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Understanding and Meeting the Health Care Needs of Students with Severe Disabilities

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8.01 Students with Special Health Care Needs Defined

Learning Outcome

Identify the types of health care conditions likely to be present in students with complex health care needs that require specialized knowledge to assure their inclusion in school settings.

8.02 General Knowledge of Health Care Procedures

Learning Outcome

Describe methods to help school personnel develop the essential general knowledge to assure safe care of students with complex health care needs in school settings.

8.03 Understanding Specialized Health Care Procedures

Learning Outcomes

1. Describe specialized roles and responsibilities of school personnel as related to the provision of health care to students with complex health care needs.

2. Describe methods to help school personnel develop the essential specialized skills to assure safe care of students with complex health care needs in school settings.

8.04 Care Coordination Through Communication

Learning Outcome

Describe communication processes necessary to assure health, safety, and inclusion of students with complex health care needs in school settings.

8.05 Inclusion in the General Education Setting

Learning Outcomes

1. Describe procedures to ensure that students with special health care needs are included successfully and accepted by peers.

2. Describe methods for teaching students with special health care needs so that they can participate in performing the routine health care procedures; and describe methods to embed other instructional goals into health care procedures.

8.06 Other Considerations Related to the Education of Students with Special Health Care Needs

Learning Outcome

Identify other issues and practices essential for the safe care and effective education of students with complex health care needs.

INTRODUCTION

Tube feeding, suctioning, ventilation, catheterization. These are all health care procedures frequently needed by individuals with specific medical conditions, and most often are provided in hospitals settings. However, they are also needed by some individuals with severe intellectual and multiple disabilities, and while they are at public schools being educated in general education settings alongside their peers without disabilities. The need for these health care services for students while at school is a relatively recent phenomenon and it has come about as a result of the evolution of some practices, both medical and educational, and in society's changed attitudes toward individuals with disabilities. In the past, often young children dependent on medical technology did not live long enough to be students (Lehr, 1990). Now, improved medical care has enabled them to live past critical care periods; however, often with a continued need for health care support, including the use of medical technology, to sustain their health. Further, if young children did survive the critical care period and they had an ongoing need for health care support, they were educated in hospital settings, institutions, or at home (Lehr, 1990). Now, with the increasing inclusion of students with severe disabilities in general education schools and classes, and the increased portability of medical equipment necessary for the provision of the needed health care services, many of these students are now being educated in general education settings and receiving the needed services right there at school (Rehm, 2002).

Providing health care services, while also educating these students, is a complex task. Their care requires a great deal of specific information about and competency in implementing the health care procedures the students need. But provision of the health care services is an essential first step only. Yes, first and foremost, students have to be safe at school, but they also have to be treated as students and not just as patients. It is critical that the students' educational, as well as health care needs, be met and that a team of professionals work to integrate the students' care with education (Lehr, 2014).

This chapter is designed to first create a clear understanding of what it takes to meet the health care needs of students while they are at school. This understanding has to start with the definitions and terminology used in the field. But students with special health care needs are more than the terms used to describe them. Vignettes of several students with special health care needs are presented and are designed to give a clearer picture of the students and the complexities of their needs.

In subsequent sections of this chapter, we describe the basic preventive procedures that must be put in place to make school settings safe, not just for these students, but all students. These include implementation of universal precautions and hygienic care providing practices. Next we will provide general information about many of the specific health care procedures that are required by students in schools. The information included is intended to give broad background information about some of the likely health care services some students need, but it is important to note the information included is insufficient to assure competence in administering the procedures. Later in this chapter, we discuss the types and level of training necessary by different personnel in school who interact with the students. Finally, we will discuss the critical need for communication among the school community, family, and health care providers, and critical issues surrounding students with special health care needs.

STUDENTS WITH SPECIAL HEALTH CARE NEEDS DEFINED

A broad definition of children with special health care needs is provided by the U.S. Health Resource and Services Administration, Maternal and Child Health Bureau, as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). These children have a wide range of health conditions, and those health conditions affect daily functioning in a variety of ways. The health conditions that may result in the need for special health care include asthma, diabetes, epilepsy, etc. The impacts include difficulty with respiration, eating, digestion, and other basic functions.

Surveys by the Child and Adolescent Health Measurement Initiative of the Maternal and Child Health Bureau (2012) reveal an increased number of children reported in this broad category of children with special health care needs over the past decade and a half. In 2001, the percentage was 12.8%; in 2005/2006, 13.9%; in 2009/2010, 15.1%, and in the more recent survey in 2012, the reported number was 19.8%. There are no data that exist regarding the number of students who have severe disabilities along with special health care needs. It is logical to assume, however, that while the number of students with severe disabilities is low (generally considered to be 1% of the general population of students), the proportion of those students with special health care needs is higher than in the general population.

It must be noted that while the phrase *students with special health care needs* is what is used in this chapter, others refer to this population of students, particularly those who are dependent on medical technology, as medically fragile. As Lehr noted elsewhere (1990), this terminology is not accurate and it is off-putting. While careful attention must be paid to ensure these students' care and safety, it is the case that if the children survive long enough to become students, they are not fragile, but are instead quite resilient. Moreover, the term "medically fragile" seems to cause alarm among those who have responsibility for providing services to them: If they are fragile, perhaps they will break. It is for these reasons that the term *students with special health care needs* is used.

Anh

Anh is a five-year-old kindergartener who loves Pinkie Pie from My Little Pony *and anything that is the color pink. She has cerebral palsy and has been in inclusive programs since she began preschool. She receives specialized instruction, related services, and adapted materials to participate in school activities such as morning circle, readers' workshop, math block, lunch, etc.*

She is non-ambulatory, and uses a wheelchair for mobility, and her one-to-one aide pushes her wheelchair. She uses a prone stander to strengthen her leg muscles, and is being evaluated for the use of a gait trainer to support her as she learns to walk. She communicates using a combination of vocalizations, eye gaze, reaching toward objects and picture communication symbols, and hitting a BigMack® voice-output device.

She was diagnosed with failure to thrive as an infant, and receives a substantial portion of her caloric and fluid intake through a G-tube. The current plan is to increase the amount of food she ingests by mouth and is now receiving small amounts of pureed foods. Strawberry yogurt seems to be Anh's preference, as she often selects it via eye gaze when presented with several options. She uses a conversation board to engage in social interaction with her peers during lunch.

Ahn also has a tracheostomy tube (trach) through which she breathes, and she requires periodic suctioning. Anh is able to signal her need for suctioning by hitting a switch on her wheelchair. The trach cover ensures that small objects such as glitter, beads, sand, etc. used by kindergartners do not enter the trach tube.

D'Shawn

D'Shawn is a fourth grader, and he likes the cartoon, Monsters vs. Aliens. *He is a survivor of a near-drowning accident. As a consequence of the accident, he lost his ability to walk, had respiratory failure due to hypoxemia, and is dependent on a ventilator to assist his breathing. Although he has not yet met the criteria for ventilator weaning, he is reported to be improving.*

Since transferring to the school district at the beginning of the year, he has been included in the general classroom setting. He has a nurse that accompanies him at all times, including on the bus ride to and from school. D'Shawn uses a manual wheelchair that he is learning to propel and a Dynavox EyeMax® for communication.

Hector

Hector is a ninth grader who is an avid Red Sox fan and can recite many baseball statistics. He has a diagnosis of autism, and the transition from middle school to high school has been challenging, but the use of video modeling has improved his social skills. He is taking core classes with his general education peers, and all materials are adapted for him. He particularly enjoys his algebra class, because his teacher often includes baseball as the context for the word problems.

Hector has a seizure disorder for which he receives medication; however, he continues to have generalized seizures about once a month. All staff members have been trained to respond to his seizures by providing basic first aid, and to allow him to rest after the seizures occur. After he regains full alertness after the seizure, he sometime becomes agitated, because these seizure was an interruption to his familiar and preferred routines.

Hector is also allergic to peanuts, and although the school is a nut-free environment, he has an EpiPen® (i.e., epinephrine injector) with him at all times. His teachers have been trained on the use of the EpiPen®. He has also received instruction to distinguish "safe" from "non-safe" foods (i.e., those that contain peanuts) based on food type and appearance, and the teachers are teaching him to read ingredients lists.

GENERAL KNOWLEDGE OF HEALTH CARE PROCEDURES

To best accommodate students like Ahn, D'Shawn, and Hector, all schools should have in place both preventive health care procedures and procedures that can be implemented in the case of emergencies, both big and small. Knowledge of what to do if Hector has an allergic reaction is key, but it is insufficient if the only one who knows what to do in the case of an emergency is the school nurse. Data show that few schools have full-time nurses and that they travel from school to school within districts (National Association of School Nurses, 2007). What if the nurse is not in the school building at his time of need? And, since Ahn is trach dependent and her airway must be cleared periodically via a suction tube, not only do school personnel have to have the specialized expertise necessary to perform the suctioning, but more careful attention must be paid to the general environment in terms of hygienic care-providing practices as well. Ahn is quite vulnerable to infection due to the opening in her throat. To decrease the risk of transmission of infectious diseases, including even just the common cold, careful handwashing, sanitizing, and disposal methods must be used to minimize risks to her—and to all students—in the school.

Hygienic Practices in Schools

Schoolwide attention to implementation of universal precautions and infection control is necessary for the care of *all* children and critical for the care of students like Ahn, D'Shawn, and Hector. Their compromised health makes them more vulnerable to infections. Other students with severe disabilities also may demonstrate behavioral patterns (e.g., pica, lack of control of body secretions, etc.) that put them at an increased risk for disease transmission. But proper handwashing routines on the part of staff and students, as well as specific routines related to sanitization of classroom surfaces and materials and appropriate diaper disposal, decrease the risk of transmission of infectious and contagious diseases for all students.

Universal Precautions

Universal precautions "is an approach to infection control to treat all human blood and certain human body fluids as if they were known to be infectious for HIV, HBV and other bloodborne pathogens" (Occupational Safety and Health Administration, n.d.).

Initially, the use of appropriate handwashing techniques and use of personal protective equipment (e.g., gloves), regardless of the known health status, were intended to minimize risk of infection and reduce stigmatization of individuals who had tested positive for HIV. Now, The Center for Disease Control (CDC, 2011a) advises the use of standard precautions when handling blood, bodily fluids, secretions, excretions, and mucous membrane regardless of the infection status of the individuals who are being cared for. While routine in hospital and health care settings, they are not standard practice in schools, but need to be.

Handwashing. Simple handwashing is a critical first step to prevent the transmission of diseases. Handwashing should occur prior to food preparation, consumption of meals, feeding children, treatment of injuries, and following the use of the toilet, diaper changes, and potential contact with bodily fluids including those from coughing/sneezing, playing in sandbox and playground structures, and disposal of garbage (CDC, 2013a; National Resource Center for Health and Safety in Child Care and Early Education, 2011a). The CDC recommends that all staff and students be trained to use correct handwashing techniques. They provide posters that can be printed out and posted near sinks and that delineate the following steps (CDC, 2013a):

- **Wet** your hands with clean, running water (warm or cold), turn off the tap, and apply soap.
- **Lather** your hands by rubbing them together with the soap. Be sure to lather the backs of your hands, between your fingers, and under your nails.
- **Scrub** your hands for at least 20 seconds. Need a timer? Hum the "Happy Birthday" song from beginning to end twice.
- **Rinse** your hands well under clean, running water.
- **Dry** your hands using a clean towel or air dry them.

One additional step recommended by the American Academy of Pediatrics is that the faucet be turned off using disposable paper towel, and that the used paper towel be disposed of in a trash container with lining (National Resource Center for Health and Safety in Child Care and Early Education, 2011a). Also, it must be noted that the recommendation by the CDC (2013b) is that, whenever possible, soap and running water be used for handwashing and that alcohol-based sanitizers be used only when running water is not available. If sanitizers must be used, the CDC (2013b) suggests the alcohol content be at least 60%.

Disinfecting the Environment. A hygienic learning environment can be maintained through adherence to a schedule of cleaning ("physically removing all dirt and contamination"), sanitizing ("reducing germs"), and disinfecting ("destroying germs") of areas used for food preparation, meals, and toileting as well as the classroom furniture and materials (National Resource Center for Health and Safety in Child Care and Early Education, 2011b). A cleaning calendar that identifies materials that must be cleaned, sanitized, or disinfected prior to or subsequent to use, on a daily, weekly, or monthly basis should be developed. Of particular concern are the objects that have been mouthed by students, including those that may have been used during meals and for speech therapy. These objects should be placed in a separate area to be washed, sanitized, and dried before subsequent use. (For more information, see the National Resource Center for Health and Safety in Child Care and Early Education, 2011c, Appendix K: Routine schedule for cleaning, sanitizing, and disinfecting.)

Waste Disposal. For students who require diapering, a protocol to minimize contamination should be followed. This includes methods for decreasing transmission of body fluids between the students and the staff and among multiple students. Soiled diapers should be placed in "washable, plastic-lined, tightly covered receptacles, with a firmly fitting cover that does not require touching with contaminated hands or objects, and should be provided within arm's reach of diaper changing tables" (National Resource Center for Health and Safety in Child Care and Early Education, 2011d, Standard 5.2.7.4: Containment of soiled diapers). Hands-free receptacles eliminate the need to touch a lid or handle with soiled, gloved hands. (For more information, see National Resource Center for Health and Safety in Child Care and Early Education, 2011e, Standard 3.2.1.4: Diaper changing procedure.)

Allergy Control. Another type of preventive care in the classroom or school is designed to reduce allergens in the school environment. For some, allergic reactions can be mild (cold-like, or a mild skin irritations), while for others, allergic reactions can be life-threatening. Recognizing the possible seriousness of allergic reactions is an important step in making sure that schools are safe for all students, especially since it appears that allergies in children are increasing (Jackson, Howie, & Akinbami, 2013). Allergies are the result of an individual's immune system reacting to substances to which most other individuals do not react. The substances are considered foreign bodies, and the immune system works overtime to fight off the foreign bodies. The substances can be encountered via food (e.g., peanuts), the air (e.g., ragweed, animal dander), direct skin contact (e.g., poison ivy, latex), medications, (e.g., penicillin), or insect bites (bee or wasp stings). The reactions can be mild requiring no care, or severe, which can lead to anaphylaxis, and possibly anaphylactic shock, requiring rapid treatment. Given an understanding of the potential seriousness of allergic reactions, attempts can be made to prevent individuals' contact with the sources of the problems, or if not possible, to provide emergency treatment as necessary. What follows is information about some of the most common allergies affecting students in schools and preventive responses to them.

The most common foods that trigger an allergic response are "milk, eggs, fish, crustacean shellfish, wheat, soy, peanuts, and tree nuts" (Boyce et al., 2010, p. 1105). Observable symptoms may include those that impact the skin (e.g., hives and rashes), digestive system (e.g., nausea, diarrhea), respiratory system (e.g., coughing, difficulty breathing, tightness of the chest, etc.), circulatory system (e.g., changes in pulse, blood pressure, etc. that may lead to loss of consciousness), and even the mucous membrane (e.g., swelling of the lips, tongues, and eyes) (CDC, 2013c). These reactions may occur quickly or may occur an hour or two after eating or contact. The allergic response can be mild or acute and life-threatening and may be related to the manner of exposure (e.g., ingestion, inhalation, skin contact) as well as other factors such as age, speed of absorption, and level of activity (CDC, 2013c).

Preventing ingestion and contact can decrease the risk of triggering an allergic response. Some schools ban certain food products (e.g., peanuts), something that would be necessary for Hector, and alternately, some designate allergen-free zones (e.g., specified area in the cafeteria). Preventive strategies recommended by the CDC (2013c) for the various areas and activities are described below:

- Classroom: Use designated seating to minimize exposure; and, refrain from using allergens in classroom celebrations, craftwork, science experiments, and as food reinforcers.
- Meals: Store foods in designated cubicles/lockers, discourage sharing, encourage handwashing prior to and after meals/snacks, provide information for substitute teachers.
- Cafeteria: Make meal accommodations for USDA's Child Nutrition Programs by obtaining a physician's statement, specify a separate allergen-free zone for meal preparation, send home menus to parents, maintain records of foods served for a minimum of 24 hours in case of a reaction, check food labels frequently in case of changes in ingredients.
- Transportation: Prohibit food from being consumed on buses, train bus drivers and monitors for emergency responses.

- Field trips, special events, etc.: Do NOT prevent students with allergies from participating, and do NOT require parents of students with allergies to attend, pack allergen-free meals/snacks.

Allergens are not restricted to foods, and some individuals may be allergic to products that are used in the classroom, for example gloves. Some gloves are made of latex, which is secreted from rubber trees, and often is used in the production of gloves that we use as a part of universal precautions in food handling and care providing. Individuals who have had repeated exposure (e.g., students who have had numerous surgeries, health workers who use latex gloves routinely, and individuals with spina bifida) are at higher risk of developing latex allergy (American Academy of Allergy, Asthma & Immunology, 2014; American Latex Allergy Association, 2014). It is important to remember that balloons, and in rare instances, rubber bands, erasers, and toys may contain latex and trigger a response. Furthermore, half of those individuals with latex allergy are also allergic to certain foods such as bananas, kiwis, and avocados (American Latex Allergy Association, 2014). For students who require diapering, the use of latex-free gloves is recommended whether or not these students have a latex allergy, because it helps decrease the likelihood of an individual developing one as a result of repeated exposure.

Basic Care and Emergency Preparedness

Another aspect of care is preparation for emergencies both big and small. A safe environment for all students is one in which school personnel are prepared to treat minor cuts and scrapes with basic first aid, and one in which school personnel recognize when the needs are beyond that which can be provided in school. Knowing when emergency support must be brought or when a student must be transported to more extensive care is key.

Basic First Aid and Seizure Management. Knowing how to stop bleeding, clean wounds, apply antibiotics, and cover a wound are all standard first-aid procedures that the school personnel should know. And having available the necessary supplies is part of being prepared. Knowing basic first aid for seizures, too, is key. The population of students who is the focus of this book is at higher risk for having seizure disorders than the general population. It is estimated that less than 1% of the general population have epilepsy (Epilepsy Foundation, n.d.), while, 30% of students diagnosed with autism are also diagnosed with a seizures disorder. It is estimated by the National Institute of Neurological Disorders and Stroke (2014b) that as many as half of the students diagnosed with cerebral palsy also have a seizure disorder. Thus the need to know what to do in case of a seizure is higher for school personnel working with students with special health care needs.

Students such as Hector who have a known seizure disorder can be kept safe by tailoring the responses, during and after the seizure, to the type of seizure (Schachter, Shafer, & Sirven, 2013). For seizures that do not affect the students' awareness, such as simple partial seizures, it may only be necessary to comfort the students during and after the seizure. When students have seizures that affect awareness such as is the case for some types of seizures (e.g., complex partial seizures and absence seizures), it may be necessary to guide them to or keep them in a location where they can be safe, to prevent wandering, to remove dangerous objects (e.g., sharp scissors), and to remember that they may not be able to follow verbal directions. Critical do's and don'ts as a response to students' seizures that result in the loss of awareness or consciousness—as in the case of generalized seizures—are summarized in Figure 8–1. Generally, the recommended actions include 1) the provision of care to the student having the seizure, 2) the assessment of the condition, measurement of the duration, monitoring respiration, 3) deciding whether or not to activate plans for calling emergency personnel, 4) supervising other students, and 5) communicating with parents.

FIGURE 8–1
Responding to Generalized Seizures

Do	Don't

• Stay with the student.
• Note the time to measure duration of the seizure.
• Reassure the student.
• Block sudden falls by providing support as the student falls to the floor.
• Minimize risk of injury.
  • Remove hard and sharp objects that may cause injury.
  • Cushion head.
  • Remove glasses.
• Check respiration.
  • Turn student to the side to minimize risk of aspiration.
  • Mouth should be directed downward to allow saliva to drain out rather than into the airway.
  • Remove scarves and ties that may restrict breathing.
• Provide privacy by keeping other students away.
	• Leave the student unattended.
	• Move the student unless in hazardous situation (e.g., stairs, pool).
	• Restrict movements.
	• Forcibly attempt to open the mouth.
	• Place any object inside the mouth.
	• Attempt to grab the tongue.
	• Provide any drink or food until fully conscious and alert.

(Schachter, 2014; CDC, 2011)

Because some of these actions may need to occur simultaneously, it is important to designate the individuals who will be responsible for each.

It is important to note that there is a misconception that the student will swallow the tongue during a seizure. Ill-informed individuals will attempt to insert objects into the mouth or to hold onto the tongue. These procedures should never be implemented as the objects used can break in the mouth and cause oral injury. Instead, the individual should be rolled to his or her side to prevent aspiration, as there is likely to be increased production of saliva during the seizure.

If a student has no history of seizures or his or her history is unknown, it is critical to call 911 without delay when the seizure occurs. For students who have had a history of seizures, there should be pre-established lists of conditions for which 911 should be called; all other seizures should be considered routine, and require seizure first aid, but not emergency care. The following recommendations from Schachter (n.d.) and the CDC (2011a) should serve as a guide for determining when a seizure should be considered an emergency:

- Duration exceeds five minutes.
- Duration is longer than what is observed typically.
- Difficulty with respiration is observed.
- Consciousness is not regained after the seizure.
- Seizures occur in close succession, especially without regaining consciousness in between.
- Injury occurs during the seizure.
- Seizures occur in the water (need to be checked for possibility of swallowing water).
- Additional health condition such as diabetes or heart disease is present.

Preparation for the possibility of choking includes knowledge of signs of choking and knowledge of how to use the back blow and the Heimlich maneuver. Signs indicating the need for such procedures include difficulty breathing; skin, lips, and nails turning blue; and loss of consciousness. Back blows are given in an attempt to dislodge whatever is obstructing the airway. Back blows are given by bending the student at the waist, and then with the heel of the hand, giving five blows to the student between his or her shoulder blades. An alternative is abdominal thrusts, known as the Heimlich maneuver. This is provided by standing behind the individual, wrapping your arms around the individual, making a fist with one hand and placing it slightly above the individual's navel and below the breastbone, and then grabbing that fist with your other hand. Pull inward and upward and repeat five times or until the object is dislodged. While it is best to receive training in how to use abdominal thrusts effectively, there is no certification required for its use and many, including children, have used it successfully without formal training.

Medication Administration. Many children with special health care needs are likely to need to take medication while at school. As part of a comprehensive medical history, a list of all currently used medications should be obtained prior to a student coming to school. The medications may be those often taken by the general population of school-aged children, including antibiotics for colds, ear infections, etc., but may also be more unusual, requiring that school personnel have a more extensive information of both the precautions regarding and specialized procedures for their administration.

A good source of information about specific medications is the National Institute of Health's U.S. National Library of Medicine (**www.nlm.nih.gov/medlineplus/druginformation.html**). For example, when one looks up Tegretol, the viewer is redirected to a webpage with the generic term for the drug, carbamazepine. On that page is information about (a) why it might be prescribed (an anticonvulsant used to control seizures); (b) how it should be used; (c) special precautions to be followed for its use; and (d) potential side effects, both mild (drowsiness, dizziness, etc.) and serious (chest pain, vision problems, among others). Other information is provided about safe storage of the medication and what to do in the case of an extreme reaction to its use.

The American Academy of Pediatrics (2009) developed a statement designed to serve as guidance to state departments of education and school districts in developing policies for safe administration of medication. The recommendation is that first districts be sure to comply with federal, state, and local laws and regulations regarding medication administration in schools. Many states have clear laws, and state departments of education have translated those laws into practice recommendations for schools in that state. Knowing what those specific recommendations are will help assure that the students receive their medication in a safe fashion and that procedures are consistent with local policies. The National Association of State Board of Education (n.d.) provides state-by-state policies regarding medication administration in schools (**www.nasbe.org/healthy_schools/hs/bytopics.php?topicid=4110**).

Generally, states have similar goals as that which is stated in the Massachusetts statute:

> The aim of 105 CMR 2I0.000 is to ensure that students requiring prescription medication administration during the school day will be able to attend school and to ensure that prescription medications are safely administered in schools. 105 CMR 210.000 encourages collaboration between parents or guardians and the school in this effort. (105 CMR 210.000 sec 105 CMR 210.000)

For Massachusetts, the recommendation is that policies include

1. designation of the school nurse as supervisor of the prescription medication program in schools
2. documentation of the administration of prescription medications
3. responses to a medication emergency
4. storage of prescription medications
5. reporting and documentation of medication errors
6. dissemination of information to parents and guardians. Such information should include an outline of a school's medication policies and shall be available to parents upon request.

7. procedures for resolving questions between the school and a parent or guardian regarding administration of medications. Such procedures shall provide for and encourage the participation of the parent or guardian. Existing procedures for resolution of differences may be used whenever appropriate. (105 CMR 210.000 sec 105 CMR 210.000)

Ideally, medication is administered by a full-time school nurse. The American Academy of Pediatrics (AAP) as well as the National Association of School Nurses and American School Health Association recommend that, if a nurse is unavailable, unlicensed assistive personnel such as a health aide, and less preferably, a school staff member, can be trained and supervised to administer medications.

The AAP (2009) recommends prescription medication should only be accepted when it is in its original container. The label of the container should contain the student's name, dosage, and frequency, name and contact information of the prescribing physician, pharmacy, and expiration date. They further recommend use of a form that includes the student's name, the name of the medication, required dosage, frequency, and rationale for administration at school and that both the prescribing physician, and parent/guardian sign the form.

Medication must be stored securely. For medications that must be refrigerated, it should be done so in a locked refrigerator that is not used by students and other school staff and not used to also store food. Controlled medication must be in a locked cabinet in a locked room (American Academy of Pediatrics, 2009). Additional requirements may include inventorying of each tablet/capsule to detect any difference between the original count and the log of administered quantity.

Emergency Responses

Being prepared for an emergency means more than knowing to call the school nurse or 911. The American Academy of Pediatrics (AAP) (2008) acknowledged that the rise in the number of students with special health care needs and students with chronic illnesses has increased the likelihood of medical emergencies at schools. The policy statement also acknowledges the fact that many schools lack onsite health care professionals. Consequently, the AAP emphasizes the importance of the development of clearly articulated emergency plans, and the importance of them being developed by both school personnel and individual students' clinicians, tailored to the needs of each individual student. The policy includes many other recommendations for the development of emergency plans, among them the following:

- Emergency plans should cover all locations, including the classroom and playground, and before- and after-school activities.
- Emergency information should be on hand for each student and include contact information for the parents/guardians and health care providers.
- Descriptions should include information about what constitutes an emergency as contrasted with minor illnesses or injuries.
- A clear description of procedures to be followed when emergency medical services (EMS) are called must be developed.
- Routes of access in the building should be identified.
- Roles and responsibilities should be clarified in the event of an emergency. While it may be the school nurse who has primary responsibility, it is recognized that there may not be a school nurse present in the building, in which case a responsible designee must be identified.
- Campus-wide communication systems must be developed for use in the case of an emergency.
- Practice drills should be conducted with EMS.

The AAP noted additional types of preparation necessary for students with special health care needs. First, they recommend that each student have an individualized health care plan and that specific emergency procedures be articulated as a part of that plan. The AAP further recommends that copies of that plan be available for transport to the hospital with the student in case of an emergency.

CPR Training. Knowledge of CPR training is important for school personnel working with *all* children, and even more so for those working with students with special health care needs. Some states (e.g., California, Michigan) require both CPR and first-aid training for teaching certifications; other districts and states encourage it by providing training through professional development offerings. While a general description of CPR procedures is described below, reading about CPR is insufficient for competent implementation of CPR. Training is readily available in most communities offered by the American Red Cross or the American Heart Association chapters. However, the American Red Cross and the American Heart Association also suggest that a simplified form of emergency response that requires no training can be used. They recommend untrained individuals follow a simple two-step process: Call 911 and "push hard and fast at the center of the chest" as an alternative to conventional CPR that includes 30 compressions to 2 mouth-to-mouth breaths, a procedure which requires a higher level of skill and practice. While, again, comprehensive competency training in CPR is preferred, knowing the simple two-step process can also save lives.

Anaphylaxis Emergency Responses. For children such as Hector, who experience anaphylaxis (i.e., severe life-threatening allergic reaction that includes symptoms such as hives, swelling of the lips and/or tongue, and difficulty with respiration), school staff should be trained on the use of epinephrine autoinjectors, including its safe and accessible storage, and emergency medical services following its use. Epinephrine autoinjectors include a single dose that can be injected directly into the outer portion of the thigh without the need to remove clothing. EpiPen® is a well-known brand name of an autoinjector, and Auvi-Q® (Sanofi-Aventis, 2013) provides step-by-step spoken directions on the administration of the autoinjector.

In preparation for anaphylactic emergencies, epinephrine autoinjectors must be kept in a location that would allow quick access. The storage location should be determined based on several factors. It is necessary to follow state and local regulations that may mandate medication to be stored in a locked area. The size of the school building, presence of a full-time nurse, availability of staff to communicate between different locations within the school grounds, etc. may impact storage location as well. The proximity of the health office from various locations such as the classroom, playground, cafeteria, etc. will also need to be considered (Center for Disease Control and Prevention, 2013c). It is also critical that the epinephrine autoinjector be taken on field trips and to other events occurring outside of the school property. Also, because some students will have their first anaphylactic episode while at school, the National Association of School Nurses (2012) supports the practice of maintaining a stock of epinephrine autoinjectors for non-specific students in states and localities that permit it.

Non-health workers who are permitted by state and local regulations to administer the autoinjector must be identified. Then, the designated staff should receive training that includes the recognition of the signs of anaphylaxis and the use of the autoinjector. EpiPen training devices without the needle and an iPhone app—My EpiPlan™ (Mylan Specialty, 2014)—with step-by-step directions and videos are available. Staff who will be responsible for contacting the emergency medical services, the main office, and the parents as well as those who will be charged with supervising the other students should be predetermined.

When a student is showing signs of anaphylaxis, it is imperative to react quickly. However, it is also important to reassure the student and to communicate to the student that he/she is about to be injected. The student may also need to be reminded to remain still until the injector can be removed, and reassured as the side effects (e.g., rapid heart rate, sweating, dizziness, weakness, etc.) can be startling and anxiety-provoking. Once the epinephrine injector is used, a designated individual must call emergency medical services for transport to an emergency room without exception.

Following the use of the epinephrine autoinjector, the used autoinjector should be taken along with the student to the emergency room where it will be disposed of safely. Then, the episode should be documented. Documentation should include at least the following information: date and location, allergen that caused the anaphylaxis, time that the autoinjector was administered, contact with parents and emergency medical services, professionals who responded, and any other side effects (Center for Disease Control and Prevention, 2013c).

UNDERSTANDING SPECIALIZED HEALTH CARE PROCEDURES

Knowledge and Training Levels

While in school, students with special health care needs, who are integrated in the daily routine of the day, are likely to have contact with many individuals. In these schools three types of training are recommended: (1) training that is needed by all school personnel likely to have any contact with the students, (2) child-specific training for those implementing procedures with students, and (3) training of the student him- or herself. *General training,* designed to increase understanding of health care procedures and their need, is necessary for all members of the school community. Understanding Ahn needs suctioning, and providing general information about that need and how the procedure is implemented can go far in alleviating fear and concern among school personnel around Ahn (Lehr & McDaid, 1993). Much more in-depth training, *child-specific competency-based training*, about specialized procedures is necessary for those school personnel who have direct responsibility for implementing the specific health care procedures. As Lehr (2014) pointed out

> While it is possible that some charged with responsibilities for implementing procedures with specific students have had training regarding the protocols to be used for particular health care procedures, *child specific* training is aimed at assuring that the health care provider is competent in administering the particular procedures for each specific child, and addressing each child's unique needs. Training is best provided by highly skilled health care educators, but including parents in on the training provides an opportunity for the parent/guardian to receive a "refresher course" in procedure administration and for the parent/guardian to explain specific techniques found to be effective for the individual child. (p. 245)

Porter, Haynie, Bierle, Caldwell, and Palfrey (1997) emphasized the insufficiency of one-time-only training. To assure that procedures that are being implemented are correct, ongoing monitoring should be a part of comprehensive service delivery. Fidelity of implementation of procedures as initially designed is crucial, and as the health care needs of the students change, plans should change as well.

A third important type of training should be directed at the student. *Child-specific training* is designed to teach students how to provide, to the greatest extent possible, his or her own care, or to direct it (Porter et al. 1997). Examples of student-centered objectives are provided on pages 286–287 in this chapter.

What is presented in the following sections is information about specific procedures that some students require at school, and information about who should be providing it. It must be emphasized that this information is designed to inform the reader, generally, about the need for the procedures and about the administration of the procedures themselves. The information, however, is insufficient to result in competent administration of the procedures. Competency comes only with training by experts. An additional source of general background information is the internet, recommended however, with caution. Care should be taken to seek information from credible sites, and it should also be understood that individual differences necessitate modifications to standard protocols and that the information presented should be used as a guide, not a prescription.

Responsible Personnel

Knowledge and even demonstrated competence in implementing a procedure do not mean that a procedure should be implemented by some school personnel. The question of *who* should provide what services in schools continues to be somewhat unclear (Lehr, 2014). It may be logical to assume that the health care procedures described below should be administered exclusively by school nurses, however, school nurses are not available in every school (Bergren & Monsalve, 2012). To have one in each school would prove costly, and to place students in schools where there are nurses would likely result in the more restrictive placements for students (Lehr, 2014). In response to the increased presence of students with special health care needs in schools in the 80s, a number of organizations (American Federation of Teachers, the Council for Exceptional Children, the National Association of School Nurses) developed guidelines regarding roles and responsibilities related to the provision of special health care needs services in school (Council for Exceptional Children, 1990). Additionally, states clarified their Nurse Practice Acts regarding the delineation of care as related to school-based practice. Specified in such acts is information regarding which special health care must be provided by nurses and which can be delegated to others who work under nursing supervision (Palfrey, Haynie, Porter, Bierle, Cooperman, & Lowcock, 1992). While each state has a Nurse Practice Act and many states have developed manuals that describe guidelines regarding provision of special health care services in schools (e.g., Utah State Office of Education, 2005; Oregon Department of Education, 2012), there continues to be considerable variability regarding who provides what services to students (Lehr, 2014).

Specialized Health Care Procedures

Some of the more frequently needed care procedures among students are described in the following sections. Information is included on clean intermittent catheterization, shunt monitoring, nebulizer treatments, tube feeding, tracheostomy care, and ventilator monitoring. Again, this information is designed to provide the reader with general information about the procedures and should not be considered sufficient to enable implementation of the procedures.

Clean Intermittent Catheterization

Clean intermittent catheterization (CIC) is a procedure that is used to empty the bladder by inserting a catheter from the urethra into the bladder to allow the urine to flow out of the bladder. Students with spina bifida account for the majority of those students who require CIC. Properly administered CIC and complete emptying are necessary to prevent kidney failure and urinary tract infection (Katrancha, 2008).

It is critical to determine the CIC schedule, location where the procedure will take place as well as where the materials will be stored, positioning of the student, and level of student participation. The family and urologist may recommend that the CIC be performed at a predetermined frequency level. The CIC should be performed in a location where privacy can be assured. Materials such as catheters, water-based lubricants (unless self-lubricated), wipes for cleansing the genitalia prior to CIC, mirror for female students who are learning to self-catheterize, syringe for flushing out the catheter, and gloves must be stored. Because students with spina bifida often develop a latex allergy, non-latex gloves should be used. Some students may need to lie face up, sit on the toilet, or squat depending on orthopedic abilities (Katrancha, 2008). After the CIC procedure has been completed, the catheter should be flushed out using a

FIGURE 8–2
Gender-Specific CIC Procedures

Females	Males
• Position the student so that the urethra can be visually observed. • Use disposable wipes to cleanse the genitalia including between the labia making sure to wipe backwards. • Apply lubricant to the end of the catheter with openings. • Put the other end into the toilet or other container. • Place the lubricated end of the catheter into the urethra (2–3 inches). Observe urine begin to be drained out. • Keep catheter in place until the flow stops. • Apply gentle pressure to abdomen or have student lean forward to drain any remaining urine in the bladder. • Remove the catheter in a manner that prevents drainage of the urine back into the bladder.	• Position the student. • Use disposable wipes to cleanse the genitalia making sure to wipe outwards from the tip of the penis. • Apply lubricant to the end of the catheter with openings. • Put the other end into the toilet or other container. • Position the penis so it points upward. • Place the lubricated end of the catheter into the urethra (4–6 inches) and lower penis gradually. Observe urine begin to be drained out. • Keep catheter in place until the flow stops. • Apply gentle pressure to abdomen or have student lean forward to drain any remaining urine in the bladder. • Remove the catheter in a manner that prevents dripping.

(Based on American Academy of Pediatrics, 2003, updated 2013.)

syringe. For some students, to prevent complications, it may be necessary to monitor the coloration and odor of the urine as well as its quantity (Katrancha, 2008).

The gender-specific CIC procedures are described in Figure 8–2. CIC should begin and conclude with handwashing, and each step should be clearly communicated to the student during the process. It is important to remember that some students may be able to learn to self-catheterize or at least perform some steps in the process. (See page 275 for more information about child-specific training regarding specialized health care procedures.)

Shunt Monitoring

Hydrocephalus is a condition in which the cerebrospinal fluid (CSF) in the ventricles of the brain accumulates, widening the ventricles, increasing intracranial pressure, and leading to neurological problems. It may be useful to remember that, in Greek, “hydro” means water and “cephalus” refers to the head. The human body can produce approximately one pint of CSF per day to serve as a conduit for sending nutrients and taking away waste from the brain. Typically, the CSF flows through the ventricles, base of the brain, the spinal cord, and is absorbed into the bloodstream. When there is a blockage in the ventricles that disrupts the drainage, CSF will accumulate in the brain (National Hydrocephalus Foundation, 2012a; National Institute of Neurological Disorders and Stroke, 2014a).

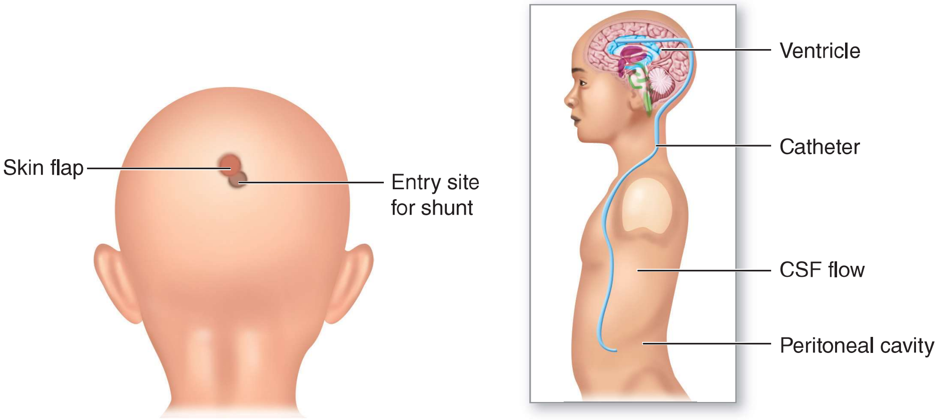
Most individuals who have hydrocephalus have a surgically implanted shunt to drain the CSF through another pathway. As illustrated in Figure 8–3, a catheter is placed into the ventricle above the blockage. That catheter is connected to a valve that regulates the flow, and another catheter runs down the neck to the site of drainage. A ventriculoperitoneal shunt drains into the stomach and a ventriculo-atrial (VA) shunt drains into the heart.

Watch “Pediatric Playbook – Hydrocephalus” at www.youtube.com/watch?v=bHD8zYImKqA.

Because the shunt does not keep functioning indefinitely, it is critical to know the warning signs of a shunt malfunction. National Hydrocephalus Foundation (2012b) describes the following symptoms of a malfunctioning shunt:

- headache or pressure within the skull
- digestive (e.g., lack of appetite, nausea, vomiting, incontinence)
- cognitive (e.g., diminished functioning)
- motoric (e.g., impaired gait)
- vision (e.g., blurring, double vision)
- mood (e.g., irritability)

FIGURE 8–3
Shunt for Hydrocephalus



(Used with permission of National Hydrocephalus Foundation.)

If emergency care is not sought, individuals may experience seizures and suffer neurological damage (National Hydrocephalus Foundation, 2012c). Therefore, it is critical to be observant, especially because some of these symptoms may be difficult to distinguish from common colds and flu as well as from characteristics of some students with severe disabilities who may already have fluctuating abilities including difficulty with balance.

Nebulizer Treatment

A nebulizer is used for young children and for those who cannot use an asthma inhaler due to their difficulty simultaneously activating the inhaler and breathing in of the released medication. A nebulizer turns the liquefied asthma medication into a mist that can be breathed in, and children can breathe in the medication using a mouthpiece or a mask. The mask may be useful for students who do not have adequate lip closure on the mouthpiece. The materials needed include the air compressor, medicine cup, tubing, medication, and a mouthpiece or a mask. Students who may need to have the nebulizer in multiple settings may benefit from portable, battery-operated compressors. The procedures are as follows (Pediatric/Adult Asthma Coalition of New Jersey, n.d.; WebMD, 2014):

- Put the compressor on a table or other sturdy surface (never the floor).
- Connect the compressor and the bottom end of the nebulizer.
- Connect the medicine cup of the nebulizer and the mouthpiece or mask.
- Place the medication into the medicine cup.
- Activate the compressor to allow the mist to come out.
- Position the student upright.
- Place the mouthpiece in the mouth or mask over the mouth and nose.
- Allow student to breathe in the medication until the medicine cup is empty (5–10 minutes).
- If possible, instruct the student to hold his/her breath for a few seconds before exhaling.

Tube Feeding

Tube feeding is a method of providing nutrition, hydration, and medication through non-oral routes for students like Ahn. The conditions that may necessitate tube feeding include gastroesophageal reflux, cleft lip/palate, jaw and tongue thrusts and other oral motor reflexes that may make sucking and chewing difficult, and neurological

"Gastrostomy Tube: Feeding and Taping the Tube | St. Louis" at www.youtube.com/watch?v=HG5UE9YA10o.

disorders that may make coordination of breathing and swallowing challenging resulting in heightened risk of aspiration or choking. Students may rely on tube feeding for all of their caloric intake or use tube feeding to supplement eating by mouth (Ferguson, 2004). Students may have an NG-tube (nasogastric—nose to stomach), G-tube (gastric—stomach), or J-tube (jejunum), depending on factors such as duration of need. NG-tube is typically for short-term use, while a G-tube and J-tube are for the long term. The G-tubes can be placed through endoscopic or surgical procedures. Regardless of the procedure used, the tube has a disc, bulb, or balloon that secures the tube within the stomach wall.

The method of feeding may be pump controlled, gravity drip, and bolus. When a pump is used, the rate of infusion can be regulated with the mechanical pump. In the gravity-drip method, the feeding bag is placed at an elevated height to allow gravity and a clamp is provided to regulate the rate of infusion. The bolus method relies on someone using a syringe to inject food into the tube and the rate is controlled by the individual using the syringe (Mahnke, 2013).

Tube-feed schedules can be continuous (i.e., 24 hours a day), intermittent (i.e., predetermined periods), or bolus (i.e., rapid infusion) (Nutrition Support Interest Group, 2011). The advantages and disadvantages of each schedule are presented in Figure 8–4. The decision should be made in consultation with the child's gastroenterologist to select the schedule that meets the child's nutrition and hydration needs but also increases opportunities to participate in academic tasks. It is also important to consider the location of the feedings and to allow peer socialization during mealtimes. If appropriate, students can still taste food or put small amounts of food in their mouth as tolerated and without risk of choking or aspiration in order to prevent the development of oral hypersensitivity and an overactive gag reflex.

The student should be positioned in a sitting position so the student's head is elevated relative to the stomach or at a 30-degree angle. This is also known as a semi-Fowler position. Lying down flat is discouraged during and for at least one hour after the feeding to prevent reflux (Ferguson, 2004).

Complications can arise when children are fed using a G-tube. Infection of the gastrostomy site can occur and children with diabetes and those receiving therapy to suppress the immune system can be at risk. Leakage may occur due to gastrostomy site infection, aggressive cleaning, insufficient space between the internal and external bolsters, or gastric acid increase. Buried bumper syndrome, a condition in which the mucous membrane of the stomach grows to cover the internal bolster, may occur if the internal and external bolsters do not have sufficient space between them or

FIGURE 8–4

Advantages and Disadvantages of Tube-Feeding Schedules

	Advantages	Disadvantages
Continuous	Provides the slowest rate of infusion to those who cannot tolerate higher rates	Necessitates continuous attachment to the equipment
Intermittent	Maximizes opportunities for other activities Provides a transitional feeding schedule (i.e., continuous to bolus or tube to oral) Resembles eating pattern	Increases possibility of reflux, discomfort, and nausea due to the higher rate of infusion
Bolus	Provides a transitional feeding schedule (tube to oral)	Requires more hands-on time for the procedure than continuous feeding Introduces higher risk of reflux, discomfort, and nausea

(Based on Nutrition Support Interest Group. (2011). Enteral nutrition manual for adults in health care facilities. Dietitians Association of Australia. Retrieved from: http://daa.asn.au/wp-content/uploads/2011/11/Enteral-nutrition-manual-Oct-2011.pdf) there is weight gain that reduces the existing space between the bolsters. This may result in leakage, infection, decreased flow of the formula, G-tube that is difficult to move, and associated pain. The gastrostomy tube can also be accidentally removed or pulled out by the child (Itkin et al, 2011). Therefore, care must be taken to minimize the risk of complications.

Children may begin the process of transition from tube feeding to oral feeding based on input from members of the multidisciplinary team. The student should possess adequate oral motor coordination in order to swallow the food, and also be able to coordinate swallowing with breathing to minimize the risk of aspiration. The need for oral stimulation that can minimize hypersensitivity may need to be considered as well as the texture and thinness/thickness of the foods. The quantity of food eaten by mouth should be monitored to ensure adequate nutrition if tube feeding is reduced (Gottrand & Sullivan, 2010).

Tracheostomy Care

Students, like Ahn, who cannot inhale sufficient oxygen through their nose or mouth may receive surgery to create a hole (i.e., the stoma) in the trachea. A tracheostomy tube has three parts: (a) an outer cannula that maintains the opening, (b) a neckplate that anchors the ties around the neck, and (c) the inner cannula that is inside the outer cannula. Students who have a tracheostomy (trach) may require stoma care, humidification, and suctioning. In addition, the student will be unable to speak without the aid of a device such as a Passy-Muir valve (Johns Hopkins University, n.d.a&b).

While the trach may supply sufficient oxygen, it results in mucous production because the air that is breathed in through the trach tube has not passed through the nose and upper airway that serve the function of regulating the temperature, moisture level, and cleanliness of the air. This excess mucus can be expelled through the trach tube through coughing and suctioning. When using the coughing method, the student should be moved forward from an upright position and cough to expel the mucus. A small quantity of sterile saline solutions can be placed in the trach tube to make it easier for the mucus to be expelled. However, suctioning of the mucus is necessary before and after sleeping, before eating and outdoor activities, and when the student experiences increased effort in respiration or sensation and sounds of the mucus in the airway and trach tube (Johns Hopkins University, n.d.c).

Watch "Suction – Breath of Life – A Caregiver's Guide to Pediatric Tracheostomy Care" at www.youtube.com/watch?v=u6v-b7P23Vk.

The materials necessary for suctioning include the following (Johns Hopkins University, n.d.c):

- Clean suction catheter (correct size)
- Distilled or sterile water
- Normal saline
- Suction machine in working order
- Suction connection tubing
- Jar to soak inner cannula (if applicable)
- Tracheostomy brushes (to clean tracheostomy tube)
- Extra tracheostomy tube

After all materials have been gathered, the first step prior to beginning the suctioning procedures is thorough handwashing. Following are the next steps (Johns Hopkins Hospital, n.d.b):

1. The students can be suctioned either as they are seated or they can be laid flat with a roll under their shoulders.
2. The suctioning machine should be turned on and the tubing should be connected to the machine.
3. Connect the catheter to the suction connection tubing.

4. Wet the catheter with sterile/distilled water for lubrication and to test the suction machine and circuit.
5. Remove the inner cannula from the tracheostomy tube (if applicable).
6. Insert the catheter into the tracheostomy tube with your finger off the suction vent.
7. Cover the suction vent and suction for no more than 5–10 seconds, as breathing is not possible during suctioning.
8. Remove the catheter by rotating and using a slow, even motion, and intermittently placing your thumb over the suction vent.
9. Allow the patient to recover from the suctioning and to catch his/her breath. Wait for at least 10 seconds.
10. Repeat suctioning as necessary.
11. When finished, suction a small amount of distilled/sterile water with the suction catheter to clear any residual debris/secretions.
12. Reinsert the inner cannula from extra tracheostomy tube (if applicable).
13. Turn off suction machine and discard or clean catheter if it is to be reused.

Mechanical Ventilation

Mechanical ventilation is necessary when an individual has difficulty breathing independently. The difficulty may be due to damage to the nervous system, muscular system, or due to pulmonary disease that controls the lungs. D'Shawn experienced hypoxemia (lack of oxygen) during his near-drowning and damage to the nervous system that regulate his breathing. Consequently, he is dependent on a ventilator to control his breathing.

Ventilators (sometimes called respirators) may be used to provide oxygen should the individual be unable to obtain a sufficient amount independently or to eliminate carbon dioxide or to push air in and out of lungs. The ventilator can provide the primary means for respiratory support and for other students the ventilators is a supplement. The support may be continuous or intermittent, depending on the needs of the student.

The individual receives the breathing support through an endotracheal tube, inserted into the stoma in the windpipe and a machine moves the air into and out of the lungs. There are various types of ventilators used with students, but the most common type is a positive pressure ventilator, which pushes air or oxygen-rich gas into the lungs. Positive pressure ventilators are small, can be battery operated, and therefore portable, which makes education in a school setting possible. By contrast, a negative pressure machine (often referred to as an iron lung) uses vacuum-like pressure to expand the individual's chest, allowing air to flow in. This type of equipment is not portable, and, therefore, is not seen in schools.

Students assisted with breathing by ventilators must be monitored continuously to make sure they are breathing properly, and their equipment must be checked regularly to assure proper functioning. It is critical that students using ventilators be attended to by individuals who have demonstrated competence in ventilator care and in CPR.

A comprehensive care plan for these students includes consideration of school attendance if only one person is trained to provide the care and that person is absent. Ideally, more than one person have the necessary competence; alternately, arrangements are made with parents for students to not attend school on days where their health care needs cannot be met. Also, arrangements must be made for bus transportation that includes someone to monitor the student and the equipment during transportation.

CARE COORDINATION THROUGH COMMUNICATION

Coordination of care for students with special health care needs is critical. This includes between home and school, and among care providers at school. Developing plans for all procedures helps assure consistency of implementation. Further, documentation of health care events and sharing those records between home and school enables those caring for the student to have an ongoing and comprehensive knowledge of the student's health care status. The individualized health care plan, described below, is used to facilitate communication across care providers.

Individualized Health Care Plans

It has become common practice for school districts to develop individualized health care plans (IHCPs) for students with special health care needs. This is sometimes included as a part of an IEP, and developed as part of the IEP process. At other times, it is developed as an independent document that focuses specifically on the health care needs of the students. While the format of health care plans often differ, most follow the model first recommended by Porter et al. (1997). The components of the recommended IHCP include

- a description of the student's health history
- a description of the specific health care needs of the child
- a description of the child's current health status
- a description of the medications used at home and school, possible side effects of the medications taken, and a clear specification of which school personnel will be responsible for administering the medicine while the students is at school
- a description of any special dietary and nutritional needs of the student
- specialized transportation needs (types of supports and equipment needed, including on bus supervisions)
- a listing of specialized equipment needed for administration of special health care procedures, if needed
- descriptions of what constitutes an emergency and specific procedures for responding to them
- child-specific emergency plans

Plans are developed through collaboration between school personnel, parents/guardians, and the child's physician. Due to the students' complexity of needs, it is important that all who know about the needs of the students be involved in the development of the IHCP. To assure that there is agreement among the members of the team, Porter et al. (1997) recommended that the IHCP be signed by all members of the team. Some districts include the IHCP development as a part of IEP planning and include the IHCP as an appendix to the IEP.

A comprehensive individualized health care plan should address transportation as well. The Committee on Injury and Poison Prevention of the American Academy of Pediatrics, (2001, reaffirmed 2013) has provided a set of recommendations:

- Specialized seating and wheelchairs must be secured taking student's weight, manufacturer guidelines based on impact tests, etc. into consideration (see full list for more detailed information).
- Wheelchair trays must be detached prior to boarding and must be secured (not resting or propped up next to the wheelchair).
- Liquid oxygen must also be secured and signage displayed on the exterior of the school bus.
- Training for bus monitors and drivers, as well as back-up/substitute transportation staff, should be provided.
- Bus evacuation drills should include students with special health care needs.

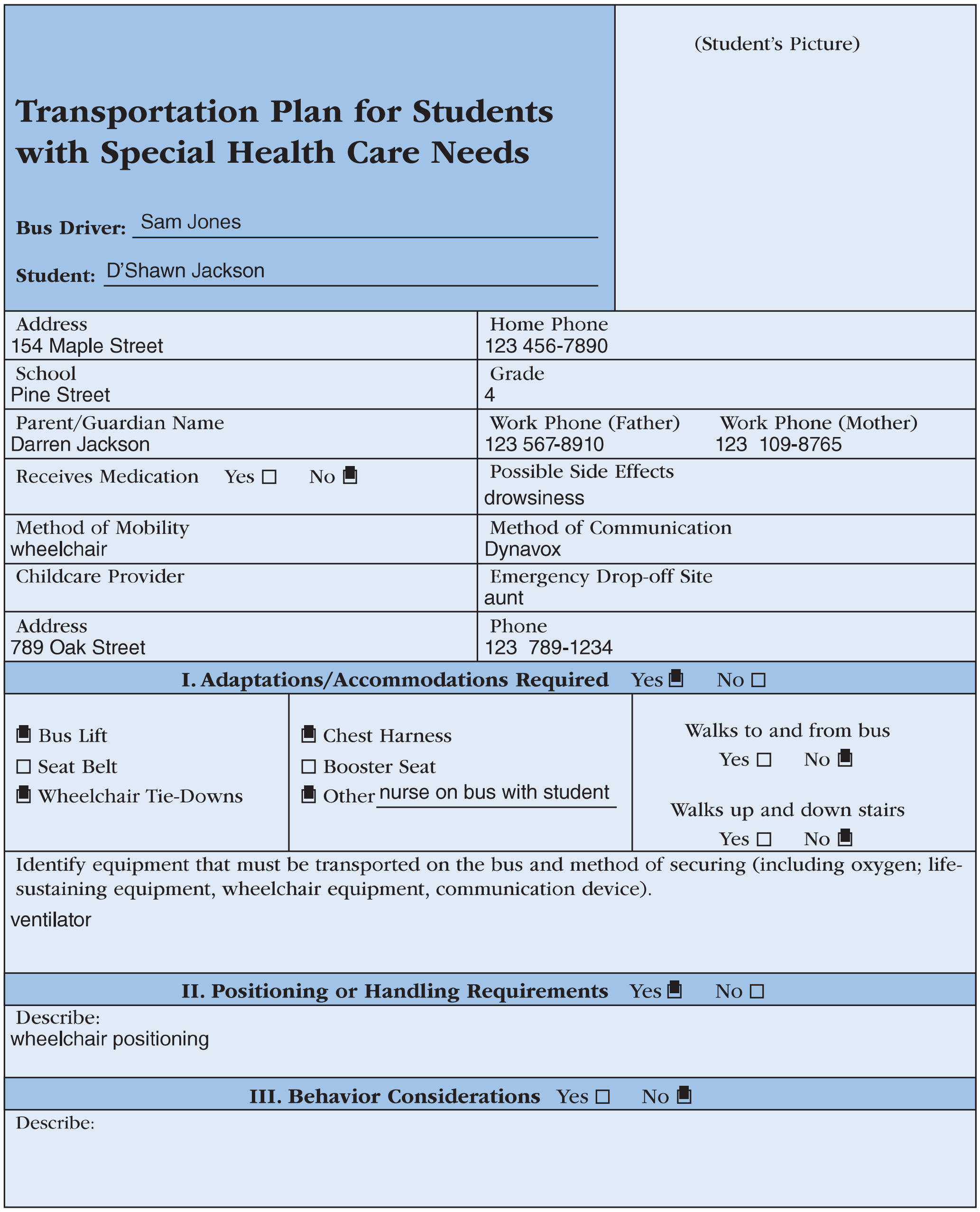
An individual transportation plan should address transport duration, equipment and securing, evacuation, emergency plan, and training of transportation staff. The training provided to transportation staff should include confidentiality of student health information, recognition of emergency situations, appropriate responses (e.g., procedures for the student, communication with dispatcher/emergency medical services, etc.), and evacuation procedures. Such training should be documented, and information reviewed periodically. The bus route should be evaluated to determine the location of hospitals (Utah State Department of Education, 2005). A sample transportation plan can be viewed in Figure 8–5.

Record Keeping

It is important for school personnel and parents to know students' health status when they are not under their care. Knowing that a student did not sleep the night before or knowing that a student had seizure activity while at school helps school personnel and parents/guardians understand the behavior of students. More importantly, records of

FIGURE 8–5

Transportation Plan for Students with Special Needs



Transportation Plan for Students with Special Health Care Needs

Bus Driver: Sam Jones

Student: D'Shawn Jackson

(Student's Picture)

Address 154 Maple Street	Home Phone 123 456-7890	
School Pine Street	Grade 4	
Parent/Guardian Name Darren Jackson	Work Phone (Father) 123 567-8910	Work Phone (Mother) 123 109-8765
Receives Medication Yes ☐ No ☑	Possible Side Effects drowsiness	
Method of Mobility wheelchair	Method of Communication Dynavox	
Childcare Provider	Emergency Drop-off Site aunt	
Address 789 Oak Street	Phone 123 789-1234	

I. Adaptations/Accommodations Required Yes ☑ No ☐

☑ Bus Lift ☐ Seat Belt ☑ Wheelchair Tie-Downs	☑ Chest Harness ☐ Booster Seat ☑ Other nurse on bus with student	Walks to and from bus Yes ☐ No ☑ Walks up and down stairs Yes ☐ No ☑

Identify equipment that must be transported on the bus and method of securing (including oxygen; life-sustaining equipment, wheelchair equipment, communication device).

ventilator

II. Positioning or Handling Requirements Yes ☑ No ☐

Describe:
wheelchair positioning

III. Behavior Considerations Yes ☐ No ☑

Describe:

(*Continued*)

FIGURE 8–5
Transportation Plan for Students with Special Needs (*continued*)

IV. Transportation Staff Training

Describe training:
ventilator monitoring
CPR
First aid

Names of Individuals Trained	Signature	Date
Nurse		

V. Student-Specific Emergency Procedure

A copy of student's emergency information/plan must be attached.

(Transportation plan for students with special needs. Utah State Office of Education. Used with permission.)

seizure activity can be helpful to students' physicians as they work to adjust medications to control the students' seizures. A seizure record- keeping form such as the one shown in Figure 8–6 makes record keeping straightforward. An app called Seizure Tracker (**seizuretracker.com**) makes record keeping and report writing an easy process.

FIGURE 8–6
Seizure Event Recording Form

Seizure Record

Date	***Time***	***Duration***	***Description***	***Other Information***
1-20	2:15 pm	3 min	Typical	
2-15	1:05 pm	4 min	Typical	
3-9	10:45 am	2 min	Nothing unusual	

Records of medication administration are also critical. Many states have specific regulations regarding the administration of and record keeping as related to medication (**www.nasbe.org/healthy_schools/hs/bytopics.php?topicid=4110**). While there are variations, below is the Massachusetts regulation as a sample:

> *210.009: Documentation and Record-Keeping*
>
> *(A) Each school where prescription medications are administered by school personnel shall maintain a medication administration record for each student who receives prescription medication during school hours.*
>
> *(1) Such record at a minimum shall include a daily log and a medication administration plan, including the medication order and parent/guardian authorization.*
> *(2) The medication administration plan shall include the information as described in 105 CMR 210.005(E).*
> *(3) The daily log shall contain:*
>
> > *(a) the dose or amount of prescription medication administered;*
> > *(b) the date and time of administration or omission of administration, including the reason for omission;*
> > *(c) the full signature of the nurse or designated unlicensed school personnel administering the prescription medication. If the prescription medication is given more than once by the same person, he/she may initial the record, subsequent to signing a full signature.*
>
> *(4) The school nurse shall document in the medication administration record significant observations of the prescription medication's effectiveness, as appropriate, and any adverse reactions or other harmful effects, as well as any action taken.*
> *(5) All documentation shall be recorded in ink and shall not be altered.*
> *(6) With the consent of the parent, guardian, or student where appropriate, the completed prescription medication administration record and records pertinent to self-administration shall be filed in the student's cumulative health record. When the parent, guardian or student, where appropriate, objects, these records shall be regarded as confidential medical notes and shall be kept confidential, except as provided in 105 CMR 210.000.*

INCLUSION IN THE GENERAL EDUCATION SETTING

Increasingly, students with special health care needs are being educated alongside their peers without disabilities. As with all students with severe disabilities, mere placement in the general education setting will not guarantee acceptance. Included in the following sections are considerations for program planning that will help facilitate students' full inclusion in general education settings as students.

Acceptance by Peers

As mentioned previously, inclusion of students with special health care needs is increasing (AAP, 2008). It is still, however, not yet commonplace for school personnel to have had experience with students with special health care needs, particularly those with complex health care needs. The first step that must be taken, as described previously, is that of assuring that the student is entering a school setting where routine practice includes use of universal precautions and hygienic care providing practices, and where emergency plans are in place for all students. Further, general information about the special health care needs for specific students must be made available to all, and extensive student-specific training must be provided to those implementing the care. All this serves to make sure students are safe, but this is insufficient to make sure the students' educational needs are being met as well. Considering these students as a student and not just a patient is crucial (Lehr, 1990; 2014). As mentioned previously in this chapter, terminology used to describe students with special health care needs is important. Referring to a student as medically fragile places the focus on the health care needs of the student and not on the student as a student. And the term can be as off-putting to a classmate as it is to school personnel.

Students with special health care needs may also have some unique educational needs that must be addressed. They may miss more school than their peers, and they may not be as available for learning as their peers. Rest after a routine seizure decreases instructional time. Accommodating these needs requires careful planning and support such that the student can continue to be able to be a part of the classroom, despite these interruptions to presence in the classroom.

Lehr (2014) pointed out that students' interactions with peers may be influenced by their teachers' reactions to their medical needs. For example, consider how different peers' reactions may be when suctioning is treated as routine as contrasted with that of a medical emergency. Consider the difference in peer interactions if students are considered sick and in need of tube feeding versus healthy because they are being tube fed (Lehr, Greene, & Powers, 2003). Parents and educators can be helpful in increasing peers' understanding of students with special health care needs. Consider the training one parent provided to a class of students prior to his son's joining the group after having had a tube inserted for feeding. A Curious George-like stuffed animal, who happened to eat via tube rather than by mouth, visited the class during which time procedures were explained and the first grade students could ask whatever questions they had.

Specialized Education Content

Students with special health care needs should have access to the general education curriculum as should all students. But in addition, there are some unique goals that should be included in these students' programs. Their IEPs should include goals and objectives related to their learning to either implement their own health care procedures or at least direct their care. Developing appropriate habits related to handwashing is a good place to start (Lehr, 2014), but further, students can learn, for example, to perform their own clean intermittent catheterization or understand why they need a particular procedure or when they need it. Consider the independence of a student who, while unable to assemble the needed equipment necessary for feeding, was able to explain to another how to do so. Independence, in this case, was not assembling the equipment by himself, but independence was in his ability to explain what his needs were.

Consider a student who requires suctioning. While self-suctioning is difficult even for skilled adults and may not be a realistic goal for a student with special health care needs, a student could be taught to demonstrate *some* steps in the process even if he or she cannot do all the steps in the process, thus embodying the principle of partial participation (Baumgart et al., 1982). Consider these possible student-centered objectives for suctioning:

- Anh will signal need for suctioning.
- Anh will describe the equipment needed for suctioning.
- Anh will describe the steps necessary to perform suctioning.

For G-tube feeding, the learning objectives could be the following (Lehr, 2014; modified from Lehr & Macurdy, 1994):

- Student will explain the reason for the alternative eating method.
- Student will describe the steps necessary to implement the procedure.
- Student will indicate the desire to eat/be fed.

- Student will measure feeding liquid to be placed in feeding bag or syringe.
- Student will pour food into feeding container.
- Student will clean or direct cleaning of feeding equipment.
- Student will feed self though a G-tube.

Watch "Gastrostomy Tube: Feeding and Taping the Tube | St. Louis Children's Hospital" at www.youtube.com/watch?v=HG5UE9YA10o.

Maximizing Educational Opportunities

It is true that at times the implementation of health care procedures can be time consuming. But, with thoughtful planning, it does not have to significantly decrease instructional time. Consider these descriptions and how the environment can be arranged to maximize educational opportunities:

Diaper-changing while working on communication skills, versus changing diapers in silence

Tube feeding the student in the cafeteria while other students are eating and where there are opportunities for social interaction, versus tube feeding a student in the nurse's office, in isolation, with no other students around

Having the student participate in the process of collecting the needed materials by following a picture checklist of what is needed for tube feeding, versus having the teacher get the materials before feeding the student. Consider this food preparation much in the same way as you would think about other students learning to set the table and prepare the food.

OTHER CONSIDERATIONS RELATED TO THE EDUCATION OF STUDENTS WITH SPECIAL HEALTH CARE NEEDS

While the focus thus far has been on the specific health care needs of students and strategies to integrate them into schools so that their health care needs *and* educational needs are met, there are some other issues that should be discussed to best understand this population of students. Among the issues addressed in this section of this chapter are discriminatory access to treatment and to least intrusive treatments, do-not-resuscitate orders, and preparation for death and dying.

Medical Discrimination

There is a long history of medical discrimination against students with special health care needs (Crossley, 1996; Lehr, 2014). In one highly publicized case in 1982, so-called Baby Doe was denied corrective surgery for her defective esophagus, and denied hydration and nutrition on the basis of her having been born with Down syndrome. The following year, Baby Jane Doe, who was born with spina bifida along with the related disabilities of hydrocephaly and microencephaly, was not provided with life-saving surgery to repair the opening in her spine, a procedure that would have been provided had the baby not presented with other disabilities (Crossley, 1996; Lehr, 2014). The decision to withhold treatment was reported to be based on the assumption that because the baby also would have had an intellectual impairment, the baby would also have had a poorer quality of life (Lehr, 2014). Media attention to these cases raised questions in light of 1978 regulations for the Rehabilitation Act of 1973, that stated

> *No otherwise qualified individual with a disability in the United States, as defined in section 7(20) shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any*

> *program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. (Section 504, Rehabilitation Act of 1973)*

Subsequent regulations issued by the U.S. Department of Health and Human Services required the posting of notices reminding medical personnel that discrimination on the basis of a disability was illegal based on Section 504 of the Rehabilitation Act. Furthermore, it stated that medical discrimination such as those that were demonstrated in the Baby Doe case were to be reported. This requirement was challenged, as it was the parents who made the decision to deny treatment and not the medical personnel. Crossley (1996) pointed out that a subsequent attempt to decrease medical discrimination was accomplished through the Child Abuse Amendments of 1984, which specified that states receiving federal funds had to have in place procedures for reporting instance of medical discrimination and neglect (42 U.S.C.A. section 5106a(b)(10) (West 1983 & Supp. 1995). Crossley (1996) noted that those regulations remain in place although their effectiveness is questioned.

Two other highly publicized cases pointed out other forms of medical discrimination, one involving a young man with Down syndrome who had a life-threatening heart condition and another involving keeping alive anencephalic children for the purpose of organ harvesting. Phillip Becker, physically, was considered a good candidate for corrective heart surgery. Advocates who befriended him when they volunteered at the facility where he resided strongly supported the surgery, however, his parents, who retained legal custody, refused permission for the surgery. The parents eventually gave up parental rights and the advocates adopted Phillip clearing the way for his successful surgery. This occurred, however, as Lehr (2014) pointed out

> *… only after a long battle which put front and center in the media the issues of parental rights and quality of life decisions. The parents' reason for denying treatment was their concern for the quality of Phillip's life as an adult with an intellectual impairment after they passed. They preferred he die rather than live a long life with a disability. In this case, the state decided to sever parental rights, making way for the successful surgery for Phillip. (p. 238)*

Anencephaly is a neural tube defect in which the baby is born without parts of the brain and skull. Babies with anencephaly typically die a few days after birth. Given their prognosis, they are considered by some to be good candidates for organ harvesting which raise many legal and ethical questions (American Academy of Pediatrics, 1992; Crossley, 1996; Fost, 1986). Standard practice for organ harvesting includes harvesting only after the patient is considered brain-dead. Babies with anencephaly are not brain-dead; they have minimal brain functioning. In 1987 an infant with anencephaly was transported to a California hospital so that it could be used as a live donor for organ transplant. The transplantation was challenged on the basis of the legal standard of "brain-dead" and on the basis of the ethical concern about the slippery slope of lowered standards on the basis of the baby's intellectual disability (Crossley, 1996). Crossley (1997) noted the ethical discussions continue, although the practice of transplantation from newborns with anencephaly does not.

The question of unnecessary treatment was raised with the so-called "Pillow Angel." Ashley X has encephalopathy and little volitional control of body functioning, and requires tube feeding (Ouellettee, 2008). In an effect to slow puberty, which she was demonstrating prematurely, and slow her growth so as to enable her to be more easily positioned and handled by her parents, she was prescribed growth attenuating hormones. Arguments were made both for and against the treatment (Lehr, 2014). Some argued this was a treatment that would not have been used had the child not had a disability and thus was an intrusive and unnecessary treatment. Others argued that the treatment could result in a better quality of life as it would allow the parents to care for Ashley at home longer than would otherwise be possible. And yet others argued the focus was on the wrong issue: It should instead have been on the lack of supports for families that would make home care easier (Ouellette, 2008).

Ireys, Wehr, and Cooke (1999) noted "many current definitions of medical necessity require evidence that a service will significantly improve a person's health status" (p. 2). However, according to Ireys et al.,

> *Many children and adults with disabilities frequently need health or medical services that will* ***maintain*** *[emphasis added] their functional capacity. Defining as medically necessary only services that improve their health status means that they will be denied many services vital to their day-to-day lives. (p. 2)*

Do Not Resuscitate

Schools now have students in attendance who may succumb to their chronic illnesses (Adelman, 2010). In some cases, despite aggressive care, their chances of survival are unlikely. In some cases, parents express wishes that their children not be provided with life-sustaining treatment at school, and request do-not-resuscitate (DNR) orders be honored. DNR orders are commonplace in hospital settings, whereby patients can express wishes as related to their end-of-life care. Schools, however, are not medical facilities, and parents are making decisions not for themselves but instead for their children. This dilemma and the differences have resulted in some states developing policy guidelines for schools to follow when such requests are made. Adelman (2010) found, however, that most districts do not have a policy in place regarding DNR orders and there continues to be concern about the legal and moral implications of practices (Zacharski, Minchella, Gomez, Grogan, Porter, & Robarge, 2013).

Zacharski et al. (2013) noted that the DNR process typically begins with a request from parents. Then, it is a school nurse who leads the process of determining state and local policies and clarifies those policies with school administrators, by communicating with the hospital care team, and conducting team meetings with school personnel and the family to discuss the plan. Zacharski et al, recommended attention to many factors including the consideration of the composition of the planning team, consultation with hospital personnel, identification of key personnel who must be informed of the plan, identification of key staff who must be trained, articulating the difference between acute care needs and end of life needs, and transportation in the event of death.

Additionally, the checklist notes important attention to the staff's moral cultural and ethical issues (p. 73) and the needs of other students and staff. Heller et al. (2009) argue

> *The death of a child is one of the most traumatic experiences that can occur within a family. It is also traumatic for teachers and other educational professionals when a student dies. (p. 291)*

Teacher preparation programs focused on the education of students with special health care needs should incorporate training on dealing with DNR orders, death, and dying. School personnel may struggle with DNR orders based on personal and ethical beliefs and with the seemingly contradictory request to honor a DNR order to end a life while at the same time implementing an IEP designed to improve a life. Helping school personnel understand differing perspectives, both personal and legal, may aid them in dealing with this complex situation. Death and dying are topics that are rarely discussed in schools. While some advocate that it be a general part of the school curriculum, at the minimum, it should be a part of training for school personnel working with students who have a high likelihood of dying due to terminal illnesses or those with complex health care needs. And some of that training should focus on helping teachers understand how to explain death and dying to students. Heller et al. recommend that students be provided with factual information and the opportunity to communicate about the death.

Often families will turn to the school for emotional support and, as Heller et al. (2009) note, at times school personnel assume a position of strength for the family and ignore their own feeling of grief. Counseling for school personnel is an important support under these circumstances.

LEARNING OUTCOME SUMMARIES

8.01 Students with Special Health Care Needs Defined

Learning Outcome

Identify the types of health care conditions likely to be present in students with complex health care needs that require specialized knowledge to assure their inclusion in school settings.

Students with special health care needs include those who may have asthma, seizure disorders, tracheostomy, hydrocephalus, and various other conditions. While the incidence of children with special health care needs and intellectual disabilities is unknown, what is known is that the overall incidence of students with special health care needs is increasing. Therefore, schools must be prepared to maintain a safe and healthy learning environment and meet the educational needs of these students.

8.02 General Knowledge of Health Care Procedures

Learning Outcome

Describe methods to help school personnel develop the essential general knowledge to assure safe care of students with complex health care needs in school settings.

Basic knowledge of preventive practices and first-aid training are necessary. Proper handwashing; cleaning, sanitizing, and disinfecting the environment; proper waste disposal; and allergen control help maintain a clean and safe learning environment for all students. Training in seizure management and first aid, compliance with regulations for medication dispensation at school, plans for emergency responses, training in responding to anaphylaxis, and CPR should be provided.

8.03 Understanding Specialized Health Care Procedures

Learning Outcomes

1. *Describe specialized roles and responsibilities of school personnel as related to the provision of health care to students with complex health care needs.*
2. *Describe methods to help school personnel develop the essential specialized skills to assure safe care of students with complex health care needs in school settings.*

Knowledge, skill, and training levels of special health care procedures should be differentiated for three groups of individuals: all individuals within the school, individuals who are implementing the special health care procedures, and the student him-/herself. There are various specialized health care procedures that may be necessary depending on the needs of the student. Clean intermittent catheterization is a method for emptying the bladder that requires gender-specific procedures to be followed. Students with hydrocephalus require close monitoring for signs of shunt malfunction. A nebulizer that turns liquid asthma medication into a mist that can be breathed in must be used for children who cannot use an asthma inhaler. Tube feeding is a method for providing not only nutrients but also hydration and medication to students who cannot eat by mouth. Students with a tracheostomy tube will require suctioning of the mucus to clear the airway. Finally, students who require mechanical ventilation will need to have close monitoring of their respiration and the functioning of their equipment.

8.04 Care Coordination Through Communication

Learning Outcome

Describe communication processes necessary to assure health, safety, and inclusion of students with complex health care needs in school settings.

Collaboration of family members and care providers at school is critical to maintaining the health and safety of students with special health care needs. An individualized health care plan that outlines the student's special health care needs, medication, special dietary/nutritional needs, transportation needs, description of routine health care procedures and necessary equipment, and emergency plans allow the team to preplan and coordinate care. Meticulous record keeping and communication of health status and medication administration are also essential.

8.05 Inclusion in the General Education Setting

Learning Outcomes

1. Describe procedures to ensure that students with special health care needs are included successfully and accepted by peers.

Successful inclusion and peer acceptance of students with special health care needs can be facilitated through several methods. Sensitive language use can help students with special health care needs be viewed as students and not patients. When done with sensitivity, explanation of health care procedures to the classmates help de-mystify them without stigmatizing the student.

2. Describe methods for teaching students with special health care needs so that they can participate in performing the routine health care procedures; and describe methods to embed other instructional goals into health care procedures.

The principle of partial participation should apply to health care procedures, with students participating in their own care to the extent possible. Furthermore, it is possible to embed other instructional goals related to communication, socialization, and fine- and gross-motor skills into the implementation of the special health care procedures.

8.06 Other Considerations Related to the Education of Students with Special Health Care Needs

Learning Outcome

Identify other issues and practices essential for the safe care and effective education of students with complex health care needs.

Children with special health care needs have been subjected to medical discrimination and denied care due to the presence of a disability. Some students may have do-not-resuscitate orders, and schools must be prepared to address them within the context of state and local policies while also being considerate to the emotional responses of family members and school staff.