the safe and effective participation of the child in school from the time the child departs for school until he or she returns home. Transportation, transition from the bus to the classroom, classroom involvement, transitions within school, access to the cafeteria, and participation in physical education must all be considered. Within each of these settings, a range of factors must be jointly identified and provided: (a) specific services needed by the child, (b) personnel requirements, (c) training needs of personnel, (d) equipment needs, (e) potential problems or emergencies, (f) emergency plans, and (g) back-up plans for absent staff.

When the medico-educational team determines and agrees upon needs in each of these areas, objectives for each participant must be established to ensure that resources are available to provide the child with a safe environment that enables him or her to learn effectively. For example, objectives may be included for (a) the local and state education agencies; (b) community agencies; (c) school personnel such as the school nurse, school counselor, physical therapist, occupational therapist, teacher, aides, bus driver, and cafeteria personnel; (d) medical personnel such as the physician, occupational therapist, and the nurse/health coordinator; (e) the parent; and (f) the child. Objectives should be based on the resources accessible to and competencies demonstrated by each participant. Pooling skills and talents across all participants and sharing information and expertise with targeted personnel requiring assistance is the key to facilitating a successful transition for the child from the medical to the educational setting.

Service Delivery in Rural Settings for Students Who Are Medically Fragile

Personnel within rural communities frequently feel that they are not able to maintain comprehensive service delivery in either their medical or educational environments. School administrators and teachers in rural areas may feel particularly vulnerable and inadequate due to the inability of their community and school to meet some of the complex, high-tech, health-related needs exhibited by children who are medically fragile and who remain dependent on medical technology. Success in rural education settings in providing the appropriate care to these children can be accomplished through the following preparations:

1. Medical teams at major hospitals and rehabilitation centers should be developed. These teams must accept the responsibility for developing and implementing comprehensive transition plans for children which consider transitions from hospital and rehabilitation settings to community schools.

2. Educational teams must be developed within all school systems that have the capability of establishing linkages with medical teams. Use of school health nurses as liaisons between educational personnel and hospitals is critical.

3. Medical teams and educational teams must be willing to provide feedback to one another regarding the child's health-related needs, resources, and training requirements. Information exchange is imperative if safe, inclusive environments that are conducive to optimum learning are to be maintained for children who are medically fragile.

If these basic tenets are not in place within a community and state, it is suggested that a state-wide coalition for students who are medically fragile be initiated. Provision of comprehensive services in predominantly rural areas depends upon cooperative relationships between agencies and individuals within the community, as well as networking between communities. Successful service delivery is contingent upon knowledge of existing resources and developing innovative approaches to accessing these resources when situations arise that demand services that are not available in traditional and direct ways. Development of these resources requires a general awareness by all agencies throughout the community and across the state regarding the need to share information and resources about children who are medically fragile and who remain dependent on medical technology while in a school setting.

A model coalition. The Coalition for Students Who Are Medically Fragile and Technologically Dependent was initiated in April, 1993, to address the needs of students with special health needs in schools across Alabama. The primary concern of the Coalition was the increasing number and complexity of needs exhibited by these children at a time when resources in educational settings were being diverted from special care populations. The founders of the coalition were also concerned about the rural nature of the state in which most school systems had extremely limited resources. Potential participants in the coalition were contacted from a variety of disciplines, settings, and communities. They included parents, educators, nurses, physicians, physical therapists, occupational therapists, speech pathologists, social workers, school counselors, special education coordinators, case managers, hospital discharge planners, child life directors, school superintendents, principals, and legal advocates.

The Coalition employed a broad, multidisciplinary perspective to reach a consensus regarding (a) the population of children currently served within medical and educational environments, (b) the future population requiring services based on medical trends, and (c) a vision statement. The Coalition collaboratively developed a series of purpose statements which would guide the work of the group regarding service delivery to students who are medically fragile and/or technologically dependent while they are in educational settings. The following purposes have been identified: (a) gain clarification of professional roles and responsibilities in educational settings; (b) ensure appropriate training for families, caregivers and all educational personnel involved in the child's educational process; (c) develop recommendations regarding guidelines for state-wide implementation to meet health-related and educational needs of these students; (d) develop grass-roots lobbying of legislators to gain funding for personnel preparation programs, inservice and community-based training and provision of appropriate direct services; (e) develop and provide educational awareness to the general public; (f) ensure that the State Department of Education requires teachers who work with students who are medically fragile and technologically dependent to be certified in Orthopedic and Other Health Impairments; and (g) ensure that Alabama has at least one graduate level personnel training program to certify teachers in Orthopedic and Other Health Impairments.

Each of the purpose statements was assigned to a working committee charged with the responsibility of developing appropriate goals and objectives. The professional roles and

responsibilities have been studied from the perspective of the needs of different communities across Alabama, as well as from information from the literature that implied best practice, and guidelines that had been developed in other states. In the process of conducting literature reviews, the Roles and Responsibilities Committee of the Coalition discovered that the school nurse, in conjunction with the nurse/health care coordinator from the hospital or rehabilitation center, could form an effective partnership to act as liaisons between the medical and educational communities. Further examination of the literature revealed that school nurses have frequently been cut from school systems, leaving a number of schools without nursing services. These findings assisted another working group, the Lobbying and Legislative Committee, to establish an important objective that focused on increasing funding for the school nursing program through lobbying efforts in the state legislature. Although still in the developmental stages, the work of the Coalition is already achieving goals to meet the needs of students who remain dependent on medical technology while in Alabama school systems.

The key to the success of the Coalition for Students Who Are Medically Fragile and Technologically Dependent is collaboration between disciplines across the medical and educational fields, coupled with a willingness to develop legislative, and professional support from the State Department of Education, the Academy of Pediatrics, the Nursing Association, and the Board of School Nursing. This requires tremendous involvement and time commitments from professionals, but it is a promising approach for developing collaborative partnerships that can be used across the state to benefit all communities, especially rural areas that are predominant across the nation.

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