The Comprehensive SCHOOL HEALTH MANUAL

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Massachusetts Department of Public Health

Chapter 7

STUDENTS REQUIRING SPECIALIZED HEALTH SERVICES

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About The Information in This Manual

From time to time, the Massachusetts Department of Public Health may update some of the materials. Please check the School Health Manual online to see if there are any recent updates.

Please be certain to check for new laws and regulations that may be in effect after publication of this Manual. You may find the Massachusetts General Laws online at http://www.mass.gov/legis/laws/mgl/ and the Code of Massachusetts Regulations at http://www.lawlib.state.ma.us/cmr.html. These sites are periodically updated, but are not the official version of the Massachusetts General Laws (MGL) or Code of Massachusetts Regulations (CMR). You should always refer to an official edition of the MGL and CMR. Official editions may be found at the Statehouse Bookstore and many public and law libraries.

Chapter 7

STUDENTS REQUIRING SPECIALIZED HEALTH SERVICES

Children and youth with special health care needs are defined by the federal Maternal and Child Health Bureau as those who:

- have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition; and
- require health and related services of a type and amount beyond that required by children generally.

Special health care needs may range from asthma, cystic fibrosis, and diabetes to autism and bipolar disorder. Because some children with special health care needs also have special education needs, this chapter provides a brief description of the planning and process for determining eligibility for special education and, if appropriate, implementing Individualized Education Plans. However, this chapter's major focus is on the safe inclusion of students with specialized health care needs in school settings. It identifies the school nurse as the case manager while emphasizing the need for care planning prior to school entry, during all transitions, and as the child transitions into adulthood. It concludes with brief descriptions of a few of the chronic conditions most commonly found among students in Massachusetts schools.

SCOPE OF THE PROBLEM

Growing Incidence of Chronic Illnesses and Disabilities in the School Setting

Nearly 15% of Massachusetts children have special health care needs. The State and Local Area Integrated Telephone Survey (SLAITS) of Children with Special Health Care Needs, a national survey conducted in 2000–2002, found that more than 220,000 children (14.67%) in the Commonwealth were reported to have at least one special health care need. Of the total group of children with special health care needs reported in the SLAITS survey, approximately 5% are considered to have a severe chronic illness, which is defined as one that interferes significantly with normal functioning and development. Ninety-six percent of the Commonwealth's children with special health care needs are educated in public school settings.

Information about special health care needs in Massachusetts schools is collected by the Essential School Health Services Program (ESHS), formerly the Enhanced School Health Services Program. These programs, implemented in schools covering approximately half of the Commonwealth's student population, are required to submit monthly and annual summary data reports. The annual reports provide valuable snapshots of the prevalence of chronic illnesses and disabilities, and the consequent impact on school nursing practice in public schools, in a diverse sample of Massachusetts schools. They summarize such health and activity indicators as number and type of medications prescribed and dosages administered in schools, number of individual health care plans, number and types of specialized procedures performed by school nurses, and other information pertaining to children with special health care needs. The annual program summary data reports may be found at http://www.mass.gov/dph/fch/schoolhealth/shpubs.htm.

Advancements in Technologies and Medical Practice

Medical advances have resulted in the survival of children and adolescents with a variety of conditions and diseases previously associated with short life expectancy. Cystic fibrosis, childhood leukemia, diabetes, juvenile rheumatoid arthritis, renal disease, and pediatric HIV (perinatally acquired) are examples of conditions for which life expectancy has been substantially increased. Advances in the field of genetics have identified previously unknown conditions, such as mitochondrial and metabolic diseases, and produced new treatment modalities for these conditions.

An expanding array of technologies to support basic life functions is available to children and adolescents with complex medical conditions. These technologies include devices for mechanical ventilation, gastrostomy feedings, delivery of intravenous medications, and renal dialysis. New devices are relatively portable, making home care and mobility possible for children who once would have been hospital- or residential program-bound. School personnel, with careful planning, training, and ongoing consultation, can now accommodate the health service delivery needs of students who require such technologies in the school setting.

Many of the medical procedures mentioned above were once considered rare and/or clearly outside the responsibility of schools. Now they are part of standard school nursing services. The practice of school nursing will continue to expand as children and adolescents with a wide range of chronic conditions enter schools in the Commonwealth, and as the technology to meet those needs continues to develop.

The inclusion of children and youth with special health care needs in school settings provides benefits for all students. For the former, it offers opportunities to share the spontaneous experiences from which children learn, grow, and develop social skills. For *all* children and adolescents, it provides opportunities to learn from each other and experience diversity in the school community.

LEGAL/REGULATORY ISSUES

Since children with chronic illness spend more time away from their families in school than in any other institution, appropriate school policies and programs are critically important to their health, as well as to their growth and development. There are four major laws (and associated regulations) that relate to children with disabilities and education. These laws cover the accommodations, instruction, and services to which a child is entitled and may receive in school. Most also address education in the least restrictive environment, as defined below:

The Least Restrictive Environment (LRE)

LRE means that children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the general educational environment occurs only when the nature or severity of the child's disability is such that education in general classes with the use of supplementary aids and services cannot be achieved satisfactorily. If a child cannot attend school at all for medical reasons, then the school system must provide education services either at home or in the hospital.

IDEA: Individuals with Disabilities Education Act

IDEA is the federal special-education law. Part B, the section of IDEA that bears most directly on this chapter, ensures that eligible students with disabilities aged 3–21 receive a free and appropriate public education (FAPE). Part C of IDEA works differently and includes both preventive services and direct services for children aged 0–3 who have or are at risk for having a disability or developmental delay. This includes infants and toddlers who develop at a different, or at a slower, rate than most other children. These services are called Early Intervention (EI).

IDEA Part B requires public schools to provide those services needed by students with one or more disabilities, when the disability adversely affects their ability to make effective educational progress. IDEA further stipulates that supports and services be provided to students in the least restrictive environment. Under IDEA, a child is eligible for special education if the following three conditions are met:

- the child's disability falls into 1 of 13 disability categories (listed below); and
- the child is not making effective progress in school because of his or her disability; and
- the child requires special education and possibly related services in order to make effective progress.

The 13 disability categories listed in IDEA are autism, deafness, deaf-blindness, emotional disturbance, hearing impairment (including deafness), learning disability, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, speech or language impairment, traumatic brain injury, and visual impairment (including blindness).

Each public school child who receives special education and related services must have an Individualized Education Plan (IEP). (**Note:** Although IDEA uses the term Individualized Education *Program,* Individualized Education *Plan* is the more common usage and will be used throughout this chapter.) The IEP is a legally binding document that guides the delivery of special education supports and services for a particular student with a disability, so each IEP must be designed for that student. IDEA mandates a role for parents/guardians on the team that designs the IEP and makes allowance for the parents/guardians or the school district to invite individuals who have knowledge or special expertise regarding the child to participate as members of the team.

For additional guidance and detail about important provisions of IDEA, refer to the state special education website at http://www.doe.mass.edu/sped/.

Section 504 of the Rehabilitation Act of 1973

Some children with special health care conditions do not need special education services. These children, although not covered by either Massachusetts Special Education Law and Regulations or IDEA, may be protected by other federal laws related to civil rights for individuals with disabilities. Section 504 of the Rehabilitation Act of 1973 is a broad civil rights law that protects the rights of individuals with disabilities in programs and activities that receive federal financial assistance.

Public school districts are recipients of federal funds, and U.S. Department of Education regulations implementing Section 504 define the obligations of these schools and the rights of students. A child may be eligible for some services under a 504 Plan if he or she has a physical or mental health disability (or is perceived to have such a disability) that limits one or more major life functions. For example, the law guarantees the rights of a child who has asymptomatic HIV infection or who has a parent with HIV infection. Although such a child might not be eligible for special education, he or she is protected by Section 504 from discrimination or exclusion from education and is eligible to receive education-related services in any public or private school that receives federal funds.

Section 504 does not require an IEP document but does require a plan. It is recommended that the school district document in writing that a group of people knowledgeable about the student (including the parents/guardians and school nurse) has been convened and that they have specified the agreed-upon services.

A 504 Plan for students with special health care needs can provide for health or disability-related accommodations and, in some cases, services that are necessary for a student to participate fully in the school environment and programs. For example, if a child uses a wheelchair, plans must be made to ensure that the school is wheelchair-accessible. If a child takes prescription medications during school hours, provision will be made for dispensing and monitoring the medications under the school nurse's direction. (See Chapter 6 for further discussion of medication administration in schools.)

A 504 Plan should include:

- a school evaluation;
- a letter from the student's primary care provider describing the disability, related problems, and needed medications and/or treatments;
- accommodations to be provided — physical and instructional;
- an Individual Health Care Plan (IHCP); and
- a copy of the Emergency Information Form for Children with Special Health Needs.

See Exhibit 7-1 for a table that compares IDEA and Section 504.

The Americans with Disabilities Act of 1990 (ADA)

The Americans with Disabilities Act of 1990 (ADA) specifies that as of January 26, 1992, public entities and public accommodations must ensure individuals with disabilities full access to and equal enjoyment of all facilities, programs, goods, and services. ADA extends many of the rights and duties defined by Section 504 to public accommodations such as restaurants, hotels, theaters, stores, doctors' offices, museums, private schools, and child care programs.

Massachusetts Special Education Law and Regulations

The state statute at M.G.L. c.71B and the implementing regulations currently at 603 CMR 28.00 are Massachusetts's special education law and regulations.

The Massachusetts law and regulations, as written, are aligned with the provisions of IDEA. Both federal and state laws require public school systems to provide a free and appropriate education (FAPE) to eligible children with disabilities aged 3–21 in the least restrictive environment. Although the terminology used in the Massachusetts regulations to describe the disability categories under which children may be eligible for services differs slightly from the wording in IDEA, the disabilities included are essentially the same. School districts are required to provide necessary services to assist students who are eligible for special education and services. However, special-education law does not require school districts to provide "medical services" except for certain services that are evaluative or diagnostic in nature. As previously stated, not all children with special health care needs are entitled to or require special education.

Massachusetts's IEP process and forms show a clear intent to ensure that all students are provided with challenging and relevant educational programs with high expectations for educational progress and preparation for independence in adult life, including postsecondary education and employment. Massachusetts guidance on developing IEPs links sound practice with statutory and regulatory requirements. In addition to improving outcomes for current services, this is an important step in providing new services to students with disabilities.

Note: The above listing of laws and regulations is not intended to be comprehensive. Additional references to laws and regulations that relate to specific situations are mentioned within the text of this chapter. Please be certain to also check for new laws and regulations that may be in effect after publication of this Manual. The Massachusetts General Laws may be found online at http://www.mass.gov/legis/laws/mgl/ and the Code of Massachusetts Regulations at http://www.lawlib.state.ma.us/cmr.html. These sites are periodically updated, but are not the official version of the Massachusetts General Laws (MGL) or Code of Massachusetts Regulations (CMR). Always refer to an official edition of the MGL and CMR.

POLICY IMPLICATIONS FOR SCHOOLS

Most schools are likely to encounter many children and adolescents with special health care needs. School health policies and programs are critically important to the growth and development of these students, allowing them the fullest possible opportunity for participation in academic and extracurricular activities.

District and Schoolwide Planning

School districts and individual schools must meet the challenges of providing services for all children, and particularly to those with special health care needs. These challenges include: comprehensive planning for entry into school; coordination with classroom teachers and community providers; the transport of children with complex health conditions; care of these children before, during, and after school hours at school-sponsored events; classroom and facility adaptations for daily functioning; advanced educational planning for prolonged or periodic hospitalizations; and transitioning to new schools and to adult environments, as applicable. School districts may also be called upon to have procedures for medication administration, revision of classroom curricula and routines to meet an individual child's physical and health-related needs, and development of emergency plans. For some terminally ill children, there may be challenges of implementing Comfort Care orders in the school setting.

Population Needs Assessment

To facilitate planning and implementation of appropriate services, training, and education, schools and school districts need to know the extent of special health care needs within their student population. For this reason, the Massachusetts Department of Public Health (DPH) recommends that every school and district conduct an annual health needs assessment, which includes the number and types of special health care needs in the school population. (See Chapter 2 for a discussion of the development of a community and school health needs assessment.) This assessment would include *all* students with special health care needs, not just those requiring special education services and IEPs.

Importance of a Medical Home

Caring for children with special health care needs requires schools to collaborate closely with the child's primary care provider or "medical home." The American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and national Maternal and Child Health Bureau (MCHB) are working together to promote medical home partnerships between families caring for children with special health care needs and their pediatricians. Medical home is a health care delivery approach that recognizes families as the principal caregivers and centers of strength and support for children. Children and their families who have a medical home receive the care they need from a physician whom they trust. Pediatric health care professionals and parents/guardians act as partners in a medical home to identify and access all the medical and nonmedical services needed to help children achieve their maximum potential. The AAP believes that the medical care of children should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (American Academy of Pediatrics, 2002). Additional information regarding Massachusetts leadership activities to help build medical home capacity in the state can be found at http://www.medicalhomeinfo.org/resources/state/massachusetts.html.

School nurses, parents/guardians, and the medical home need to work in partnership to plan the care of children with special health care needs within the school setting. With appropriate written consent from parents/guardians, ongoing communications between school health professionals (i.e., school nurses and physicians) and providers should be encouraged, in order to benefit the child's care.

The School Nurse's Role

The school nurse is central to all aspects of care and service delivery for students with special health care needs. The National Association for School Nurses (NASN) considers the school nurse to be the case manager for these students in the school setting. In a position paper on the subject, NASN states: "Delivery of health care in the school setting requires the coordination of multiple health and non-health related services. The school nurse has the knowledge, skills, judgment, and critical thinking, inherent in nursing education and authorized through nursing licensure, to perform efficiently in the role as case manager." In this role, the school nurse "provides oversight of care and services while serving as the point of contact for communication among the student, family, school staff, and health care provider." Specific activities attached to serving as case manager for students with special health needs may include:

- being knowledgeable about the services needed by students with special health care needs, after collaboration with the student, family, and health care provider;
- being knowledgeable about services available in the community and assisting families in obtaining needed services;
- screening for students who would qualify and benefit from case management services for their health care needs;
- providing leadership in interdisciplinary team meetings to assist in planning services to meet the students' health and educational needs;
- implementing the health team's plan of care, by providing either direct or indirect care;
- coordinating continuity of care between the home and school;
- monitoring and evaluating interventions provided for in the health care plan;
- monitoring and evaluating progress toward identified health and educational goals; and
- training, monitoring, and evaluating personnel delegated to perform specific nursing care.

When a student has a health-related condition, a health assessment is conducted by a physician and reviewed by the school nurse. Any additional relevant information should be added from the school health service program. Based on this assessment, the school nurse identifies those health issues that are pertinent to the student's educational progress and recommends services or program modifications that the student requires.

All schools should require that an Individual Health Care Plan (IHCP) be developed for any student with special health care needs who requires clinical assessment and/or care in order to participate in the educational process. The IHCP may be required whether or not a student meets the eligibility requirements for special education.

PLANNING FOR THE NEEDS OF INDIVIDUAL STUDENTS

Thoughtful planning for students with special health care needs promotes quality school-based care, helps to ensure that these students are able to participate to the fullest possible extent in educational and social opportunities, and minimizes the potential for liability, which may be a concern of many school personnel. This kind of planning requires ongoing communication and collaboration among parents/guardians, school personnel, individuals representing a range of disciplines, community providers, specialists, and, when appropriate, the student. The goal is to provide the best possible service delivery to the student.

Special Education Eligibility and Individual Education Plans

This section provides only a brief overview of how special education eligibility is determined and the general process used to develop an Individual Education Plan (IEP). The focus of the remainder of this chapter is on health care planning for students with special health care needs.

Special education is defined as specially designed instruction to meet the unique needs of a given student and/or related services that are necessary for him/her to access the general curriculum.

Specially designed instruction means that there is a need to adapt the content, methodology, delivery of instruction, and/or performance criteria for a student to make effective progress. Related services are developmental, corrective, and other supportive services. Within Massachusetts, related services necessary to access the general curriculum are considered special education and may be provided alone or in combination with specially designed instruction.

If the student *only* requires accommodations, then that student is not eligible for special education. Accommodations are adaptations to presentation or setting that can typically and easily occur in general education (such as preferential seating, wearing eyeglasses, or providing extra time on tests).

The Individual Education Plan (IEP)

An initial evaluation must be completed to determine eligibility. Parents/guardians, or any person in a caregiving or professional position concerned that a student may have a disability or concerned about a student’s development, may refer a student for an initial evaluation to determine whether the student needs special education. Upon receipt of this referral, the school district must send notice to parents/guardians and obtain their consent to conduct an evaluation in compliance with 603 CMR 28.04(1). The notice sent to the parents/guardians should describe the types of assessments recommended by the district and should include, at a minimum, an educational assessment and an assessment in the area of the suspected disability. The school may recommend, or the parents/guardians may additionally request, a comprehensive health assessment, a psychological assessment, or a home assessment. Within 30 school days of receiving parent/guardian consent, the school district must evaluate the referred student, and within 45 days of receiving such consent, the school district must schedule a team meeting to discuss the evaluation results and determine if the student is eligible for special education.

An eligibility determination must be made by a team of people that includes parents/guardians and qualified professionals knowledgeable about the evaluation information. For students with special health care needs, the team should include the school nurse.

The evaluation process should be sufficiently comprehensive and individualized to identify the child’s unique needs, and it must specifically assess *whether the disability is causal to an inability to make educational progress,* a finding that is pivotal in the eligibility determination. (Additionally, the law clearly states that students may not be determined eligible solely because of a need for reading or math instruction or because of limited English proficiency or social maladjustment.)

No single procedure should be used as the sole criterion of eligibility. Relying on a single test or single test battery for all students would not be adequate or legally appropriate. Evaluation can include formal and informal assessments and other evaluation strategies, if needed. Other appropriate sources of evaluative information include:

- parents/guardians;
- observation;
- work samples;
- interviews; and
- cumulative record review.

It may be appropriate and possible for school staff to complete some or all of the assessments, but if the district does not have a staff member qualified to assess a student's area of suspected disability, it should contract outside agencies or evaluators to ensure that team members have sufficient information.

If a student is found eligible for special education, the team will also develop an IEP for the student. Key elements of the IEP process are:

- use of information from the evaluation assessments in development of the IEP, so that the IEP addresses the individual needs of the student in relation to his or her disability;
- consideration of access to the general curriculum;
- consideration of how the disability affects the student's learning;
- development of goals and objectives that make the greatest difference for the student; and
- choice of a placement in the least restrictive environment that is able to deliver the services of the student's IEP.

For additional information on special education, how disabilities are defined in the law, eligibility determination, the IEP process, and guides for parents/guardians, refer to the Special Education section of the DOE website at http://www.doe.mass.edu/sped. Several documents contained there may be of particular assistance:

- *Is Special Education the Right Service?* (see http://www.doe.mass.edu/sped/2001/elig_drft01.pdf)
- *The IEP Process Guide* (see http://www.doe.mass.edu/sped/iep/proguide.pdf)
- *A Parent's Guide to Special Education* (see http://www.fcsn.org/parentguide/pgintro.html)

The Individual Health Care Plan (IHCP)

An individual health care plan (IHCP) is designed to ensure that the child receives the health services he or she needs during the school day (such as health assessments, treatments, or administration of medication). The IHCP should allow for the coordination of needed health care services and emergency planning for the student within the school setting. Like the IEP, an IHCP should be developed to support the child's participation in classroom activities and other school-related events such as sports and field trips. For a student who is eligible for special education, the IHCP should be developed in coordination with the IEP. The IHCP should also address any training needs for school staff, so that the plan is understood and implemented appropriately. To the extent possible, the plan should provide for the performance of health care procedures in a manner that minimizes disruption of the educational process both for the individual student and for other students present.

The IHCP is individualized to reflect the child's specific medical, nursing, and educational needs. (Exhibit 7-2 is a sample form that may be used to obtain accurate information for the school about an individual student's medical needs.) Review and revision of the IHCP may occur either separately or else as part of the review and revision of an IEP. If elements of the IHCP are incorporated in the IEP, however, a notation can be made in the IEP indicating that the IEP team may not need to reconvene for a change in medication dosage or frequency of a specific treatment, unless those changes substantially impact the student's health care and access to educational services.

The development of the Individual Health Care Plan is a collaborative process that should involve the child's family, the child (when appropriate), the school nurse, the school physician (when appropriate), other school staff, community health providers, and medical specialists, where indicated. Because the IHCP becomes the guide for meeting a student's health-related needs, the school nurse is responsible for coordinating and developing the IHCP. The school nurse serves as the link between child/family and other school personnel, as well as between school personnel and community health care providers in primary and tertiary care settings.

The IHCP must be developed in compliance with state, federal, and local health laws; state and federal education laws; state and federal confidentiality laws; and standards of practice for nursing and medicine. As with any communication, a child's right to privacy should be protected. See Massachusetts Student Records Regulations 603 CMR 23 at http://www.doe.mass.edu/lawsregs/603cmr23.html?section=all.

The IHCP Planning Process

The planning process begins prior to the entry into school or, for a student who is already in school, immediately upon the determination of need by the family, the school, and/or the health provider. The team should develop and document strategies for the care and monitoring of each student. Planning should also reflect long-range objectives and desirable outcomes for the child, including emotional, physical, cognitive, and social adaptations to a health condition. It should also include plans for teaching self-care as appropriate.

Assessment

Assessment is a systematic collection and analysis of information about the student's health; it is the function of physicians and registered nurses and can never be delegated to, or assumed by, other personnel. The essential data for assessment typically include physical findings/needs/adaptations, strengths, coping strategies, communication needs, social and emotional relationships, family issues, and what resources are available/needed.

A home visit is recommended for children with very complex health needs. This will help the school staff begin to establish a relationship with the family and child, observe the child in his or her natural environment, and determine how care needs have been met prior to school entry. A home visit provides an opportunity to plan for future school attendance, identify required school health services, support family goals for self-care and independence, assess family strengths and needs, establish rapport with individuals who provide a support system for the student, and evaluate the need for community health resources. Home visits should be documented in the student's health record.

If a home visit is determined to be unnecessary or is not possible, the school nurse should find an opportunity to meet with the parents/guardians and child, at which time the child's health status can be reviewed.

Another component of the health assessment is the review of the physician's or other licensed provider's orders for medical intervention and equipment; it is an opportunity to learn about technology, medications, and procedures used in the specific child's care. The review should include orders and plans from both the primary care provider and the specialty care providers, as appropriate (see Exhibit 7-2).

Family Participation

Parents/guardians should be actively engaged as planning partners. They see their child in diverse settings and thus best understand how different environments and activities affect the child's health and development.

Because family participation is of the utmost importance, convenience for parents/guardians (both time and location) should be a priority when meetings are planned. Information provided by the school about the child's health, school health activities, and resources should be introduced in terms that are understandable to parents/guardians. Parent/guardian participation in training is invaluable to professionals involved in their child's care, offering child-specific techniques and considerations.

When English is not the family's primary language, any required communication between the school and the family must be in the family's primary language. This includes providing appropriate translation services at all meetings and translating applicable written materials. When parents/guardians of a child are deaf or hearing-impaired, an interpreter must be provided. School personnel must always protect the confidentiality of the student and family.

Preparatory Planning Meeting

School personnel may find it useful to convene a preparatory planning meeting with parents/guardians to initiate discussion of the child's needs, map out the planning process, and identify key participants in the process. (This should occur prior to the formal planning meeting and school entry.)

Planning Meeting

The planning meeting is an opportunity for all the key participants, including the family, student (as appropriate), health care provider, school nurse, and other school personnel, to communicate, address important issues, and develop an individualized plan of care prior to school entry or reentry.

The meeting should identify the school nurse who will serve as the child's health care coordinator at school, as well as other internal and external contacts who should also be involved in the development of the child's health care plan. The meeting provides the opportunity to organize and seek training for any special care a child will require.

The identification of the responsible party for the payment of special services or caregivers may be an issue for the school, parents/guardians, providers, or insurers. Those responsible for the child's care should try to resolve financial details before the child enters school.

Training

Providing appropriate training to care for children with special health care needs is a major challenge for schools. Some elements of training are generic and reflect skills or knowledge necessary or desirable for children with a variety of special health care needs or diagnoses (e.g., the need for development of specific IHCPs or group training on such issues as seizure management). Other training needs address issues related to diseases and conditions with varying levels of severity in a variety of the body's organ systems. Because the school nurse, teachers, other school personnel, and the child's peers need to understand the child's condition and its impact on performance, the school district has a responsibility to provide training for its staff regarding the specific health condition.

The IHCP also identifies areas in which training for a specific child's care is needed by those school personnel and/or others who may be involved in the care at school, or in transit to or from school: teachers and administrators, lunchroom personnel, bus drivers and monitors, coaches, and other school staff. Some school staff or transportation providers may require one-on-one training involving more specific procedures identified for care of a child. Community emergency medical service personnel may require training or briefing as well. The school nurse usually has the responsibility for organizing the training to meet a specific child's needs.

The child's parents/guardians and a school nurse (familiar with equipment and procedures involved in a child's care) may be the appropriate trainers. Other options, in collaboration with the school nurse, are the child's primary care provider, home nursing personnel, or outside consultants. DPH's MASSTART program provides collaborative consultation services to help schools and families develop health care plans for children with complex diagnoses and/or medical requirements that may call for in-school training. (See Resources at the end of this chapter for additional information.)

Completing an IHCP

An IHCP is designed to guide the planning process. The completed forms are documentation of the planning process. (Model forms are available to guide this process.)
When completed, the IHCP should be:

- signed by the school nurse writing the plan, the child's parents/guardians, and the primary care provider (for complex care); and
- maintained with the child's special-education plan or school health record.

Some or all of the following forms may be useful in the IHCP development process:

- ***Individualized Health Care Plan Checklist*** (Exhibit 7-3): This is an overview of areas in which care planning for the student may be necessary. Almost every child or adolescent with a special health concern will need special considerations by the school setting at some point. The set of special services potentially needed is quite broad and includes the following:
    - support therapies (physical, occupational, speech and language);
    - modified physical education;
    - schedule modifications;
    - transportation;
    - building accessibility;
    - toileting or lifting assistance;
    - school health services (including administration of medications, implementation of medical procedures, emergency preparations, and care coordination);
    - counseling services (for school, career, and personal issues); and
    - sensitivity training and support (for peers and school staff).
- ***Individualized Health Care Plan for the School Setting*** (Exhibit 7-4): This form contains pertinent information about the child, such as names of parents/guardians, addresses, and phone numbers; in addition, it provides a summary sheet for the dates of pertinent assessments, interviews, meetings, physician/licensed provider's orders, training, and review of the health care plan. More detailed information about these assessments is described on the Background Information form (see below).

- ***Important Personnel*** (Exhibit 7-5): This form is a list of key personnel responsible for the student's care. It includes: (a) both school and primary care providers, (b) those responsible for training and supervision of care, and (c) dates of training(s).
- ***Background Information*** (Exhibit 7-6): This form contains a brief medical history, home assessment summary, identified special health care needs, the child's baseline health status, required medications and diet, and transportation needs. The course of the student's condition prior to the school's involvement is an important part of the database. The medical history, self-care, family, and lifestyle factors provide a broad understanding of the student's current health status that will enable school personnel to recognize and/or predict patterns in a child's health status and evaluate changes over time.
- ***Procedure Information Sheet*** (Exhibit 7-7): This sheet contains directions for performing a special clinical procedure, including frequency, required equipment (storage and maintenance), child-specific information, and special considerations. Staff planning and coordination are required for implementing labor-intensive procedures to accommodate daily functions. This will ensure consistency and continuity of care by the school, home, and health care facility or provider.
- ***Possible Problems (Complications/Concerns)*** (Exhibit 7-8): This is a list of any problems that might occur relating to a specialized health care procedure and recommended actions to address them. (For example, in a gastrostomy tube feeding, the tube may become dislodged.)
- ***Nursing Notes*** (Exhibit 7-9): Consistent with standards of nursing practice, documentation should include such areas as health needs, goals, action/interventions, and evaluation. (See Chapter 6, "Nursing Practice in the School Setting" for further information.)
- ***Daily Log for Procedures*** (Exhibit 7-10): This log documents child-specific information as to the administration of the procedure, including date, time, notes, observations, and name of person responsible.
- ***Emergency Plan*** (Exhibit 7-11): This form is a list of potential child-specific emergencies and what to do, so that prompt, appropriate action can occur. (**Note:** The emergency care plan should never substitute for a comprehensive IHCP addressing all the student's relevant needs.) The team should design a document for each student's emergency procedures. In compliance with federal law regarding exchange of information, plans are to be shared with other school personnel, including ancillary staff such as lunchroom workers, custodians, and bus drivers. In addition, a simple set of instructions identifying individuals to notify in an emergency should be discussed carefully with the student's parents/guardians.
- ***Emergency Telephone Procedure*** (Exhibit 7-12): This form provides a detailed guideline for information that may be needed by the emergency medical team respondent; it identifies the school official to be notified and provides additional information as to procedures to be followed. (See Chapter 2 for emergency policies and protocols.)
- ***Emergency Information*** (Exhibit 7-13): This sheet lists telephone contacts for parents/guardians, key emergency providers, and local hospitals, should an emergency occur.
- ***Parent/Guardian Authorization for Specialized Health Care*** (Exhibit 7-14): On this form, parents/guardians must provide written permission for administering specialized health care to the student.
- ***Physician's Order for Specialized Health Care Procedure*** (Exhibit 7-15): This form is documentation of the licensed provider's order and special recommendations for administering a clinical procedure in the school setting.

TRANSITIONS

A student with special health care needs experiences a series of transitions during the educational process. These may include, but not be limited to, transition between: (a) early intervention and school, (b) school buildings within a school district, (c) school districts, (d) school and hospital, and (e) school and adulthood, which may include independent living or transfer to another state agency serving adults with disabilities. Each transition represents a challenge for the student, his/her family, and the responsible staff. Frequently the school nurse is the case manager guiding the planning, collaboration, and communication necessary to ease the transition; however, all team members from both the original site and the new site should be involved. The goal is to support the student during the change and ensure a seamless provision of services essential to his/her education, health, and well-being.

Transition from Early Intervention

Many children with special health care needs are served in early intervention (EI) programs prior to entering school. EI is a community-based system of developmental services for children up to age 3 who manifest, or are at risk of, developmental delay. In most of these cases, the EI program will assist in making a referral for a determination of special-education eligibility, since the EI programs are well aware of the special-education programs provided by public school districts. Federal and state government funds support the Commonwealth's EI system, and Massachusetts law (M.G.L. c.721) requires that third-party insurers reimburse for these services. If a child is then found eligible for special education, Part B of IDEA ensures that eligible students with disabilities aged 3–21 receive a free and appropriate education.

In Massachusetts, the eligibility criteria for EI are broad and include children who experience environmental as well as biological risks. Not all children who are eligible for EI in the state of Massachusetts will automatically be eligible for special education upon school entry. If a child moves from EI to school, it is the responsibility of both EI and school personnel to ensure a smooth transition at age 3. **Note:** Permission from parents/guardians is required to share information.

Since efforts to plan services for students require close collaboration between families and school personnel, a program will be most successful if it addresses the priorities of the family and capitalizes on its strengths and abilities. As the transition to school approaches, parents/guardians and staff from agencies involved with the child's care should share information about the child with one another and with the school in which the child will enroll. Communication will help to avoid duplication of assessments, evaluations, and resources and to effectively obtain any additional necessary information.

Parents/guardians should notify the school and the school nurse as early as possible when a child with special health care needs will be enrolling, especially one who needs medical care on an ongoing basis for his or her needs (e.g., diabetes, cancer, asthma). (This also applies to the child whose needs are short-term, for example, an infection requiring antibiotics.)

When the child's education and health needs are extensive, the EI staff may refer the child to the local school district for special-education evaluation. This should occur as soon as possible after a child reaches the age of 2½ and no later than 6 months in advance of enrollment. Early notification is critical for adequate education, health, and safety planning. Facilitating a comfortable and successful transition to the school setting requires:

- a timely referral process;
- timely transfer of updated medical and developmental evaluations with recommendations;
- a meeting between parents/guardians, the EI provider, and school personnel;

- communication between the early-childhood coordinator and/or the special-education director, teacher, school nurse, school physician, and therapists, for the purpose of sharing information needed for health care planning;
- opportunities for parents/guardians to visit the school setting;
- opportunity for parents/guardians to obtain information on the Massachusetts Special Education Law and Regulations; and
- provision of information to parents/guardians about peer support networks, such as parent advisory councils.

School personnel can promote timely notification about enrollment of children with special health care needs by building close ties with health care and EI providers in their communities and/or region. These providers can then offer school contact information to parents/guardians to begin the planning processes.

In addition to parents/guardians, other referral sources may include primary care providers in the community, hospital clinic staff, specialists, care coordinators from DPH (see http://www.mass.gov/dph/fch/care/index.htm for more information) or other state agencies, and home-care nursing providers. However, if a referral is made by anyone other than parents/guardians, family consent is required. The parents/guardians of a student with HIV, for example, are under no obligation to inform a new school of their child's health status. If they do choose to tell school personnel, parents/guardians alone, in consultation with the primary care provider, should decide which individuals they wish to inform about their child's health status (see Chapter 8).

Transitions Within the School System

Like all students, students with special health care needs will move from one school program to another, and from one school building to another, as they continue their educational program. The Individual Health Care Plan provides the blueprint for continuity of care in these situations. The transitions may require changes in the IHCP to accommodate the student in the new setting, as well as staff training to ensure safe care. The school nurse in the initial setting is responsible for sharing information with the nurse in the new setting. Transfer of school health records from school nurse to school nurse is critical.

Transitions Between School and Hospital

Occasionally, a student with a special health care need (who may or may not have an Individualized Education Plan) may be hospitalized due to a significant change in his/her health status. If a student must remain at home or in a hospital (with a medical documentation of need) for 14 school days in any school year, the local school district shall arrange for provision of educational services in the home or hospital to allow the student to continue his or her educational program. These services shall not be considered special education unless the student has been determined eligible for such services and the services are included in the student's IEP (603 CMR 28.03(3)(c)).

It is important that the school nurse and the family maintain open communication, so that changes in health needs are identified and changes to the IHCP are addressed prior to the student's returning to school. Some changes may require additional staff training for school personnel and the school nurse, which should be implemented prior to the student's return.

Transition to Adulthood

Transition services, a term used in IDEA, describes a coordinated set of activities that may address, among other issues, the assessment, planning process, and educational and community experiences for students with disabilities as they turn 16 and prepare for transition to adult life. The intent of transition requirements in special-education law is to create opportunities for youth with disabilities that result in positive adult outcomes. Addressing these requirements may include:

- raising expectations for youth outcomes;
- engaging in specific programs or services available in the general education curriculum;
- assessing for interests, preferences, and needs;
- building self-awareness, self-identity, self-esteem, and self-determination skills;
- utilizing the community for supports;
- socializing and developing long-term relationships;
- participating in activities both at school and in the community; and
- engaging in and/or leading the transition planning process.

The IEP contains specific elements related to planning and goals for older students during the transition years (ages 16–21). Transition planning is integrated into the development of the IEP. The school district must have, and document, a discussion about the student's transition needs by the time the student is 15. This is to ensure that, if transition goals or objectives are appropriate, they are incorporated into the IEP by the time the student turns 16.

In Massachusetts, the IEP begins with a vision statement. For older students, this statement aids team members in looking toward the future as they determine the student's transition needs, goals, and services. As a student approaches graduation, the team must also consider the student's graduation status, the possibility of a referral for Chapter 688 services (services from adult human-service providers — see http://www.doemass.org/sped/688/), and the involvement of adult service agencies. As the student nears or reaches age 17, the team must discuss the transfer of special education and health care rights and responsibilities at the age of majority (age 18).

In preparation for independence, employment, and other post-school activities, the team is required to write IEPs that are responsive to students with disabilities. The commitment of students, parents/guardians, educators, adult agency staff, and community members is required to help students reach their visions and become active participants and contributors to society.

The school nurse has an important case-management role during the transition process. Responsibilities are especially challenging in cases where the student has complex needs, such as suctioning, gastrostomy tube feedings, medication administration, and monitoring. Often these service needs require additional staffing, coordination, and funding through the state agencies providing services to the adult population, to ensure that an appropriate and viable transition plan is identified and implemented.

SELECTED CHRONIC CONDITIONS

In the school setting, students with chronic health conditions require monitoring; appropriate and timely care to maintain health status and prevent emergencies; and timely intervention should an emergency occur. As discussed previously, the school nurse is the professional responsible for managing the care and for training other personnel, as appropriate to the individual student's needs. The goal is to provide necessary services and a safe environment, thereby permitting the student to attend school and participate in the educational process.

Within today's student population, a wide range of health conditions of varying severity are likely to be present. It is not possible, within a single chapter, to provide detailed information about more than a few. The specific conditions discussed below were selected because they are often seen in the school setting. Research on health conditions is constantly being expanded and updated, so the information presented here should be regarded as only a starting point for education on these topics.

Asthma

Asthma is characterized by chronic inflammation of the airways that causes episodes of wheezing, coughing, and difficulty in breathing. Asthma is among the most common chronic diseases in the U.S. today, with an estimated 15 million cases nationwide. The disease often begins in childhood and is one of the leading causes of school absence, emergency room visits, and hospitalizations.

Historically, asthma care focused on treating acute episodes. The current approach emphasizes the prevention of episodes by reducing inflammation in the lungs through the use of daily medication. With long-term maintenance therapy, students should experience a reduction in the number and severity of asthma episodes, fewer absences from school, and fewer early dismissals from class, thus enabling them to participate fully in the classroom educational experience. Furthermore, when asthma is managed effectively, students should enjoy unrestricted participation in all school activities.

Massachusetts Initiatives: Massachusetts Asthma Action Plan

The Managed Care and Public Health Collaborative of New England has identified four key components essential for best practices in caring for pediatric asthma:

- regular assessment and monitoring, including severity classification;
- control of environmental factors and triggers that contribute to symptoms and disease severity;
- pharmacological therapy, including long-term inhaled anti-inflammatory medications; and
- educating the child, the family, and other caregivers on how to follow a written asthma management plan.

In 2001, the Massachusetts Health Quality Partners (MHQP) and representatives from 21 Massachusetts health care organizations joined together to endorse an initiative to promote a key component of best practices in the management of pediatric asthma: the use of written asthma management plans. This initiative included the development and distribution of the Massachusetts Asthma Action Plan (MAAP).

The child’s physician or health care provider completes and returns the MAAP to the school nurse. The school nurse facilitates the implementation of the MAAP and works with parents/guardians and health care providers to promote its use as a key tool in the management of asthma.

The three-part multicolored MAAP forms are available free of charge through the Massachusetts Health Promotion Clearinghouse (http://www.maclearinghouse.com/CatalogPageFrameSet.htm). Plans are available in English, Spanish, Portuguese, Haitian Creole, Chinese, Vietnamese, Khmer, and Russian and may be viewed and/or ordered online, or ordered by calling the consumer information line at 800-952-6637. School nurses are encouraged to request that parents/guardians give the MAAP to the child’s primary care provider (PCP) for completion. Many school nurses give the MAAP forms to parents/guardians at the end of each school year so that a completed form will be available when the new school year begins. In addition, with consent from parents/guardians, school nurses are encouraged to provide regular feedback to the PCP regarding the child’s response to the medical regimen. An example would be sharing peak flow readings with the PCP.

Research has shown that asthma programs using written asthma action plans have resulted in significant reductions in patient morbidity and service utilization, such as emergency room visits and hospitalization. In schools, written asthma action plans will enhance communication among the school, parents/guardians, student, and physician, as well as improve the overall outcome in the management of asthma. Additionally, students learn to self-manage their asthma. The MAAP should be considered an essential part of the IHCP for all students who receive management of or treatment for asthma in the school setting.

A brief assessment tool from the National Asthma Education and Prevention Program and the National Association of School Nurses offers guidance to school nurses in determining how well an asthma action plan is working for a student. This tool is available online at: http://www.nhlbi.nih.gov/health/prof/lung/asthma/asth_act_plan_frm.pdf.

Management of Asthma in the School Setting

Effective management of asthma requires a partnership among the student; parents/guardians; the primary care provider; specialist; and school staff including the administrator, school nurse and school physician, bus driver, teachers, coach, and guidance counselor. The school plays an important role in helping students by providing support and implementing an individualized asthma management program. The nurse assesses the student with asthma and collaborates with other team members to develop an IHCP that includes, but is not limited to:

- a current MAAP with peak flow monitoring (or specific written parameters for medication dosage when the asthma becomes symptomatic);
- a list of medications and a plan for taking them, especially noting which ones need to be taken during school hours;

    > **Note:** In 2002, language was added to the Regulations Governing Administration of Prescription Medications in Public and Private Schools stating that no school district may prohibit students with asthma or respiratory diseases from possessing and administering prescription inhalers in accordance with DPH regulations on self-administration of prescription medications (105 CMR 210.006). See Chapter 6 for further discussion of medication administration and self-administration.

- plans for daily management, including how to avoid or control known triggers;
- early signs of an asthma episode, which, when noted by the student, should always be taken seriously (may include cough, changes in breathing, itchy chin or neck, or clipped speech);
- a specific plan of action for school personnel in case of early warning signs or an acute episode, which may include immediate notification of the school nurse (a student exhibiting early signs of an asthma episode should be accompanied by an adult to the nurse’s office);
- a clearly defined emergency plan — a student’s IHCP should be consulted at the first sign of an acute episode of asthma; and
- specific plans for staff members to educate, counsel, and support the student in self-management of asthma.

In addition, many school nurses offer instruction on asthma management for students and families. Some also offer asthma support groups.

Diabetes

The majority of school-age youth with diabetes have Type 1 diabetes. Individuals with Type 1 diabetes do not produce insulin and must receive insulin through injections, an insulin pump, or other delivery device. Type 1 diabetes, previously known by the terms insulin dependent diabetes (IDDM) or juvenile-onset diabetes, is the most common endocrine disorder of youth and affects about 1 in 800 children. It is not contagious, and it is not caused by eating too much sugar. It is never treated by diet alone or with oral medications (unlike Type 2 diabetes). Children living with Type 1 diabetes require care during school hours.

Type 2 diabetes, formerly known as noninsulin-dependent diabetes or adult-onset diabetes, typically affects adults but is increasing in youth. Students with Type 2 diabetes may be able to control their disease with diet and exercise alone, or they may require oral medications or insulin injections. Children with Type 2 diabetes, especially those using insulin, also have to manage their diabetes during school hours.

Management of Diabetes in the School Setting

Aggressive management of Type 1 diabetes involves frequent blood glucose monitoring and sometimes 4 or 5 insulin injections each day. Lowering the average blood glucose has been scientifically proven to delay or postpone the devastating long-term complications of diabetes (blindness, kidney failure, and nerve damage). Part of the child's diabetes treatment plan may routinely occur during school hours. Management of a student's diabetes should be incorporated into a student's IHCP. Information that should be in the IHCP includes:

- the definition of hyperglycemia for that particular student, and the recommended treatment;
- frequency of blood glucose testing;
- written orders from the student's physician outlining the dosage and indications for insulin administration and/or glucagon administration, if needed;
- times of meals and snacks, and indications for additional snacks for exercise;
- full participation in exercise and sports, any contraindications to exercise, or accommodations that must be made for that particular student;
- accommodations for school trips, after-school activities, class parties, etc.;
- education of all school personnel who may come in contact with the student about diabetes, on how to recognize hypoglycemia and hyperglycemia, and when to call for assistance;
- medical and/or treatment issues that may affect the educational progress of the student with diabetes; and
- how to maintain communications with the student, the parents/guardians, the child's health care team, the school nurse, and the educational staff. (Brown & Kent, 2000)

Insulin

Insulin dosage is determined by body size, activity level, state of health, dietary intake, and duration of diabetes, rather than severity of diabetes. Nowadays, insulin is usually administered in multiple daily injections, through an infusion pump or infusion pen, but new technologies are developing rapidly. Student responsibility for insulin injections should commence when his/her emotional maturity indicates this is an appropriate goal, and it is agreed upon by the school nurse, parents/guardians, the child, and health care professionals. The school nurse is responsible for insulin administration and/or supervision (if the student is self-administering), as specified in the IHCP and consistent with the Regulations Governing the Administration of Prescription Medications in Public and Private Schools (105 CMR 210.000). (See Chapter 6.)

Note: In 2005, M.G.L. c.71, s.54B was amended to add the following statement: *"Notwithstanding any general or special law or regulation to the contrary, no school district shall prohibit students with diabetes from possessing and administering glucose monitoring tests and insulin delivery systems, in accordance with department of public health regulations concerning students' self-administration of prescription medications."* Schools must follow the self-administration regulations (105 CMR 210.006) in this special situation.

Glucose Monitoring

Monitoring of diabetes (staff should avoid using the word "testing" just as they should try to avoid "diabetic" and "dieting," because of their subtle negative connotations) has changed in recent years so that more and more youth are checking their own "finger-stick" blood glucose levels. The student's health care provider should recommend a target range for blood glucose levels. All blood glucose levels that are monitored in school should be recorded, sent home to be assessed by parents/guardians, and shared with the health care provider. As indicated in the student's IHCP, parents/guardians should be notified immediately of extremely high or low glucose levels. Some teachers have creatively used examples of these numbers to explore averages, ranges, and graphing.

Note: The amendment to M.G.L. c.71, s.54B mentioned above applies to possession and administration of glucose monitoring tests by students, as well as insulin delivery systems. *In this situation, schools must also follow the self-administration regulations (105 CMR 210.006).*

Hypoglycemia

Hypoglycemia occurs when the blood glucose level is too low for the body to function properly. It is caused by excess insulin in the system or too little food, often brought about by unplanned excess activity. The best way to document that a hypoglycemic reaction (also called an insulin reaction) is taking place is to observe symptoms and obtain a blood glucose level at that moment. Obtaining actual blood glucose levels is necessary for appropriate treatment decisions. Students who have been assessed by the school nurse to self-monitor (105 CMR 210.000) may monitor their glucose levels, observing universal precautions, with immediate notification of the results to the school nurse. Treatment decisions are made based on the IHCP.

Mild hypoglycemia can cause very subtle symptoms, which school staff should learn to recognize: inattentiveness, mood or behavioral changes, speech pattern change, poor penmanship, or lower-than-expected achievement on an exam. Tremulousness, pallor, sweating, headache, or stomach pains can be caused by low blood glucose. *Moderate hypoglycemia* is similar, but the symptoms are of slightly greater intensity or duration.

Generally, the response to mild or moderate hypoglycemia consists of one of the following (or comparable substitutes): 3 or 4 glucose tablets, or 4 to 6 ounces of juice or regular soda (no extra sugar needed), or 7 Life Savers (any flavor). Fifteen minutes after treatment, blood glucose should be checked again. If the blood glucose level remains low when rechecked, repeat one of the above treatments. Most (90%) of the time, however, a single treatment will correct hypoglycemia. The child should remain quiet while waiting for blood glucose to return to normal. The licensed provider should give instructions as to the appropriate treatment of hypoglycemia for the individual child. *A student suspected of having hypoglycemia should not be permitted to go to the nurse alone.* *Severe hypoglycemia* produces the same symptoms as described above, plus either loss of consciousness or convulsions. Treatment of a rare daytime episode of severe hypoglycemia may require an injection of glucagon by the school nurse (or intravenous glucose if paramedics are present). (**Please note:** Under 105 CMR 210.000, the administration of injectable medications (other than epinephrine by auto-injector to a child experiencing a life-threatening allergic event) may not be delegated to unlicensed personnel.) It is recommended that children who may require emergency glucagon injections attend a school with a full-time school nurse. The child's health care provider orders the treatment specific to the individual child. Plans for contacting the physician, parents/guardians, or medics should be in place (as part of the IHCP) for such rare emergencies. Usually, severe hypoglycemia does not occur unless several factors converge and contribute to the reaction simultaneously (e.g., delayed meals or snacks with extra activity, major emotional trauma).

Because modern diabetes treatment does not preclude occasional episodes of hypoglycemia, teachers should be encouraged to learn about it so that it can be recognized and prevented, or at least easily treated in its early stages.

Ketoacidosis

Diabetic ketoacidosis (DKA) is the seriously elevated blood glucose levels associated with dehydration and coma and is very unlikely to occur during school hours. Unlike hypoglycemia, it does not develop quickly or unexpectedly and is most often associated with an intercurrent infectious disease such as a viral illness. Most children with diabetes need to stay home when they are ill to ensure they receive extra monitoring, extra salty fluids, and extra insulin. Recurrent DKA is often the result of omitted insulin injections or other physical/psychological stresses (AADE Position Statement, 1994). The child with diabetes who is ill or vomiting may need adjustments in insulin and diet. Parents/guardians should always be notified of these problems as soon as they occur.

Food

Meal plans are a key component of diabetes treatment and should take into account food preferences, insulin levels, and activity needs. A diabetes meal plan should provide a consistent source of food without large amounts of concentrated sugars. A food plan is a “diet” only when obesity coexists with diabetes. Adjustments for activity changes are also required, and snacking needs should be based on blood glucose results, with advice from the diabetes treatment team. Whether or not eating school lunches is permitted depends on treatment goals, fat content of meals, and nutritional consistency from day to day. School departments should provide fresh, tasty, and inexpensive meal options for everyone, including those with diabetes (see Chapter 9).

Special events or holidays do not always have to be celebrated with sugary foods or snacks. Adult event planners at school should consult with the health care team and provide adequate notice to parents/guardians so that students with diabetes are able to participate with only minimal changes to what is served. Responsibility for counting carbohydrates should be a collaborative effort among parents/guardians, the student (as appropriate), food service staff, and school nurses.

School Participation

Children with diabetes can be full participants in both curricular and extracurricular school life, including field trips. Knowledgeable and supportive school staff can assist in the treatment of diabetes so that there is minimal interference with learning objectives. Age-appropriate behavior, participation, and educational goals typically do not demand extraordinary adaptations due to diabetes. In cooperation with the family and nursing and medical staff, schools should encourage students with diabetes to reach their full potential.

School attendance should be monitored by parents/guardians, school nurses, and teachers. Because excessive absences may reflect poor glucose control, they should be documented and brought to the attention of the health care professionals involved with the diabetes treatment program.

Physical Education and Recess

School exercise may appear to be a source of concern because students with diabetes who are taking insulin cannot automatically counterbalance changing physical demands without prior planning. Ideal scheduling would provide for physical education periods at the same time each day so that food or insulin adjustments can be made appropriately. Whether and when extra food should be provided should be discussed with the health care provider. The worst time for physical education is the hour just prior to lunch, when most of the morning meal has begun to “wear off” and the likelihood of insulin-induced hypoglycemia is at its peak.

Psychosocial Issues

With a diagnosis of diabetes, psychosocial sensitivities may emerge. When school nurses, administrators, and teachers receive and act on current information about diabetes, they can make school a safe place for students with diabetes. Words are important; the preferred term is “a child with diabetes,” not “a diabetic child.” If school staff creatively use the process of diabetes management as a resource for education, they encourage increased self-esteem for these students. Science or math lessons that reflect day-to-day issues about diabetes, nutrition, and data collection make learning fun and pertinent. Books that include diabetes as part of the subject matter are useful. Among those recommended by the Juvenile Diabetes Research Foundation, New England Chapter, is Kim Gosselin’s *Taking Diabetes to School,* designed to help educate classmates aged 6–11. See the Resources section at the end of this chapter and the Juvenile Diabetes Research Foundation website for additional children’s books about diabetes.

Many resources are available on the management of children with diabetes in the school setting (see the Resources section at the end of this chapter). *Helping the Student with Diabetes Succeed: A Guide for School Personnel,* published by a Joint Program of the National Institutes of Health and the Centers for Disease Control and Prevention (2003), is especially useful and may be obtained at the National Diabetes Education Program website at http://www.ndep.nih.gov.

Please note: While the federal guidelines address medication administration, each state may have different regulations in this area. The Regulations Governing the Administration of Prescription Medication in Public and Private Schools (105 CMR 210.000) apply in Massachusetts (see Chapter 6).

Life-Threatening Allergies (LTAs)

Food allergies affect 11 million Americans, including 6% to 8% of children. The rate of peanut allergies in children has doubled from 1997 to 2002. In caring for children with LTAs, schools face the dual challenges of providing a safe environment and an appropriate emergency response should an anaphylactic reaction occur.

Eight foods are the most common food allergens and cause more than 90% of all food allergic reactions: milk, eggs, peanuts, tree nuts (such as walnuts and almonds), soy, wheat, fish, and shellfish. Peanuts and tree nuts alone account for 92% of severe and fatal reactions. Among children, allergies to milk and eggs are most common. In addition, many individuals are allergic to multiple foods. Children with severe food allergies also have a higher rate of other allergic disease, including asthma and eczema, which can complicate recognition of anaphylaxis and place students at higher risk. Fatal anaphylaxis is more common in children with food allergies who have asthma, even if the asthma is mild and well controlled. Life-threatening allergic reactions may also be triggered by insect stings, medications, latex rubber, cold, stress, and exercise.

Anaphylaxis

Anaphylaxis is a potentially life-threatening medical condition occurring in allergic individuals after exposure to their specific allergens. Anaphylaxis refers to a collection of symptoms affecting multiple systems in the body. The *most dangerous symptoms* include respiratory involvement, reduction in blood pressure, and/or shock, which are potentially fatal. Other symptoms are:

- hives;
- difficulty swallowing;
- vomiting;
- wheezing;
- itching (of any body part);
- difficulty breathing, shortness of breath;
- swelling (of any body part);
- sense of doom;
- stomach cramps;

- itchy lips, tongue, mouth, and/or throat;
- red, watery eyes;
- fainting or loss of consciousness;
- change of voice;
- dizziness, change in mental status;
- runny nose;
- flushed, pale skin;
- coughing; and
- cyanotic (bluish) lips and mouth area.

Management Guidance

In 2001, the Asthma and Allergy Foundation of America, New England Chapter (AAF/NE), the Massachusetts Department of Education (DOE), DPH, the Massachusetts School Nurse Organization (MSNO), parents/guardians, and other professional organizations collaborated to develop a manual that gives clear advice to schools about the care of students with food allergies. The document, *Managing Life Threatening Food Allergies in Schools,* identifies the school's role and responsibilities, provides guidance on development of an IHCP, and includes specific information from DPH regarding training and delegation. This manual should be available in all schools, but it also can be downloaded from the DOE website at http://www.doe.mass.edu/cnp/2002/news/allergy.pdf.

Strong emphasis is given to the need for planning and development of an IHCP prior to the student's entry into school. Consistent with the interdisciplinary model, a team meeting that includes parents/guardians should occur as soon as possible after the school learns of the planned enrollment of a child with any type of life threatening allergy. Because the school nurse is a critical to both planning and emergency response, the guidelines recommend that *every school building with a student at risk for anaphylaxis from a food allergy should have a full-time school nurse.*

The guidelines also:

- emphasize the role of the school nurse as developer, facilitator, educator, and supporter of the school-based program;
- stress the need for comprehensive school policies;
- establish the school administrator's role and commitment as critical to policy implementation and enforcement; and
- define the responsibilities of all involved personnel, including food service staff.

For students with LTAs, the most important aspect of management in the school setting should be prevention. All school personnel should be educated on LTAs and how to prevent exposure. As vital partners in prevention, food service staff are essential to school planning and implementation efforts.

Preparing for and Handling Emergencies

The school must also be prepared for emergency response to a life-threatening allergic event. For an anaphylactic reaction, epinephrine is the treatment of choice and should be given immediately. (See position statement of the American Academy of Asthma, Allergy and Immunology at http://www.aaaai.org/media/resources/academy_statements/advocacy_statements/ps26.asp.)

Prescription medicine regulations 105 CMR 210.000 permit school nurses (in schools registered with DPH) to train unlicensed personnel to administer epinephrine, during a life-threatening event, by auto-injector to an individual previously diagnosed with a known allergy. DPH encourages all school districts and nonpublic schools to register for this purpose (see Chapter 6 for information on registration). DPH also encourages school nurses to obtain a signed protocol from the school physician to permit the former to administer epinephrine to previously undiagnosed individuals experiencing their first anaphylactic reaction in the school setting. The school nurse should maintain a supply of epinephrine for this purpose.

Because of the danger of biphasic reactions, any individual receiving epinephrine should be transported by trained emergency medical service personnel to the closest emergency medical facility.

As part of its continuous quality assurance program, DPH requires that a form (available at http://www.mass.gov/dph/fch/schoolhealth/medadmin.htm) be completed and sent to DPH each time epinephrine is administered in the Commonwealth's schools. In addition, DPH prepares periodic health briefs on Epi-Pen administration in the schools, available on the school health service website.

Seizure Disorders

A seizure is a temporary electrical disturbance in the brain causing involuntary movements or paralysis, sensations, change in consciousness, or combinations of these. Many conditions can mimic seizure, including fainting, migraine headache, tics, reflux, and pseudoseizures. Although pseudoseizures can look and feel like epileptic seizures, these episodes are not caused by electrical disruptions in the brain, and they are classified into two major groups: *physiologic* and *psychogenic.* Physiologic seizures may result from a variety of causes, including changes in heart rhythm (cardiac arrhythmia), sudden drops in blood pressure (syncopal episodes), or very low blood glucose (hypoglycemia). Other physical conditions, such as sleep disorders and movement disorders, may produce symptoms that can look like seizures. Psychogenic seizures are thought to be caused by stressful psychological experiences or emotional trauma.

Seizures that recur without a known treatable cause are called epilepsy. The Epilepsy Foundation of America estimates that 315,000 U.S. schoolchildren age 14 and under currently have epilepsy. Children in certain populations are at higher risk for developing epilepsy, including those with mental retardation or cerebral palsy, those who have experienced febrile seizures in infancy or very early childhood, and those whose parents have epilepsy. Not all of those who have a single, unprovoked seizure will develop epilepsy. An estimated 120,000 children under 18 have a first convulsion each year, and current research indicates that only one-third are likely to develop epilepsy.

Seizures are often controllable with medication; 70% of people with epilepsy can be expected to enter remission (defined as 5 or more years seizure-free on medication). Certain forms of epilepsy specific to childhood may even resolve completely without medication as a child matures (see descriptions of syndromes below). But in 10% of cases, seizures cannot be brought under control, even with optimal medical management.

Epilepsy is a broad classification encompassing seizures of many different types, depending on which part and how much of the brain is affected by the electrical disturbance. People may experience more than one type.

In ***partial seizures,*** the electrical disturbance is limited to a specific area of one cerebral hemisphere. Partial seizures are subdivided into simple partial seizures (in which consciousness is retained), and complex partial seizures (in which consciousness is impaired or lost). Partial seizures are the most common type of seizure experienced by people with epilepsy. Virtually any movement, sensory, or emotional symptom can occur as part of a partial seizure, including complex visual or auditory hallucinations.

Generalized seizures affect both cerebral hemispheres and may produce loss of consciousness, either briefly or for a longer period of time, and are subcategorized into several major types:

- **Generalized tonic-clonic seizures,** also known as grand mal seizures, involve all or most of the brain and are characterized by stiffening and jerking movements involving muscles on both sides of the body.
- **Myoclonic seizures,** characterized by a brief muscle jerk resulting from an abnormal discharge of brain electrical activity, usually involve muscles on both sides of the body, most often the shoulders or upper arms.
- **Absence seizures** are characterized by a 5-to-15-second lapse of consciousness, during which the eyes may flutter, stare, or move upward.
- **Atonic seizures** are characterized by sudden loss of muscle tone, which may cause falls and potential injury but are not usually associated with loss of consciousness.

Epilepsy is also evaluated and discussed in terms of syndromes, which takes a number of characteristics into account, including the type of seizure, typical EEG recordings, clinical features such as behavior during the seizure, the expected course of the disorder, precipitating features, expected response to treatment, and genetic factors. Syndromes likely to be seen in epilepsy that occurs during childhood include:

- **Benign Rolandic Epilepsy,** also known as benign partial epilepsy of childhood, accounts for more than one-third of all cases of epilepsy that begin in middle childhood and is thought to be genetically determined. Most children outgrow it within 5 years or by age 14–15. Most seizures occur during sleep. Seizures start as simple partial, usually beginning in the face. There may be drooling and temporary inability to speak, although consciousness is preserved. The seizures then generalize to tonic-clonic convulsions.

- **Childhood Absence Epilepsy** accounts for 2% to 4% of all cases of epilepsy in children and is inherited. Seizures are nonconvulsive staring spells and tend to occur in clusters. Children with this syndrome are otherwise normal; as a group, their IQ scores are 10 points above average. Forty percent outgrow the seizures. Remission is most likely when the child is young at onset, the seizures are easily controlled with medication, and there are no other neurological problems. Approximately half of children with this condition go on to have a generalized tonic-clonic seizure. Risk is reduced if seizures are quickly controlled with medication.

- **Frontal Lobe Epilepsy** produces brief, often dramatic, seizures that may occur in clusters. Partial seizures beginning in the frontal lobe may produce weakness or inability to use certain muscles, including those that make it possible to talk. Sudden thrashing movements during sleep are also characteristic, as is posturing with the head jerking to one side, and the arm rising with it into a brief, frozen state. Sometimes a generalized convulsion follows. Frontal lobe epilepsy has significant social effects because the seizures it generates are more likely to involve brief episodes of screaming, bicycling movements, or even movements suggestive of sexual activity.

- **Juvenile Myoclonic Epilepsy** (also called Janz's syndrome, impulsive petit mal, myoclonic epilepsy of adolescence, and jerk epilepsy) is characterized by sudden jerks of arms and legs, especially on awakening. Juvenile myoclonic epilepsy generally appears at puberty and is usually not outgrown. It is also associated with generalized tonic-clonic seizures. Seizures may be precipitated by sleep deprivation, early awakening, alcohol and drug use, stress, strong emotion, photic stimulation, and menstruation.

- **Landau-Kleffner syndrome** causes children to have trouble understanding spoken language and sometimes to lose the ability to speak. It usually manifests between the ages of 3 and 7. Children with this syndrome may seem not to hear or understand what is said to them. Language for many of these children will improve slowly over time but may not return to a normal level for age. Many, but not all, children will also have seizures. Seizures may vary in type, occur during sleep, and be quite infrequent. Even in the absence of seizures, EEGs show epilepsy-related abnormalities.

- **Lennox-Gastaut syndrome** (also known as myoclonic-astatic epilepsy) typically involves more than one type of seizure. Combinations of seizures include atypical absence seizures (starting with automatic behavior without conscious control), tonic seizures (stiffening), and atonic or astatic seizures (drop attacks). Onset is usually between 1 and 5 years of age, and the condition usually results in some degree of mental retardation by age 6. Skills are lost, sometimes dramatically, in association with uncontrolled seizures. Many children with this syndrome wear protective helmets to prevent injuries caused by repeated falls during seizures. Some are prone to develop *nonconvulsive status epilepticus* (a continuous seizure state that is associated with a change in the child's level of awareness), which requires medical intervention to bring it to an end. As children with Lennox-Gastaut syndrome grow older, the types of seizures change. Drop seizures abate and are replaced by partial, complex partial, and secondarily generalized convulsions. Among teenagers with Lennox-Gastaut, complex partial seizures are the most common form. This seizure syndrome is difficult to treat and often does not respond to the usual medications.

- **Progressive Myoclonic Epilepsy** is a rare form of epilepsy with myoclonic and tonic-clonic seizures. Children with this condition may have trouble maintaining balance and may experience rigid muscles. There is also a loss of mental ability. A gene for this disorder has recently been discovered.

- **Rasmussen's syndrome** (also known as Rasmussen's encephalitis) begins in childhood and produces a slow deterioration of one whole hemisphere of the brain, with loss of function on the opposite side of the body. An autoimmune response to a viral infection has been suggested as a possible cause. Various types of treatment have been attempted, including surgical removal of the affected side of the brain. In children, the remaining hemisphere may compensate for functions lost, but weakness on the affected side will remain. The condition typically starts with seizures, with weakness appearing later. Simple partial seizures affecting movement are the most common form.

- **Reflex Epilepsy** is the name given to seizures triggered by individual sensitivity to sensory stimulation in the environment. The most common form is photosensitive epilepsy — seizures caused by exposure to intense or fluctuating levels of light. Some people have seizures triggered by flashing lights or rapidly alternating light and dark patterns. The condition usually begins in childhood and may be outgrown by adulthood. A flickering fluorescent light, the flicker of sunlight while driving past standing trees, certain video games, or flashing strobe lights can trigger seizures in photosensitive people. The reflex response may be absence (staring) seizures, myoclonic (jerking) seizures, or generalized convulsions. Wearing polarized sunglasses with blue lenses has been cited as good protection against photosensitive reflex seizures. While flashing or flickering light is the most common trigger for reflex epilepsy, rare triggers include certain sounds, music, tone of voice, reading, immersion in hot water, and even eating.

- **Temporal Lobe Epilepsy** is one of the most common forms of epilepsy. Its site is the temporal lobes, located on the sides of the head just above the ears. Complex partial seizures with automatisms (unconscious actions) such as lip smacking or rubbing the hands together are the most common seizures in temporal lobe epilepsy. Seventy-five percent of patients also experience simple partial seizures, which may include such features as a mixture of thoughts, emotions, and feelings that are hard to describe; sudden emergence of old memories or feelings of strangeness in familiar surroundings; hallucinations of voices, music, smells, or tastes; and feelings of unusual fear or joy. While partial seizures dominate, approximately half of people with temporal lobe epilepsy have generalized tonic-clonic seizures as well. Memory problems may develop over time in people with this syndrome.

Note: The Epilepsy Foundation was the source for much of the information presented in this section. See http://www.epilepsyfoundation.org for more information about the foundation's work.

Treatments and School Responsibility

The goal of epilepsy treatment is to eliminate seizures or at least make the symptoms less frequent and less severe. Long-term anticonvulsant drug therapy is the most common form of treatment, although surgery and other treatment methods are sometimes indicated, if medications do not bring seizures under control.

Partial seizures are both the most common type of seizures and often the most difficult to control with medication. Several drugs are available to treat partial seizures, and they may be prescribed singly or in combination. For the best possible seizure control, medication must be taken every day on time as prescribed, thus necessitating the availability of professional school nurses. Stopping the medicine suddenly for any reason may cause serious rebound seizures and result in status epilepticus, a condition in which a person suffers from continuous seizures and may have trouble breathing.

The school nurse, as case manager and student advocate, is responsible for working with parents/guardians and primary medical providers to create an IHCP and an emergency response plan for students with epilepsy. The school nurse also has responsibility for supervising the administration and monitoring of medications during school hours, ensuring that students are able to participate safely in activities such as field trips and school sports. S/he is also responsible for educating classroom teachers about the child's specific condition and type of seizures so they can make appropriate observations and respond effectively in the event of a seizure. (See also Chapter 6 for discussion of Regulations Governing the Administration of Prescription Medications in Public and Private Schools.)

Teachers are in the best position to observe a child for possible seizures or adverse effects of medication. If the teacher notices any unusual behavior, such as staring, lip smacking, repetitive hand movements, or involuntary movements, the school nurse should be told and the parents/guardians and the doctor informed. These behaviors may represent seizures. In addition, certain problems such as tremor, lethargy, nausea, or double vision may indicate a need to adjust dosages of medications.

Sometimes seizures continue even though medication is being taken exactly as prescribed. Some degree of seizure persistence is estimated to occur in 25% of the diagnosed population. Studies have shown that rectal diazepam gel is a safe and effective treatment for acute, repetitive, or prolonged seizures, which require immediate treatment. The National Association of School Nurses, in a position statement adopted in November 2003, concluded that administration of rectal gel or rectal suppository medication for control of seizures in students at school and during school-related activities is the function of the school nurse. Ongoing nursing assessment is needed, and there is potential for adverse reactions such as respiratory distress. This is consistent with the

Massachusetts Regulations Governing the Administration of Prescription Medications in Public and Private Schools, which prohibit the delegation of medication administration to unlicensed personnel. Other medications and routes of administration that will increase options for treatment of acute, repetitive, or prolonged seizures are currently under study.

One treatment for intractable partial seizures is electrical stimulation of the brain via the vagus nerve. The U.S. Food and Drug Administration (FDA) has approved the use of vagus nerve stimulation (VNS) in patients over the age of 12. This procedure uses a pacemaker-like device implanted in the chest wall to provide intermittent stimulation to the vagus nerve, which affects swallowing, speech, breathing, and many other functions. VNS may prevent or shorten some seizures. A 2003 report said that this treatment has reduced partial seizures by 50% or more in about one-third of patients, with no adverse effects. In Massachusetts, VNS management currently may not be delegated to unlicensed personnel (2005).

A special high-fat, low-carbohydrate, low-protein diet (the ketogenic diet) is also sometimes used to control seizures that are difficult to control with medications. Managing this diet in the school setting requires active involvement of the school dietician and the school nurse. Foods must be eaten in correct combinations and be very strictly weighed and measured. Even a small mistake in portions can interfere with effectiveness and precipitate a seizure. In addition, the diet can have significant side effects, and its use requires careful monitoring.

Children whose seizures are not well controlled often experience social, emotional, and academic problems. IHCPs should reflect interventions to improve seizure control, support the child in the school setting, and, to the degree possible, prevent these issues.

Children with “Do Not Resuscitate” or “Comfort Care” Orders

Children with terminal illnesses are attending school in increasing numbers. As the status of a child’s health declines, a family may make the difficult decision not to prolong the child’s life and request a Do Not Resuscitate (DNR) order. A DNR order is executed by a physician, authorized nurse practitioner, or authorized physician assistant, with the consent of parents/guardians, and issued according to the current standard of care.

If a child has a DNR order, he or she should also have a Comfort Care/DNR Order Verification form for emergency response and ambulance transport use. As of January 22, 2007, this form may be downloaded from the Department of Public Health’s Office of Emergency Medical Services website, at http://www.mass.gov/dph/oems. It must be printed out, completed in full, and signed by an authorized physician or authorized nurse practitioner, in accordance with instructions on the form. A Comfort Care/DNR form (either the original or a copy) is the **only** authorized way for prehospital emergency care providers, such as emergency medical technicians (EMTs, first responders), to recognize a patient with a current, valid DNR order. EMTs and first responders called to a school will honor a DNR only if the child has a Comfort Care/DNR form. Without this form, EMTs and other first responders who are called to a school will provide emergency treatment, including resuscitation, in accordance with standard EMS protocols, and transport to a hospital. The following website provides further information: http://www.mass.gov/dph/oems.

School districts should prepare a policy on the care of the child with a DNR order. Special consideration must be given to meeting child and family needs, as well as the needs of other students and staff. The child should only attend a school that has a full-time school nurse. Local emergency medical services should be informed (with written permission from parents/guardians) that there is a child in the school with a DNR/CC order.

Respecting the family's wishes involves much preplanning in the school setting. An individualized care plan should be developed with the family, in collaboration with the child's physician and the school physician. It should include:

- how the child will be moved to the health room or other designated area if serious distress or death should occur at another location in the school;
- what, if any, comfort measures should be given to the child;
- protocols for notification of the family;
- if the child has died in school, who will do the pronouncement of death (physician, nurse practitioner, or physician assistant); and
- how the deceased will be removed from the school. This may involve planning with the family's designated funeral home and include such factors as type of vehicle, where it will park, who will clear the corridors, and what kind of stretcher or other method of transport will be used. (**Please note:** By law, EMS providers are not permitted to move the deceased.)

The plan should address what will happen if the child is in distress but does not appear to face imminent death. The response should include immediate consultation with parents/guardians and, consistent with the plan, contact with the local EMS provider. If EMS is called, and the child has a Comfort Care/DNR form, the EMT or first responder can provide comfort care measures and transport to a hospital. The type of care that EMS is able to provide in this situation is spelled out in the Comfort Care Protocol in the above-referenced website.

When assigning responsibility for pronouncement of death, keep in mind that nurse practitioner (NP) and physician assistant (PA) pronouncements function as "removal permits" that allow the deceased to be removed from the school grounds by a funeral director. However, the NP or PA who pronounces the death must try, before the pronouncement, to reach the attending doctor so that the doctor can declare the death and complete the death certificate. If the attending doctor cannot be reached before pronouncement, notification must be given as quickly as possible of the event and the location to which the child's body has been removed so that the doctor can complete the death certificate. State law (M.G.L. c.46, s.9) requires that a physician or medical examiner complete the death certificate.

When a plan is in place, the school nurse, in collaboration with the family, should convey the plan to the appropriate school staff and administrators, answering any questions that they may have.

Whenever a death occurs in the school, a crisis team must be activated immediately to assist the family, staff, and students in coping with the loss. Special consideration must be made for any students or staff who witness the death, especially if (per DNR orders) no resuscitative treatment was performed either by school staff or EMS. Questions such as, "What if this happens to me?" and "Will they do anything for me?" may need to be addressed.

SUMMARY

As children with increasingly diverse and complex health care needs enroll in the Commonwealth's schools, it is vital that schools provide the care necessary to meet their health care needs and maximize their participation in the educational process. This requires careful planning, communication, care coordination, and ongoing collaboration among parents/guardians, providers, and school personnel. School nurses perform an essential case-management role in this process, ensuring that planning, health care delivery, training, and ongoing assessment are in place.

RESOURCES: MASSACHUSETTS AGENCIES AND ORGANIZATIONS (GENERAL)

The Arc of Massachusetts
Phone: 781-891-6270
Website: http://www.arcmass.org
The Arc enhances the lives of individuals with cognitive and developmental disabilities and their families. Arc helps to improve supports and services in the community.

Brain Injury Association of Massachusetts (BIAMA)
484 Main Street #325
Worcester, MA 01608
Phone: 800-242-0030 (Brain Injury Info Line)
Phone: 508-475-0032 (general information)
Fax: 508-475-0040
E-mail: biama@biama.org
Website: http://www.mbia.net/
BIAMA is the leading advocate for assuring that persons who experience brain injuries in the Commonwealth have adequate services to meet their needs. Information and resource referral are offered to those who are newly injured, as well as to survivors, families, and professionals who are seeking information on brain injury services and resources.

Easter Seals/Massachusetts
State Headquarters:
484 Main Street
Worcester, MA 01608
Phone: 800-922-8290
Fax: 508-831-9768
TTY: 800-564-9700
E-mail: info@eastersealsma.org
Website: http://ma.easterseals.com
Easter Seals Massachusetts provides services at more than 100 locations statewide, including:

- **Boston:**
  89 South Street, 1st Floor
  Boston, MA 02111
  Phone: 617-226-2640
  Fax: 617-737-9875

Federation for Children with Special Needs
1135 Tremont Street, Suite 420
Boston, MA 02120
Phone: 800-331-0688 (in MA) or 617-236-7210
Fax: 617-572-2094
Website: http://www.fcsn.org
The Federation is a parent-operated organization. Its website provides access to and information about laws related to health and educational rights and access issues. (See also Massachusetts Family Voices, below.)

Institute for Community Inclusion (ICI)
Institute for Community Inclusion/UCEDD
UMass Boston
100 Morrissey Blvd.
Boston, MA 02125
Phone: 617-287-4300
Fax: 617-287-4352
TTY: 617-287-4350
E-mail: ici@umb.edu

Website: http://www.communityinclusion.org
ICI is currently involved with school districts throughout the Commonwealth, assisting with the inclusion and empowerment of students with disabilities through technical assistance, training, and research. These activities are funded through a number of state and federal discretionary programs and include the areas of assistive technology, Person-Centered Planning, self-determination and leadership, transition from school to adult life, expanding inclusive recreational and community living options, and the inclusion of students with complex medical health care needs. The projects support restructuring and best practices in general education with learning as the central activity for all students. ICI is based at the University of Massachusetts Boston with additional offices at Children's Hospital Boston.

MassCARE (Massachusetts Community AIDS Resource Enhancement)
Massachusetts Department of Public Health
250 Washington Street, 4th Floor
Boston, MA 02108
Phone: 617-994-9819
Fax: 617-624-5990
TDD/TTY: 617-624-5992
MassCARE provides HIV-related specialty medical care, care coordination, and support services for women, infants, children, and adolescents with HIV/AIDS in community-based health centers and pediatric practices. It provides outreach to pregnant women and obstetrical providers to ensure early identification, enrollment, and enhanced care of pregnant women with HIV and to prevent HIV transmission from mothers to infants. It also provides outreach and support to perinatally infected, newly diagnosed, and at-risk adolescents through teen groups and community education. It promotes an active consumer network of meetings and activities for families.

Massachusetts Commission for the Deaf and Hard of Hearing
150 Mt. Vernon Street
Fifth Floor, Suite 550
Dorchester, MA 02125
Phone: 800-882-1155 or 617-740-1600
Fax: 617-740-1699
TTY: 800-530-7570 or 617-740-1700
Emergency Interpreter Services: 800-249-9949
Website: http://www.mass.gov/mcdhh
The Commission is the Commonwealth's principal agency working on behalf of people of all ages who are deaf and hard of hearing. Children's specialists in the Department of Case Management and Social Services established three specialized regional positions (Boston, Plymouth, and Springfield) to identify needs and issues, provide information about hearing loss, make referrals to appropriate specialized resources, and assist parents in working with other agencies. In addition, children's specialists also consult with or educate other service providers about the special needs of children who are deaf or have hearing loss.

Massachusetts Department of Education (DOE)
350 Main Street
Malden, MA 02148-5023
Phone: 781-338-3000
Three areas of DOE may be of assistance:

- **Program Quality Assurance Services (PQA)**
  Website: http://www.doe.mass.edu/pqa/
  PQA implements DOE's compliance monitoring and complaint management procedures for school districts, charter schools, educational collaboratives, and approved public and private day and residential special-education schools. It also provides technical assistance to school personnel and the public regarding the implementation of education laws and regulations.
- **Special Education Planning and Policy Development Office (SEPP)**
  E-mail: specialeducation@doe.mass.edu
  Website: http://www.doe.mass.edu/sped/
  SEPP develops special education policy and plans for statewide programs in related areas. Its website provides recent administrative advisory information, information on guides to the IEP, and

other technical assistance guides developed by DOE. Publications may also be obtained in hard copy at 781-338-3375.

- **Nutrition, Safety and Health Office (NSH)**
  Website: http://www.doe.mass.edu/hssss
  NSH is responsible for the coordinated school health programs.

Massachusetts Department of Public Health (DPH)
Division for Perinatal, Early Childhood, and Special Health Needs
250 Washington Street
Boston, MA 02108
Phone: 617-624-5070
Fax: 617-624-5990
TTY: 617-624-5992
Website: http://www.mass.gov/dph/fch/dshn.htm
The Massachusetts Department of Public Health (DPH) Division for Perinatal, Early Childhood, and Special Health Needs provides resources and services to families with children with special health needs through the Community Support and Care Coordination programs. Families may access these programs by calling the Community Support Line (800-882-1435) for information regarding eligibility for public benefits programs (SSI, CommonHealth, MassHealth), family-to-family supports (Family Ties), the Flexible Family Support Fund, care coordination services, and community-based programs. Care coordinators assist families to obtain services, coordinate with schools and medical providers, and provide consultation to parents/guardians, educators, and medical and social service providers regarding resources and services for children with special health care needs.

MASSTART
Central Regional Health Office, DPH
180 Beaman Street
W. Boylston, MA 01583
Phone: 508-792-7880
Website: http://www.mass.gov/dph/fch/masstart.htm
MASSTART is a free consultation and technical support service for parents/guardians whose children have complex health conditions or students who are assisted by technology, school nurses, and other school or health care personnel. Services provided by this program include staff training and consultation/information on health care technologies such as tube feedings, ventilators, and oxygen, as well as on diagnosis-specific health management in the school. With the family’s permission and involvement, MASSTART also provides child-specific consultation regarding health care and emergency planning for students who are assisted by technology or have complex health conditions. DPH’s Bureau of Family and Community Health, Division for Special Health Needs funds MASSTART. For more information or to make a referral, contact the Central Regional Health Office or the provider in your region:

- **Northeast and Greater Boston**
  Children’s Hospital
  300 Longwood Avenue
  Boston, MA 02115
  Phone: 617-355-4664
  Fax: 617-730-0049
- **Southeast Region**
  Centrus Premier Home Care
  225 Water Street
  Plymouth, MA 02360-4041
  Phone: 508-747-3521
  Fax: 800-698-8200 or 508-746-6706
  TTY: 800-698-8200
- **Central Region**
  UMMHC
  Pediatric Pulmonary and CF Center
  55 Lake Avenue North
  Worcester, MA 01655

Phone: 508-856-4155
Fax: 508-856-2609
E-mail: PageDO2@ummhc.org

- **Western Region**
  Baystate Medical Center Children's Hospital
  759 Chestnut Street
  Springfield, MA 01199
  Phone: 413-794-3406
  Fax: 413-794-8411
- **Office of Emergency Medical Services**
  Office of Emergency Medical Services
  2 Boylston Street, 3rd Floor
  Boston, MA 02116
  Phone: 617-753-7300
  Fax: 617-753-7320
  Website: http://www.mass.gov/dph/oems/
  OEMS is a source of information and forms related to Comfort Care/DNR orders.
- **School Health Unit**
  Phone: 617-624-6060
  Fax: 617-624-6062
  TTY: 617-624-5992
  Website: http://www.mass.gov/dph/fch/schoolhealth
  DPH's School Health Unit, Division of Primary Care and Health Access provides ongoing consultation to school health personnel and families regarding planning for students with special health care needs, including entry and retention. It also collects data on prevalence of health conditions; administers a School Health Institute that provides ongoing professional education for school nursing, medical, and other staff; and assists schools in developing guidelines and protocols for the management of children with special health care needs in the schools.

Massachusetts Family TIES (Together In Enhancing Support)
Phone: 800-905-TIES (8437)
Website: http://www.massfamilyties.org/
Family TIES of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illnesses. It is administered by parent coordinators housed in each of DPH's regional offices. Messages may be left at the toll-free number shown above. Coordinators retrieve these messages twice a day, Monday through Friday, and return calls as soon as possible. Only direct referrals to the program can be accepted. Calls from all parents, professionals, or members of the community supporting families of children with special needs are welcome. A comprehensive directory of resources for families of children with special needs of all kinds is available in PDF format on the website.

Massachusetts Family Voices
1135 Tremont Street, Suite 420
Boston, MA 02120
Phone: 800-331-0688 x210 or 617-236-7210 x210
Fax: 617-572-2094
E-mail: massfamilyvoices@aol.com
Website: http://www.massfamilyvoices.org
Massachusetts Family Voices at the Federation for Children with Special Needs is a state chapter of Family Voices, a national grassroots network of families, friends, and professionals brought together by a common concern for children with special health care needs.

May Institute
One Commerce Way
Norwood, MA 02062
Phone: 800-778-7601 or 781-440-0400
TTY: 781-440-0461
E-mail: info@mayinstitute.org

May Institute is a treatment, research, and training center specializing in autism, brain injury, mental retardation, pervasive developmental disorder (PDD), and behavioral health care needs.

National Kidney Foundation of Massachusetts, Rhode Island, New Hampshire and Vermont
85 Astor Avenue, Suite 2
Norwood, MA 02062-5056
Phone: 800-542-4001 or 781-278-0222
Fax: 781-278-0333
Website: http://www.kidneyhealth.org

The foundation's mission is to prevent kidney and urinary tract disease, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplant.

NERGG, Inc. (New England Regional Genetics Group)
P.O. Box 920288
Needham, MA 02492
Phone: 781-444-0126
Fax: 781-444-0127
Website: http://www.nergg.org
NERGG is a consortium of genetic health service providers, representatives of the New England public health community, consumer groups, and individuals with interest in genetics. It promotes health of children and adults by increasing awareness of genetic concerns, understanding of the role of genetics in health care, and knowledge of the availability of appropriate services. Educational materials produced by NERGG include *Just like Me? Children Talk about Spina Bifida,* a video produced in conjunction with the Massachusetts Health Research Institute, and *Guidelines for the Management of Students with Genetic Disorders: A Manual for School Nurses (5th Ed.)*. The latter covers general topics for the school nurse and contains chapters on 5 specific genetic disorders: sickle cell disease, myelodysplasia, cystic fibrosis, muscular dystrophy, and diabetes.

New England ADA & Accessible IT Center
Phone/TTY: 800-949-4232
E-mail: ADAinfo@NewEnglandADA.org
Website: http://adaptiveenvironments.org/neada/
The New England ADA & Accessible IT Center provides information and guidance on the Americans with Disabilities Act, Section 508, and accessible information technology to individuals living in New England. The website includes an online store, where ADA documents and other publications may be ordered.

New England Center Deafblind Project
175 North Beacon Street
Watertown, MA 02472
Phone: 617-972-7515
Fax: 617-972-7354
TTY: 617-924-5525
E-mail: NEC@perkins.org
Website: http://www.necdbp.org/index.htm
The New England Center Deafblind Project is funded by the United States Department of Education, Special Education Programs, under the Individuals with Disabilities Education Act (IDEA), to assist state education agencies in developing their capacity to adequately serve children and youth who are deafblind.

New England SERVE
101 Tremont Street, Suite 812
Boston, MA 02108
Phone: 617-574-9493
Fax: 617-574-9608
E-mail: info@neserve.org
Website: http://www.neserve.org

New England SERVE works on many diverse projects with one common goal: to improve the quality of health systems for children with special health care needs and their families. It established the Massachusetts Consortium for Children with Special Health Care Needs, a working group dedicated to high-quality, responsive, and family-centered systems of care, and it continues to convene and facilitate its activities.

PAL, the Parent Professional Advocacy League
Phone: 866-815-8122
Website: http://www.ppal.net
PAL is a statewide network of parents/guardians and professionals supporting children with mental, emotional, and behavioral needs.

Starlight Starbright Children's Foundation of New England
The Schrafft Center
529 Main Street, Suite 608
Charlestown, MA 02129
Phone: 617-241-9911
Fax: 617-241-0066
Website: http://www.starlightnewengland.org
The mission of the Starlight Starbright Children's Foundation is to alleviate some of the loneliness and pain that children feel while enduring the difficulties associated with having a serious illness.

RESOURCES: NATIONAL AGENCIES AND ORGANIZATIONS (GENERAL)

ABLEDATA
8630 Fenton Street, Suite 930
Silver Spring, MD 20910
Phone: 800-227-0216
Fax: 301-608-8958
TTY: 301-608-8912
E-mail: abledata@orcmacro.com
Website: http://www.abledata.com
ABLEDATA provides a national database of information on assistive technology and rehabilitation equipment. Information specialists are available to answer questions, provide information, and perform searches. ABLEDATA is sponsored by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

Americans with Disabilities Act (ADA)
Phone: 800-514-0301 (Information line)
TDD: 800-514-0383
Website: http://www.usdoj.gov/crt/ada/adahom1.htm
The ADA website houses information, frequently asked questions, publications, etc. on the Americans with Disabilities Act, which is the short title of United States Public Law 101-336, 104 Stat. 327 (July 26, 1990), codified at 42 U.S.C. §12101 et seq., signed into law on July 26, 1990. The ADA is a wide-ranging civil rights that prohibits, under certain circumstances, discrimination based on disability. It affords similar protections against discrimination to Americans with disabilities as the Civil Rights Act of 1964, which made discrimination based on race, religion, sex, national origin, and other characteristics illegal.

Assistive Technology Resource Center (ATRC)
100 Institute Road, Room 129
Worcester, MA 01609
Phone: 508-831-6056
Fax: 508-831-5680
E-mail: atrc@wpi.edu

Website: http://www.wpi.edu/~atrc
ATRC disseminates technical information regarding availability and use of assistive devices for individuals with disabilities in central Massachusetts.

Association for the Care of Children's Health (ACCH)
19 Mantua Road
Mt. Royal, NJ 08061
Phone: 609-224-1742
Fax: 609-423-3420
Website: http://www.acch.org/acch/
Website with links to numerous websites and publications in the field of children's health.

American Academy of Child and Adolescent Psychiatry (AACAP)
3615 Wisconsin Avenue NW
Washington, DC 20016-3007
Phone: 202-966-7300
Fax: 202-966-2891
Website: http://www.aacap.org
Publications: *The Child with a Long-term Illness* and *Children and Adolescents and HIV/AIDS,* Nos. 19 and 30 of the series, *Facts for Families* (updated 1999). Other fact sheets deal with conditions such as Asperger's Disorder, autism, and Tourette Syndrome. Fact sheets may be reproduced for personal or educational use without written permission and are available in English and Spanish at http://www.aacap.org/publications/factsfam or by calling the AACAP circulation clerk at 800-333-7636 x131.

American Academy of Pediatrics (AAP)
National Center of Medical Home Initiatives
141 Northwest Point Blvd.
Elk Grove Village, IL 60007
Phone: 847-434-4000
Fax: 847-228-7035
E-mail: medical_home@aap.org
Website: http://www.medicalhomeinfo.org
The National Center works in cooperation with federal agencies, particularly the Maternal and Child Health Bureau (MCHB), to ensure that children with special needs have access to a medical home. The National Center provides support to physicians, families, and other medical and nonmedical providers who care for children and youth with special needs.

Band-Aides and Blackboards
Website: http://www.faculty.fairfield.edu/fleitas/contents.html
This website, created by an RN, offers information about what illness and disability feel like from the perspective of children with these medical problems. It includes resources for teachers and school nurses on a variety of conditions.

Center for Applied Special Technology (CAST)
40 Harvard Mills Square, Suite 3
Wakefield, MA 01880
Phone: 781-245-2212
E-mail: cast@cast.org
Website: http://www.cast.org
CAST's mission is to expand learning opportunities for all individuals, especially those with disabilities, through the research and development of innovative, technology-based educational resources and strategies, based on the principles of Universal Design for Learning. CAST has earned international recognition for its work.

Children's Health Council
650 Clark Way
Palo Alto, CA 94304

Phone: 650-688-3625
Website: http://www.chconline.org
Resource: *Medically Fragile Children in School: A Guide Book for Teachers* is written for classroom teachers who encounter students with medically fragile conditions. It provides valuable accommodations, references, and resources for everyday challenges.

Collaborative Center for Assistive Technology and Training (CCATT)
97 Hawley Street
Northampton, MA 01060
Phone: 413-586-4900
Fax: 413-586-0180
E-mail: info@collaborative.org
Website: http://www.collaborative.org
CCATT is an assistive technology training and evaluation center serving western Massachusetts. It provides consultation to schools and offers a weekly open lab time for parents/guardians and professionals to promote product awareness.

Council of Educators for Students with Disabilities, Inc.
13091 Pond Springs Road, Suite 300
Austin, TX 78729
Phone: 512-219-5043
Fax: 512-918-3013
Website: http://www.504idea.org
The Council provides Section 504 and IDEA training and resources for educators.

DisabilityInfo.gov
Website: http://www.disabilityinfo.gov
DisabilityInfo.gov is a comprehensive online resource designed to provide easy access to disability-related information and programs available across the government on numerous subjects, including health and education.

DRM Regional Resource Directory
Website: http://www.disabilityresources.org
DRM Regional Resource Directory is a resource site, operated by the publisher of Disability Resources Monthly newsletter, to link subscribers and others with a disability to organizations and agencies in their own states or communities. It offers the DRM WebWatcher, a subject guide to online disability resources that can be used to find national and international resources, documents, databases, and other informational materials about specific disabilities or disability-related topics.

Family Village
Website: http://www.familyvillage.wisc.edu/
The Family Village website provides information, resources, and communication opportunities for people with disabilities, families, and providers. Family Village includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much more.

Family Voices, Inc.
2340 Alamo SE, Suite 102
Albuquerque, NM 87106
Phone: 888-835-5669 or 505-872-4774
Fax: 505-872-4780
E-mail: kidshealth@familyvoices.org
Website: http://www.familyvoices.org
Family Voices is a national, grassroots clearinghouse for information and education concerning the health care of children with special health needs.

Federation for Children with Mental Health Needs
1101 King Street, Suite 420
Alexandria, VA 22314
Phone: 703-684-7710
Website: http://www.ffcmh.org
A national family-run organization dedicated exclusively to helping children with mental health needs and their families achieve a better quality of life

Health Care Transitions
Institute for Child Health Policy
University of Florida
P.O. Box 100147
Gainesville, FL 32610-0147
Phone: 352-265-7220
Fax: 352-265-7221
Website: http://hctransitions.ichp.ufl.edu/
The mission of the Health Care Transition Initiative at the University of Florida is to increase awareness of, gain knowledge about, and promote cooperative efforts to improve the process of transitioning from child-centered (pediatric) to adult-oriented health care for all adolescents and young adults. Current efforts focus on those with disabilities and special health care needs. Activities carried out through the Transition Initiative include research, product development, and networking. One pertinent research project is Health Care Transition and the Schools (ICARE).

Individuals with Disabilities Education Act (IDEA)
Website: http://www.ideapractices.org/lawandregs.htm

National Center on Birth Defects and Developmental Disabilities (CDC)
E-mail: bddi@cdc.gov
Website: http://www.cdc.gov/ncbddd/default.htm
The National Center on Birth Defects and Developmental Disabilities promotes the health of babies, children, and adults, and enhances the potential for full, productive living.

National Center on Low-Incidence Disabilities
University of Northern Colorado
McKee Hall Campus Box 146
Greeley, CO 80639
Phone/TTY: 800-395-2693
E-mail: nclid@listserv.unco.edu
Website: http://www.NCLID.unco.edu

National Center on Secondary Education and Transition (NCSET)
Institute on Community Integration
University of Minnesota
6 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455
Phone: 612-624-2097
Fax: 612-624-9344
E-mail: ncset@umn.edu
Website: http://www.ncset.org
NCSET is a partnership of 6 organizations nationally recognized for a wide range of efforts focused on the secondary education and transition of youths with disabilities.

National Dissemination Center for Children with Disabilities/National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013

Phone/TTY: 800-695-0285
Fax: 202-884-8441
E-mail: nichcy@aed.org
Website: http://www.nichcy.org
NICHCY provides disability-specific information and state-by-state listings of resources.

National Down Syndrome Society (NDSS)
666 Broadway
New York, NY 10012
Phone: 800-221-4602 or 212-460-9330
Fax: 212-979-2873
E-mail: info@ndss.org
Website: http://www.ndss.org
NDSS provides education, research, and advocacy for people with Down Syndrome and their families.

National Heart, Lung and Blood Institute (NHLBI) Information Center
P.O. Box 30105
Bethesda, MD 20824-0105
Phone: 301-592-8573
Fax: 240-629-3246
E-mail: NHLBIInfo@rover.nhlbi.nih.gov
Website: http://www.nhlbi.nih.gov
NHLBI conducts educational activities for health professionals and the public, including development and dissemination of materials related to diseases of the heart, blood vessels, lung, and blood, with an emphasis on prevention.
Resource: *Students with Chronic Illnesses: Guidance for Families, Schools and Students* presents positive actions schools and families can take to address issues common to many chronic diseases. It is intended to help schools design a more coordinated approach to meeting the needs of students with chronic illnesses.

National Institute of Neurological Disorders and Stroke
NIH Neurological Institute
P.O. Box 5801
Bethesda, MD 20824
Phone: 800-352-9424 or 301-496-5751
TTY: 301-468-5981
Website: http://www.ninds.nih.gov

National Kidney Foundation (NKF)
30 East 33rd Street
New York, NY 10016
Phone: 800-662-9010 or 212-889-2210
Fax: 212-689-9261
E-mail: info@kidney.org
Website: http://www.kidney.org
Serving kidney patients and families, transplant recipients of all types, and donors and donor families, NKF provides an array of educational and supportive programs.

National Organization for Rare Disorders (NORD)
55 Kenosia Avenue
P.O. Box 1968
Danbury, CT 06813-1968
Phone: 800-999-6673 or 203-744-0100
TDD: 203-797-9590
Fax: 203-798-2291
E-mail: orphan@rarediseases.org
Website: http://www.rarediseases.org

NORD provides detailed medical information, support group listings, and other resources for specific disorders.

National Resource Center on AD/HD
8181 Professional Place, Suite 150
Landover, MD 20785
Phone: 800-233-4050 or 301-306-7070
Fax: 301-306-7090
Website: http://www.help4adhd.org
The National Resource Center (NRC) on AD/HD, A Program of CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder), was established in 2002 to be the national clearinghouse for the latest evidence-based information on AD/HD. The NRC provides comprehensive information and support to individuals with AD/HD, their families and friends, and the professionals involved in their lives.

Starlight Starbright Children's Foundation
1850 Sawtelle Boulevard, Suite 450
Los Angeles, CA 90025
Phone: 800-315-2580 or 310-479-1212
Fax: 310-479-1235
E-mail: info@starlight.org
Website: http://www.starlight.org
Starlight Starbright brings together experts from pediatric health care, technology, and entertainment to create programs that educate, entertain, and inspire seriously ill children. Programs are available for kids with asthma, diabetes, sickle cell disease, burn injuries, cancer, kidney disease, and cystic fibrosis.

U.S. Department of Education
Office for Civil Rights (OCR)
Customer Service Team
550 12th Street SW
Washington, DC 20202-1100
Phone: 800-421-3481
Fax: 202-245-6840
TDD: 877-521-2172
E-mail: OCR@ed.gov
Website: http://www.ed.gov/about/offices/list/ocr/index.html
OCR serves student populations facing discrimination and the advocates and institutions promoting systemic solutions to civil rights problems. It provides technical assistance to help institutions achieve voluntary compliance with the civil rights laws that OCR enforces.

Office of Special Education and Rehabilitative Services (OSERS)
U.S. Department of Education
400 Maryland Avenue SW
Washington, DC 20202-7100
Phone: 202-245-7468
Website: http://www.ed.gov/about/offices/list/osers/index.html
OSERS provides a wide array of supports to parents and individuals, school districts, and states in three main areas: special education, vocational rehabilitation, and research. The website offers news and information on the Individuals with Disabilities Education Improvement Act of 2004 (IDEA).

RESOURCES: SPECIFIC HEALTH CONDITIONS

Attention Deficit Disorders (ADD, ADHD)

AD-IN, Inc. (Attention Deficit Information Network)
58 Prince Street
Needham, MA 02492
Phone: 781-455-9895
Fax: 781-449-1332
E-mail: adin@gis.net
Website: http://www.addinfonetwork.org
AD-IN, Inc. is a non profit volunteer organization that offers support and information to families of children with ADD, adults with ADD, and professionals, through a network of AD-In chapters.

Children and Adults with Attention Deficit Disorders (CHADD)
8181 Professional Place, Suite 150
Landover, MD 20785
Phone: 800-233-4050 or 301-306-7070
Fax: 301-306-7090
E-mail: national@chadd.org
Website: http://www.chadd.org
CHADD is the nation's leading non-profit organization serving individuals with AD/HD and their families. CHADD has over 16,000 members in 200 local chapters throughout the U.S. Chapters offer support for individuals, parents, teachers, professionals, and others.

Attention Deficit Disorder Association (ADDA)
P.O. Box 543
Pottstown, PA 19464
Phone: 484-945-2101
Fax: 610-970-7520
E-mail: mail@add.org
Website: http://www.add.org
The mission of ADDA is to provide information, resources and networking to adults with AD/HD and to the professionals who work with them.

Asthma/Allergy

Allergy & Asthma Network Mothers of Asthmatics
2751 Prosperity Avenue, Suite 150
Fairfax, VA 22031
Phone: 800-878-4403
Fax: 703-573-7794
Website: http://www.aanma.org
AANMA is a national nonprofit network of families whose desire is to overcome, not cope with, allergies and asthma.

American Academy of Allergy Asthma & Immunology (AAAAI)
555 East Well Street
Milwaukee, WI 53202
Phone: 800-822-2762 or 414-272-6071
E-mail: info@aaaai.org
Website: http://www.aaaai.org
Materials: *Allergy and Asthma Tool Kit for School Nurses* is available at http://www.aaaai.org/professionals.stm.

American College of Allergy, Asthma & Immunology (ACAAI)
85 West Algonquin, Suite 550
Arlington Heights, IL 60005
Phone: 847-427-1200
Fax: 847-427-1294
E-mail: mail@acaai.org
Website: http://www.acaai.org
ACAAI is dedicated to improving the quality of patient care in allergy and immunology, through research, advocacy, and professional and public education.

American Lung Association of Massachusetts
460 Totten Pond Road, Suite 400
Waltham, MA 02451-1991
Phone: 781-890-4262
Fax: 781-890-4280
E-mail: info@lungma.org
The American Lung Association's *Open Airways For Schools (OAS)* is an asthma management program for schoolchildren aged 8–11 who have been diagnosed with asthma. It is taught as 6 40-minute sessions during the school day by a certified instructor. The program's goals are to improve asthma self-management skills, decrease asthma emergencies, raise asthma awareness among parents/guardians, and promote broader asthma management coordination among physicians, parents, and schools.

Asthma and Allergy Foundation of America (AAFA)
Phone: 800-7-ASTHMA (800-727-8462)
E-mail: info@aafa.org
Website: http://www.aafa.org
AAFA's website offers a variety of educational tools and resources. There are regional chapters, including:

- **New England Chapter**
  220 Boylston Street
  Chestnut Hill, MA 02467
  Phone: 877-2-ASTHMA (877-227-8462) or 617-965-7771
  Fax: 617-965-8886
  E-mail: info@asthmaandallergies.org
  Website: http://www.asthmaandallergies.org

CDC's School Asthma Program
Centers for Disease Control and Prevention
Division of Adolescent and School Health
4770 Buford Highway NE
Mail Stop K-12
Atlanta, GA 30341-3717
Phone: 888-231-6405
E-mail: HealthyYouth@cdc.gov
Website: http://www.cdc.gov/HealthyYouth/Asthma/

Massachusetts Department of Public Health
Center for Environmental Health
Phone: 617-624-5757
Fax: 617-624-5777
TTY: 617-624-5286
Website: http://www.mass.gov/dph/beha
The above website provides results and information about Student Asthma Surveillance Surveys.

National Heart, Lung and Blood Institute Health Information Center
P.O. Box 30105
Bethesda, MD 20824-0105
Phone: 301-592-8573

Fax: 240-629-3246
E-mail: NHLBIInfo@rover.nhlbi.nih.gov
Website: http://www.nhlbi.nih.gov
NHLBI's Health Information Center offers a variety of resources, including:

- *Managing Asthma: A Guide for Schools* (2003 Edition): Updated in 2003 to follow the latest asthma treatment guidelines, this 36-page guide includes easily reproducible information sheets on how peak flow meters and metered-dose inhalers work, a fill-in asthma action plan template to keep on file, an information sheet on the early signs of an asthma attack, sources of additional information about asthma, and more.
- *Asthma and Physical Activity in the School:* This is an easy-to-read booklet for teachers and coaches who want to help students with asthma participate in sports and physical activities. It covers the causes of asthma, symptoms of an asthma attack, how to avoid and control asthma triggers, how to help students who take medications, and how to modify activities to match children's current asthma status, and it also includes a reproducible student asthma action card.

National Jewish Medical and Research Center
1400 Jackson Street
Denver, CO 80206
Phone: 800-222-LUNG (5864)
E-mail: lungline@njc.org
Website: http://asthma.nationaljewish.org/
National Jewish Medical and Research Center's website offers information about asthma symptoms, asthma medications, and asthma management. Call the toll-free Lung Line to ask a specialized nurse questions about asthma, allergies, or other lung disease.

New England Asthma Regional Council (New England ARC)
The Medical Foundation
622 Washington Street, 2nd Floor
Dorchester, MA 02124
Phone: 617-451-0049 x504
Website: http://www.asthmaregionalcouncil.org
New England ARC is a coalition of public agencies, private organizations, and researchers in New England working to address environmental contributors to asthma.

Autism

Autism and PDD Support Network (Autism-PDD.Net)
P.O. Box 1596
Pleasanton, CA 94566
Website: http://www.autism-pdd.net
Autism-PDD.Net offers online information, support, and resources helping with issues pertaining to autism spectrum and pervasive developmental disorders (ASD & PDD).

Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
Phone: 800-328-8476 or 301-657-0881
Website: http://www.autism-society.org
There are chapters around the country, including:

- **Massachusetts Chapter**
  47 Walnut Street
  Wellesley Hills, MA 02481-2108
  Phone: 781-237-0272 x17

The Autism Support Center (ASC)
6 Southside Road
Danvers, MA 01923

Phone: 800-7-AUTISM (800-728-8476) or 978-777-9135
Fax: 978-762-3980
E-mail: asc@nsarc.org
Website: http://www2.primushost.com/~nsarc/
ASC empowers families who have a member with autism or related disorder by providing current, accurate, and unbiased information about autism, services, referrals, resources, and research trends. It also provides educational opportunities for families, professionals, and communities; promotes networking; increases community awareness; and advocates for services and opportunities.

Autism Research Institute (ARI)
4182 Adams Avenue
San Diego, CA 92116
Fax: 619-563-6840
Website: http://www.autismwebsite.com/ari/index.htm
ARI is primarily devoted to conducting research, and to disseminating the results, on the causes of autism and on methods of preventing, diagnosing, and treating autism and other severe behavioral disorders of childhood.

Center for the Study of Autism
P.O. Box 4538
Salem, OR 97302
Website: http://www.autism.org
The Center provides information about autism to parents/guardians and professionals and conducts research on the efficacy of various therapeutic interventions. Much of its research is in collaboration with the Autism Research Institute.

Cerebral Palsy

Cerebral Palsy of Massachusetts
Children's Development Center
43 Old Colony Avenue
Quincy, MA 02170
Phone: 617-479-7443
Fax: 617-749-5352
Website: http://www.masscp.org
Cerebral Palsy of Massachusetts provides a continuum of community based services that support the efforts of children and adults with developmental disabilities to live as independently as possible in the least restrictive environment.

Diabetes

American Association of Diabetes Educators (AADE)
100 W. Monroe Street, Suite 400
Chicago, IL 60603
Phone: 800-338-3633
Fax: 312-424-2427
Website: http://www.aadenet.org
AADE is a professional association dedicated to promoting the expertise of the diabetes educator, ensuring the delivery of quality diabetes self-management training to the patient and contributing to the future direction of the profession.

American Diabetes Association
Attn: National Call Center
1701 North Beauregard Street
Alexandria, VA 22311
Phone: 800-DIABETES (800-342-2383)
E-mail: AskADA@diabetes.org (for diabetes-related questions or to request a diabetes information packet)

Website: http://www.diabetes.org
There are offices around the country, including:

- **American Diabetes Association (Local)**
  330 Congress Street, 5th Floor
  Boston, MA 02110
  Phone: 888-DIABETES (888-342-2383) or 617-482-4580
  Fax: 617-482-1824

Children with Diabetes
5689 Chancery Place
Hamilton, OH 45011
E-mail: info@childrenwithdiabetes.com
Website: http://www.childrenwithdiabetes.com
The mission of Children with Diabetes is to promote understanding of the care and treatment of diabetes, especially in children, to increase awareness of the need for unrestricted diabetes care for children at school and in child care, to support families living with diabetes, and to promote understanding of research into a cure.

Diabetes Association, Inc. (DAI)
170 Pleasant Street, Suite 203
Fall River, MA 02721
Phone: 508-672-5671
Website: http://www.diabetesma.org/
DAI's mission is to improve the health and well-being of the communities that DAI serves by advancing diabetes prevention, early detection, education, and disease management.

GrandmaSandy.com
Website: http://www.grandmasandy.com
GrandmaSandy.com offers free download of games and books about Type 1 diabetes for young children.

Joslin Diabetes Center
One Joslin Place
Boston, MA 02215
Phone: 617-732-2400
Website: http://www.joslin.org/

Juvenile Diabetes Research Foundation International
120 Wall Street
New York, NY 10005-4001
Phone: 800-533-CURE (2873)
Fax: 212-785-9595
E-mail: info@jdrf.org
There are multiple chapters, including:

- **Juvenile Diabetes Research Foundation**
  New England Chapter/Bay State
  20 Walnut Street, Suite 318
  Wellesley Hills, MA 02481
  Phone: 781-431-0700
  Fax: 781-431-8836
  E-mail: baystate@jdrf.org
  Website: http://www.jdrf.org/baystate

Massachusetts Diabetes Prevention and Control Program
250 Washington Street, 4th Floor
Boston, MA 02108
Phone: 617-624-5070

Fax: 617-624-5990
Website: http://www.mass.gov/dph/fch/diabetes/index.htm

National Diabetes Education Program (NDEP)
National Diabetes Education Program
One Diabetes Way
Bethesda, MD 20814-9692
Phone: 301-496-3583 (Office of Communications and Public Liaison, NIDDK, NIH)
Phone: 800-438-5383 (to order educational materials)
E-mail: ndep@info.nih.gov
Website: http://www.ndep.nih.gov/resources/school.htm
NDEP is a partnership of NIH, CDC, and more than 200 public and private organizations, including the Massachusetts Diabetes Prevention and Control Program. Publications include *Helping the Student with Diabetes Succeed,* a comprehensive guide designed to empower school personnel, parents/guardians, and students to create a safe learning environment and equal access to educational opportunities for all children with diabetes.

National Diabetes Information Clearinghouse (NDIC)
1 Information Way
Bethesda, MD 20892-3560
Phone: 800-860-8747
Website: http://diabetes.niddk.nih.gov/index.htm
NDIC is an information dissemination service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health (NIH), one of eight health agencies of the Public Health Service under the U.S. Department of Health and Human Services. NDIC was established in 1978 to increase knowledge and understanding about diabetes among patients, health care professionals, and the general public.

Food Allergies

Food Allergy & Anaphylaxis Network (FAAN)
11781 Lee Jackson Hwy., Suite 160
Fairfax, VA 22033-3309
Phone: 800-929-4040
Fax: 703-691-2713
E-mail: faan@foodallergy.org
Website: http://www.foodallergy.org
FAAN works to raise public awareness, provide advocacy and education, and advance research on behalf of all those affected by food allergies and anaphylaxis. It offers a variety of resources for schools, including free food allergy information programs for elementary, middle, and high schools and guidelines for managing students with food allergies. The organization also operates informational websites for children and teens, which may be accessed via the main site.

HIV/AIDS

AIDS Action Committee
294 Washington Street, 5th Floor
Boston, MA 02108
Phone: 800-235-2331 or 617-437-6200
Fax: 617-437-6445
TTY: 617-437-1394
Website: http://www.aac.org
Founded in 1983, AIDS Action Committee of Massachusetts is a not-for-profit, community-based health organization whose mission is to stop the HIV/AIDS epidemic by preventing new infections and optimizing the health of those already infected. The website contains valuable information about HIV/AIDS and the services the organization provides.

AIDSinfo
http://www.aidsinfo.nih.gov/
AIDSinfo, a website sponsored by the U.S. Department of Health and Human Services, offers fact sheets, brochures, and other resources; provides support services to men, women, and children living with HIV/AIDS; educates the public about HIV; and advocates for fair and effective AIDS policy.

AIDS Project Worcester
85 Green Street
Worcester, MA 01604
Phone: 800-756-4148 or 508-755-3773
Fax: 508-795-1665
TTY: 800-756-4148
E-mail: info@aidsprojectworcester.org
Website: http://www.aidsprojectworcester.org
AIDS Project Worcester provides a variety of services for families or individuals living with HIV or AIDS, including case management, alternative therapies, food bank, mental health services, family services, and counseling.

Boston Pediatric and Family AIDS Project Respite Care
55 Dimock Street
Roxbury, MA 02119
Phone: 617-442-8800
Fax: 617-442-1702
This organization provides money for a friend or relative to care for children of HIV-positive parents on a short-term basis.

HIV InSite
Website: http://hivinsite.ucsf.edu/InSite
This informational site was developed by the Center for HIV Information (CHI) at the University of California San Francisco (UCSF), one of the world's leading health sciences institutions.

The SPARK Center (formerly the Children's AIDS Program)
255 River Street
Mattapan, MA 02126
Phone: 617-534-2050
Fax: 617-534-2057
E-mail: cap@bmc.org
Website: http://www.bmc.org/pediatrics/special/CAP/overview.html
The SPARK Center provides therapeutic, medically-specialized programs for children of all ages with HIV/AIDS.

The Home for Little Wanderers
271 Huntington Avenue
Boston, MA 02115
Phone: 888-466-3321 or 617-267-3700
Fax: 617-267-8142
TTY: 617-927-0699
Website: http://www.thehome.org
The Home for Little Wanderers provides a trained person to provide hourly or overnight care for children who are infected or affected by HIV.

Massachusetts Community AIDS Resource Enhancement (MassCARE)
(See listing under General Resources)

New Bedford Child and Family Services: Family Ties
800 Purchase Street
New Bedford, MA 02740

Phone: 508-990-0894
E-mail: dlanagan@cfservices.org
Website: http://www.cfservices.org

Hemophilia

National Hemophilia Foundation (NHF)
116 West 32nd Street, 11th Floor
New York, NY 10001
Phone: 212-328-3700
Fax: 212-328-3777
Website: http://www.hemophilia.org
NHF has many programs, including:

- **HANDI: The Information Service of NHF**
  Phone: 800-42-HANDI (800-424-2634)
  Fax: 212-328-3799
  E-mail: handi@hemophilia.org

New England Hemophilia Association
347 Washington Street, Suite 402
Dedham, MA 02026-1862
Phone: 781-326-7645
Fax: 781-329-5122
E-mail: neha@theworld.com
Website: http://www.newenglandhemophilia.org
New England Hemophilia Association is dedicated to empowering individuals and families with bleeding disorders through building local and region-wide communities, providing diverse information sources, dynamic programming, individual and legislative advocacy, and financial aid.

Seizure Disorders

Awareness and Access to Care for Children and Youth with Epilepsy (AACYE)
National Initiative for Children's Healthcare Quality (NICHQ)
20 University Road, 7th Floor
Cambridge, MA 02138
Phone: 866-787-0832 or 617-301-4900
Fax: 617-301-4899
E-mail: info@nichq.org
Website: http://www.nichq.org/nichq
NICHQ is an education and research organization dedicated solely to improving the quality of health care provided to children. NICHQ's AACYE initiative aims to improve systems of care for children and youth with epilepsy, especially those residing in medically underserved areas.

Centers for Disease Control and Prevention
Epilepsy
4770 Buford Hwy, NE
MS K-51
Atlanta, GA 30341-3717
Website: http://www.cdc.gov/epilepsy/index.htm
CDC's epilepsy website details current partnerships and health promotion activities being supported by the agency's epilepsy program. A variety of informational resources are available, including *You Are Not Alone,* a toolkit developed specifically for parents of teens who have epilepsy.

Citizens United for Research in Epilepsy (CURE)
730 N. Franklin Suite 404
Chicago, IL 60610

Phone: 312-255-1801
Fax: 312-255-1809
E-mail: info@CUREepilepsy.org
Website: http://www.CUREepilepsy.org

Epilepsy.com
Website: http://www.epilepsy.com
Epilepsy.com is an online resource provided by the Epilepsy Therapy Development Project, which supports innovative treatment research through direct grants and participation in the Partnership for Research in Pediatric Epilepsy. The mission of Epilepsy.com is to inform and empower two groups of patients and their families: those facing newly diagnosed epilepsy, and those struggling with epilepsy that has resisted treatment. Epilepsy.com was created to provide in-depth information about epilepsy and the many treatments that are available for it, in a form accessible to nonprofessionals.

Epilepsy Education Association, Inc.
1025 Creekside Ct., Apt. C
Mishawaka, IN 46544
Phone/Fax: 219-273-4050
Website: http://www.iupui.edu/~epilepsy
The Epilepsy Education Association is dedicated to promoting education about epilepsy.

Epilepsy Foundation of America (EFA)
8301 Professional Place
Landover, MD 20785-2238
Phone: 800-332-1000 or 301-459-3700
Fax: 301-577-4941
TTY: 800-332-2070
Website: http://www.epilepsyfoundation.org/
EFA works to ensure that people with seizures are able to participate in all life experiences and to prevent, control, and cure epilepsy through research, education, advocacy, and services. It conducts several programs at the national level, including:

- **School Nurse Training Program: Managing Students with Seizures**
  Website: http://www.epilepsyfoundation.org/programs/schoolnurse.cfm
  This special section of the Epilepsy Foundation website provides resources and supplementary material to assist the school nurse with better managing and supporting students with seizures and epilepsy. It provides Seizure Action Plan forms, epilepsy fact sheets, and other online resources. Books, pamphlets, and videos are also available for purchase. Videos include *Seizure Disorders and the School I* (Elementary); *Seizure Disorders and the School II* (Secondary); and *Seizure First Aid.*

Epilepsy clients throughout the U.S. are served by affiliated Epilepsy Foundation offices in nearly 100 communities, including:

- **Epilepsy Foundation of Massachusetts and Rhode Island**
  540 Gallivan Boulevard, 2nd Floor
  Boston, MA 02124-5401
  Phone: 888-576-9996 or 617-506-6041
  Website: http://www.epilepsymassri.org

Epilepsy Institute
257 Park Avenue South, Suite 302
New York, NY 10010
Phone: 212-677-8550
Fax: 212-677-5825
E-mail: website@epilepsyinstitute.org
Website: http://www.epilepsyinstitute.org

Epilepsy in Young Children
Website: http://www.kidsepilepsy.com/
This support site is for parents/guardians and other caregivers of children with epilepsy.

Parents Against Childhood Epilepsy (PACE)
7 East 85th Street, Suite A3
New York, NY 10028
Phone: 212-665-PACE (7223)
Fax: 212-327-3075
E-mail: pacenyemail@aol.com
Website: http://www.paceusa.org
PACE was founded by a group of parents in response to their experiences in caring for the medical, physical, social, educational, developmental, and emotional needs of their children who suffer from epilepsy and severe seizure disorders. In addition to funding research, this not-for-profit organization provides support, education, and information-sharing for families and caregivers of children who suffer from epilepsy.

Sickle Cell Anemia

New England Regional Newborn Screening Program
Sickle Cell Division
State Laboratory Institute
305 South Street
Jamaica Plain, MA 02130
Phone: 617-522-3700 x457

Spina Bifida (Myelodysplasia)

Arnold-Chiari Family Network
c/o Kevin and Maureen Walsh
67 Spring Street
Weymouth, MA 02188

Massachusetts Spina Bifida Association
456 Lowell Street
Peabody, MA 01960-2741
Phone: 781-531-6789
E-mail: apbcon@mindspring.com

National Resource Center on Spina Bifida
Spina Bifida Association of America
4590 MacArthur Boulevard NW, Suite 250
Washington, DC 20007-4226
Phone: 800-621-3141 or 202-944-3285
E-mail: sbaa@sbaa.org
Website: http://www.sbaa.org
The National Resource Center on Spina Bifida provides confidential information and referral services, responding to questions about health care, education, employment, benefits, and more. It is the only clearinghouse of information exclusively dedicated to spina bifida. The site contains fact sheets, FAQs, links, and publications.

NERGG, Inc. (New England Regional Genetics Group)
(See listing under Massachusetts Agencies and Organizations (General).)

RESOURCES: READING MATERIAL FOR CHILDREN AND TEENS

4–8 years:

- Anderson, M. E. (2000). *Taking cerebral palsy to school*. Plainview, NY: Jayjo Books.
- Carpenter, P. (2000). *Sparky's excellent misadventures: My A.D.D. journal.* Washington, DC: Magination Press.
- Carter, A. R. & Carter, C. S. (1998). *Seeing things my way.* Morton Grove, IL: Albert Whitman & Company.
- Carter, A. R. & Carter, C. S. (2000). *Stretching ourselves: Kids with cerebral palsy.* Morton Grove, IL: Albert Whitman & Company.
- Carter, A. R. & Carter, C. S. (2001). *I'm tougher than diabetes!* Morton Grove, IL: Albert Whitman & Company.
- Carter, S. M., Carter, A. R. & Young, D. (1999). *I'm tougher than asthma!* Morton Grove, IL: Albert Whitman & Company.
- Galvin, M. & Ferraro, S. (2001). *Otto learns about his medicine: A story about medication for children with ADHD* (3rd ed.). Washington, DC: Magination Press.
- Gosselin, K. (1996). *Zooallergy: A fun story about allergy and asthma triggers.* Plainview, NY: Jayjo Books.
- Gosselin, K. (1998). *Taking asthma to school* (2nd ed.). Plainview, NY: Jayjo Books.
- Gosselin, K. (1998). *Taking diabetes to school* (2nd ed.). Plainview, NY: Jayjo Books.
- Heelan, J. R. & Simmonds, N. (2000). *Rolling along: The story of Taylor and his wheelchair.* Atlanta, GA: Peachtree Publishers.
- Heelan, J. R. & Simmonds, N. (2002). *Can you hear a rainbow?: The story of a deaf boy named Chris.* Atlanta, GA: Peachtree Publishers.
- Henry, C. S., Gosselin, K. & Schader, K. (2001). *Taking cancer to school.* Plainview, NY: Jayjo Books.
- Monroe, R. P. (1998). *When will I feel better?: Understanding chronic illness.* St. Louis, MO: Concordia Publishing House.
- Moss, D. M. & Schwartz, C. (2006). Updated re-release. *Shelley, the hyperactive turtle.* Bethesda, MD: Woodbine House.
- Smith, N. (2002). *Allie the allergic elephant: A children's story of peanut allergies.* Colorado Springs, CO: Jungle Communications.
- Thomas, P. & Harker, L. (2002). *Don't call me special: A first look at disability.* Hauppauge, NY: Barron's Educational Series.

9–12 years:

- Esherick, J. (2004). *The journey toward recovery: Youth with brain injury.* Broomall, PA: Mason Crest Publishers.
- Gosselin, K. (1998). *The ABC's of asthma: An asthma alphabet book for kids of all ages*. Plainview, NY: Jayjo Books.
- Gosselin, K. (1999). *Trick-or-treat for diabetes: A Halloween story for kids living with diabetes.* Plainview, NY: Jayjo Books.
- Gosselin, K. (2002). *Taking seizure disorders to school: A story about epilepsy* (2nd ed.). Plainview, NY: Jayjo Books.
- Huegel, K. & Verdick, E. (1998). *Young people and chronic illness: True stories, help, and hope*. Minneapolis, MN: Free Spirit Publishing.
- Jackson, L. & Attwood, T. (2002). *Freaks, geeks and Asperger Syndrome: A user guide to adolescence.* New York: Routledge.
- Libal, A. (2004). *Chained: Youth with chronic illness.* Broomall, PA: Mason Crest Publishers.
- Libal, J. (2004). *Finding my voice: Youth with speech impairment.* Broomall, PA: Mason Crest Publishers.
- McAuliffe, A. (1998). *Growing up with diabetes: What children want their parents to know.* New York: Juvenile Diabetes Foundation Library.
- Nadeau, K. G., Dixon, E. B. & Beyl, C. (2004). *Learning to slow down & pay attention: A book for kids about ADD* (3rd ed.). Washington, DC: Magination Press.

- Quinn, P. O. & Stern, J. M. (2001). *Putting on the brakes: Young people's guide to understanding Attention Deficit Hyperactivity Disorder.* Washington, DC: Magination Press.
- Weiner, E. (1999). *Taking food allergies to school.* Plainview, NY: Jayjo Books.
- Weiss, J. H. (2003). *Breathe easy: Young people's guide to asthma* (2nd ed.). Washington, DC: Magination Press.

Young Adult:

- Kaufman, M. (1995). *Easy for you to say: Q&As for teens living with chronic illness or disability.* Toronto, ON: Key Porter Books.
- Kent, D. & Quinlan, K. A. (1997). *Extraordinary people with disabilities.* Chicago, IL: Children's Press.
- Lutkenhoff, M. & Oppenheimer, S. G. (1997). *Spinabilities: A young person's guide to spina bifida.* Bethesda, MD: Woodbine House.

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EXHIBITS

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Exhibit 7-1 Comparison of IDEA and Section 504

IDEA	Section 504
Costs for IDEA services cannot be a factor in decision making.	At the primary and secondary school level, 504 accommodations must provide a free appropriate public education equal to that provided to nondisabled students. [1]
Special education and related services.	General and special education.
Parental and student involvement is mandated.	Parental and student involvement is **not** mandated.
Students with disabilities.	Students with a physical or mental impairment that substantially limits a major life activity or who have a record of or are regarded as having such an impairment.
Individualized Education Plan (IEP).	504 Plan.
Comprehensive assessment, including formalized evaluations to determine needs as identified in IDEA.	Does not specify process of assessment.
Applies to elementary and secondary educational settings.	Applies to elementary, secondary, and postsecondary education settings and work settings.
Formalized structure and process specified in the legislation.	Structure and process are unspecified and ambiguous in the legislation.
Due process procedure within school setting for complaints. Appeal to BSEA. Complaint to Department of Education.	Due process within school system. Appeal to BSEA. Complaint to Department of Education. Complaint to Office for Civil Rights in U.S. Department of Education.
Complaints monitored by state and federal departments of education.	Complaints monitored by local school district and state department of education.
Accommodations, services, and supports to provide Free Appropriate Public Education (FAPE) to enable student to make effective educational progress within least restrictive educational setting.	Accommodations, services, and supports to provide student with equal access to the educational program and provide FAPE designed to meet the educational needs of students with disabilities as adequately as the needs of nondisabled students.
Transition services must be provided, beginning at age 14.	Does not specify provisions of transition services.
Federal funds provided to states for implementation of IDEA.	No federal funds are provided for implementation of 504 plans.
Statute sets forth requirements; state educational agencies oversee compliance by local school districts.	Section 504 of Rehabilitation Act of 1973 imposes duties on all recipients of federal funding. Similar requirements imposed on public and private entities by Americans with Disabilities Act of 1990.
IEP plan is reevaluated every 3 years.	No time period regarding reevaluation is specified.

Adapted from:
Anderson, W., Chitwood, S., & Hayden, D. (1997). Negotiating the special education maze: A guide for parents and teachers (3rd ed.). Bethesda, MD: Woodbine House; deFur, S. & Patton, J. (1999). Transition and school-based services: Interdisciplinary perspective for enhancing the transition process. Austin, TX: PRO-ED; and Smith, T. & Patton, J. (1998). Section 504 and public schools. Austin, TX: PRO-ED.

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[1] Postsecondary schools are not required to provide accommodations that alter the fundamental nature of the program or that impose undue hardship.

Exhibit 7-2 IHCP Medical Information Form

Clinician: ____________________ **Contact person:** ________________ **Facility:** ______________________ **Phone:** _______________________ **Emergency Phone:** ______________	**Student name:** _________________ **School:** _______________________ **Date:** _________________________ **Previous Update:** _______________ ***(shall be updated at least annually)***

The purpose of this form is to provide accurate information to the school about an individual student's medical needs. It is a prerequisite for any accommodations. For ongoing communication to occur, both the parent(s)/guardian(s) and the health care provider must sign the release of medical information authorization on the back of the form, as per the federal regulations concerning sharing of educational and health information.

Conditions: __________________ Allergies:	**Treatment Plan:** ________________
Equipment: ___________________ Procedures: ☐ No Equipment ☐ No Procedures	**Activity Level:** ☐ **No Restrictions** **Restrictions: (check all that apply)** ☐ **No contact sports** ☐ **No exertion other than walking** ☐ **No exposure to cold air (such as at recess, bus stop, physical education)** ☐ **No stairs** ☐ **Other (specify):** ______________________
In School Medications: ☐ **YES – Authorization attached *** ☐ **NO – Medications not given in school** **** State regulations require parent/ guardian and physician authorization of nurse administration of school medications***	**Other Medications:** ***(Please list all medications child takes, even if not given during school hours.)***

Medical Transportation:

- ☐ **Door to door (child has no exercise tolerance)** **duration:**_______________
- ☐ **Corner to corner (limited exercise tolerance)** **duration:** ________________
- ☐ **Special vehicle (wheelchair)**
- ☐ **PFT's if asthmatic: please attach last pulmonary function testing** _____________

<u>Medical transportation is provided for medical reasons only.</u> Safety issues (i.e., bullies, bus stop location, walking distance, parental/guardian illness) require other solutions. Please discuss this with the school nurse.

Other Adaptations:

Tutoring Plan: (anticipated total absence of > 2 weeks/yr. for chronic illnesses such as sickle cell, cystic fibrosis, etc.)

____

____

Special Diet: ____

____

____

Access accommodations: (e.g., bathroom, elevator, etc.) ___________________________

____

____

Primary Care Provider Signature: ____

Authorization for Healthcare Provider and School Nurse to Share Information:

I authorize my child's school nurse to assess my child as regards his/her special health care needs and to discuss these needs with my child's primary care provider, as needed through the school year. I understand this is for the purpose of generating a health care plan for my child. I understand I may withdraw this authorization at any time and that this authorization must be renewed annually.

________________________________ ___________________________ __________

Parent/Guardian Signature Print Name Date

School Use Only

☐ **USS team involved**
date presented: ___________________
☐ **Action taken:** ________________________

____

____

____

____

____

____

- ☐ **Transportation provided**
- ☐ **Other accommodations provided**
- ☐ **Personnel trained (if applicable)**
- ☐ **Parent/Guardian authorization**
  Feedback to clinician given

ATTACHMENTS:

- ☐ **Emergency Plan**
- ☐ **Medication Plan**
- ☐ **IEP Health Accommodations**
- ☐ **Field Trip Plan**

Child also has:

- ☐ **IEP**
- ☐ **504 Plan**
- ☐ **Individual Psychosocial plan**

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Exhibit 7-3 Individualized Health Care Plan Checklist

Preparation for Entry:

☐ Home Visit/Assessment ______________ (date)
☐ Health History ______________ (date)
☐ Planning Meetings ______________ (date) ______________ (date) ______________ (date)
☐ Staff Training Meetings ______________ (date) ______________ (date) ______________ (date)
☐ Educational Team Meetings ______________ (date) ______________ (date) ______________ (date)

Health Care Plan Included in:

☐ Student Record ______________ (date)
☐ Individualized Education Program ______________ (date)
☐ Individualized Student Accomodation Plan ______________ (date)

Health Care Plan

☐ Health Assessment ______________ (date)
☐ Physician's Order for Medications ______________ (date)
☐ Health Care Procedure ______________ (date)
☐ Student-Specific Procedural Guidelines ______________ (date)
☐ Procedural Skills Checklist ______________ (date)
☐ Problems/Goals/Actions ______________ (date)

Emergency Plan

☐ School ______________ (date)
☐ In Transit ______________ (date)

☐ Health Care Plan Reviewed by Physician ______________ (date)
☐ Signed by Parent, Education Administrator, School Nurse/Health Care Coordinator ______________ (date)

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Exhibit 7-4

____
(School Nurse/Health Care Coordinator)

____
(Education Coordinator)

Individualized Health Care Plan

Student Information:

______________________ (Name) ______________________ (Birthdate)

______________________ (Parent/Guardian) ______________________ (Address)

Mother/Guardian______________________ (Home telephone) ______________________ (Work telephone)

Father/Guardian______________________ (Home telephone) ______________________ (Work telephone)

______________________ (School) ______________________ (Grade/Class)

Languages spoken: Student__________________Caregiver(s) ______________________

Immunizations:______________________ (date and type)______________________

Primary Physician:______________________Telephone:______________________

Specialty Physicians:______________________Telephone:______________________
______________________ Telephone:______________________
______________________ Telephone:______________________
______________________ Telephone:______________________
______________________ Telephone:______________________

In Emergency, Notify:

Name:______________________Telephone:______________Relationship:____________
Name:______________________Telephone:______________Relationship:____________

Exhibit 7-5

Name:____ Date:_________________________

Important Personnel

School contacts:

____ ____

____ ____

____ ____

____ ____

Training
Direct caregivers: Student-specific General

______________________________________ ________________ (date) ________________ (date)

______________________________________ ________________ (date) ________________ (date)

Substitute caregivers/back-up staff:

______________________________________ ________________ (date) ________________ (date)

______________________________________ ________________ (date) ________________ (date)

______________________________________ ________________ (date) ________________ (date)

______________________________________ ________________ (date) ________________ (date)

Student-specific training done by:

____________________________________ ______________________________________ (date)

General staff training done by:

____________________________________ ______________________________________ (date)

Peer awareness training done by:

____________________________________ ______________________________________ (date)

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Exhibit 7-6

Name:________________________________ Date: ________________________

Background Information

Brief health

history:____

Special health care needs of the student:____________________________________

Other considerations:______________________________________

Student participation in care:______________________________________

Baseline status (i.e. skin color, activity/energy level, blood pressure, pulse, temperature, respirations):______________________________________

Medication (dose, route, time):______________________________________

Diet:____

Allergies:____

Transportation needs:______________________________________

What is the transportation emergency communication system?______________________________________

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Exhibit 7-7

Name:______________________________ Date:_______________

Procedure Information Sheet

Procedure:____

Frequency:_______________________ Times:________________________

Position of student during procedure:____

Ability of the student to assist/perform procedure____

____

Suggested setting for procedure:____

Equipment (include make and model, when applicable):

Daily:_____________________	Emergency:_____________________
____________________________	____________________________
____________________________	____________________________
____________________________	____________________________
____________________________	____________________________
Checked by:_________________	Checked by:_____________________
Storage:____________________	Storage:________________________
Maintenance:________________	Maintenance:____________________
Home care company___________	Home care company_______________

Child-specific techniques and helpful hints:____

____

____

____

____

Procedural considerations and precautions:____

____

____

____

____

____

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Exhibit 7-8

Name:____ Date:__________________________

Possible Problems

Observation	Reason	Action

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Exhibit 7-9

Name:_______________________________________ Date:_________________________

School Nurse:__________________________________

Individualized Health Care Plan

Date	Health Need/Nursing Diagnosis	Goals	Action/Intervention	Evaluation

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Exhibit 7-10 Daily Log

Name:______________________________School: ______________________________

Procedure(s): ____

Parent/Guardian_________________________Telephone Number______________________

Date/Time	**Procedure notes**	**Observations**	**Name**

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Exhibit 7-11 Emergency Plan

Name:____ Date:__________________________

Child-specific emergencies

If you see this	Do this

If an emergency occurs:

1. Stay with child.

2. Call or designate someone to call the nurse.

- **State who you are.**
- **State where you are.**
- **State the problem.**

3. The school nurse will assess the child and decide whether the emergency plan should be implemented.

4. If the school nurse is unavailable, the following staff members are trained to initiate the emergency plan:

____

____

____

____

____

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Exhibit 7-12 Emergency Telephone Procedure

Name:____ Date:___________________

1. Dial 911 and/or designated emergency response team.

2. **State who you are:** “ I am____________________________, a nurse/teacher/paraprofessional in the ____school.”

3. State where you are:

School name:______________________________________

Address:____

City:____

4. State what is wrong with student.

5. **Give specific directions** (e.g. which school entrance should be used, location of student).

6. **Do not hang up.** Ask for the information to be repeated and provide any other necessary information. Hang up only when all information has been received and is correct.

7. Notify people.

a. School principal or school official in charge of the building at that time:____

(telephone number)

b. School back-up personnel:____

(Name) (telephone number)

8. State the following:

“Emergency plan for_____________________________________is in effect.”

“The student is located____.”

9. Do the following:

a. Meet the emergency response team.

b. Direct the emergency response team to the emergency area.

c. Call parents and other necessary individuals (including physician).

An adult should be designated to accompany student in the ambulance.

Hospital that the student should be transported to:_.

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Exhibit 7-13 Emergency Information

Name:____Birthdate:________________

Address:______________________________________Telephone number______________

Mother/Guardian:____

Home telephone number:__________________ Work telephone number:________________

Emergency numbers:

Emergency medical response team:____________________ Work telephone number:________________

Other contact:________________________________ Telephone number:____________________

Health insurance:______________________________ Telephone number:____________________

Fire:____ Telephone number:____________________

Police:______________________________________ Telephone number:____________________

Home care company:____________________________ Telephone number:____________________

Ambulance:___________________________________ Telephone number:____________________

Gas company:_________________________________ Telephone number:____________________

Electric company:______________________________ Telephone number:____________________

Preferred hospital:____________________________ Telephone number:____________________

Local hospital emergency room:____________________ Telephone number:____________________

Primary physician:______________________________ Telephone number:____________________

Dentist:_______________________________________ Telephone number:____________________

Specialists:

____ Telephone number:____________________

____ Telephone number:____________________

____ Telephone number:____________________

____ Telephone number:____________________

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Exhibit 7-14

Parent/Guardian Authorization for Specialized Health Care

We (I), the undersigned, who are the parents/guardians of

____
(Name) (Birthdate)

request the following health care service/service(s)____

____

____

____

____

be administered to our child. We understand that a qualified designated person or persons will be performing the above-mentioned health care service. It is our understanding that in performing this service, the designated person or persons will be using a standardized procedure that has been approved by our physician.

____
(Physician's Name) (Address) (Telephone number)

We will notify the school immediately if the health status of________________________ changes, we change physicians, or there is a change or cancellation of the procedure.

We understand that the above procedure should be scheduled before or after school hours whenever possible.

Signature of parents/guardians:______________________________

____

Address: ______________________________

Telephone numbers ______________________________
(Home) (Work)

Date:________________________

This authorization form is from Pupil Personnel Services (1983). *Recommended Practices and Procedures Manual.* Chicago: Illinois State Board of Education; adapted by permission.

Exhibit 7-15

Physician's Order for Specialized Health Care Procedure

Student's Name:____Birthdate: _____________

Physician's Name (Print):____ Address:______

Address:____

Telephone:_________________________

Signature:____

Date:________________________

☐ I have reviewed and approve the Health Care Plan as written.
☐ I have reviewed and approve the Health Care Plan with the indicated changes/suggestions.

Procedures:

Name	Frequency	Indications	Date of Order	Expiration Date

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