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ABSTRACT

This booklet provides a broad-based definition of the population of students with special health needs and offers information about specific subcategories of conditions. These subcategories include traumatic brain injury; pediatric human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS) and AIDS-related complex; and technology-assisted students. The booklet discusses these students' unique educational needs. It includes information about model policies, programs, and practices that have improved the ability of school systems to provide effective programs. Family and student concerns are also addressed. A list of six HIV/AIDS curricula resources and four other resources concludes the booklet. (JDD)

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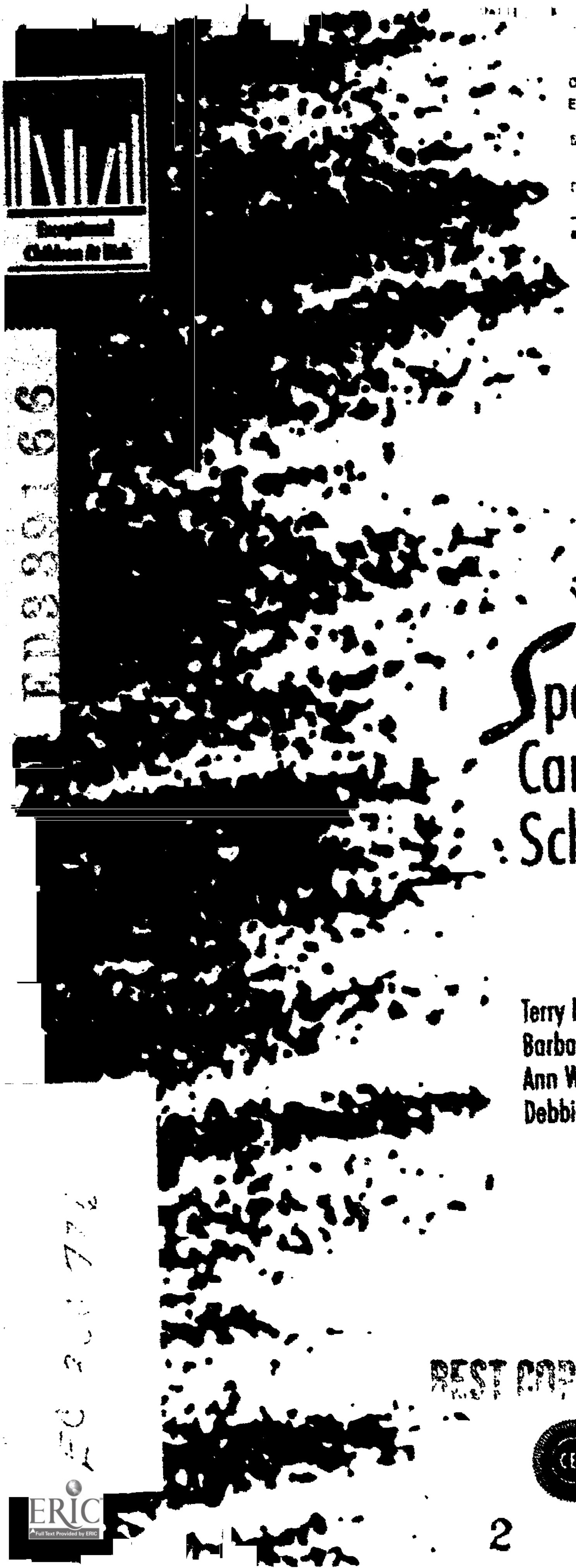

Special Health Care in the School

Terry Heintz Caldwell
Barbara Sirvis
Ann Witt Todaro
Debbie S. Accouloumre

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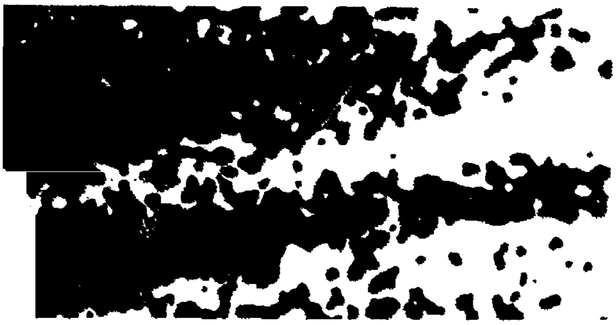

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Foreword

EXCEPTIONAL CHILDREN AT RISK
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Many of today's pressing social problems, such as poverty, homelessness, drug abuse, and child abuse, are factors that place children and youth at risk in a variety of ways. There is a growing need for special educators to understand the risk factors that students must face and, in particular, the risks confronting children and youth who have been identified as exceptional. A child may be at risk *due to* a number of quite different phenomena, such as poverty or abuse. Therefore, the child may be at risk *for* a variety of problems, such as developmental delays; debilitating physical illnesses or psychological disorders; failing or dropping out of school; being incarcerated; or generally having an unrewarding, unproductive adulthood. Compounding the difficulties that both the child and the educator face in dealing with these risk factors is the unhappy truth that a child may have more than one risk factor, thereby multiplying his or her risk and need.

The struggle within special education to address these issues was the genesis of the 1991 CEC conference "Children on the Edge." The content for the conference strands is represented by this series of publications, which were developed through the assistance of the Division of Innovation and Development of the U.S. Office of Special Education Programs (OSEP). OSEP funds the ERIC/OSEP Special Project, a research dissemination activity of The Council for Exceptional Children. As a part of its publication program, which synthesizes and translates research in special education for a variety of audiences, the ERIC/OSEP Special Project coordinated the development of this series of books and assisted in their dissemination to special education practitioners.

Each book in the series pertains to one of the conference strands. Each provides a synthesis of the literature in its area, followed by practical suggestions—derived from the literature—for program developers, administrators, and teachers. The 11 books in the series are as follows:

- *Programming for Aggressive and Violent Students* addresses issues that educators and other professionals face in contending with episodes of violence and aggression in the schools.
- *Abuse and Neglect of Exceptional Children* examines the role of the special educator in dealing with children who are abused and neglected and those with suspected abuse and neglect.
- *Special Health Care in the School* provides a broad-based definition of the population of students with special health needs and discusses their unique educational needs.
- *Homeless and in Need of Special Education* examines the plight of the fastest growing segment of the homeless population, families with children.
- *Hidden Youth: Dropouts from Special Education* addresses the difficulties of comparing and drawing meaning from dropout data prepared by different agencies and examines the characteristics of students and schools that place students at risk for leaving school prematurely.
- *Born Substance Exposed, Educationally Vulnerable* examines what is known about the long-term effects of exposure *in utero* to alcohol and other drugs, as well as the educational implications of those effects.
- *Depression and Suicide: Special Education Students at Risk* reviews the role of school personnel in detecting signs of depression and potential suicide and in taking appropriate action, as well as the role of the school in developing and implementing treatment programs for this population.
- *Language Minority Students with Disabilities* discusses the preparation needed by schools and school personnel to meet the needs of limited-English-proficient students with disabilities.
- *Alcohol and Other Drugs: Use, Abuse, and Disabilities* addresses the issues involved in working with children and adolescents who have disabling conditions and use alcohol and other drugs.
- *Rural, Exceptional, At Risk* examines the unique difficulties of delivering education services to at-risk children and youth with exceptionalities who live in rural areas.

- *Double Jeopardy: Pregnant and Parenting Youth in Special Education* addresses the plight of pregnant teenagers and teenage parents, especially those in special education, and the role of program developers and practitioners in responding to their educational needs.

Background information applicable to the conference strand on juvenile corrections can be found in another publication, *Special Education in Juvenile Corrections,* which is a part of the CEC Mini-Library *Working with Behavioral Disorders.* That publication addresses the demographics of incarcerated youth and promising practices in responding to their needs.

1. Introduction

Students with special health needs are increasingly seeking school services. An overview of the issues and challenges, this chapter provides a broadbased definition of the population and their unique educational needs.

Although the incidence of chronic health conditions remains the same, the prevalence is increasing (Ireys, 1988) due to improved technology, treatment, and prenatal and emergency care. Approximately 10% to 15% of American infants, toddlers, children, and youth have chronic health conditions, and 1% to 2% have severe conditions (Hobbs & Perrin, 1985). Children with chronic and infectious conditions, very premature babies, and emergency victims are surviving and living longer (Task Force on Technology-Dependent Children, 1988), and these youngsters are increasingly seeking school services. Trends such as "increased population, de-institutionalization and de-hospitalization, viability of school participation because of improved technology and treatments, increased parental expectations, and expanded interpretations of the educational rights of students" (Caldwell & Sirvis, 1991, p. 14) have challenged educators to provide appropriate educational services as well as health services that "are not educational in nature but must be completed during the school day" (Graff, Ault, Guess, Taylor, & Thompson, 1990, p. 1).

This book describes some of the challenges inherent in providing educational programs for students who have special health conditions and includes information about model policies, programs, and practices that have improved the ability of school systems to provide effective programs. A functional definition of the population and current information related to specific subcategories of conditions are presented, and educational issues and practitioner and program implications are examined. Family and student concerns, as well as the policies and procedures that affect the provision of educational services, are addressed.

Overview

Thousands of children in the United States have special health needs impacting their daily lives and their ability to benefit from education. These children receive services in regular and special education classrooms in their neighborhood schools, special schools, hospitals, or homes. Without educational accommodations, these students have difficulty attending a full schedule of classes, going on field trips, and making and maintaining friendships. The issues inherent in providing a safe and stimulating school program for children with special health needs can be complex. General issues that affect all children with special health needs include the following:

- Determining the safety and risk management issues surrounding school participation and then finding the balance between safety concerns and developmental needs of the students.
- Addressing realistic emergency and daily care needs in the context of the least restrictive environment.
- Creating a plan for the transition of a primary focus from a student's medical care to educational needs.
- Revising health care routines to accommodate medical needs and school schedules while allowing for the least disruption of each.
- Incorporating health routines as part of a student's curriculum in order to develop student responsibility for self-care.
- Developing resources necessary to provide the appropriate amount of care for the child in the school setting (e.g., actual versus perceived care needs, appropriate personnel to provide care, meeting daily and potential emergency needs).
- Establishing fiscal responsibility and resources and liability for provision of care, staff training, and technical assistance.
- Planning for training personnel to provide health care procedures and emergency intervention, including initial skill preparation and ongoing technical procedure review.
- Preparing faculty, staff, and classmates for maximizing a student's participation in educational and extracurricular experiences.
- Developing mechanisms for ongoing communication among parents, educators, and health care professionals.

The final issue regarding the education of children with special health needs is so personal and individual to each educator that it is difficult to capture, and yet it significantly impacts programs. Children with special health needs may challenge the values of educators. Do we value a life that may be short? Can we look beyond a sometimes terrifying array of tubes and machines to see the student? Can we deal with our own fears about sickness and death? These issues will not be addressed here, but they remain a profound personal challenge that must be faced by every educator who becomes involved with these students.

Definition

Students with special health needs defy simple definition. Public Law 94-142 (the Education for All Handicapped Children Act of 1975) includes the terminology "limited strength, vitality, or alertness" in its definition of "other health impaired." A Council for Exceptional Children task force (1988) provided another definition of students with special health needs: "(They) require specialized technological health care procedures for life support and/or health support during the school day. These students may or may not require special education" (p. 2). Although these definitions begin to provide understanding of the health and educational needs that can exist, they do not encompass all of the unique medical conditions and educational needs of students with special health conditions (Sirvis, 1988).

The health problems of students with special health conditions are quite different from the usual childhood illnesses that affect most children. Special health needs can affect these children for a significant period of time. As a result of their health conditions, they will most often have chronic and acute medical problems requiring daily treatment, medications, and sometimes hospitalization. These procedures can be painful and embarrassing, consume a significant amount of time, be extremely frightening, isolate the children, and temporarily impact their ability to concentrate, grow, develop, and play (Hobbs, Perrin, & Ireys, 1985).

Included in the population of students with special health conditions are infants and children with chronic conditions such as asthma, those who have body deformities, those who are medically fragile, those who are supported by technology, those with infectious conditions, and those whose conditions have neurological implications (Caldwell & Sirvis, 1991; Caldwell, Todaro & Gates, 1991). Students in each of these groups have common problems related to their health condition, but they also have specialized problems resulting from their particular conditions that affect their ability to access educational services.

Since *chronic conditions* such as asthma, diabetes, and seizure disorders are frequently invisible (Kleinberg, 1986), limited efforts may be made to address the significant problems students with these conditions face in school. There is a need for ongoing communication among families, health care providers, and educators. Without effective ongoing communication, a teacher may not know that a child with a seizure disorder is agitated because his medications have been changed, or may not understand that a student with diabetes is "daydreaming" because of changes in her blood sugar values (Caldwell et al., 1991). A second problem relates to emergency planning. Even if emergencies are rare, teachers need to be able to distinguish the parameters of an emergency and to recognize warning signs, symptoms, and immediate dangers.

Teachers and administrators need to be prepared so that they neither over- or underreact (Caldwell & Sirvis, 1991). *The Community Provider's Guide* (Caldwell, Todaro, & Gates, 1989) contains emergency forms that can be individualized for children with chronic conditions. Finally, children with chronic conditions can have frequent school absences that necessitate intervention. The cumulative effect of frequent absences year after year will eventually affect academic achievement. Interventions that address communication, emergency planning, and school absences should be part of the planning process (Bigge, 1991).

Children with *body deformities* such as burns, cranial-facial deformities, and serious skin disorders face many separate and significant problems in the school setting. Efforts to prepare classmates, schoolmates, and staff should begin before a child enters school. Frequently, the child can be a part of the planning, and every effort should be made to develop a plan that has the child's agreement. The other crucial issue for these students is the provision of ongoing psychosocial support. At the Surgeon General's Conference on Home Care (Sweeney, 1987), a young man with a cranial-facial deformity spoke about his school experience. He reported that school had been "awful." Each time he went in for surgery, he and his classmates expected he would look like everyone else, but that never happened. When asked whether he would have been better off not attending school, he replied, "Definitely not, but there could have been someone there I could talk to who could help me with these issues. I should have had an adult to discuss this with." Formal efforts could have helped him to deal with his own painful issues and develop coping mechanisms to deal with his friends and persons in the community.

Some children are *medically fragile*. They may function daily on a seemingly healthy course but then may have an emergency that is not easily predictable and can have immediate catastrophic results. Some may be in their final stages of a disease process and have frequent emergencies that are difficult to manage. Medically fragile children require a team approach to decision making so that the environment selected is neither too restrictive nor too dangerous. They also require frequent reassessment to keep abreast of changes in their status that would warrant changes in their educational program. Finally, they require flexible programming so that as many as possible of their social and educational goals can be met, for example, through a combination of home instruction and classroom experiences (Caldwell et al., 1991; Caldwell & Sirvis, 1991).

Three other subcategories of special health care needs will be discussed in some depth in the following chapters. Specific types of infectious conditions, neurological conditions, and conditions that require technology have been selected to illustrate practitioner and programming concerns and resources.

2. Neurological Conditions: Traumatic Brain Injury

Students with traumatic brain injury have varying degrees of functional ability, requiring serious review of individual educational needs and consideration of program-related issues including evaluation, personnel training, placement, and transition.

This chapter provides specific information about interventions for students who are survivors of traumatic brain injury (TBI). Many of the recommendations can be applied to program development for other students who have neurological conditions including brain tumors, infections such as meningitis and encephalitis, cerebral vascular accidents, anoxic injuries, and problems caused by the ingestion of toxins (Savage, 1991).

Impact and Implications

> A traumatic brain injury (TBI) is an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment. (National Head Injury Foundation [NHIF], 1985, p 1)

As reported by the Federal Interagency Head Injury Task Force (1990), 2 million head injuries occur each year in the United States. As a result of TBI, 75,000 to 100,000 Americans will die. Each year 70,000 to 90,000 people will suffer lifelong physical, intellectual, and psychological disabilities. Three fourths of the people sustaining TBI are under the age of 34, and 18,000 are children (NHIF, 1987). Most head injuries are a result of motor vehicle accidents, but young children and senior citizens are

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By Debbie S. Alcouloumre and Terry H. Caldwell

Technical editors: John D. Wasserman, Neurobehavioral Specialist; Joseph Nadell, Neurosurgeon; Karen Perry, Speech/Language Pathologist; Rita Jackson, Hospital Educator; Jeanette Ray, Senior Rehabilitation Counselor; and Linda Reine, Occupational Therapist.

also frequently injured as a result of falls and abuse (Bagnato & Feldman, 1989).

A TBI may result in damage at the point of impact and at the point where the brain rebounds off the skull on the side opposite the side of impact. More subtle but demonstrably significant diffuse injury occurs to nerve cells as a result of shearing, twisting, and turning of the brain (Hawley, 1984). These types of brain injury, occurring immediately after trauma, are termed *primary*, but serious *secondary* damage can occur in a delayed response to primary brain damage. In TBI, secondary brain damage is most frequently caused by bleeding (hemorrhage) or the abnormal accumulation of blood in the brain (hematoma), brain swelling (edema), or oxygen deprivation (hypoxia). After TBI, damage is commonly dispersed throughout the brain, most particularly in the frontal and temporal regions (Wasserman, 1990).

It is difficult to describe the effects of TBI because of the unique interplay among all the components of the injury. These include the location and severity of injury, length of time since injury, length of coma, and presence of posttraumatic amnesia. Additionally, the availability of support systems and rehabilitation, as well as present and future lifestyle (Hawley, 1984), merge after the injury with other variables including intelligence; personality; and physical, cognitive, and emotional states. In children and adolescents, the variables of recovery become more complex because of the injury's impact on the natural course of development (Wasserman, 1990; Ylvisaker, 1991a).

In general, TBI may result in physical, cognitive, social, emotional, and/or behavioral changes. The systems affected and the recovery process following TBI are unique for every person. A TBI may be mild, moderate, or severe. Of students with head injuries, 10% of those with mild head injuries, 66% of those with moderate injuries, and 100% of those with severe injuries will have a long-term disability (Berrol, 1991). Recovery timelines are also difficult to predict. Although significant progress may be apparent in the first 18 to 24 months following the injury, a survivor can experience periods of significant recovery years later, or the survivor may plateau.

Coma: Total Dependence. A serious TBI usually results in a loss of consciousness (coma) that may last only a few minutes or may extend for days, weeks or even months (NHIF, 1985). Some survivors never regain consciousness and will respond minimally to their environment. Some may not respond to any stimulation, even to pain. Others may respond to stimulation in a consistent and automatic fashion.

The goal in recovery is to establish a means of communication and to increase the person's ability to interact meaningfully with the environment. Programming will focus on the maintenance of health, body integrity (e.g., positioning and movement to reduce contractures), and the provision of sensory stimulation. During this stage of recovery, it is important to observe the survivor and document changes in response. Even small changes can mean that the survivor is making progress and may require changes in programming routines. A sensory stimulation record includes information concerning the date, time, overall functioning of the person (e.g., "Restless"), intervention, and response (e.g., "Grimaced when rock music was played"). This record can help document changes and/or consistency of response to a defined program of stimulation.

Early Post-Coma Stage: Supported Function. The survivor who "wakes up" from coma can experience substantial confusion. Early postcoma recovery is characterized by impaired alertness, slowed thinking, attention and concentration deficits, agitation, disorientation, and irritability (Chance, 1986; Howard, 1983, 1991). It takes tremendous effort on the part of a student after coma to participate even in simple school activities (Howard, 1988). The person with TBI will easily fatigue physically, mentally, and emotionally, and frequent rest periods may be necessary (Howard, 1983).

During the period after coma, many survivors display agitation. They may have maladaptive behaviors including impulsivity, egocentricity, impaired judgment, sexual disinhibition, verbal and physical aggression, and noncompliance (Zenicus, 1991). Students may experience shortened attention spans, inability to handle change, and low tolerance for frustration. These students appear to benefit from a highly structured program that includes formalized behavior management (Howard, 1991). The program should adapt the environment to maintain safety and manage behavior so that eaucational goals can be established and achieved. New learning at this period of time can be difficult; therefore, learning must focus on the structure and logistics of participation (i.e., learning expectations, and how to get around in the environment). At the same time, most students will be recovering previously learned information and improving their ability to access this information consistently.

Learning Stage: Modified Independent Function. Most survivors move beyond agitation and, despite some confusion, are able to begin the process of learning. The "Criteria for Regular School Admission" (Cohen, Joyce, Rhoades, & Welks, 1987) provides a key index of abilities that students must have in order to be ready to participate in more academically focused learning situations. These criteria include the following:

- Attend to a task for 10 to 15 minutes.
- Tolerate 20 to 30 minutes of general classroom stimulation.

- Function within a group of two or more students.
- Engage in some type of meaningful communication.
- Follow simple directions.
- Give evidence of learning potential.

Programs for students who function at this level of recovery will focus on identifying and developing their strengths and remediating barriers that prevent them from reaching home, community, social, and vocational goals.

Every person who has sustained TBI has to reframe his or her life. An adolescent who had established independence may suddenly be dependent on parents for basic needs such as feeding, dressing, and toileting. An excellent student with dreams of college and a career may no longer have the attention or the ability to learn new information. A high school athlete may experience physical difficulties, and a student who is a drama major may no longer be able to remember her lines or speak clearly. Many individuals after TBI report that they have difficulty making friends and are often alone (Olson & Henig, 1989). Lifetime goals such as graduating from high school, working, getting married, or even driving may have to change (Grossman, 1990). These students need to set new, attainable goals such as remembering a friend's name, fixing lunch, walking two blocks, or working in a supported employment program. A major consideration of education must be to assist the student in developing new, meaningful, and achievable goals.

TBI affects not only the injured person but also the family. Family members' dreams and hopes are often shattered. Many family members report that their spouse/parent/child is a "different person" since the accident (Caldwell & Alcouloumre, 1990; Grossman, 1990; NHIF, 1985). One husband stated, "This is just not the woman that I married." It is essential that the family be treated as a co-patient/survivor as well as an integral member of the school team (Hosack, 1991; Howard, 1983).

Practitioner Concerns

What can educators do to help students with TBI develop new goals and find success? Certain principles provide the foundation for successful educational programs for students with TBI:

- Take responsibility for self.
- Look at change as a challenge.
- Learn to appreciate and develop what you have.
- Be persistent.

- Affirm your own worth.
- Make use of available resources. (Brady, 1989)

Each student with TBI will present unique challenges to teachers, classmates, and family members. Each must have an educational plan and interventions selected for the individual's situation and abilities.

Functional Abilities and Educational Progress. Depending on their recovery, students will fall into one of three general programming categories. Students who remain in a coma will be totally dependent. Those who remain confused will require maximum support and supervision. Those who can learn new skills will be able to function somewhat independently, although deficits in behavior and executive function can mean that supervision will always be required. Educators will work with other team members to provide appropriate intervention at each level (Caldwell & Alcouloumre, 1990).

Coma. Students who remain in a coma or a semicomatose state require a program that focuses on sensory stimulation and maintenance of body integrity. Range-of-motion exercises of all body parts are performed to prevent contractures that could interfere with care. Pressure relief and positioning prevent skin breakdowns and can enhance breathing and other body functions. Appropriate medical care is also important.

As part of a stimulation program, there should be continuous attempts to establish a reliable method of communication with the student. If the student blinks his or her eyes, moves fingers, nods his or her head, or makes sounds, these actions need to be explored as a possible method of communication even when they are not consistent. Sensory stimulation including the use of music, pictures, persons, and objects that were meaningful to the student prior to the injury are used to encourage consistent and voluntary responses. Some programs use other types of multisensory stimulation including loud noises and strong smells to attempt to elicit a response. Each student requires continual monitoring to record changes and progress.

After the Coma. When survivors first "wake up," they are usually very confused. Those who have just come out of a coma and those who remain at this level of recovery require a simple, non-distracting, and constant setting. They also require predictable routines, participating in the same type of activities at the same time each day with the same staff. Interaction can be difficult; personnel must explain changes beforehand and get feedback, avoid surprises, start slowly in the morning or after naps, and orient this type of student frequently to time, date, place, and identity. At this level of recovery, new learning is difficult and information learned previously can be retrieved only inconsistently. The student requires the opportunity to practice and overlearn material. Meaningful and age-appropriate activities can help motivate the student. Objectives should focus on learning functional information, such as location of needed areas in the environment, expected behavior in particular settings, and expected routines. In addition, the student will need to continue to rebuild a repertoire of previously learned information. If a student remains at this level of recovery, additional focus should be to improve working relationships with support staff, develop the skills necessary to compete in supported employment, and learn skills needed to live in a supported community situation.

New Learning Stage. Students who fit into the third programming category have increased attention and less confusion. This group is ready to participate in more independent academic or vocationally focused endeavors. Many of the environmental and interactive strategies used in the second programming category will continue to benefit students as they recover. Structure, consistency, use of functional activities, opportunity to practice, and constant positive reinforcement for desired behaviors continue to be important strategies to promote learning (Caldwell, Todaro, & Gates, 1989; Chance, 1986; Howard, 1988; Lehr, 1991; Zenicus, 1991).

Memory and attention deficits are still impediments to learning at this stage of recovery. Useful memory strategies include improving competence in the development of cued systems, improving persistence in practice, and pairing new information with previously learned information. Structure, appropriate change of activities, time limits, frequent positive feedback, and self-monitoring can all be used as interventions to improve attention. Students can frequently participate in designing their own interventions including self-monitoring with charts, using notebooks or daily planners, and finding ways to time attention. Teachers can help develop simple systems of prompts and cues.

Individualized education program (IEP) objectives should focus on remediating deficits that impair the student's ability to learn and work. Although it is extremely difficult to change a person's social skills (Ylvisaker, 1991b), poor social skills may still affect the student's functioning in school. Social skills development relating to both peers and adults is an important IEP goal. Objectives should focus on the development of cued systems, increase in attention, and strategies for relearning and practicing social skills, as well as goals for controlling impulsivity, verbal and physical aggression, egocentricity, and inappropriate sexual behaviors (Cohen, 1991). The primary goal is to ensure academic and social success (Ylvisaker, 1991a). (Sample IEPs are found in Caldwell et al., 1989.)

Programming, especially during the first year following injury, will require regular reviews and updates consistent with the changes that the student experiences (Ylvisaker, 1991a). Family and student expectations need to be considered along with realistic future options such as higher education, vocational issues, and community-based programs.

Programming Issues

StudentTraining. Students who return to school systems where personnel have not received information and training demonstrate 60% more problems than their peers who have returned to prepared schools. Training should include information on facilitating a student's orientation to faculty, schoolmates, classmates, and parents. Basic information concerning head injury and its social, behavioral, and cognitive implications can be included. Teachers will also need specific training regarding behavior management of a student with neurological impairments, alternative learning strategies that capitalize on the student's learning style, strategies to enhance memory (including the development of cued and associated systems), and social skills development. Ongoing training and support can minimize the difficulties experienced by a teacher (Ylvisaker, 1991).

Evaluation. Timing, frequency, content, and environment are all important aspects of evaluation. Timing can affect the results in two ways. Evaluations completed too early in the recovery process may not demonstrate the student's strength, which is usually previously learned information. Evaluations completed later in the recovery process may also be deceiving when the child's mastery of old learning results in a high score on standardized knowledge tests. Test results should be augmented with information concerning the child's ability to learn new information. Otherwise, if memory or attention is impaired, the student will experience increasing academic deficits and decreasing achievement scores.

Evaluations should be made frequently to provide the teacher with important teaching information. School system evaluations may not be scheduled frequently enough. Although the student may not require a full evaluation, frequent teacher evaluation and some form of yearly evaluation can provide important information about the student's changing learning abilities and patterns.

In order to plan school programs adequately, information about past educational functioning, including behavior, and about the student's injury and recovery process will be needed. Assessment should seek information about sensory systems, levels of developmental functioning (intellectual, language, academic, social, motor, and self-care skills), memory abilities, behavior, attention, and judgment. Self-initiation skills, need for structure, ability to self monitor, need for supervision, and assistance with planning should also be considered (Caldwell et al., 1989).

The environment in which the student is evaluated can affect the validity and adequacy of an evaluation. Students recovering from TBI usually do not have good generalization skills. Isolated, concrete skills demonstrated in an artificial test situation may not reflect functional behaviors in a classroom, community, or work situation. In addition, some types of information required in areas such as behavior, judgment, and self-initiation cannot be obtained in an isolated test situation (Ylvisaker, 1991). Functional assessment in usual environments is more likely to provide useful information about performance potential.

Eligibility for Special Education. The determination of eligibility for special education services can be a complex issue for administrators. Many children who have experienced a mild injury will not qualify for school services because their deficit is not apparent at the time they return to school. Memory and attention problems, as well as more subtle neurological deficits, can negatively affect school progress and frequently warrant the child's participation in special resource programs, even though this may initially seem unnecessary. The proactive development of resources to support the child can influence the long-term outcome. It is possible that as states implement the TBI classification included in the Individuals with Disabilities Education Act (IDEA) (Public Law 101-476), they will develop mechanisms to identify, serve, and support students with TBI.

Transitions. The mechanisms for appropriate transition to school must be developed before a child with TBI is actually discharged from the hospital or rehabilitation center. Professionals are becoming increasingly aware of the unique requirements of rehabilitation for children and adolescents (Fralish, 1991). It is common for students to spend weeks or even months in hospital and rehabilitation facilities, but they will spend years in school (Ylvisaker, Hartwick, & Stevens, 1991). For the best results, the rehabilitation team should collaborate with the school from the beginning of the rehabilitation process until the child successfully reintegrates into school. School records, including preinjury academic achievement, possible learning difficulties, and preinjury behavior problems, are important pieces of information to share. Schoolbooks and other learning materials and input from teachers are also important aspects of rehabilitation. During the initial contact, methods for sharing information and interagency program planning need to be established (Ylvisaker, 1991b). It is important for the rehabilitation team to stay involved with the transition process for as long as the school deems necessary (Caldwell et al., 1989; Savage, 1991). A school reentry checklist form was developed by Ylvisaker and colleagues (1991); it examines pertinent academic and behavioral components essential for returning to school.

Children and adolescents with TBI challenge rehabilitation professionals, public school officials, and family members in determining the best course to prepare these youngsters for their altered future. Without collaboration and teamwork, "all too many brain injured students spend their time wasting away; useless to themselves and a burden to their family" (Chance, 1986, p. 68).

Placement. There is no perfect place for students who are post TBI to learn; therefore, a blend of services will be most beneficial. Classroom characteristics affecting placement include the student-teacher ratio; classmate characteristics; the teacher's expertise and comfort with neurological conditions and behavior management, ability to provide the amount of structure a student requires, and personality; and the curriculum.

Two cautions are necessary. The first is that students who have survived head injury and who will have long-term disabilities including significant memory and attention deficits usually will not benefit from a strictly academic situation. A long-term, realistic outlook necessitates functional, community-based programming. The second caution relates to graduation. Frequently students are injured during their senior year after they have almost finished their credit courses. Although graduation appears to be a "gift," it is often only a temporary answer to a lifetime, complex problem, because it makes the student ineligible for vocational programs, community training, and supported employment through the school system. Some schools have found creative ways to manage this problem. They have allowed the student to receive a certificate of achievement at the graduation ceremony and to participate in a program at job sites rather than on campus. This allows the student some sense of moving on, which can be important to self-esteem (Catlin, 1990), while also supporting the need for continued educational intervention.

3. Pediatric HIV, AIDS, and AIDS-Related Complex

A disease that breaks down the immune system, AIDS requires consideration of physical symptoms and psychosocial aspects; treatment impacts and infection control (universal precautions); education of all children, parents, and professionals regarding AIDS in general; and development of appropriate placement options and educational programs.

By the end of June 1990, the Centers for Disease Control reported that 84,164 adults and adolescents had died from acquired immune difficiency syndrome (AIDS). National figures from the Centers for Disease Control for the last 7 years show a dramatic rise in pediatric AIDS cases. In 1983, 74 instances were reported; in 1986, there were 302; by the end of 1989, 526 cases were reported and 292 children had died. By the end of June 1990, 1,266 children under age 13 in the United States had died from AIDS.

AIDS is a disease that breaks down the body's immune system and its ability to fight certain infections and cancers. It is diagnosed by the presence of the human immunodeficiency virus (HIV) and an opportunistic infection or cancer. The presence of the HIV virus in the body results in a range of conditions from no symptoms to symptoms related to AIDS.

The AIDS virus cannot be spread through casual contact; it is weak and cannot survive outside the body. Not one case of AIDS is known to have been transmitted in a school, day care center, or foster care setting or through other casual person-to-person contact. Long-term studies support the fact that AIDS is not spread through the kinds of contacts children have with one another such as touching, hugging, or sharing meals and bathrooms. In adults and adolescents, AIDS is spread from person to person through the exchange of body fluids, namely blood and semen. The usual methods of infection are through IV drug use or sexual contact with someone carrying the AIDS virus.

The majority of pediatric AIDS cases result from transmission of the virus from mother to child before or during birth or occasionally during breastfeeding. Overall, there is a 30% to 50% chance that an infected mother will pass the virus on to her infant. Even if an infant tests positive for antibodies to the AIDS virus, he or she still may not be infected with HIV. The antibodies cross the placenta, so all children of an infected

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Technical editors: Michael Kaiser, Doctor, and Audrey Johnson, Nurse, Pediatric AIDS Program, Children's Hospital, New Orleans.

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mother will initially test positive. However, if a child is not infected, the antibodies will disappear after about 15 months. The signs of HIV infection in babies include poor weight gain, fevers, swollen glands, breathing problems, skin rashes and sores, serious infections, and slow growth and development. Some infants and children have been infected through transfusion of blood or blood products. Since mid-1985, all donated blood has been screened for the presence of HIV; blood transfusions and hemophilia treatment now pose only a very small risk (Caldwell, Todaro & Gates, 1989).

Infected adults and children show different symptoms, although the virus is exactly the same. Rather than the dementia experienced by some adults with AIDS, many children experience progressive encephalopathy (dysfunction of the brain). They often have problems with growth and development; that is, their development starts to slow, and, in severe cases, they begin to lose milestones (e.g., a child will lose the ability to walk). Each child's course will be different (Bale, 1990). Children with AIDS have problems with bacterial infections, not just the opportunistic infections adults get. For example, children with AIDS get a chronic pneumonia that is seen only rarely in adults. Ear infections and thrush, a fungal infection of the mouth, are common symptoms in HIV-positive children. By contrast, Kaposi's sarcoma, a skin cancer seen in many adult patients, rarely shows up in children.

Treatment

Treatment changes frequently, and some treatments are experimental or controversial. At present, four major components are the focus of treatment. Although AIDS is still an incurable disease, the antiviral drug AZT (zidovudine azidothymidine) has been associated with the first component, prolonged survival (Bale, 1990). This drug, and any new drugs developed in the future, will be used to attempt to stop the disease process. The second component of treatment involves the control of the infections and cancers that infect the person whose immune system is depressed. Many children require nutritional support that provides "adequate caloric and protein intake" (Rubinstein, 1987, p. 29). AZT also significantly reduces the frequency of opportunistic infections (Bale, 1990), and a variety of other antibiotics and medications are used. Gamma globulin is frequently used in an attempt to prevent bacterial infections. The third component of treatment is education. Since there is no vaccine or cure for AIDS, education about HIV issues such as prevention, mode of transmission, and universal precautions is high on the list of priorities. The fourth component of treatment, family and program support, has become particularly crucial in the care of infants, toddlers, and children with AIDS. "The child and family have multiple medical, social, and emotional needs" (Boland, 1987, p. 41). Supportive treatment may require intensive support for the biological family or alternatives such as foster care when the family cannot care for the child. It also requires that educators "develop methods to maximize the skills of the children, to minimize the stigma associated with AIDS, and to provide safe environments for children with impaired immunity" (Bale, 1990, p. 21).

The major problem for children and their families continues to be isolation. Children with AIDS are rejected in many situations, including day care and school. Pain, discomfort, and the prognosis, in combination with the isolation, make AIDS a devastating disability for children and the families who care for them (Caldwell et al., 1989).

Educational Concerns

Education, team decision making, and program modification are important school considerations for children with AIDS and other infectious conditions. Education includes the preparation of staff, community, and students regarding universal precautions and AIDS. Team decision making is a process that involves the family, school personnel, and health personnel in making decisions regarding educational placement and programming.

Infection Control (Universal Precautions). The spread of infection has always been a concern in day care and educational programs. New concerns regarding the spread of AIDS have drawn attention to the need to update caregiver skills regarding appropriate precautions. The guidelines contained in this section apply generally to the spread of *all* infectious conditions. The specific concern in AIDS is blood or blood-contaminated fluids.

Direct skin contact with body fluids should be avoided by using disposable gloves. Even when gloves are used, hands should be washed properly afterward. Care should be taken to dispose of contaminated gloves and supplies properly. Unanticipated skin contact with body fluids may occur in situations in which gloves may not be immediately available (e.g., when wiping a runny nose, applying pressure to a bleeding injury outside the classroom, or helping a child in the bathroom). In these instances, hands and other affected skin areas of all exposed persons should be routinely washed with soap and water. Clothing and other *nondisposable* items (e.g., towels used to wipe up body fluid) that are soaked through with body fluids should be rinsed and placed in plastic bags. If presoaking is required to remove stains (e.g., blood or feces), gloves should be used to rinse or soak the item in cold water prior to bagging. Clothing should be sent home for washing with appropriate directions to parents or other caregivers. Contaminated *disposable* items (e.g., tissues, paper towels, diapers, gloves) should be placed in plastic bags and disposed of immediately. Routines should be established with the janitorial department. Changing areas, tables, and toys should routinely be cleaned with the disinfectant recommended by the school system. A solution of bleach and water (one part bleach to nine parts water, remixed every 24 hours) can be used.

Proper hand washing requires the use of soap and water and vigorous washing under a stream of running water for at least 15 seconds. Soap easily removes soil and microorganisms. Rinsing under running water carries away dirt and debris. Paper towels should be used to dry hands thoroughly and turn off the faucet.

Note: Always check the policies and procedures of the agency in which you are employed (State of Connecticut, 1985).

Teaching Children About AIDS

What do children need to know about sexuality and AIDS and when do they need to know it? While it is difficult to generalize a standard appropriate to all children, it is possible to establish age-specific guidelines to meet the needs of children and adolescents for sexuality and HIV education.

Although special education students need to learn the same concepts as their peers, there are limited curriculum materials available. The Association for the Advancement of Health Education and The Council for Exceptional Children convened a team to review regular education curricula to ascertain whether or not they could be adapted to meet the needs of students in special education. A list of six curricula that can be modified for use in special education classes is included at the end of this chapter.

Preschoolers. During the first 4 years of life, health and sexuality education are centered within the family. Small children are interested in their bodies, bodily functions, and life in general. Education at this age is basic. Preschoolers learn as much from the nonverbal behavior of adults as from their words. Adults should model good health behaviors and teach children that they must begin to develop responsibility for their personal health and safety. When children reach age 3, adults can begin to talk to them about germs and contagion. For example, a child can understand that washing his or her hands before eating is a way of protecting the body from disease, although any mention of HIV is still years away.

Preschoolers should also be taught to refuse rides or other offers from strangers and to say "no" to any kind of touching that makes them feel uncomfortable. Parents should answer all questions about the body, sex, and health as openly and honestly as possible. With this age group, adults may take cues regarding what the child is ready to know from the child's questions. How a child's questions are answered at this early age may well set the stage for more involved discussions as the child gets older. If the child needs more information, he or she will almost always ask more questions.

Ages 5 to 8. Young children have heard about HIV and AIDS and may be curious and worried about the disease. This is an age of fears, and children might worry that they themselves, or mommy and daddy, will develop AIDS and die. The pediatrician or parent may have to reassure the child that he or she won't get the disease. A 5- or 6-year-old child may hear the word AIDS on the news and ask about it, but the most he or she can understand is that it is a serious disease that has killed some people. Second and third graders can understand more complicated issues of health and sexuality. The obvious occasion presented by a cut finger, for example, can be used as a catalyst to talk about infections entering the body and being carried by the blood.

Children should be asked what they have heard about AIDS, and any misconceptions should be corrected. Young children should be taught that everyday activities such as going to school, playing in the park, and using public restrooms do not expose them to the virus that causes AIDS. They should also know that it is safe to play with a child who has AIDS. Young children should be taught that the needle used by a doctor to give a shot does not spread AIDS because the needle is clean; only dirty needles can be contaminated with the virus.

Ages 9 to 12. Children of this age are beginning to experience puberty. They need clear and specific information about all aspects of human sexuality. Preteens learn a great deal from a sexually explicit world—some of it false—and they certainly have a great interest in sex. Unfortunately, preadolescents will rarely ask questions. They often have learned to be embarrassed about sex.

Preteens need to understand fully:

- Accurate information about sexual intercourse and other forms of human sexual expression.
- The possible consequences of sexual intercourse, including pregnancies and sexually transmitted diseases, one of which is AIDS.
- That the risk of AIDS increases with each sexual contact and that a person may look and feel perfectly healthy and still carry and be able to transmit the AIDS virus.
- The many harmful effects that can come from drug abuse.

Teenagers. Teenagers must be acknowledged as sexually maturing human beings with personal control over their decisions regarding sexual behavior. Parents need to communicate their values regarding sexual morality to their children while acknowledging that they may choose to reject family and societal values. Teenagers are ready for a frank discussion of the various ways in which HIV infection is spread. They need to understand fully the modes of transmission as well as the sexual and personal behaviors that increase the risk of exposure to HIV infection. Language is particularly important here, since misunderstandings can be fatal. Phrases such as "body fluids" are simply too vague. Adults should try to use words that teenagers know, even slang or street terms, and then ask questions to test their understanding. It should be emphasized throughout the teen years that abstinence from intimate sexual contact and IV drug use virtually assures safety from contracting HIV. However, teenagers also need to know that if they choose to be sexually active there are certain precautions that can reduce the risk of contracting AIDS.

With all age groups, the challenge in AIDS education is to provide the information needed, while avoiding the fear and hysteria that can accompany talking about the disease. We must emphasize that the AIDS epidemic is no one's fault and that *it is not who you are but what you do* that determines personal risk for contracting AIDS. There are four essential concepts that all children must understand concerning AIDS:

1. AIDS is a viral disease, not a gay disease. It is caused by an infectious organism, not a lifestyle. People with AIDS deserve the same compassion as people with any other severe, chronic, or terminal illness.
2. AIDS is not easily transmitted. People will not contract AIDS in normal day-to-day contacts with others.
3. Under the proper circumstances, anyone can contract AIDS. HIV infection is not influenced by a person's age, sex, or sexual orientation. Sharing IV needles or having unsafe sex with an infected person can expose anyone to AIDS.
4. You can protect yourself against AIDS. By not sharing IV needles (or preferably not using IV drugs at all!) and having safe sexual contacts (or not having sex), young people can prevent exposure to the HIV virus. (Kaiser, 1988)

Program Concerns

School administrators are often asked to make difficult decisions regarding school placement of children with AIDS. The following guidelines are adapted from those of the Governor's Task Force on AIDS, State of Louisiana. The State's recommendations, which are consistent with those of the American Academy of Pediatrics, are as follows:

1. Decisions regarding the type of educational and care setting for a child infected with HIV should be based on the behavior, neurological development, and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using a team that includes the student's physician, school health and public health personnel, the parent or guardian, and the personnel associated with the proposed care or educational setting. In each case, the risks and benefits to both the infected student and others in the setting should be weighed.
2. For most infected students, the benefits of an unrestricted setting would outweigh the risk of acquiring potentially harmful infections in the setting and the apparent nonexistent risk of transmitting HIV. These children should be allowed to attend school and after-school day care and to be placed in a foster home in an unrestricted setting.
3. For infected preschool-age children, neurologically disabled students who lack control of their bodily secretions or who display behavior such as biting; and those students who have uncovered, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings. Children infected with HIV should be cared for and educated in settings that minimize exposure of other children to blood or body fluids.
4. Because other infections in addition to HIV can be present in blood or body fluids, all schools and day care facilities, regardless of whether children with HIV infection are attending, should adopt routine procedures for handling blood or body fluids. Soiled surfaces should be promptly cleaned with disinfectants. Disposable towels or tissues should be used whenever possible, and mops should be rinsed in the disinfectant. Those who are cleaning should avoid exposure of open skin lesions or mucous membranes to the blood or body fluids.
5. The hygienic practices of children with HIV infection may improve as they mature. Alternatively, hygienic practices may deteriorate if a child's condition worsens. Evaluation to assess the need for a restricted environment should be performed regularly.
6. Children born to mothers with AIDS are at increased risk of acquiring HIV infection. Physicians should consider testing the children for evidence of HIV infection. These children also need to be followed closely for problems with growth and development and given prompt and aggressive therapy for infections and exposure to potentially lethal infections such as chicken pox. Knowledge that a student is infected will allow parents and other caregivers to take precautions when exposed to the student's blood and body fluids.

7. Mandatory screening as a condition for school entry is not warranted based on available data.
8. Persons involved in the care and education of a child infected with HIV should respect the child's right to privacy, including maintaining confidential records. The number of personnel who are aware of the child's condition should be kept at the minimum needed to assure proper care of the child and to detect situations in which the potential for transmission may increase.
9. All educational and public health departments, regardless of whether children with HIV infection are involved, are strongly encouraged to inform parents, children, and educators regarding HIV and its transmission. Such education would greatly assist efforts to provide the best care and education for infected children while minimizing the risk of transmission to others (Bigge, 1991).

Summary

Most students who are HIV positive or who have AIDS are able to participate in their existing educational programs. When they are symptomatic, attendance may be irregular and they may require programming modifications. Several excellent models for home programming exist. The Baltimore City Schools CHIP Program provides instruction at home without a waiting period for students who have chronic illnesses. Louisiana provides extended school year services for students in special education who miss more than 25 days a year because of a chronic illness. Other school systems provide telecommunications so that the student is "attached" to the classroom by camera and is able to benefit from the exchange of information in the classroom. These modifications are important, but they must be applied carefully as a result of the student's illness and not as a result of the fears of the community.

4. Technology-Assisted Students: The Child Who Is Ventilator Assisted

Medical and educational issues for students who require ventilator assistance for life support include careful screening of health-related needs; development of appropriate staff training and emergency care plans; and implementation of educational programs that address needs for safe transportation, transition, and least restrictive environment.

Students who are supported by technology are those who "require the routine use of a medical device to compensate for the loss of a life-sustaining body function and require daily and ongoing care and/or monitoring by trained personnel" (Office of Technology Assessment, 1987, p. xiii). These students may be dependent on mechanical ventilators or other device-based respiratory or nutritional support such as tracheostomy tubes, oxygen support, or intravenous and/or enteral (tube) feeding (Task Force on Technology-Dependent Children, 1988). This group of students appears to be increasing in the school-age population, but it is still difficult to determine the size of the technology-dependent population. The Task Force on Technology-Dependent Children (1988) provided the following estimates:

> Ventilator assistance—680 to 2,000; parenteral nutrition—350 to 700; prolonged intravenous drugs—270 to 8,275; other device-based respiratory or nutritional support—1,000 to 6,000; apnea monitoring—6,800 to 45,000; renal dialysis—1,000 to 6,000; other device-associated nursing—unknown, perhaps 30,000 or more. (p. 63)

This chapter focuses on students who have pulmonary problems that require ventilation. Ventilation, the movement of air into the lungs, can be accomplished through two technologies. Air can be drawn into the lungs through negative pressure ventilation, using an iron lung or a portable pulmowrap. Through this process, the "abdomen and/or chest wall is pulled outward, lowering the diaphragm which pulls air into the lungs. Air is then passively exhaled" (Caldwell, Todaro, & Gates, 1991,

Technical editors: A. Joanne Gates, Director; Rick Anguzza, Coordinator; and Meg Pomeroy, Nurse Coordinator, Ventilator-Assisted Care Program, Children's Hospital, New Orleans

p. 61). This section focuses on the second technology, positive pressure ventilation as delivered through an artificial airway. When this method is used, air is pushed into the lungs by a ventilator and then passively exhaled. The ventilator can provide predetermined amounts of air that enter the body in timed and measured numbers of breaths. Frequently, the student is able to stimulate his or her own breaths and does not need the ventilator to initiate the timing or number of breaths required (Anguzza, 1990).

Positive pressure ventilation can be delivered through a nasal mask or oral/nasal mask, but it most often is applied through an artificial airway such as a tracheostomy tube, a hollow tube surgically inserted through a small incision made below the larynx or voice box (R. Anguzza, personal communication, March 29, 1991). The tracheostomy tube bypasses the upper airway, including the nose and mouth (Whitesel, Carlin, & Cimo, 1987). Because the nose warms air and acts as a filter, the student may need moisture added to the ventilator air when a tracheostomy is used. The student may also need assistance in coughing up mucus. Suctioning is the process by which mucus is drawn out through the tracheostomy tube using a suction catheter attached to a vacuum pump. Suctioning can also be used to clear mucus in the nose and mouth.

Each student's ventilator requirements, which are prescribed by the physician, are different. Some students require 24-hour-a-day ventilation and others require less. Some students require additional humidification. Still others require oxygen enrichment. Finally, some students require suctioning and others are able to cough up mucus through a tracheostomy. Major changes in both the size and function of ventilators have made home and school care possible for many children who are supported by ventilation. Most portable ventilators weigh about 30 to 40 pounds and can be carried underneath a wheelchair, in a wagon, or on any other wheeled device. They are powered by regular household current but, for mobility, can also run on an internal or external 12-volt battery (Anguzza, 1990).

Conditions Often Requiring Ventilation

Students who have impaired respiratory function and who require mechanical ventilation most frequently fall into three categories: children with traumatic injuries such as spinal cord injuries and chest injuries, those with birth or genetic disorders, and those with neuromuscular diseases (Anguzza, 1990). Deficits can be the result of major lung, muscle, or neurological problems (Jaudes, 1991). Sample conditions will be presented to describe health and educational needs in each category (Caldwell, Todaro, Gates, Failla, & Kirkhart, in press).

Traumatic Injuries. Children who have sustained a high-level spinal cord injury may have impaired function of the diaphragm and other respiratory muscles that impairs their ability to draw air into the lungs. Their lung tissue is not damaged, and oxygenation and ventilation occur normally once the air reaches the lungs. These students frequently require ventilation 24 hours a day, making them totally dependent on the ventilator (Lucus, 1984). They are also extremely limited in voluntary movement because of the high-level spinal cord injury and may need to rely on motorized wheelchairs, feeding devices, environmental controls, and computers for writing.

Birth-Related Genetic Disorders. Infants, toddlers, and young children can have several different conditions that affect their pulmonary status and require intervention such as the use of supplemental oxygen, moist air, and/or a ventilator (Kettrick, 1982). Each birth-related disorder has a different physiological ramification, and not all children who are ventilated at birth will require lifetime ventilation. Some may be weaned from the ventilator and have their tracheostomy tubes removed when they are toddlers or in early childhood.

Students who have bronchopulmonary dysplasia usually are born prematurely and require high levels of oxygen at birth, which may cause lung damage. Some of these infants and toddlers require ventilation and higher than normal levels of oxygen in order for their lungs to process the oxygen their bodies require. Infants who experience anoxia at birth may have developmental delays and will have school needs that reflect these delays. Another condition apparent at birth that necessitates ventilation is central alveolar hypoventilation or sleep apnea. When these students sleep, the involuntary system that stimulates breathing fails. Brain, heart, and lung damage is possible from apneic episodes and may result in developmental problems.

Neuromuscular. Werdnig-Hoffman is one of several types of progressive neuromuscular disorders that result in muscle weakness. The prognosis is dependent on the type of atrophy and the age of onset. Earlier onset can mean much faster progression of the symptoms. Eventually, children with progressive neuromuscular disorders experience lung problems. Their lungs fail to function because the muscles of respiration become progressively weaker and prevent them from inhaling sufficient air. For these students, respiratory failure is one of the most common causes of death (Bleck & Nagel, 1982). These students may require the use of a mechanical ventilator for only part of the day, usually at night (Lucus, 1984). Adequate ventilation at night gives them enough energy for the day. As their disease progresses, students may require more frequent ventilation. These students may also be extremely limited in voluntary movement (Kettrick, 1982), relying on motorized wheelchairs, feeding devices, environmental controls, and computers and tape recorders for classwork and tests.

Practitioner Concerns

When making educational plans for students who are ventilator assisted, it is important to define both the health and education needs related to their conditions. The checklists shown in Figures 1 and 2, when used in conjunction with the local education agency's educational evaluation and the physician's prescription, can provide a comprehensive picture of a student's needs.

Program Concerns for Students Who Require Ventilator-Assisted Care

The major programming concerns for children who are technology assisted revolve around collaboration; trained and supervised staff to provide care; a system to monitor and update skills; an emergency care plan; a program in the least restrictive environment; a transition plan; and, finally, transportation that is safe for the student and his or her equipment.

Collaboration. Collaboration is essential when working with children who are technology assisted, and the role of the family is an essential one. Some families provide direct care at home, others manage care. Therefore, the family's role is essential in determining educational and health needs and coordinating health and education resources. The family can link health care personnel and educators, or act as liaison between the two. Within the school system, a contact person—often a school nurse or special education administrator—can facilitate planning so that the resources needed for the child will be ready before the child enters school. If family members are also skilled in providing care, they may be able to assist in training direct caregivers (Caldwell & Kirkhart, 1991).

Since home health care for these children is relatively new, there are few school health professionals specifically trained in the care of children who require ventilation (Caldwell, Todaro, & Gates, 1991). This makes it important for the school system to work closely with the hospital discharge team, even if that team is not nearby. Many school systems and health departments will send a nurse to a regional care center (e.g., a children's hospital) to receive training. The family can assist in the development of working relationships with health care providers from the center and from the community. The relationship between the health care team and the school system should be ongoing, with contacts made at critical points in the child's school and health care programs (e.g., at

FIGURE 1
Screening Checklist for Health Considerations

Student Identified Need	**School Response**
	Pulmonary System
____ Tracheostomy	____ Suctioning as needed ____ Trach ____ Nose ____ Mouth ____ Tracheostomy cleaning* ____ Tracheostomy change* ____ Emergency tracheostomy change or replacement ____ Recognition of signs and symptoms of distress
____ Ventilator	____ Initiation and removal of ventilation at prescribed times ____ Monitoring settings after transportation ____ Monitoring settings at scheduled times ____ Troubleshooting of equipment ____ Use of resuscitator bag ____ Recognition of signs and symptoms of distress
____ Supplemental oxygen	____ Initiation and removal at prescribed times ____ Monitoring of the system ____ Recognition of signs and symptoms of distress
____ Respiratory treatment	____ Chest physiotherapy (CPT)* *Normally completed at home
	Overall Health Status
____ Monitoring	____ Vital signs ____ Mental/emotional status ____ Heart and lung status ____ Signs and symptoms of impending problems, e.g., temperature maintenance, autonomic disreflexia
	Nutritional Function
____ Nutritional deficits	____ Oral supplements ____ Supplements through gastrostomy tube ____ Fluid supplements ____ Signs and symptoms of impending problems
____ Aspiration	____ Gastrostomy feeding through a tube or button ____ Recognition of signs and symptoms of impending problems

FIGURE 1 - Continued

Urinary and Bowel Function

____ Urinary incontinence	____ Catheterization ____ Diapering ____ Monitoring intake and output ____ Recognition of signs and symptoms of impending problems
____ Bowel incontinence	____ Monitoring of bowel function ____ Monitoring of nutritional status ____ Recognition of signs and symptoms of impending problems

Skin and Postural Considerations

____ Posture	____ Support of trunk, neck, head, and extremities ____ Repositioning ____ Transfer ____ Signs and symptoms of impending problems
____ Skin concerns	____ Pressure relief ____ Repositioning ____ Recognition of problems ____ Signs and symptoms of impending problems

Note: Adapted from Caldwell, Todaro, Gates, Failla, and Kirkhart (in press). The implementation of these health procedures requires a physician prescription, documented training, and supervision.

the beginning of a new school year or after adjustment of ventilator settings).

Another important relationship is with the student's equipment vendor. The vendor can assist in troubleshooting problems with equipment, provide direct intervention in the case of equipment failure, and provide training and technical assistance (Pomeroy, 1990). Contact with the vendor also can be made through the family.

Collaboration among agencies can also be essential to the ability of a child to obtain adequate educational services. Although the courts have upheld the responsibility of school systems to provide health services, many school systems are blending funding from Medicaid, Title V, and the private sector with local and state education dollars in order to provide these services (Bergman, 1989; Caldwell & Kirkhart, 1991; Caldwell & Sirvis, 1991).

FIGURE 2
Screening Checklist for Educational Considerations

Student Identified Need	**School Response**
____ Impaired motor function	____ Assistance with activities of daily living ____ Assistance with mobility, transfers, etc. ____ Academic classwork and set-up for individual activities including reading and studying ____ Modification in amount of work to be completed ____ Modifications in how the student generates classwork and tests, i.e., use of computers, tape recorders, and human recorders
Impaired Vocalization	
____ Tracheostomy prevents air flow past vocal chords	____ Medical and speech/language evaluation to determine whether or not another tracheostomy can be used or air flow can be induced
____ Vocal cords paralyzed or musculature required to articulate affected by disease, i.e., spinal muscular atrophy	____ Augmentative communication
Logistical Considerations	
	____ Transportation to and from school ____ Assistance with establishing health care routines that result in the least school interference possible ____ Assistance with participation in field trips and extracurricular activities
Psychosocial Issues	
	____ Assistance with issues such as peer relations, making friends, and dating ____ Assistance in developing ability to improve tolerance, direction, or independent completion of health care
Graduation Issues	
	____ Assistance in selecting and securing job training and employment ____ Transition to higher education

Note: Adapted from Caldwell et al. (in press).

Staff Concerns. Currently, there are no standard formulas for determining the number of staff necessary to care for the health needs of children assisted by technology. Some children need procedures that can be provided at a scheduled time each day. These children will rarely experience emergencies associated with the procedure. For them, the scheduled services of a health care professional (e.g., catheterization or gastrostomy feedings) may take 20 minutes to 1 hour. Children who require ventilation and/or suctioning do not fall into this category. They have health needs that require care "*PRN, pro re nata, as the situation demands*" (*American Heritage Dictionary*, 1985, p. 1543). This factor and the nature of the emergencies that can occur with students who are ventilator assisted necessitate that a trained caregiver be with the student the entire time (Caldwell & Kirkhart, 1991). If a child has a gastrostomy tube and that tube falls out, the student will be safe and can probably tolerate the loss for hours—sufficient time to get home or to a hospital or doctor's office. If a ventilator system malfunctions, or a tracheostomy tube becomes dislodged or plugged, however, the child will require immediate intervention.

Most students who require scheduled health procedures can be served by itinerant personnel or personnel who serve other roles in the school. Some school systems have a school nurse who completes scheduled procedures. Sometimes the parent or a home health nurse is paid to come into the school to provide a procedure. In other situations, the school nurse supervises the provision of the procedure by an itinerant or school-based licensed practical nurse (LPN), classroom aide, or health assistant (Caldwell, Todaro, & Gates, 1989). Some students who require health care *PRN* will need to have a designated trained person with them at all times to provide health care. Some systems employ carefully trained and supervised health aides; other systems use LPNs or registered nurses (RNs). Decisions regarding the level of training or licensure are based on policies and procedures adopted by the school system, the system's resources, and state regulations regarding the practice of nursing care.

In addition to the level of training, consideration must be given to determining the actual time needed for scheduled care needs of a student or groups of students. For instance, a student who requires catheterization (30 minutes a day) may also require pressure relief or repositioning every 30 minutes (11 pressure reliefs x 5 minutes + 4 repositionings x 10 minutes = 95 minutes/day); assistance with eating (30 minutes/day); assistance in setting up tasks (60 minutes/day); and assistance with notetaking (120 minutes/day). A student who requires this much assistance will most often require a full-time assistant despite the fact that each of these procedures can be scheduled. Likewise, special education and regular education teachers who welcome children with special health needs in their classes may have two or three students with special health conditions. The cumulative classroom needs warrant a full-time person to provide for all of the students' health needs. Many school systems do not have funding mechanisms that allow cumulative student health needs to generate a position; therefore, student care is difficult to finance.

Another important question concerns staff qualifications. As previously mentioned, selection is frequently guided by system policies and state laws. *Guidelines for the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting* (Joint Task Force, 1990), developed jointly by professional organizations representing educators and health care personnel, provides recommendations concerning delegation of health care to persons who are not physicians or nurses. Chapter 6 of this book includes information about the guidelines as well as recommendations for training and supervising for professional and nonlicensed staff.

A System to Monitor and Update Skills. A system to monitor and update the skills of nonlicensed personnel providing care is an essential component of risk management (Martin, 1989). There are no set timelines for supervision. *Decisions regarding the amount and type of supervision provided are dependent on the professional judgment of the nurse, physician, or therapist providing training.* (Skill checklists, which include an evaluation component, are contained in *The Community Provider's Guide* [Caldwell et al., 1989].)

Emergency Care Plans. Despite excellent plans, children who require ventilation may have emergencies, and not every emergency room is set up to handle their needs. It is imperative that school personnel establish a relationship with emergency personnel in the community and be prepared to respond to emergencies in school.

Emergencies can be the result of a physiological breakdown, an equipment failure, or a natural disaster. Schools must be prepared to respond to all three situations (Caldwell et al., 1991). For instance, a physiological breakdown can occur if a student's tracheostomy tube becomes blocked or dislodged. If this happens, efforts are first focused on opening the airway. The tracheostomy tube is unblocked by suctioning or cleaning. If this does not work, the tube is replaced. If the student is still not getting the air needed, CPR is administered (Whitesel et al., 1987). Anyone who works with persons who have tracheostomies must be trained to provide step-by-step intervention and CPR. (Emergency procedures are outlined in *Getting It Started and Keeping It Going* (Whitesen, Carlin, & Cimo, 1987), a training manual for caregivers of children who are supported by pulmonary technologies.) When a caregiver is carefully trained and efforts are made to check that the child is carrying extra supplies and equipment, an emergency can be managed competently.

Every child who attends school and uses a ventilator, a suctioning machine, and/or a tracheostomy tube should carry spare equipment. For every electrical piece of equipment a child uses, there should be a manual backup (Caldwell et al., 1991). The ventilator can be replaced by a resuscitator bag, which is a hand-operated method for pumping air into the lungs. The suctioning machine can be replaced by a DeLee suctioning catheter, which requires that a caregiver suck on a tube to provide the vacuum required to draw mucus into a trap container. Tracheostomy tubes can become blocked or dislodged and may need to be replaced. Extra tracheostomy tubes and a tube one size smaller than the child's normal tracheostomy should be carried for emergency replacement (Anguzza, 1990). (*Getting It Started and Keeping It Going* contains a list of typical equipment and supplies a child carries to school. Procedures to inventory equipment and supplies at the beginning of each day are recommended.)

The third type of possible emergency involves natural disasters. In San Francisco, earthquakes may occur. In New Orleans, hurricanes are common. Each geographic area has its own type of potential natural disaster. Despite the type, the major steps in planning are the same and revolve around notification of emergency disaster personnel. In Louisiana, the Ventilator-Assisted Care Program (VACP) notifies agencies such as the Red Cross, the fire department, and the local emergency room that a child who requires ventilation is in the community. Exact information about what the child will need both at home and at school is provided, and personnel are frequently trained to implement emergency procedures for a specific child who is supported by technology. Program personnel also notify the telephone company and the electric company. Whenever possible, these companies place individuals who are supported by ventilation on a priority list for reinstatement of service (Caldwell et al., 1991). If priority reinstatement is not possible, arrangements may have to be made with the hospital to admit the child during natural disasters.

Least Restrictive Environment. Many students who are ventilator assisted can benefit from inclusion in their regular classes in their neighborhood schools. Resources such as personnel to provide care are essential to the ability of school systems to implement full inclusion (Caldwell & Kirkhart, 1991). Decisions that separate children from their neighborhood friends must be made carefully since these students already experience difficulties in making and maintaining friends because of their health care schedules. One situation that may warrant the movement of a child from a neighborhood school is the lack of availability of emergency medical care. Despite the fact that emergency treatment is initiated immediately by the direct caregiver, access to emergency room care could be important. Some local education agencies (LEAs) will move a student to a school that is closer to a community hospital or health clinic equipped to manage the student's emergency. In some large urban areas, LEAs transport students to a regular campus that has a full-time nurse who remains on campus and can provide emergency backup.

Transition Plan. Transitional needs can be related to the child, the family, staff training needs, or the LEA. The child may need to reenter the neighborhood school slowly because of long-term hospitalization. A part-time school day with supplemental home instruction may initially be appropriate. Family members frequently will have experienced several of the child's health crises, so it may be difficult initially for them to deal with a move from a hospital to a school. In some cases, family members will want to stay in the building with the child until they feel comfortable that the child is safe. The inclusion of parents as part of the training team can help allay some of their fears. Transitions may be related to an LEA need (e.g., a school will have to add a ramp or add a sink in the vicinity of the child's classroom), but the most frequent need is staff training. All transitions should be carefully planned with objectives and timelines so that a transition plan does not end up being the child's permanent educational plan (Caldwell et al., 1991; Caldwell & Kirkhart, 1991; Caldwell & Sirvis, 1991).

Transportation. Transportation of students who require ventilation can be complex. Every student who is ventilator assisted requires trained personnel to provide care during transportation as well as a way to transport equipment and supplies securely. Many school systems pay a parent or family member to provide transportation. In other systems, the person who provides care in school rides on the bus with the child. Usually, the shorter the distance the child is transported, the safer that child is. Efforts must be made to plan ahead for emergencies so that the driver will be familiar with the closest emergency services on the route.

Summary

Despite excellent preplanning for provision of services, school systems are often stymied in trying to provide services to children supported by medical technology. The complexities are magnified by the great diversity of practice standards, the lack of standardized training curricula, and the impact of these issues on risk management. (These issues will be addressed in Chapter 6 and in the "Resources" section, which contains references on risk management.)

5. Parent and Student Concerns

Families of children with special health care needs face challenges related to responsibility, time, finances, normalcy, support, and uncertainty.

Children with special health needs and their families face critical situations that make everyday living difficult. In 1988, The Council for Exceptional Children amended its policies, adding information about students with special health conditions. The recommendations of the Ad Hoc Committee on Medically Fragile Students addressed family and student needs and suggested that special education "establish support systems for staff, students, and families to assure the availability of student and parent advocates; [provide] information on related issues [including] legal support, home health care, heath care financing . . .; [provide] information on support groups unique to the student's and family needs . . .; and establish opportunities for staff interaction and professional support." (CEC, 1988, p. 5)

Why did the educational community recognize support of the family as essential to the ability of educators to provide adequate intervention? Why is state-of-the-art health care family centered? This chapter provides an overview of the special issues faced by families and children with special health conditions. Resources with more specific information are listed at the end of the book.

Family Changes

> I depend on professionals to communicate with me and my family, and to understand all of what it takes emotionally, physically, and financially, to be patient and to show respect. All families are different and expectations need to be realistic, not based on an idea of children we see on telethons. (Blanchard, 1990)

Professionals are in an advantageous position to assist parents in coping with stresses. Many children with special needs and their families possess far more strengths than weaknesses, and they experience more successes than failures. Professionals can play an important role in identifying the strengths of both the child and the family. They can approach each family anew, discovering that family's individual coping

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Technical editors: Peggy LeBlanc, Parent Coordinator; Dell Amos, Parent Resource Developer; Kathryn Kirkhart, Psychologist, Private Practice; Ruth E. Eisler, Social Worker, Children's Hospital, New Orleans.

methods and demonstrating respect by incorporating the family's cultural and socioeconomic differences into their recommendations. Professionals can use terminology that stresses the positive, healthy aspects of the child. They can take responsibility for using wording that will sensitize the parents and themselves to the idea that a child with a chronic illness or disabling condition is a *child first*. Professionals can talk of the child's "using a wheelchair" as opposed to being "wheelchair bound." They can speak of the child as "a person who has . . . " rather than as a "handicapped" or "afflicted" person.

Tankersley, Waterman, and Witt (1985) surveyed families of children with chronic health problems to assess parental concerns about the child's treatment regimen. They organized responses in terms of six themes: responsibility, time, finances, normalcy, support, and uncertainty. The survey revealed that these themes presented significant challenges no matter what the family's resources. The effect of these areas on family functioning continues to be studied. The following sections present insights from the survey, introduced by quotations from the mother of a son who has cystic fibrosis (Caldwell, Todaro & Gates, 1989).

Responsibility

> The weight of knowing that your child's physical health is in your hands can be overwhelming. You have to become familiar with medications, physical therapies and deal with professionals. For instance, we became responsible for CPT treatments every morning and evening. Decision making becomes complicated because you can't make decisions on your own and you must select and depend on so many different professionals. You must also find services which may be rare. And, on top of all this, you must make sure that there is a balance, that your energy is not being sapped, and that you have energy for the other members of your family (LeBlanc, 1990).

All parents have innumerable responsibilities. Parent of children with special needs have additional responsibilities such as providing special diets, medications, exercises, and therapies for their children. They manage technical equipment, schedule medical appointments, attend appointments, and more. The responsibilities sometimes belong to a single parent, a working parent, or a foster parent with other responsibilities. It is difficult to manage everyday responsibilities in addition to the special responsibilities incurred because of a child's health condition without slighting siblings or spouse.

Time

> Life becomes dictated by the clock because not only do you have to get regular activities like going to school in but you must also make time for therapies and medications. You lose spontaneity because you must think about therapy every morning and every evening. Then there are the time consuming, frequent clinic visits where you spend a full day seeing the team. (LeBlanc, 1990)

Time is a precious resource. Not only do parents have additional responsibilities when parenting children with special needs, they also have to find time to dedicate to family life. Health care appointments, paperwork, decision making, and care provision all take time. For some parents, this means revising employment schedules, leisure pursuits, and personal goals. A growing problem for families in managing time and priorities is isolation from extended family and friends.

Finances

> The obvious expenses include hospitalizations and medications. Other expenses such as frequent trips to clinics, special foods and equipment are not always so obvious. Another parent told me her electric bill had skyrocketed because of her son's ventilator and oxygen condenser. In many cases, families cannot receive assistance unless they become impoverished. My husband cannot easily change jobs or we may lose my son's insurance. Many families feel trapped. They can't change jobs, and they can't make too much money. (LeBlanc, 1990)

Financial demands are usually a strain. Health care and health equipment are costly. Expenses can include transportation, food, clothing, medications, equipment, insurance premiums and co-payments, paid caregivers, and therapists. Lost salary can be a problem when a parent misses work to care for the child.

Normalcy

> It is very difficult to give to everyone in the family—time, finances, energy. We have trouble at times dealing with our own feelings. I'm not always comfortable but must deal with other's feelings and rejections as well. It can be difficult to make sure that he has enough social opportunities. He struggles with the diet and treatments, and other families struggle to find care during recreational activities. No one wants their mother with them at all times. (LeBlanc, 1990)

There is no such thing as "normalcy," because all families are different. However, normalizing the lives of a child and his or her family when chronic illness is present means trying to include regular and desired events in daily activities even when it means finding a unique solution to a barrier to participation. Examples include finding and modifying special equipment, planning ahead, making a place accessible, carrying along special foods or medical treatments, or including other caregivers.

Support

> Support can really broaden your perception. I've been able to find professionals who support, accept me and respect my individual needs. Sometimes all I need is someone to listen and other times I really need advice. I have gained from all kinds of support and I think there is no one way .... When I work on legislative issues I most often work with a general disability group, but there are times when I want to talk to someone else who has a child who has cystic fibrosis. I don't think one can substitute for the other. (LeBlanc, 1990)

Support in rearing a child with a chronic health problem should come from the community at large. Support can be provided by professionals, extended family members, friends, churches, civic and volunteer groups, and specific parent support groups. The greatest difficulty of family life is not the accomplishment of a single activity or a day's activities, but the ongoing nature of the needs. It helps to have some regular assistance by others.

Uncertainty

> Having a child with a special health need can be like living on a roller coaster. The ups and downs are never expected and sometimes you feel that you are falling into darkness. Then, there are the decisions regarding when to try new treatments or stop treatment. Nothing is simple or easy. (LeBlanc, 1990)

Uncertainty causes anxiety. The child's condition and future are often unpredictable. Many elements of the chronic disease cannot be fixed and must be managed on a day-to-day basis with continuous problem solving and decision making by parents and professionals. The decision makers are often uncertain and even at odds with various recommendations. Like the illness itself, the uncertainty can be stressful. Parents often ask themselves, "Am I doing the right thing?" Doubts can fuel more uncertainty, even guilt or anger.

A Family's Perspective

Families face many dilemmas in raising children with special health needs. They often play the roles of physician, nurse, and parent, and they must balance safety issues, allowing for the greatest degree of independence possible, regardless of disability. Probably the most complex decision some families make is whether or not to send their child to school. No one can make guarantees, and the benefits must always be considered in light of the risks. The perspective of one of the authors of this book and the family of such a child are presented in the following section.

A few years ago, I worked with a family struggling to make a decision about whether or not their child should attend school. The child was a precocious little 5-year-old boy who had spinal muscular atrophy. I was one of a team the family selected to help them make the decision and to provide training for the school staff. It was a tremendously difficult decision because the child's immune system was compromised and no one could guarantee his safety. I saw the mother and father struggle to comply with their son's wishes despite their own tremendous fears. I believe this struggle is one that is shared by thousands of parents and professionals who serve children with chronic health conditions. Robert Carroll died 5 months after he began school. Were we right to have supported him in his desire to go? There is no easy or right answer to this question; yet, at his funeral service, the words his sister said comforted me. I've included them for others who are involved in this type of decision making. Robert's mother and father told me that their pediatrician, Steven Hales, M.D., had helped them make the decision with this quote: "A ship is always safer in port but it was never meant to stay there, it was meant to sail the open seas." I hope this quote will help you launch many ships to sea. (T. Caldwell)

Eulogy to Robert Ashford Carroll

Clyde, Germaine, and Vanessa Carroll
as delivered by Vanessa Carroll
on February 6, 1990

Robert Ashford Carroll, for all of us that knew and loved him, had strength, courage, and wisdom far beyond that of a six-year-old. Whether we called him Robert, Rob, Bob, Bubba, Booger, or Googie Bear, he always showed his great love of life, and in doing so, affected everyone around him.

Robert was always the "little trooper." Robert had a life of pain from the time he was born till the time he died. No matter how much pain he was in, he was always smiling, and Robert was always a happy child with a smile on his face. No matter how bad the moment was, he could always make others happy. When Robert was born, he was expected to live only two months, but he showed everyone for he lived six years; yet he lived more in those six years than some people live in sixty.

Robert was the greatest thing that happened to everyone. He amazed everyone how such pureness, compassion, and love ever existed. He influenced every one of you that is here today. There is a certain part of Rob in each and every one of you. I could say when Robert died I lost the greatest brother and best friend a person could ask for, but I didn't lose him. I will always have him in my heart, and so will all of you.

He loved to watch wrestling and football, for they displayed the physical and athletic strength that he was born without.

Before Robert passed away he achieved things that he was so proud of, such as school. He loved his school, he had his own wonderful friends and his own very special teacher. Going to school, just for a small amount of time, meant more to him than anything else in the whole wide world. He learned more in those five months of school than some people learn in a lifetime.

He loved each and every one of you in a special way, and he would want you to remember him the way he always was, happy and having fun. Although his life of pain is over, and he is now having a great time running and playing Nintendo without anyone having to help him, or with any machine's help, ours is just beginning. We all have to learn to go on with life without that little certain push that he always was, but that little certain push will always be with us, in our hearts.

Parent Support

It made me feel so much better to know that I am not the only one with the angry and lost feelings I have. Never again will I ever think that I am the only one with my kind of child.

We found out when we met the other families that they were just as curious and fearful as we were. But we all had the same goal in mind for ourselves. Quality of life can be all you want it to be even with a handicapped child in the midst. (*SKIP of Louisiana Newsletter*,1990), pp. 2–3)

There are many organizations for parents that represent a particular diagnosis or generic family need. These organizations can be local or affiliated with a national organization. One such organization is SKIP (Sick Kids [Need] Involved People), an organization for families of children who are technology assisted. The SKIP objectives and comments from parents regarding the organization are reprinted here to demonstrate some of the characteristics and functions of parent organizations:

> SKIP is designed to facilitate the family's smooth transition from hospital to home.
>
> SKIP is there to help families obtain their child's maximal developmental and health potential within the natural environment of the home.
>
> SKIP believes that every child has the right to an enriching, meaningful, productive and as normal a life style as the child's limitations allow.
>
> SKIP believes in the concept of family-to-family support and promotes this through visits, phone calls and the annual family camp. (*SKIP of Louisiana Newsletter*, 1990, pp. 2–3)

6. Service System Considerations

Health care and educational systems should share responsibility and coordinate intervention efforts, training, and technical assistance.

Children with special health conditions and their families depend on a number of federal, state, and local service systems to obtain many of the health, social, and educational services they require. Implementation across states will vary, but systems such as Title V programs (sometimes called Children with Special Health Needs or Crippled Children's Programs) can provide access to teams of specialists, equipment, and even hospitalization. By virtue of their diagnosis and the financial status of their families, children may be eligible for Medicaid and Supplemental Social Security benefits and may receive well health care screening and evaluation, hospitalization, limited home health services, and equipment. Some medical and social service agencies also provide respite care and case management. Finally, education agencies may provide the crucial special services that make it possible for a student with special health needs to benefit from education.

Despite what seems to be a vast number and range of services, many children do not have the resources they require. Significant lack of resources in some areas may be caused by the limiting policies and procedures of service systems or limited training of personnel regarding the requirements of children with special health conditions and their families. Health and social services procedures and policies can be insurmountable barriers. One parent described the process of applying for respite care services. He sat through six interviews with six different social services workers who told him that he qualified for services but that there was no money available (Chronic Illness Program, 1989). Parents of children who are technology assisted can be forced into poverty because of the Medicaid "spend down" formula (Crippled Children's Program, 1987). One family spent their 10-year savings ($10,000 for a house) on a funeral plot so that their daughter's medical bills for a traumatic brain injury could be paid (Rehabilitation Family Group, 1990).

The policies of the educational system can also make it difficult for students to obtain access to an appropriate education. School systems have not always seen their role as custodians of children's health. Administrators and teachers have resisted providing the health services necessary for these students to attend school. Even when they attend school, discriminatory practices may keep them from participating in their neighborhood school's regular education classes or from attending field trips and participating in extracurricular activities.

New movements toward shared responsibility and coordinated care among agencies and families are establishing precedents that will allow a full spectrum of coordinated services. Families, health, education, and social services agencies are beginning to plan together. The CEC Ad Hoc Committee on Medically Fragile Students (CEC, 1988) highlighted the need for coordinated delivery of related and noneducational services, recommending the designation of agencies as responsible for particular services; the development of interagency agreements; and the designation of a case manager to access, coordinate, and appropriate services for each student. In many states, Public Law 99-457, the Education of the Handicapped Amendments of 1986, has provided the mechanism to develop interagency coordinating councils. The current Title V legislation also stresses shared responsibility and working relationships with families and agencies. Policies and procedures are beginning to change.

Service systems have not been prepared for the increase in the number of children with special health conditions who are seeking services in the community and the severity of their problems. This lack of preparedness makes coordinated, high-quality home and school care difficult to provide. Three specific aspects of system preparation need to be considered. First, training issues focus on children currently seeking school and community services who have complex technology and treatment needs that require specialized care. A system of orientation, training for individual student needs, supervision, and updates for health professionals can enhance the ability of service systems to provide that care. Second, delegation has been a complex issue for nurses working in schools because, in many situations, it is not practical or necessary to have a nurse present for every health procedure completed for a student. On the other hand, nurse practice acts in many states prevent the delegation of these procedures to nonlicensed individuals. Completion of health training procedures by special education personnel has been haphazard in many situations without nurses involved in either training or supervision of direct caregivers. Finally, the role of school nurses in the care of children with special health care needs must be considered. Ironically, at a time when the population of children with special health care needs is increasing, the number of school nurses available in many school systems is decreasing (Haydel, Kilgore, & Lagasse, 1990).

This chapter provides only an introduction to these issues, which will become increasingly more crucial in the coming years. Several organizations have efforts under way and can provide current information about models of collaboration. These include The Council for Exceptional Children, the National School Nurse Association, the Association for the Care of Children's Health, the TAP and CAPP programs through the Federation for Children with Special Needs, and United Cerebral Palsy.

Training and Technical Assistance

Training and technical assistance are essential for four reasons. First, they allow children to obtain services that are safe and appropriate to their health needs. Second, they promote staff comfort and provide the opportunity for school personnel to discuss their fears, learn the skills they require, and practice procedures until they are comfortable. Third, they address parents' fears and provide the opportunity for parents to collaborate to ensure adequate school care for their child. Finally, they are essential to a school system's risk management plan. A documented training plan that includes orientation, hands-on training, and adequate updates indicates well-planned efforts to provide a safe school experience for a child. (Chronic Illness Program, 1987)

Training Guidelines. Training begins before a child with special health needs enters a particular school. The CEC Ad Hoc Committee on Medically Fragile Students has recommended inservice, preservice, and continuing education programs emphasizing the following elements:

- Awareness and understanding of students' health care, emotional, and educational needs.
- Knowledge of common medical and health terms.
- Knowledge of medical characteristics including etiology and implications.
- Knowledge of physical, developmental, and emotional characteristics.
- Knowledge of appropriate curricular and environmental modifications.
- Knowledge of the roles and responsibilities of the heath care professional in the classroom.
- Knowledge of the importance and necessity for establishing support systems for personnel, students, and families.
- Knowledge of resources for the family. (CEC, 1988, pp. 5–6)

In addition to generalized training provided in group settings, student-specific training is required. This training can be provided collaboratively by the parents and a licensed professional, frequently the school nurse. Student-specific training provides the opportunity to address the specific needs of the child as outlined in the child's prescription and care plan. It allows the opportunity to practice daily and emergency care and outline the implications of the child's health needs for the school.

Recommendations for Student-Specific Training

1. Secure individualized prescriptions and protocols, including warning signs and symptoms. Develop these in collaboration with parents and health care providers.
2. Begin training prior to the child's return to his or her community. Have a parent observe and/or participate in the training.
3. Train at least two people so that back-up care is available. Delivery of care by a consistent provider or providers is important to the child's health.
4. Train all personnel who will work with the child to deal with emergency situations (i.e., bus driver, adapted physical education teacher, or anyone else who will be teaching the child). Recommend that the program administrator and/or secretary learn emergency procedures.

5. Provide back-up care for a designated period. An expert (i.e., qualified professional, trained parent caregiver) should be present for continued training and on-site back-up care. The length of back-up care is determined by the care provider's competency and comfort. It is recommended that at least five trial procedures including emergency procedures performed with 100% accuracy be documented before a care provider works independently.
6. Document training using an individualized checklist. The trainer and parent sign the checklist after training is completed.
7. Provide supervision. Rechecks are recommended by the trainer, with time lines based on the complexity of the procedures and the competency of the care provider.
8. Include recognition and implementation of emergency procedures as part of training and rechecks.

Barriers and Solutions. There are major barriers to the provision of adequate training by school systems. Fear, uncertainty, and resistance to change continue to exist among professionals, care providers, and parents. There is often a lack of communication between health and education agencies. There are many territorial issues, liability issues, and a lack of understanding of the roles and regulations of licensed professionals. These barriers are being edged aside as efforts are made to increase communication and interdisciplinary, interagency planning. Professional organizations such as The Council for Exceptional Children, the National School Nurse Association, and the National Education Association are working together to describe roles and responsibilities and recommend policies and procedures.

Summary. Three cautions should be heeded before a school system develops a training plan. First, not all health professionals have experience in dealing with children with special health needs. For instance, the nurses on an oncology (cancer) unit have specialized training in caring for patients who have cancer. If a patient is admitted to the unit who has cancer and a tracheostomy, then those nurses may not have specialized skills in tracheostomy care and the pulmonary nurse specialist will have to provide a review. Educators cannot expect every health professional to know how to manage every type of child, so there must be facilitation of a linkage between school health providers and specialists who are often miles away in a children's hospital. Opportunities must also be provided for school health personnel to secure professional updates and information.

A second caution relates to the ongoing need for training. Once an educator learns how to teach reading, he or she should be ready to teach reading to all children with only limited supervision. However, the provision of health procedures by nonlicensed personnel requires training that is individualized for every child and supervision on an ongoing basis. Initial training is important, but it is not sufficient to guarantee the safety of the child.

Finally, all school personnel should have basic training in order to care for their students and protect their own health. The basic training for each teacher should include CPR (cardiopulmonary resuscitation), general first aid, and universal precautions (infection control).

Training Models

Massachusetts. Project School Care, affiliated with Boston Children's Hospital, is a collaborative project involving local school systems and parent organizations. Project personnel provide training for referred students. The project has also published a manual for school personnel, *Children Assisted by Medical Technology in Educational Settings: Guidelines for Care.*

Maryland. The Specialized Health Needs Interagency Collaboration (SHNIC) is a statewide technical assistance project to assist school and related-services personnel, including school and community health professionals, in managing the specialized health needs of students with developmental disabilities and disabling conditions within the educational setting. The project receives referrals regarding children who require tube feedings, catheterization, specialized respiratory care, post-head-trauma care, or other specialized health procedures within the special education setting. Project personnel provide on-site training and consultation involving an individual child or group of students, workshops regarding particular health-related topics, and information and referral (Sciarillo, Draper, Green, Burkett, & Demetrides, 1988).

California. The State of California has provided leadership in the development of guidelines for the implementation of health care procedures in school. In 1990 the state updated its original guidelines to include Administrative Concerns, Specialized Physical Health Care Services Procedures Requiring a Physician's Authorization, Preventing the Spread of Infectious Diseases, and Routine Care Not Requiring a Physician's Authorization. The guidelines include sample forms for specialized care of equipment and emergency planning. The California Department of Education, in collaboration with the California School Nurse Organization, has provided regional workshops regarding the implementation of the guidelines. Through the California School Nurse Association, regional nurses are available to provide technical assistance.

Louisiana. Louisiana has several programs affiliated with the Children's Hospital in New Orleans, including The Ventilator-Assisted Care Program, The Pediatric AIDS Program, and the MCH National Center for the Preparation of Providers of Care. These programs receive support from a variety of sources including the Bureau of Maternal and Child Health, State Medicaid, Title V, and the U.S. Department of Education, Office of Special Education.

In the 1989 legislative session, training on the implementation of catheterization by nonlicensed personnel was mandated by the legislature. As a result of those efforts, 8 hours of training must be provided for every nonlicensed person who is performing catheterization in school, and supervision must follow the guidelines of the Nurse Practice Act. *Guidelines for the Implementation of Act 1048, Bulletin 1885* reviews the law and then provides a comprehensive outline that addresses anatomy, classroom and social-emotional implications, universal precautions, and training to perform the procedure.

Role of the School Nurse

For many school nurses, it feels as though a revolution is coming. School nurses frequently provide children's major contact with health care professionals, and they must now deal with students with more severe impairments who are seeking opportunities to attend school (Carstens, 1990). Efforts are under way in many states to examine and clarify their nurse practice acts with regard to the ability of school systems to hire nonlicensed personnel to provide health care for students. Cognizant of the need to define roles, The Joint Task Force for the Management of Children with Special Health Needs was developed. Comprised of representatives from national professional organizations, including the American Federation of Teachers, The Council for Exceptional Children, The National Association of School Nurses, Inc., and the National Education Association, the task force developed a matrix listing 66 special health care procedures. The matrix "delineates the persons who are qualified to perform each of the procedures, who should preferably perform the procedures, and the circumstances under which these persons would be deemed qualified. . . . Qualified assumes that the individual has received appropriate training in the procedures" (Joint Task Force, 1990, p. 4). For example, mechanical ventilator monitoring requires a physician's order. Those qualified to monitor the ventilator include an RN (no conflict with nursing professional standards), an LPN with RN supervision, and a school health aide with RN supervision and inservice training. Teachers and related services personnel can provide services on an emergency basis; "others" (e.g., school secretaries), should not perform this task. The document provides an excellent example of collaboration between health and education agencies. It also provides a tool that can be used by states' educational and health organizations in order to develop relevant policies and procedures. This document is just the beginning, as the populations of children with special health care needs who are seeking school services continue to change.

In many school systems, school nurses and special education personnel are beginning to identify the role of the school nurse in regard to the entire special education process (Caldwell & Todaro, 1990, 1991). Nurses are participating in the identification of children. They are able to help teachers identify problems that result from a particular health condition or treatment. During assessment, the nurse, as part of the multidisciplinary team, recommends interventions that may be completed in the regular education setting and that may make it possible for the student to be accommodated without special education intervention. If a full evaluation is required, the school nurse collects relevant medical information and then interprets it so that other team members can have a greater understanding of the neurological, psychosocial, and behavioral ramifications of both the condition and treatment. When eligibility is being determined, a nurse may be called upon to assess whether or not special resources will be necessary for the child to progress in the educational setting. Part of that assessment involves determining whether a particular service is a medical service or a health-related service, and whether or not it needs to be completed during the school day. The nurse also plays an integral role in the development of an individualized education program. The IEP provides the opportunity for the family and nurse to outline what the student's specific needs are and to assist in determining how those needs will be met. In addition, the family and nurse collaborate with other school personnel to provide valuable information about the selection of IEP objectives that will assist the student in developing skills in tolerance, direction, and/or independent completion of a special health procedure.

If nurses are involved in the placement process, they can provide information about school environment and staffing needs. Is the school building accessible? Are electrical outlets adequate? Is there space for equipment and supplies and access to water? What are the staffing needs? Will staff need training? Should other students be prepared? The nurse, along with the family, will often serve as the student's advocate during this process. The nurse will be able to address the staff's fears and encourage placement in the least restrictive environment.

In the final stage of the process, reevaluation, the nurse again has an important role. Frequently, reevaluation of children with special health needs is completed yearly. Between those evaluations, the nurse will have monitored the appropriateness of the student's health care plan. Is the student receiving all the services required? Do staff members who are assisting the student in maintaining health have adequate skills?

Is their supervision sufficient? Is a revision of placement or continued staff training warranted?

There are continuing questions about the role of the school nurse in regard to the delivery of special education services to children with special heath needs. Few systems have an adequate number of nurses to provide the array of services needed. Adequate funding is not available; it is limited by a lack of local dollars and the inability of many systems to secure money through third party billing. As the number and complexity of care needs increase in school, the need for increased availability of nursing as a related service will become an increasingly crucial issue.

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Resources

HIV/AIDS Curricula Resources

The following curricula were reviewed by a team of special educators and health educators participating in an HIV Prevention Education Project conducted by the Association for the Advancement of Health Education and The Council for Exceptional Children. The curricula listed below received a rating of at least 8 on a 1-to-10 scale, with 1 being "poor" and 10 being "excellent." Although these curricula were not designed specifically for students in special education, reviewers believe they can be adapted to meet the instructional needs of students with exceptionalities.

AIDS Education—Supplemental Teaching Guide
Columbus Health Department, AIDS Program
181 Washington Boulevard
Columbus, OH 43215

AIDS Instructional Guide, Grades K–12
New York State Education Department
The University of the State of New York
Bureau of Curriculum Development
Albany, NY 12234

AIDS Prevention through Education—Sample Curriculum
South Dakota Department of Education
700 Governors Drive
Pierre, SD 57501-7841

AIDS Supplemental Guide—Health Education
Hawaii Department of Education
Office of Instructional Services
General Education Branch
P.O. Box 2360
Honolulu, HI 96804

Education Guide to AIDS and other STDs
Stephen R. Sroka, Ph.D.
Lakewood, OH 44107

Note: Adapted from Byrom, E., & Katz, G. (In press). *HIV/AIDS prevention. Resources for special educators.* Reston, VA: The Council for Exceptional Children.

Instruction About AIDS in Wisconsin Schools
Wisconsin Department of Public Instruction
1255 South Webster Street
P.O. Box 7841
Madison, WI 53707-7841

Other Resources

Children Assisted by Medical Technology in Educational Settings: Guidelines for Care
Community Services Program: Project School Care
Boston Children's Hospital
300 Longwood Avenue
Boston, MA 02115
(617) 735-7275

Community Re-entry. (1988). [Brochure].
National Head Injury Foundation
Suite 812
1140 Connecticut Avenue, N.W.
Washington, DC 20036
(202) 296-6443

Getting It Started and Keeping It Going: A Guide for Respiratory Home Care of the Ventilator-Assisted Individual (1991 revision)
National Maternal and Child Health Center
Children's Hospital
200 Henry Clay Avenue
New Orleans, LA 70118

Guidelines and Procedures for Meeting the Specialized Physical Health Care Needs of Pupils
Sales Unit, Bureau of Publications
California Department of Education
P. O. Box 271
Sacramento, CA 95802-0271

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Exceptional Children at Risk

A set of 11 books that provide practical strategies and interventions for children at risk.

- *Programming for Aggressive and Violent Students.* Richard L. Simpson, Brenda Smith Miles, Brenda L. Walker, Christina K. Ormsbee, & Joyce Anderson Downing. No. P350. 1991. 42 pages.
- *Abuse and Neglect of Exceptional Children.* Cynthia L. Warger with Stephanna Tewey & Marjorie Megivern. No. P351. 1991. 44 pages.
- *Special Health Care in the School.* Terry Heintz Caldwell, Barbara Sirvis, Ann Witt Todaro, & Debbie S. Accouloumre. No. P352. 1991. 56 pages.
- *Homeless and in Need of Special Education.* L. Juane Heflin & Kathryn Rudy. No. P353. 1991. 46 pages.
- *Hidden Youth: Dropouts from Special Education.* Donald L. Macmillan. No. P354. 1991. 37 pages.
- *Born Substance Exposed, Educationally Vulnerable.* Lisbeth J. Vincent, Marie Kanne Poulsen, Carol K. Cole, Geneva Woodruff, & Dan R. Griffith. No. P355. 1991. 28 pages.
- *Depression and Suicide: Special Education Students at Risk.* Eleanor C. Guetzloe. No. P356. 1991. 45 pages.
- *Language Minority Students with Disabilities.* Leonard M. Baca & Estella Almanza. No P357. 1991. 56 pages.
- *Alcohol and Other Drugs: Use, Abuse, and Disabilities.* Peter E. Leone. No. P358. 1991. 33 pages.
- *Rural, Exceptional, At Risk.* Doris Helge. No. P359. 1991. 48 pages.
- *Double Jeopardy: Pregnant and Parenting Youth in Special Education.* Lynne Muccigrosso, Marylou Scavarda, Ronda Simpson-Brown, & Barbara E. Thalacker. No. P360. 1991. 44 pages.

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