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EDUCATING STUDENTS WITH COMPLEX HEALTH CARE NEEDS IN PUBLIC SCHOOLS: THE INTERSECTION OF HEALTH CARE, EDUCATION, AND THE LAW

DONNA H. LEHR, PH.D.* JILL GREENE, M.S.**

I. INTRODUCTION

In the 1980s, students with complex health care needs, a sub-population of students with special needs, were described as the newest challenge facing school district administrators.¹ Since their arrival in schools in the 1980s, each time a new student enrolls, they raise serious concern, and even fear, among many school administrators, few of whom have prior experience with such students.² Many administrators consider the health care needs of such students to be beyond those which should be met within their schools, and that the health care needs of these students are more extensive than that which is within the scope of school nursing services.³

The Education of All Handicapped Children Act,⁴ (EAHCA) signed in 1975 and now known as the Individuals with Disabilities Education Act⁵ (IDEA), requires states to assure that all students with disabilities receive a uniquely designed educational program.⁶ Prior to the passage of this law, school districts had a long history of providing school nursing services aimed at promoting the health and safety of the general population of students who attend their schools, and as

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^{1.} This unique population of students continues to pose challenges to school administrators each time a school district initially assumes responsibility for providing them an education. See Debra Viadero, 'Medically Fragile' Students Pose Dilemma for School Officials, EDUCATION WEEK, Mar. 11, 1987, at 1, 14.

^{2.} See id. at 1.

^{3.} See Donna H. Lehr & Mary Jo Noonan, Issues in the Education of Students with Complex Health Care Needs, in PERSONS WITH PROFOUND DISABILITIES: ISSUES AND PRACTICES, 139 at 148. (Fredda Brown & Donna H. Lehr, eds., 1989).

^{4.} Pub. L. No. 94-142, 89 Stat. 773 (1975) (codified as amended at 20 U.S.C. §§ 1400-1490 (Supp. V 1999)).

^{5. 20} U.S.C. §§ 1400-1490 (1994 & Supp. V 1999). See Individuals with Disabilities Education Act Amendments of 1991, Pub. L. No. 102-119, 105 Stat. 587 (1991) (changing the name of the statute to the Individuals with Disabilities Education Act).

^{6. 20} U.S.C. § 1412(a)(1)(A), (a)(4) (Supp. V 1999).

a result of the IDEA, the scope of school nursing services broadened as the range of students served by public schools expanded. As students with complex health care needs began attending school, however, the nature of school nursing care required even further change to meet the more diverse needs of these students.⁷

Who were these students? Where did they come from? Why were administrators so concerned about their presence in schools? What were the legal and programmatic decisions made regarding these students' educational programs? The purpose of this article is to address these questions and the issues and practices that have evolved over the past fifteen years as this unique, and growing population of students participate in educational programs in public schools all throughout the country.

Before proceeding with a discussion of the issues and practices surrounding the education of students with complex health care needs, a discussion regarding the terminology used to describe this population of students and their prevalence is appropriate. The students who are the focus of this article have been referred to in the literature as having "special health care needs" or as being "medically fragile." The term special health care needs was first used by former U.S. Surgeon General C. Everett Koop in 1987 when he inaugurated a campaign focused on improving the lives of children with special health care needs and their families.⁸ He characterized children with special health care needs as having a broad range of disabilities and illnesses that vary in intensity and duration.⁹ He acknowledged that within this group is a very small number of children dependent on technology for sustaining life,¹⁰ and therefore, different terminology is necessary to distinguish them from the larger group of children with special health care needs. It is this subgroup that is the focus of this article.

The term "medically fragile" is commonly used to describe this population of children; however, the authors find this term undesirable for several reasons. First, by virtue of surviving long enough to be students, this term seems contradictory. Perhaps they could more

^{7.} Schools now routinely provide more specialized nursing services including seizure management, first aid, glucose monitoring, and administration of asthma treatments. See Lehr & Noonan, supra note 3.

^{8.} C. Everett Koop, U.S. Dep't of Health and Human Services, Surgeon General's Report: Children with Special Health Care Needs (June 1987).

^{9.} Id. at 7. The Surgeon General noted that flexible systems of "family-centered, community based coordinated care" must be available for children with special health care needs. Id.

^{10.} See id.

aptly be referred to as medically "resilient." A second reason for avoiding the term "medically fragile" is based on concern about the immediate reaction observed among school personnel when they are notified that a "medically fragile" student is about to attend their school. The label seems to lead to the question, "If they are so fragile, why are they at school?" The term "medically fragile" is a sensational one that can raise a level of concern beyond that which is productive to the goal of assuring an appropriate education for individual students.

Instead, we have purposefully chosen to use the term "complex health care needs" to describe this subgroup of students with special health care needs. These students require educational programming decisions that are considerably more complicated to make than those which are necessary for most students. Educational program planning teams must take into consideration the ways in which the students' health care needs interact with their educational needs. The legal rights of students and questions about the responsibilities of schools and the personnel working within schools has made service delivery to these students a very complex process. It is hoped that the descriptor "complex" will be able to be dropped as issues and questions are resolved and education programs for this subgroup becomes more routine.¹¹ For now, however, it seems to aptly describe the students.

II. THE POPULATION OF STUDENTS WITH COMPLEX HEALTH CARE NEEDS

Students with complex health care needs includes children who, in the past, often did not live beyond critical period of illnesses; few lived long enough to become students.¹² Traditionally, the children who did survive their critical care periods required ongoing nursing care and received their education in hospitals or institutions where trained medical personnel were available to provide the needed health care services.¹³ However, changes in society's attitudes toward

^{11.} Donna H. Lehr, Providing Education to Students with Complex Health Care Needs, 22 Focus on Exceptional Children, Mar. 1990, at 1, 3.

^{12.} Lehr & Noonan, *supra* note 3, at 140. Improvements in medical technology, however, enable many more of these children to survive serious illnesses, often with ongoing needs for intrusive health care services. *See* Donna H. Lehr & Pat McDaid, *Opening the Door Further: Integrating Students with Complex Health Care Needs*, 25 FOCUS ON EXCEPTIONAL CHIL-DREN, Feb. 1993, at 2. These services include monitoring of oxygen or ventilators necessary to aid or enable breathing, tracheostomy suctioning and care, osteomy care, urethral catheterization, dialysis, I.V. feeding, and nasal or gastric tube feeding. *See* Lehr & Noonan, *supra* note 3, at 141-147.

^{13.} See Viadero, supra note 1, at 14.

where people with disabilities should live, the so called "deinstitutionalization" movement, resulted in individuals residing in their communities with their families, rather than remaining in hospitals or being placed in institutions.¹⁴

Federal support for the placement of children with complex health care needs in family homes was exemplified in 1981 when President Reagan approved the use of federal Medicaid funds to pay for the costs of in-home care for a child named Katie Beckett. Previously, Medicaid funds could only be used to pay for services provided in approved institutional settings such as hospitals, nursing homes or centers for individuals with developmental disabilities.¹⁵ Katie's mother preferred to have her child reside in their family home; however, the cost of her care was prohibitive.¹⁶ Katie's mother successfully argued that the nursing services her daughter required could be provided in her home, and at a cost less than that of providing the same care in a hospital.¹⁷ What resulted was the so-called "Katie Beckett Waiver" program.¹⁸ This program enables states to use federal Medicaid funds more flexibly to cover the costs of health care services in the home and community rather than just in institutional settings, regardless of the income and assets of the family.¹⁹ This contributed to an increase in the number of children residing in their family homes and in their home communities.²⁰

The educational equivalent of the deinstitutional movement is the shift towards educating students with disabilities in least restrictive environments (LRE). As one of the key principles of the IDEA, the LRE requirement provides that, whenever appropriate students with disabilities should be educated alongside their non-disabled peers.²¹ As a result of the passage of the IDEA in 1975, school districts could no longer merely provide students with severe disabilities, including those with complex health care needs, with in-home tutoring for a

^{14.} See id.

^{15.} See Joseph P. Shapiro, The Mothers of Invention, U.S. NEWS AND WORLD REPORT, Jan. 10, 1994, 38 at 40.

^{16.} See id.

^{17.} See id.

^{18.} Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. 97-248 § 134, 96 Stat. 324, 375 (1982); see Shapiro, supra note 15, at 40.

^{19. 42} U.S.C. § 1396(e)(3)(C) (Supp. V 1999).

^{20.} See Lehr & McDaid, supra note 12, at 3; see also Shapiro, supra note 15, at 40.

^{21.} See 20 U.S.C. § 1412 (a) (5) (A) (Supp. V 1999).

limited amount of time.²² Nor, could these students automatically be placed in institutions, or special schools.²³

Parents and other child advocates argued that services must be brought to students rather than placing students where specialized services were readily available.²⁴ For all students with disabilities, including those with complex health care needs, this meant that school districts had to consider the placement of individual students in general education schools and, when deemed appropriate, had to provide skilled nursing services in the school.²⁵ As a result, students with complex health care needs began attending the same schools as their peers in their neighborhoods.²⁶

Since there is no generally agreed upon term to describe this subpopulation of students, there are no accurate counts of the prevalence of children with complex health care needs in schools. In 1998, the number of children with special health care needs, from infancy to eighteen (18) years old, made up approximately 18% of the total population of children in the United States.²⁷ The number of children who were identified as "experienc[ing] a need for assistance or special equipment in conducting the activities of daily living (eating, bathing, dressing, etc.) because of a chronic physical or mental condition" was estimated to be 0.2% nationwide.²⁸ It is important to note that these estimates are of the prevalence of *children*, not school aged students. No data could be located regarding the number of students in these categories, but it is expected that these numbers are even lower. However, while the present number of students in this group is low, it is generally agreed that the prevalence of children with complex health care needs who attend school will increase in future years.²⁹

29. See U.S. Congress, Office of Technology Assessment, Technology-Dependent Children: Hospital v. Home Care – A Technical Manual, OTA-TM-H-38, May 1987, at 4; Judith S. Palfrey

^{22.} See Dept. of Educ. v. Katherine D., 727 F.2d 809 (9th Cir. 1983) (holding that the Department of Education did not provide Katherine a free and appropriate education during the 1980-81 school year by offering her a homebound program with no academic instruction when Katherine had already demonstrated she was able to attend regular classes so long as certain health care services would be provided by a school nurse).

^{23.} See 20 U.S.C. § 1412(a)(5)(A), (D) (Supp. V 1999).

^{24.} See Roncker v. Walter, 700 F.2d 1058 (6th Cir. 1983); 20 U.S.C. § 1400(a)(5)(D) (Supp. V 1999).

^{25.} See 20 U.S.C. § 1400(c)(2)(E) (Supp. V 1999).

^{26.} See Lehr, supra note 11, at 7.

^{27.} Paul W. Newacheck et al., An Epidemiological Profile of Children with Special Health Care Needs, 102 PEDIATRICS 117 (1998). The definition of special health care needs used in this research was "those who have or are at increase risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health care related services of a type or amount beyond that required by children generally." *Id.* at 117.

^{28.} Id. at 120-1.

III. LEGAL CHALLENGES IN THE EDUCATION OF STUDENTS WITH COMPLEX HEALTH CARE NEEDS³⁰

School district administrators' reaction to the arrival of students with complex health care needs at school has varied. Some, while recognizing their responsibility to educate *all* students with disabilities,³¹ questioned their legal responsibility to provide these students with the extensive health care services they required during the school day. Discussions occurred in Individualized Educational Program (IEP) team meetings, in administrative hearings, and in the courts regarding who was responsible for paying for the costs of the health care services needed by the students.³² Differences in decisions regarding this issue were based on varying interpretations of the meaning of the terms "related services" and "medical services" as defined in the IDEA.³³

Related services are defined by the IDEA as:

transportation and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling . . . as may be required to assist a child with a disability to benefit from special education³⁴

31. See Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, § 6, 89 Stat. 773 (1975) (requiring that all students with disabilities be provided with a free appropriate educational program). Numerous challenges to this so-called zero reject provision of the law occurred; however, the courts have upheld challenges to this provision. See Timothy W. v. Rochester Sch. Dist., 559 EHLR 480 (D.N.H. 1988), aff'd, 875 F.2d 954 (1st Cir. 1989).

32. See Donna H. Lehr, U.S. Supreme Court Requires School District to Pay for Nursing Services for Student with Complex Health Care Needs, TASH NEWSLETTER, Mar. 1999, at 28.

33. See Stephan B. Thomas & Constance Hawke, Health Care Services for Children with Disabilities: Emerging Standards and Implications, 32 THE J. OF SPECIAL EDUC., 226, 226 (1999) (providing a comprehensive discussion on this point).

34. 20 U.S.C. § 1401(22) (Supp. V 1999).

et al., Project School Care: Integrating Children Assisted by Medical technology into Educational Settings, 62 J. OF SCH. HEALTH, Feb. 1992, at 50, 54.

^{30.} See Leslie Seid Margolis, The Provision of School Health Services to Students with Disabilities: The Intersection of Health Care Policy, Education and the Law in the Post-Garret F. Era, 5 J. OF HEALTH CARE L. & POL'Y (forthcoming Spring 2002); Ellen Callegary, The IDEA's Promise Unfulfilled: A Second Look at Special Education and Related Services for Children with Mental Health Needs after Garret F., 5 J. OF HEALTH CARE L. & POL'Y (forthcoming Spring 2002) (for more in depth discussion of the legal issues affecting children with special health care needs).

In contrast, a medical service must be solely "for diagnostic and evaluation purposes."³⁵ Some school district administrators interpreted tube feeding or tracheostomy suctioning as medical procedures that are not diagnostic in nature.³⁶ Consequently, these administrators did not consider the administration of these procedures within the scope of their school district's responsibility.³⁷ Other district administrators interpreted related services as including anything the students needed to enable them to benefit from special education.³⁸ Those districts assumed financial responsibility for providing the health care services necessary for the students to attend school.³⁹

The result of variable interpretations by individual administrators, IEP teams, and the courts was varying service delivery models for students with special health care needs that were not necessarily based on the unique needs of the students, but rather on the districts' interpretations of their responsibilities under the law. In one model, students attended schools; however, instead of the school paying for the provision of the students' health care services, parents provided services themselves during the school day.⁴⁰ In other cases, the parents assumed fiscal responsibility for nurses or others to provide the needed services.⁴¹ In yet another model, tutors provided by the school district educated students at home. In this latter model, students received in-home tutoring ranging from several hours a day to several hours a week.⁴²

Some parents, not satisfied with these options, challenged school districts' decisions and as a result, a considerable number of due process hearings and court cases ensued. The United States Supreme Court decided two cases that specifically focused on whether health care services needed by students were considered "related services" or "medical services." In 1984, in *Irving Independent School District v. Tatro*,⁴³ the Court held that clean intermittent catheterization (CIC) was a related service and as such the school district was responsible for providing this health care service while the student, Amber, who had

35. Id.

37. Id.

- 39. See id.
- 40. See id.
- 41. See id.
- 42. See id.

^{36.} See, e.g., Fulginiti v. Roxbury Township Public Sch., 921 F. Supp. 1320, 1322 (D.N.J. 1996).

^{38.} See Lehr, supra note 32, at 28.

^{43.} Irving Indep. Sch. Dist. v. Tatro, 468 U.S. 883 (1984).

spina bifida, attended school.⁴⁴ The Court determined that Amber needed CIC in order to attend school; therefore, the service fell within the "related services" provision of the IDEA.⁴⁵ The Court went on to find that the procedure was not medical in nature.⁴⁶ CIC was acknowledged as a relatively simple procedure that could be scheduled for administration at set times during the day and was similar to procedures already being provided by school nurses throughout the country.⁴⁷ In fact, Amber's mother, who was not a medical professional, was taught to provide CIC,⁴⁸ and furthermore, it was expected that, ultimately, Amber would learn to administer the procedure herself.⁴⁹

While this decision provided guidance to school districts responsible for students who needed CIC, it did little to clarify school district responsibility for other, more complicated health care procedures.⁵⁰ What if the health care services needed by the students require constant monitoring as in the case of students who require intermittent, as needed, tracheostomy suctioning about which judgements must be made regarding when to suction? What if the student was dependent on a ventilator and required constant monitoring of vital signs? These were questions raised in federal courts throughout the country, and often court decisions were made based on "conflicting interpretations of federal statutes and regulations . . . leaving educators and parents in a quandary over the level and extent of health services that children with disabilities are entitled to receive."⁵¹

Then in 1999, the U.S. Supreme Court considered the interpretation of the terms "related services" and "medical services" under the IDEA in *Cedar Rapids Community School District v. Garret* F.⁵² Garret F. was a high school student with a severed spinal cord due to a motorcycle accident at age 4. As a result of the accident, Garret was paralyzed and required intermittent urinary track catheterization, tracheostomy tube suctioning, and ventilator monitoring on a continuous basis. Initially, Garret's aunt attended school with him and provided the care he needed throughout the day. Later, his family paid others to provide the care. When his parents asked the school district to assume

- 47. See id.
- 48. See id. at 885.
- 49. See id.
- 50. See Lehr, supra note 32, at 29-30.
- 51. Thomas & Hawke, supra note 33, at 226.
- 52. Cedar Rapids Cmty. Sch. Dist. v. Garret F., 119 U.S. 992 (1999).

^{44.} See id. at 891.

^{45.} See id. at 890.

^{46.} See id. at 891.

the cost of his health care services, the district refused, arguing that the services were not related services but were medical in nature.⁵³ The Iowa Department of Education found the school district responsible for paying for the cost of providing Garret's healthcare while he attended school.⁵⁴ Subsequent appeals to the District Court for the Northern District of Iowa,⁵⁵ and the Court of Appeals for the Eighth Circuit,⁵⁶ upheld the Department of Education's decision. In 1997, the U.S. Supreme Court granted certiorari.⁵⁷ On March 3, 1999, the Court handed down a decision, with a vote of seven to two, ruling that the health care services required by Garret were *related services* and that the Cedar Rapids Community School District was responsible for paying for the cost of providing the services.⁵⁸ The Court stated:

This case is about whether meaningful access to the public schools will be assured, not the level of education that a school must finance once access is attained. It is undisputed that the services at issue must be provided if Garret is to remain in school. Under the statute [IDEA], our precedent, and the purpose of the IDEA, the District must fund such "related services" in order to help guarantee that students like Garret are integrated into the public schools.⁵⁹

It is not yet clear what impact the *Garret F*. decision has had, or will have, on school practices; however, there are obvious fiscal implications as the costs of providing care for students with complex health care needs can be expensive.⁶⁰ The Supreme Court decision was clear: school districts are responsible for paying for health care for students who require constant health care services. The challenge facing school district administrators is also clear: enabling students to receive an appropriate education in the least restrictive environment in a manner that assures for their health and safety in a cost economic fashion.⁶¹

IV. MEETING THE HEALTH CARE AND EDUCATIONAL NEEDS OF STUDENTS IN SCHOOLS

In the shadow of the numerous disagreements between parents and school districts regarding fiscal responsibilities for the provision

- 57. Cedar Rapids Cmty. Sch. Dist. v. Garret F., 523 U.S. 117 (1998)
- 58. See Garret F., 119 U.S. at 1000.

- 60. See Lehr, supra note 32, at 29.
- 61. Id. at 29-30.

^{53.} See Garret F., 119 U.S. at 995-96.

^{54.} Cedar Rapids Cmty. Sch. Dist. v. Garret F., 24 IDELR 648 (N.D.Iowa, 1996).

^{55.} Cedar Rapids Cmty. Sch. Dist. v. Garret F., Case No. C95-5-EJM (N.D. Iowa, 1996).

^{56.} Cedar Rapids Cmty. Sch. Dist. v. Garret F., 106 F.3d 822, 823 (8th Cir. 1997).

^{59.} Id.

of health care services, many school districts and families quietly agreed upon IEPs in which the school districts assumed the costs for providing the health care services for the students in their charge.⁶² These IEP teams focused their attention on ways of providing a quality educational program to students with complex health care needs, and did not question their responsibility to provide the services.

Prior to the relatively recent *Garret F.* decision, over a decade of experience had been gained in providing both quality care and appropriate education for students with complex health care needs. Personnel from multiple disciplines, often from multiple agencies, collaborated to plan, implement, and monitor comprehensive programs for students. Teams included parents, school administrators, teachers, school and community nurses and physicians, occupational and physical therapists, and paraprofessionals.⁶³ Agencies that were represented included schools, home health care agencies, medical equipment supply companies, state departments of public health and state departments of education, health maintenance organizations, and private medical practices.⁶⁴

Thoughtful, collaborative planning focused on the delineation of procedures for meeting the health care needs and the educational needs of the students. Critical aspects of planning for successful comprehensive programs for students with complex health care needs discussed in the literature include:

- carefully developed health care plans;⁶⁵
- delineated roles and responsibilities of key personnel;⁶⁶
- access to information and training for members of the school community;⁶⁷
- consideration of attitudes toward students with complex health care needs;⁶⁸ and
- educational plans based on the unique instructional and support services needs of the students.⁶⁹

- 68. Id.
- 69. Id.

^{62.} See id. at 28.

^{63.} See Lehr, supra note 11, at 3; Lehr & McDaid, supra note 12, at 4.

^{64.} See Donna H. Lehr & Sally Macurdy, Meeting Special Health Care Needs of Students, in PROMOTING HEALTH AND SAFETY: SKILLS FOR INDEPENDENT LIVING 79 (Martin Agran, Ph.D. et al., eds. 1994).

^{65.} Lehr, supra note 11, at 7.

^{66.} Lehr & McDaid, supra note 12, at 4-6.

^{67.} Id.

Much has been learned about methods for ensuring safe care and for ensuring appropriate education for this population of students with unique and highly individualized needs. The following sections include some of the lessons learned about educating students with complex health care needs over the past 15 or so years since they first appeared in public schools.

V. Ensuring Safe Care in Educational Settings for Students with Complex Health Care Needs

First and foremost, school districts must assure that the students in their charge are provided with safe care that meets their special health care needs. This may be especially challenging for students with complex health care needs because they are few in numbers and require health care procedures that are not frequently encountered outside of hospital settings. It is unusual when school personnel have had prior experience with caring for or educating these students. Consequently, prior to students with complex health care needs attending school, many questions have to be answered: What procedures are needed? Who will implement the procedures? Who will train the health care service provider? How will the health care service provider be trained? Where will the procedures be implemented? When will the procedures be implemented? What are the equipment needs? Who will maintain and service the equipment? What back-up plans are necessary for substitute care and equipment? To systematically address these questions, educational program planning teams responsible for students with complex health care needs often begin by developing comprehensive health care plans.⁷⁰

A. Health Care Plans

Written health care plans that become a part of a student's IEP are effective vehicles for articulating answers to the many questions raised above. The National Association of School Nurses argue that such a plan is necessary for each student with a complex health condition for the following reasons:⁷¹

• The use of current care standards to develop the IHP [Individualized Health Care Plan] will assure administrators, parents, and staff that the student is properly cared for.

^{70.} See Lehr, supra note 11, at 7.

^{71.} National Association of School Nurses, Position Statement: Individual Health Care Plans, http://www.nasn.org/positons/careplans.htm (June 1998).

- Professional school nurses will communicate nursing care needs to administrators, staff, students, and parents.
- The IHP will create a safer process for the delegation of nursing care.
- The IHP can be used as input for the interdisciplinary team of the special education student.
- The IHP will serve as legal protection by showing that proper plans and safeguards were in place.
- Standardizing school nursing care through IHPs will help advance professional school nurses to case management, the next level of professional practice.

The book *Children and Youth Assisted by Medical Technology in Educational Settings*⁷² includes model forms that many have found very useful in developing health care plans. Components of their model forms include: a brief history of the student's health;⁷³ a description of the special health care needs;⁷⁴ a baseline health status;⁷⁵ a description of medications needed by the student;⁷⁶ a description of medication administration procedures and the personnel responsible for the administration;⁷⁷ unique dietary or nutritional needs;⁷⁸ unique transportation needs;⁷⁹ equipment needs;⁸⁰ anticipated problems;⁸¹ emergency plans;⁸² and approvals of the plan by the parents, school personnel, and the students' physician.⁸³ Engaging in the process of developing the health care plans seems to result in an increased comfort level of those charged with the responsibility of assuring that the student is provided with safe care.

B. Delineation of Roles and Responsibilities

While the *Tatro* and *Garret F*. decisions made the school districts responsible for providing students with specialized health care services, the decisions did not specify *who* in the school district should

- 77. See id.
- 78. See id.
- 79. See id. 80. See id. at 119.
- 81. See id. at 120.
- 82. See id. at 125-27.
- 83. See id. at 132.

^{72.} See Stephanie Porter et al., eds., Children and Youth Assisted by Medical Technology in Educational Settings: Guidelines for Care (2d ed. 1997).

^{73.} See id. at 118.

^{74.} See id.

^{75.} See id.

^{76.} See id.

provide the services. In the past, answers to the "who will do it" question have been based on various agreements made during the process of educational program planning, interpretation of laws, and interpretation of professional practice.⁸⁴ Consequently, considerable variability exists throughout the country. For example, students' health care needs are attended to by paraprofessional aides, teachers, nurses, occupational and physical therapists, or other school personnel.⁸⁵

It is often the case that decisions about who will implement specific health care procedures to students while they attend school are made by the students' IEP planning teams,⁸⁶ which are comprised of parents, educators, related service and medical personnel.⁸⁷ The team considers the unique needs of the student and then decides who will be responsible for providing the health care services to the individual student.⁸⁸

Professional organizations and laws governing professional practice have influenced decision making in this area. In 1990, the Council for Exceptional Children published the work of the Joint Task Force for the Management of Children with Special Health Needs.⁸⁹ That report contains specific recommendations regarding roles and responsibilities for school personnel for the delivery of special health care procedures in school settings.⁹⁰ The guidelines include "a matrix [that] delineates the persons who are qualified to perform each of the procedures, who should preferably perform the procedures, and the circumstances under which the persons would be deemed qualified."⁹¹ However, critics of the guidelines⁹² have cautioned that:

88. See Lehr, supra note 84, at 64.

89. JOINT TASK FORCE FOR THE MANAGEMENT OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS, GUIDELINES FOR THE DELINEATION OF ROLES AND RESPONSIBILITIES FOR THE SAFE DE-LIVERY OF SPECIALIZED HEALTH CARE IN THE EDUCATIONAL SETTING (1990). The task force included representatives from organizations including the American Federation of Teachers, the Council for Exceptional Children, the National Association of School Nurses, and the National Education Association.

90. Id.

91. Id. at 9.

92. See, e.g., Dick Sobsey & Ann W. Cox, Integrating Health Care and Educational Programming, in Educating Children with Multiple Handicaps: A Transdiciplinary Approach 217, 220 (Fred P. Orelove & Dick Sobsey eds., 3rd ed., 1996); Lehr & Macurdy, supra note 64, at 78.

^{84.} See Donna H. Lehr, The Challenge of Educating Students with Special Health Care Needs, in People with Disabilities who Challenge the System 60, at 64 (Donna H. Lehr & Fredda Brown eds., 1996).

^{85.} See id. at 64; Lehr & Noonan, supra note 3, at 155-56.

^{86.} See Lehr, supra note 84 at 64.

^{87.} See 20 U.S.C. § 1414(d)(1)(B) (Supp. V 1999).

The recommendations are based on the names of the health care procedures and the names of the roles of the individuals implementing the procedures. To ensure the safety of the students, decisions may be more appropriately based on the complexity of implementation of the procedure for individual students and the competence of the individuals implementing the procedures, regardless of their titles.⁹³

For example, the guidelines indicate that all school personnel with appropriate training can orally feed students, while only registered nurses, licensed practical nurses, and trained nursing aides should feed students with gastrostomy tubes (g-tubes).⁹⁴ In fact, for some students with oral motor dysfunction, feeding by mouth is more dangerous than tube feeding and requires a higher level of skill to prevent choking.⁹⁵ While the guidelines were intended to be just that – guidelines – they have come to serve as recommendations for practice that may not always be in students' best interests.

State laws governing the professional practice of nurses also influence decisions regarding who should provide health care to students with complex health care needs in schools. Each state has a nurse practice act that, while varying in specifics from state to state, defines the scope of responsibility for the provision of nursing services by registered nurses, licensed practical nurses, and licensed vocational nurses who are certified to practice within the state.⁹⁶ The laws, statutes, and regulations also specify conditions regarding the delegation of care to unlicensed personnel.⁹⁷

^{93.} Lehr, supra note 84, at 68.

^{94.} JOINT TASK FORCE FOR THE MANAGEMENT OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS, *supra* note 89, at 10.

^{95.} See Sobsey & Cox, supra note 90, at 222.

^{96.} See, e.g., MD. CODE ANN., [HEALTH OCC.] §§ 8-101 – 8-802 (2000), COLO. REV. STAT. ANN. §§ 12-38-101 – 12-38-133 (West, WESTLAW through 2001), Conn. Gen. Stat. Ann. § 20-87a (West, WESTLAW through 2001), Del. Code Ann. §§ 1902-1926 (West, WESTLAW through 2001), 225 Ill. Comp. Stat. Ann. 65/5-1 – 65/5-30 (West, WESTLAW through 2001), Kan. Stat. Ann. §§ 66-1113 – 66-1165 (West, WESTLAW through 2001); see also Lehr & Noonan, supra note 3, at 150.

^{97.} See, e.g., MD. CODE ANN., [HEALTH OCC.] §§ 8-6A-02 (2000), Kan. Stat. Ann. §§ 65-1124, 56-1165 (West, WESTLAW through 2001). Delegation is defined by the American Nurses Association as "the transfer of responsibility for the performance of an activity from one individual to another [with the former] retaining accountability for the outcome." American Nurses Association, Position Statement: Registered Nurse Utilization of Unlicensed Assistive Personnel, Attachment 1: Definitions Related to ANA 1992 Position Statement on Unlicensed Assistive Personnel http://www.nursingworld.org/readroom/position/uap/uapuse/ htm (Dec. 11, 1992). The National Association of School Nurses (NASN) suggests that (a) the NASN's position statement regarding roles and standards; (b) the NASN's position statement regarding delegation; (c) the codes of ethics of both the American Nurses Association and the National Association of School Nurses; and (d) the state school nursing

While school district administrators are responsible for assuring that health care procedures administered in school are provided within the law, sometimes district administrators are simply not aware of nurse practice acts nor the prohibitions on unlicensed school personnel administering certain nursing services.⁹⁸ Furthermore, wellknown shortages in budgets for school nursing and the lack of availability of school nurses makes meeting the requirements of the laws difficult.⁹⁹ For example, consider the following, not uncommon, situation encountered when a district begins planning for the attendance of a student with complex health care needs. According to that state's nurse practice act, the procedures must be administered by a registered nurse and cannot be delegated to unlicensed personnel. The only presently employed registered nurse in the district is responsible for providing school nursing services to 2,500 students in three different school buildings within the town. The school committee approves the hiring of an additional nurse to provide the student with the required health care services while at school. However, despite running an ad in the local paper for weeks, and spreading the word informally, no nurses are to be found.

It is important to note that the key to assuring that students are provided with education in the least restrictive setting is the availability of qualified personnel to provide the appropriate health care services in schools. That is, if no qualified individual is available to provide the services, it is likely that a decision will be made to send the students to where the services are, rather than bringing the needed support services to the student.¹⁰⁰ This can lead to decisions to cluster students with similar needs for nursing services or to send students to more restrictive settings where nursing services are already available.¹⁰¹ This becomes an interesting intersection of laws governing the placement of students in least restrictive settings and those governing nursing practice. While the number one criterion should be safe care, this must be considered in light of students' right to an education in the least restrictive setting. Some states, in an effort to avoid this conflict, have made changes in state laws to provide greater flexi-

certification requirements should guide decisions regarding the delegation of care. National Association of School Nurses, Issue Brief: School Health Nursing Services Role in Healthcare: Delegation of Care, http://www.nasn.org/briefs/delegation.htm (visited Jan. 14, 2002).

^{98.} See Lehr & Noonan, supra note 3, at 150-53.

^{99.} Terty H. Caldwell et al., Entrance and Planning Process for Students with Special Health Care Needs, in Children and Youth Assisted by Medical Technology in Educational Settings: Guidelines for Care, 41, 55 (Stephanie Porter et al, eds., 2d ed. 1997).

^{100.} Sobsey & Cox, supra note 92, at 220.

^{101.} Id.

bility regarding the delegation of tasks related to specialized health care services.¹⁰²

C. Information and Training

Regardless of who is responsible for providing the health care services for individual students, or where those services are to be provided, school personnel need information and training when they are educating students with complex health care needs.¹⁰³ Since concern, and sometimes fear, surround the arrival of students with complex health care needs, education and training becomes an essential way of allaying the fear of the "unknown" and assuring that the competence necessary for the provision of safe health care is available.¹⁰⁴ Training for school personnel should have the following characteristics:

- Training should be designed for a wide range of individuals in the school community, including school administrators, teachers, clerical, related service personnel, students and their families.¹⁰⁵
- Training should be differentiated based on the different levels of knowledge and skills that may be required. That is, it is not necessary for everyone to become competent in administering specific health care procedures, but it is important for many individuals to know why specific health care procedures must be provided.¹⁰⁶
- Training methods should be appropriately matched to training goals. That is, while there are many materials now commercially available that explain how to tube feed a student, reading about how to tube feed a student should not be considered sufficient training for developing competence in tube feeding.¹⁰⁷
- Training should occur prior to the time it is needed.¹⁰⁸
- Training should be sensitive to the needs of the disabled student. That is, often students, themselves, are the most qualified individuals to educate peers but, only when the individual

^{102.} Id. at 220-21.

^{103.} See Lehr & McDaid, supra note 12, at 5.

^{104.} D. H. Lehr, Preparation of Personnel to Work with Students with Complex Health Care Needs, in Critical Issues in Preparing Personnel to Work with Persons Who Are Severely Handicapped 141 (A. Kaiser & C. McWhorter eds. 1990).

^{105.} Id. at 147.

^{106.} Id.

^{107.} Id.

^{108.} Id. at 148.

students are willing to do so. Some students wish to be present when peers receive explanations regarding their health care needs; others prefer that the information sessions occur in their absence.¹⁰⁹

General and child specific training are designed to increase competence and confidence in the care providers and confidence in families entrusting schools with the care of their children.¹¹⁰ General training is designed for school personnel who do not have responsibility for administering the specific health care procedures, but who have key roles in creating a positive climate of acceptance for students with complex health care needs.¹¹¹ General training provides an opportunity to dispel myths, increase general knowledge about the students and their needs, and discuss concerns.¹¹² It has been recommended that the content of general training should include a review of the health care plan and procedures for obtaining emergency medical care for specific students.¹¹³

Specific student training is aimed toward developing *competence* in those individuals who will be responsible for implementing specific health care procedures.¹¹⁴ Even when the person designated to provide the care is a trained medical professional, such as a registered nurse, or a licensed practical or vocational nurse, one cannot assume that the individual is competent in implementing the specific health care procedures required by the student.¹¹⁵ Even if the nurse responsible for implementing the health care procedures is a veteran school nurse it may have been a considerable length of time, if ever, since that individual had experience in tube feeding a patient. Additionally, even if the experience was relatively recent, an individual student's idiosyncrasies may necessitate child specific training. For example, the first author, when directing a federally funded demonstration project for infants with complex health care needs, received

^{109.} Id.

^{110.} Caldwell et al., supra note 99, at 55.

^{111.} See id.

^{112. &}quot;General training is designed to create positive attitudes among teachers, administrators, and classmates toward including students with a range of diverse needs in the school community; creates an opportunity for education staff to discuss concerns; addresses the concerns parents, teachers, and students may have about the social, emotional, and educational impact of attending school with a peer who has a disability or a chronic illness; and provides an overview of the child's health care needs and emergency plan." *Id.* at 56; *see* Lehr & Noonan, *supra* note 3, at 155.

^{113.} Caldwell et al., supra note 110 at 56.

^{114.} See id. at 57.

^{115.} See id.

comprehensive training in gastrostomy tube feeding from nursing instructors in a local teaching hospital. She passed the competency test in the course with flying colors! However, when she tried tube feeding a specific infant in the centered-based program, she ran into considerable difficulty. Although the protocol was being followed precisely, the student appeared agitated and feedings sessions were 90 minutes in duration, not the 30 minutes the mom reported it was taking when implemented at home. It was only after consulting with the parent and learning about the student's preference for being fed in an infant swing, while listening to country western music, was the author successful in feeding the student. Important information must be learned not just about particular preferences, but also about variations in procedure administration that may be even more critical for safe care.

In addition, the qualifications of those individuals providing the student specific training to school personnel needs consideration.¹¹⁶ There is a difference between those knowledgeable in implementation of procedures and those skilled in training others to implement the procedures. It is frequently the case that parents are the sole trainers of school personnel on child specific procedures. While they may be "expert" in the provision of health care procedures for their own children, risks to the student can be minimized if the training is provided by medical personnel who are competent in training others in the administration of the health care procedures.

Ongoing training and monitoring of procedure implementation is also frequently recommended as a part of standard practice.¹¹⁷ Personnel qualified to observe administration of procedures and provide retraining, if necessary, should be available to assure continuation of competently provided health care procedures.¹¹⁸ Similarly, frequent scheduled reviews of individualized health care plans and the corresponding roles and responsibilities for implementation of the plan can double as evaluations of a program's effectiveness and thus provide opportunities to adjust the program to ensure the health and safety of students with complex health care needs in schools.¹¹⁹

^{116.} See Lehr & McDaid, supra note 12, at 5.

^{117.} See Caldwell, supra note 99, at 59.

^{118.} Id. at 58.

^{119.} Id. at 59.

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VI. Ensuring Appropriate Educational Programs for Students with Complex Health Care Needs

There is an initial tendency to treat students with complex health care needs in school settings as patients and not students.¹²⁰ This is understandable as the first concern of personnel in school districts should be about safe care. However, once procedures for providing for the health and safety of students are in place, school personnel should turn their attention to the students' educational programs. One unique aspect of these students' educational programs should be instruction on the management of health care procedures.¹²¹ Additionally, successful programs will design other supports to facilitate physical and social access of the student in the school building and as part of the school community.¹²²

A. Instructional Focus

The goal for all students is increased independence.¹²³ For students with complex health care needs who require ongoing health care procedures, achieving independence can be more challenging. An important focus should be on increasing students' involvement in the provision of their own care.¹²⁴ All too often there is a tendency to provide the necessary care directly without involving the student in the provision of their own care. However, many students are able to learn to administer their own health care procedures. They can learn to self-catheterize, feed themselves with a g-tube, and self-suction their tracheostomies.¹²⁵ Other students who may have accompanying physical disabilities, while not being able to physically administer the procedure themselves, can learn to indicate their need for, or direct others on how to implement the care.¹²⁶ For example, consider Brad, an active kindergartner who, upon identifying the need for suctioning, goes outside his classroom to the hall and asks the nurse to suction him. Jose was taught to use a hand signal to indicate his need for suctioning by the licensed practical nurse assigned to his classroom. Jamal, who has significant limitations in his ability to use his hands, turns on the pump used for his g-tube feeding by activating a specially adapted switch. Eighteen-year-old Maria is learning to perfect her

- 122. Id.
- 123. Id.
- 124. See id.
- 125. See id.
- 126. Id.

^{120.} Lehr, supra note 11, at 5.

^{121.} See Caldwell, supra note 99, at 58.

ability to explain to others the steps involved in providing her tube feeding. This is important since, in September, she will be attending college out of town and will be responsible for independently hiring, training, and supervising her personal care attendants.

Teaching students with complex health care needs to assume responsibility for their own care can begin very early. By explaining to children what is being done and why gives children the opportunity to learn about their health care procedures. When these students participate in the preparation, administration, and cleaning up after the procedure by doing whatever steps they can, they are learning about the entire process while assuming responsibility for what they are capable of doing. This can begin at a very young age, just as meal preparation and clean up often does for young children without special health care needs. All young children like to make their own peanut butter sandwiches; the opportunity to prepare meals should be no different for students who eat by a tube instead of by mouth. There is pride in "doing it by myself."

B. Support Needs

The obvious support need for students with complex health care needs is the provision of health care services, but other types of adaptations and accommodations are also necessary. Electrical outlets for medical equipment may have to be added to classrooms.¹²⁷ Special arrangements for the safe transportation of students should be made, perhaps including the presence of competent care provision during transport.¹²⁸ Arrangements should be made with local emergency medical personnel, giving them a "heads up" regarding the presence of a student who may need emergency care.¹²⁹ Similarly, the school district and local fire departments need to develop plans for emergency evacuation of specific students in the event of a fire.¹³⁰

Additionally, students need support which is aimed at supporting their social and emotional well-being. This may be necessary to facilitate the students' acceptance of his or her condition and acceptance on the part of the school staff and the students' peers. Individual students may need to receive counseling to increase their understanding of their disability and their understanding of others' reactions to individuals with disabilities. Staff and peers should also receive informa-

^{127.} See Stephanie Porter et al., eds., Children and Youth Assisted by Medical Technology in Educational Settings: Guidelines for Care 54 (2d ed. 1997).

^{128.} Id.

^{129.} Id. at 55.

^{130.} Id.

tion and training aimed at increasing their understanding of their reactions to individuals with disabilities. Kunc wrote eloquently about the need for all to experience a sense of belonging and some of the challenges to this when an individual has a disability.¹³¹ Individuals' reaction to a student with complex health needs within a school community can vary greatly and include fear, repulsion, curiosity, and complete acceptance.¹³²

In addition to information and training, an additional support may be needed to facilitate acceptance. A program referred to as Circle of Friends is increasingly used in schools as a method for developing support for students with disabilities who are educated in general educational settings.¹³³ As a first step in this program, peers are asked to think about four concentric circles. In the first circle, they insert the name or initials of people closest to them, typically members of their immediate family.¹³⁴ In the next, they identify people with whom they often do things.¹³⁵ In the third, they identify people who they like, and with whom they do things with but less frequently than in the second circle,¹³⁶ and in the fourth, they list people who are paid to be with them (i. e. teachers, physicians, dentists, etc.).¹³⁷ The group facilitator then presents a set of circles for a student with a disability, which is, most often, in marked contrast to the ones that students have completed for themselves.¹³⁸ Peers note the large number of people paid to be with the individual and the relatively fewer number of "friends" in that person's life.¹³⁹ Peers are then asked to consider ways that the student's circles can become fuller.¹⁴⁰ This process, is the beginning point, and the Circle of Friends then continues to meet to discuss ways to increase peers' understanding and facilispecific student's inclusion in the general school tate the community.¹⁴¹

- 137. Id.
- 138. Id.
- 139. Id.
- 140. Id.
- 141. Id. at 50.

^{131.} Norman Kunc, The Need to Belong: Rediscovering Maslow's Hierarchy of Needs, in Re-Structuring for Caring and Effective Education: An Administrative Guide to Creating Heterogeneous Schools 25 (Richard A. Villa et al., eds., 1992).

^{132.} See Lehr & McDaid, supra note 12, at 6.

^{133.} See Marsha Forest & E. Lusthaus, Promoting Educational Equality for All Students: Circles and Maps, in Educating All Students in the Mainstream of Regular Education 43, 47 (SUSAN STAINBACK ET AL., EDS., 1989).

^{134.} Id. at 48.

^{135.} *Id*.

^{136.} Id. at 49.

Acceptance of an individual with complex health care needs is dependent on the attitudes and behaviors of those around the student. Consider the following two scenarios.

Christopher is a 4th grader who has been fully included in his neighborhood school since kindergarten. Chris has significant cognitive, sensory, physical, and special health care needs; he has a tracheostomy due to his inability to independently clear his airway. Care providers must listen for congestion, and mechanically suction the trachea tube to clear secretions on an as-needed basis.

When Anna is his care provider, suctioning events are surrounded by a flurry of activity. When Anna becomes aware of excessive gurgles from Christopher, others can hear Anna gasping, rushing to grab the portable, battery operated suctioning machine, rushing to Christopher's side, telling other students to quickly move aside and in a whirlwind of activity, suctioning the excessive secretions from his trachea.

Contrast Anna's care providing with Connie's. When Connie has responsibility for Chris's care, she too listens for excessive gurgles from Christopher. However, upon determining that he needs to be suctioned, she quickly but quietly collects the needed materials, moves quickly to Christopher's side, turns him around in his place, directs the students to keep attending to their work, and calmly removes the excessive mucous from his trachea.

In both cases, the care provided to Christopher was competent care. However, to "Anxious Anna" the need for suctioning is a need for emergency medical care. To "Calm Connie" the need is routine care, perhaps analogous to wiping the nose of a young child. Consider the potential impact of the different responses on Christopher; on the other students; on the flow of activities on the classroom; and on others' perception of Christopher as a student or as a patient.

VII. CONCLUSION

Students with complex health care needs present significant challenges to school personnel when they attend school. Their education in school has not yet become routine; the prevalence of the population is small, but growing and their education in neighborhood schools instead of institutions is still slowly shifting. To assure that they are educated in an environment that maintains both their health and their rights to a free appropriate public education in least restrictive settings requires comprehensive planning. Many individuals need to be involved in the planning, including both parents and professionals from within the schools and from the private and public sectors in the community. Careful decisions guided by laws, professional standards, and practical realities will enable students to be educated in a manner that addresses both their unique educational needs and their social and emotional well-being.

Success in meeting this goal is dependent, in part, on others' attitudes toward students with complex health care needs. Members of the school community, including administrators, teachers, staff, students and their families should be encouraged to examine their views of the students. Consider the potential difference between having sympathy versus empathy for specific students with complex health care needs. Different views of the role of the school in "protecting" as contrasted with "supporting" students can also affect the nature of the health care and educational services provided. Excessive protection. often a tendency in schools, particularly when students are considered "medically fragile," can interfere with a primary mission of school: building independence. Consider, too, the potential differences when a student is considered "sick" as contrasted with the view that due to the technology, the student's health is being enhanced. For example, with g-tube feeding, Brian continues to grow and thrive while prior to receiving the feeding tube, he could not obtain sufficient nutrition and his survival was unlikely. He is technology dependent, but it is the technology that makes him healthy; he is no longer sick.

This sub-population of children with special health needs is likely to continue to grow and their presence in schools is likely to increase as well. While this article has included a review of the issues and some of the practices that have evolved since the mid 1980s, little research has been done to quantify and qualify the effectiveness of our efforts. More research is needed to determine if we are, in fact, assuring that the students are receiving safe care, appropriate educational programs, and that their programs are provided in least restrictive environments in a manner that facilitates their acceptance as a member of the school community.