

UNDERSTANDING INDIVIDUALS WITH PHYSICAL, HEALTH, AND MULTIPLE DISABILITIES

Sherwood J. Best



KNOWLEDGE, SKILLS, AND DISPOSITIONS

After you have read this chapter, you will be able to:

- 1. Understand past and present perspectives on indi-
- viduals with physical, health, or multiple disabilities. 2. Compare traditional and evolving definitions,
- classifications, and models of disability.
- **3.** Identify federal disability categories for special education and related services.
- 4. Use disability classifications and labels that are objective, appropriate, and dignified.
- **5.** Describe the utility *and* the limits of disability classifications and labels.

- 6. Explore critical issues in the lives of individuals with physical, health, or multiple disabilities.
- 7. Evaluate educational service delivery systems and the challenges of effective educational inclusion for students with physical or multiple disabilities.
- 8. Identify teacher competencies specific to serving students with physical, health, or multiple disabilities and apply them to the evolving roles of special education teachers.

D^{isability} is part of the human condition. Individuals with physical, health, or multiple disabilities live in your communities; go to schools with you or your children; worship in your churches, synagogues, or mosques; volunteer in your community organizations and activities; pay taxes; shop in supermarkets; enjoy public and private recreational facilities; and partake of society in every way imaginable. They are lawyers, gardeners, homemakers, students, accountants, grocery store stockers and baggers, doctors, salespersons, and teachers. Sometimes their disabilities are visible and identifiable, and sometimes you are unaware that they have a disability. Individuals with physical, health, or multiple disabilities are people in your neighborhood who come from all walks of life, who serve society in many ways, and whose roles and opportunities continue to expand.

The first paragraph of this text deliberately used the word "you" to create a sense of separation between readers and their perceptions of persons with disabilities. In reality, the concept of "them versus us" or "them versus you" is far from the truth. Disability is a normal and inevitable part of life. The process of aging results in degrees of loss of physical agility and mobility, visual acuity, hearing, and cognitive abilities such as memory. As Kudlick (2005) stated, "Disability is the one minority every human being will join if we live long enough" (p. 61). The shift toward widespread experience of disability is noted by Lynn (2005), who stated, "In a sense, the great success of modern medicine has been to transform acute causes of death into chronic illnesses" (p. S14). This evolution in medical care challenges conceptions of health, disability, longevity, and quality of life.

The recognition that people with physical, health, or multiple disabilities live, work, and play in all communities, that anyone could become disabled through accident or disease, leads to the logical conclusion that disability is one aspect of human diversity. Federal legislation reflects this position in the following statement: "Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society" (IDEA, § 14009[c][1]).

At certain times the impact of disability makes more difference in a person's life than at other times. However, disability can have significant functional impact on education, activities, and life outcomes, especially when appropriate knowledge and accommodations are absent.

Viewing disability strictly as a deficit that requires rehabilitation or remediation reflects a medical model perspective. Advances in conceptualizing disability encompasses the interaction of disease with psychosocial stressors and environmental factors that represents a biopsychosocial model reflected in the most recent classification of functioning, disability, and health by the World Health Organization (Peterson & Elliott, 2008, p. 261; WHO, 2001). In response to a more interactive disability model, applications such as "universal design" diminish the limitations created by disability throughout society.

To reduce the functional impact of disability, teachers and others who work with individuals with physical, health, or multiple disabilities must develop knowledge, skills, and abilities that extend beyond standard pedagogy. To begin, they must have a thorough understanding of typical development in motor, sensory/perception, cognition, communication/language, social/emotional, and self-care domains. Their knowledge and skills must include the ability to accommodate and modify the general education curriculum. They must be able to incorporate essential knowledge and skills for personal self-reliance into the educational program, including domains of (1) functional living skills, (2) physical task performance, (3) fundamental and assisted communication, and (4) individualized preparation for transitions (see Chapter 5).

Teachers of students with physical, health, and multiple disabilities must have more than curricular knowledge and instructional strategies to be effective educators. They must have knowledge about a variety of disabling conditions and their implications for function. In addition, they must become familiar with the legal mandates for providing education, supplementary supports, and services. Teachers of students with physical, health, or multiple disabilities must possess the empathy and knowledge required for working with families who may be coping with highly emotional situations including chronic illness, frequent hospitalizations, and perhaps terminal outcomes. In this process, they must become partners with families and collaborate with them to meet the shared goal of student success. They must collaborate successfully with personnel from many disciplines, including therapists, doctors, nurses, speech-language specialists, and others while they function as a resource for teachers in general education. Finally, teachers must also be advocates for their students, and they must always envision the goal of self-advocacy for students and their families.

This chapter provides an overview of the uniqueness and commonalities of individuals with physical, health, or multiple disabilities. First, you will become acquainted with historic and contemporary perspectives on disability as it is defined and classified. Such perspectives provide the backdrop for a discussion of terminology and of the legal mandates in education and broader civil rights. Major issues and challenges in the lives of individuals with disabilities are reviewed. You will be presented with a variety of educational service delivery systems and teacher competencies specific to working with students with physical, health, or multiple disabilities. Finally, the evolving roles of teachers in educational service delivery will be explored, as well as the vital contributions of support personnel who help create a comprehensive educational team.

This chapter provides foundation and background information about individuals with physical, health, or multiple disabilities. This broad approach provides a deeper appreciation of disability through the lenses of philosophy, history, anthropology, psychology, and sociology.

HISTORICAL PERSPECTIVES

Individuals with disabilities have made numerous contributions to science, the arts, literature, sports, and all other areas of endeavor. However, positive opportunities and supports for people with disabilities have not always been readily available, as the following overview of perspectives suggests.

Past and Present Perspectives

Individuals with disabilities have evoked recognition throughout time and across cultures (Covey, 1997, 2005), with individual reactions or social policy ranging from extermination and abandonment to education and care. These reactions varied with environmental circumstances, individual and group beliefs, social and economic conditions, religious influences, legal attention, and medical knowledge (Covey, 1997, 2005). A brief review of historical responses to and interactions with individuals with physical, health, or multiple disabilities informs current perspectives and issues.

In ancient civilizations, the harshness of the physical environment shaped public and private reaction to individuals with disabilities. Individuals who could not contribute to group survival through their physical strength or ability to bear children would not be viewed as assets. Medical care for people with severe disabilities would have been limited or impossible. Under such basic and harsh conditions, many individuals with disabilities died in infancy or early childhood. Those who suffered illness or injury later in life fared little better. However, written artifacts revealed that attempts were made in ancient times to heal or ease the effects of illness (Lubkin, 1995).

The evolving authority of religion in Western Europe during the Middle Ages gave rise to the concept of humane interest and care (Covey, 2005). People with developmental disabilities or mental illness might be perceived as "children of God" and afforded church protection. Conversely, they were sometimes perceived as possessed by evil spirits (Scheerenberger, 1982) or representing the outcomes of sin or association with fairies, elves, or demons (Covey, 1997, 2005). Whereas the developmentally disabled "child of God" was venerated (or at least tolerated) as a blessing, the individual whose behaviors were influenced by evil spirits was believed to have willfully chosen this path. The concept of internal ("God given," medically determined, etc.) versus external (environmental, social, etc.) factors as causative has a modern corollary in viewpoints of medical versus sociocultural bases for defining disability.

Developing medical inquiry and discovery in Western Europe supported a more scientific response to disability. Understanding linkages between contagion and some diseases contributed to reforms in hospital care although the notion persisted that some disabilities (e.g., epilepsy) were also contagious (Covey, 1997). Social reform resulting from political events also influenced community reactions toward disability. For example, the French Revolution instilled a sense of community responsibility that resulted in social reform and education. The efforts of such pioneers in special education as Louis Braille, Thomas Hopkins Gallaudet, Jean Marc Gaspard Itard, and Edouard Seguin resulted in specialized instructional and behavioral adaptations for people with disabilities (MacMillan & Hendrick, 1993). Along with the efforts of these individuals came the establishment of large residential institutions to provide training and protection. However, the original vision that residential institutions for specialized training would cure people of their disabilities was not fulfilled, and they degenerated into places of custodial care.

Living situations for individuals with disabilities have moved away from segregated institutions toward independent living, paired living, and supported living in small community-based residential facilities. The inclusion of students with disabilities in general education parallels this shift and reflects the acknowledgment that individuals with physical, health, or multiple disabilities contribute positively to their families and society. The perception that a disability represents a deficit that must be treated is being replaced with the notion that a disability is but one aspect of an individual. Self-determination is also gaining prominence in the lives of individuals with disabilities, largely due to the influence of the disability rights movement.

The Disability Rights Movement

President Franklin Delano Roosevelt is credited with bringing disability issues into federal politics through promotion of his New Deal. The 1935 Social Security Act provided funds for vocational rehabilitation for people with disabilities as well as retirement and insurance benefits (Treanor, 1993). Although he was an early proponent of rights and services for individuals with disabilities, Roosevelt was reluctant to incorporate his own disability (polio) into his public image. Current scholars have criticized this behavior as an effort to promote the concept of "overcoming" disability rather than confronting its impact through political and social means (Treanor, 1993).

After World War II, disabled veterans added a powerful voice to demands for civil rights in vocational rehabilitation and physical access to jobs, services, and other life activities. Individuals with disabilities also gained from the Brown v. Board of Education decision in 1954, which prohibited racial segregation in education and provided the foundation for inclusion of students with disabilities in schools with peers without disabilities. A notable event in the 1960s was the passage of the Civil Rights Act of 1964, which provided the model for the 1990 Americans with Disabilities Act (known as the ADA). Another important piece of legislation was the Architectural Barriers Act of 1968. This law was followed by the creation of the Architectural and Transportation Barriers Compliance Board, which established minimal guidelines for physical accessibility. Independent living centers were also established during this time. Their services include advocacy programs, job training, and attendant care registries.

Treanor (1993) suggested that the civil rights protest movements of the 1960s did not significantly involve people with disabilities because their interests and energies were most closely connected to specific groups such as the March of Dimes and United Cerebral Palsy. Although they provided a much needed focus on specific disability areas, these groups also had the effect of fragmenting the voice and political power of people with disabilities. The Rehabilitation Act of 1973, followed by other disability-rights laws such as the Americans with Disabilities Act (ADA, 1990), unified and clarified civil rights of individuals with disabilities. The Disability Rights Movement, supported by advocates for independent living, gained momentum in the 1970s (Hurst, 2003). Some advocates questioned services that separated persons with disabilities and promoted the position that disability was the consequence of societal barriers and attitudes (Hurst, 2003, p. 573). See Treanor (1993) and Shapiro (1994) for detailed accounts of the disability rights movement in the United States.

COMING TO TERMS WITH TERMINOLOGY

Defining Disability

Defining the term *disability* is not as simple as one might suppose because descriptions and classifications of disabilities are influenced by social, cultural, and legal parameters. Leonardi, Bickenbach, Üstün, Kostanjsek, and Chatterji (2006) compared the current definition of disability by the United Nations (UN) Convention on the Rights of Persons with Disabilities with a proposed definition of disability that is based on the World Health Organization's International Classification of Functioning, Disability, and Health (ICF), as follows:

Current UN Convention Definition of People with Disabilities: Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (in Leonardi et al., 2006, p. 1220).

Proposed Definition of Disability Based on WHO International Classification of Functioning, Disability, and Health (ICF): Disability is a difficulty in functioning at the body, person, or societal levels, in one of more life domains, as experienced by an individual with a health condition in interaction with contextual factors (in Leonardi et al., 2006, p. 1220).

Leonardi et al. (2006) noted that the UN definition is restricted because it reflects a medical model and focuses solely on "long-term" impairments. In contrast, the ICF-inspired definition is neither strictly medical nor social in orientation. A review of models of disability and discussion of the ICF demonstrates the growth of an integrative international framework for conceptualizing disability.

Models of Disability

The **medical model** approach dominated early efforts to describe disability and health (Bickenbach, Chatterji, Badely, & Üstün, 1999; Peterson & Elliott, 2008). This model conceptualized disability as a characteristic or attribute of the individual and caused by disease, trauma, or illness. Response to disability in a medical model approach consisted of education, rehabilitation, or other intervention to correct or compensate for the effects of disability (Jette, 2006, p. 727).

Although the medical model helped advance responses to acute illnesses as well as establishing eligibility for rehabilitation and educational services, legal protection, and financial support (Chan & Leahy, 1999; Simeonsson, Leonardi, Lollars, Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003), its emphasis on medical diagnosis and treatment has been criticized for a lack of attention to the social, psychological, and behavioral aspects of illness (Allan, Champbell, Guptill, Stephenson, & Campbell, 2006; Alonso, 2004; Hurst, 2003; Peterson & Elliott, 2008). In contrast, the **social model** conceptualized disability as product of interaction between the individual and the environment (WHO, 2001). Rather than emphasizing disability as a deficit within the individual, the social model emphasized attitudes and barriers that impede or facilitate functioning. By assessing persons in relation to their living conditions and not their impairments, the social model proposed to reduce stereotypes that were reinforced by a medical model approach (Hurst, 2003). Imrie (2004) argued that both models, "while capturing aspects of people's lives, are problematical for failing to recognize that biology and society are entwined in a dialectical relationship" (pp. 287–288). Separately, both the medical and social models are incomplete descriptors of disability.

The biopsychosocial model attempts to integrate aspects of the medical and social models by considering "the interactive effects of disease [disability parameters], psychosocial stressors, and personal and environmental factors that account for varying degrees of adaptation" (Peterson & Elliott, 2008, p. 216). This model recognizes that adjustment relates not only to a specific medical condition and its treatment, but also the individual's appraisal of the disability, ability to respond or cope with it, and social supports or stressors that either mediate or exacerbate disability effects. Although it was proposed over 30 years ago (Engel, 1977), the biopsychosocial model has emerged as the current framework for classifying functioning, disability, and health. We encourage you to review Bickenbach et al. (1999) and Peterson and Elliott (2008) for in-depth discussions of the medical, social, and biopsychosocial models of disability.

World Health Organization International Classification of Functioning, Disability, and Health

The World Health Organization is an "international authority on health governed by 192 Member States through the World Health Assembly" (Allan et al., 2006, p. 236). In 1980 the World Health Organization (WHO) set forth the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980). This classification system was replaced in 2001 when the WHO proposed the current International Classification of Functioning, Disability, and Health (ICF), which is complementary to the WHO International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) (Peterson & Rosenthal, 2005; WHO, 2001). The ICF reflects the biopsychosocial model by integrating the body-oriented component of the medical model with individual and societal contexts. Furthermore, the ICF model represents a shift in perspective from "a consequence of disease classification to a component of health classification" (WHO, 2001, p. 2). Figure 1.1 illustrates the ICF conceptual framework.

In the ICF model, functioning is organized into two parts. Part 1 describes the components of **Functioning and Disability**, which is broken down into the components **Body** and **Activities and Participation**. The Body

FIGURE 1.1 Interactions between the components of the ICF conceptual framework.



Note. From *The International Classification of Functioning, Disability and Health* (p. 18), by the World Health Organization, 2001, Geneva, Switzerland: Author. Copyright 2001 by the World Health Organization. Reprinted with permission.

⁸ Part I Impact and Implications of Physical, Health, and Multiple Disabilities

component is further classified into **Body Functions** and **Body Structures**. Changes in anatomy and physiology (such as cognition, speech, etc.) characterize Body Structures and Functions. The component of **Activities** and **Participation** is characterized by individual capacity and performance (such as mobility, self-care, communication, etc.). Note that all the components that comprise functioning and disability interact with and influence each other (indicated by the double-headed arrows) (see Figure 1.1).

Part 2 of the ICF model describes **Contextual Factors** through its two components of **Environmental Factors** and **Personal Factors** (Figure 1.1). Environmental factors can either facilitate or restrict the components of body functions, body structures, or activities and participations in Part 1 of the model. Personal factors are individual attributes such as age, lifestyle, coping styles, education, etc. (Peterson & Elliott, 2008, pp. 219–220; WHO, 2001). You can learn more about the ICF conceptual framework online at www.who.int/classifications/ ICF/en/.

Where do terms like *impairment*, *disability*, and *handicap* fit into the ICF model? The WHO's International Classification of Impairments, Disability, and Handicaps (ICIDH) in 1980 defined impairment as individual loss or abnormality of psychological, physiological, or anatomical structure or function (Badley, 1993, p. 27). Disability was defined as restriction or lack (resulting from impairment) to perform within the range considered normal for a human being (Badley, 1993, p. 28). Handicap was a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (Badley, 1993, p. 29). These definitions and their meanings have changed. The current ICF model uses the term

impairment to apply to some physiological or psychological dysfunction in body structures or functions. Handicap has been replaced with the term participation restrictions. Disability includes impairments, activity limitations, or participation restrictions, and encompasses "the outcome or result of a complex relationship between an individual's health condition [impairment] and personal factors, and the external factors that represent the circumstances in which the individual lives" (WHO, 2001, p. 17). Leonardi et al. (2006) described the relationship among these terms as follows: "Impairments are interactions affecting the body; activity limitations [disabilities] are interactions affecting [an] individual's actions or behavior; participation restrictions [handicaps] are interactions affecting [a] person's experience of life" (p. 1220).

The Neuro-Developmental Treatment Enablement Model

In 1998 the Neuro-Developmental Treatment (NDT) Association adopted the ICF model of the Functioning, Disability, and Health with specific modifications. The NDT Association added a dimension to the ICF model called **motor functions**. The motor functions domain classifies disability across four dimensions: (1) system integrity/impairments, (2) effective/ineffective posture and movement, (3) individual functional activities/ limitations, and (4) participation/participation restrictions (Howle, 2001, p. 82). The NDT Association supports this model because it aids in decision making for interventions, is compatible with the NDT approach, and incorporates environmental context into individual functioning. The NDT model is shown in Figure 1.2.

FIGURE 1.2 Interactions among dimensions of the NDT enablement model.



Note. From "Interactions Among the Dimensions of the NDT Enablement Model." In J. M. Howle, (2001), *Neuro-Developmental Treatment Approach: Theoretical Foundations and Principles of Clinical Practice*, p. 83. Laguna Beach, CA: NDT Association.

DisABILITY

The terms *impairment* and *disability* are used throughout this text. In addition, the phrase "individuals with physical or multiple disabilities" is used to reflect person-first language and to reinforce the belief that disability is but one aspect of an individual. As early as 1976, Bigge used person-first language for the first edition of this text in recognition of the importance of this concept.

Despite their usefulness for communication, public recognition, funding, and service delivery, the difficulty with labels is that they acquire meaning apart from their descriptive intent. Inherent dangers occur when labels reflect stereotyped attitudes, false assumptions about capability, and promotion of negative images. Elimination of formal labeling, however, can result in professional miscommunication, loss of federal recognition and support, and the development of informal (and even more negative) labels (e.g., "dummy," "spaz"). Group stereotyping, which occurs when a phrase such as "the disabled" is used, should be avoided. Phrases such as "confined to a wheelchair," "cerebral palsy sufferer," and so forth, are unacceptable because they portray persons as helpless victims. Acceptable substitute phrases would be "wheelchair user" and "a person with cerebral palsy." Terms such as cripple and spastic, which were once considered neutral descriptors, are stigmatizing and unacceptable for general usage. The teacher should never describe individuals in a classroom by saying "There is a CP in my class" or "I have two wheelchairs and one walker." People are not equipment! The use of labels or categories to broadly describe persons with disabilities should be approached with great sensitivity; they should never be used in a manner that fails to recognize the individual as a person first.

Definitions of disabilities by specific categories reside in federal legislation and provide a framework for understanding mandated educational services. However, although it may be necessary for service providers to use disability categories for communication purposes, they must also look past categories to avoid underestimating the capabilities and potentials of individuals.

Federal Categories and Definitions

The 2004 Individuals with Disabilities Education Improvement Act (usually referred to as the IDEA) is the most recent amendment to the original Public Law (PL) 94-142 enacted in 1975. PL 94-142 established 11 categories of disability for the purpose of providing educational and related services. In 1990 passage of PL 101-476 added the categories of traumatic brain injury and autism. Orthopedic impairments, other health impairments, multiple disabilities, and traumatic brain injury are four federal categories whose members have needs addressed in this text. Although these categories have specific definitions, and a variety of conditions within the categories of orthopedic and health impairments are described in Chapters 2, 3, and 4, remember that an individual may have a disability that crosses categories.

Orthopedic Impairments. The term orthopedic impairments is used to refer to "impairments caused by congenital anomaly (e.g., club foot, absence of some member, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures.") (34 C.F.R. § 300.7[c][8], 1999). The orthopedic impairment must be sufficiently severe to affect educational performance adversely. This definition hints at the variety of impairments that are classified as orthopedic. Individuals who have orthopedic impairments may have functional limitations of movement and/or sensation and may also have health impairments. Most orthopedic impairments are stable, some are progressive, and a few are terminal.

In this text, we use the term physical instead of orthopedic for several reasons. First, the term physical is more inclusive of a broader number of categories, including neuromotor impairments, degenerative diseases, and orthopedic and musculoskeletal disorders (Heller, Alberto, Forney, & Schwartzman, 1996, p. 36). These categories are either specific to a system of the body (e.g., central nervous system/neuromotor) or process (e.g., disease). Second, the federal definition of "orthopedic impairments" contains a subcategory labeled "other," which includes examples as divergent and unrelated as cerebral palsy, burns, and amputation. Further examination of the federal definition reveals that "absence of some body part" (i.e., limb loss) is listed as a disability of congenital origin, whereas "amputation" is specifically identified in the "other" category. This overlap has resulted from using noncomparable categories that are based on time of disablement (congenital) versus miscellaneous categories (other). The child in Figure 1.3 has cerebral palsy, which is classified as an orthopedic disability.

FIGURE 1.3 A girl with an orthopedic disability uses her wheelchair and companion dog to be more independent.



Other Health Impairments. *Other health impairment* is defined as:

having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (i) Is due to chronic or acute health problems such as asthma, attention deficit or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia: and (ii) Adversely affects a child's educational performance. (34 C. F. R. § 300.7[c][9][i][ii], 1999)

As with orthopedic impairments, there are a variety of health impairments, which can be stable, progressive, or terminal. Impairments characterized by heightened alertness is a reference to attention deficit disorder and attention-deficit/hyperactivity disorder, which are not addressed in this text. Figure 1.4 shows a boy with diabetes getting ready to administer insulin.

Multiple Disabilities. Persons with multiple disabilities have more than one impairment, "the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. The term does not include deaf-blindness" (34 C.F.R. § 300.7[c][7], 1999). An important aspect of this definition is the recognition that the effects of multiple disabilities are interactive and not the sum of separate impairments added to one another. The boy in Figure 1.5 has multiple disabilities.

The interaction effects of multiple disabilities can be illustrated through examples. Individuals who have FIGURE 1.4 A boy with diabetes displays his testing kit.



FIGURE 1.5 This little boy has multiple disabilities.



cerebral palsy and mental retardation have motor disabilities associated with their orthopedic impairment, which can compromise their ability to physically perform activities of daily living such as meal preparation. Adaptations to accommodate the physical disability might include using a computer to develop a grocery list and providing directions for others to prepare the meal. However, deficits in memory and sequencing that may accompany mental retardation could hinder the ability to conceptualize the steps in preparing a meal. In this situation, individuals may need training to select from a prepared list of food items and be able to partially participate in meal preparation. Understanding the difference between motor (physical) and discrimination (cognitive) difficulties is critical to planning an appropriate educational response for individuals with multiple disabilities.

Traumatic Brain Injury. A *traumatic brain injury* (TBI) is defined as:

an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma. (34 C.E.R. § 300.7[c][12], 1999)

This definition clearly reflects variability in the nature and degree of impairment in persons who have sustained a TBI. In 1990 TBI was recognized as a separate disability category in PL 101-476, highlighting the requirement for appropriate services for this population of individuals.

The federal definitions of orthopedic impairment, other health impairment, multiple disability, and traumatic brain injury are not mutually exclusive. TBI is a good example of the dynamic in which disabilities can occur in combinations. An individual who has experienced a TBI may have orthopedic impairments resulting from neurological insults and/or damage to the musculoskeletal system. That individual may also have mental retardation or learning disabilities. There may be sensory damage such as visual or hearing impairments. Appropriate educational services and supports need to address all these issues. Evaluating these definitions makes it clear that students with orthopedic impairments, other health impairments, multiple disabilities, and traumatic brain injury are both heterogeneous and also have common needs.

LEGAL SUPPORTS AND MANDATES

Since the early 1970s, the U.S. Congress has passed numerous laws to protect the civil and educational rights of individuals with disabilities. These federal laws are referred to as *public laws* because they apply to the "public," or population of the United States. Any reference to a public law begins with the letters *PL*, followed by the session of Congress in which the law was passed, followed by a number that indicates the chronological order in which the law was passed. For example, PL 94-142 was the 142nd piece of legislation passed by the 94th Congress. Public laws are placed into codes and regulations that assist in their interpretation. State laws are then enacted to comply with federal legislation, and local education agencies use both federal and state laws to develop educational policy.

Lengthy discussion of legislation is beyond the scope of this chapter. You may want to achieve a deeper understanding of federal legislation from Web-based references at the end of this chapter or by consulting the governmental documents sections of their public or university libraries.

The implications of federal legislation related to special education and supplementary supports and services are numerous and complex. The role of special education teachers to support students with special needs in the least restrictive environment continues to expand into areas of consultation and collaboration with general education teachers. Special education teachers must also provide direct instruction based on individual need, regardless of the educational setting. The impact of learning, behavior, language and communication, and equipment/technology needs of students with disabilities in all school programs heightens the need for professionals with specific expertise. The following section highlights the mandated interface of special and general education related to state standards and assessments.

STATE STANDARDS AND THE GENERAL CURRICULUM

Educational goals for students with physical, health, or multiple disabilities must correspond to their state's standards for meeting general education curriculum goals. Under No Child Left Behind (NCLB), each state identifies its own expected grade-level and end-of-schooling standards, or outcomes, for student learning. These state standards are statements of what students should know or be able to do as a result of their education and also define the content that will be assessed (Nolet & McLaughlin, 2005, p. 5). Each state's curriculum frameworks identify and describe standards and expected student learning outcomes that serve to guide educators to select learning targets and instruction for their students. Standards may be organized by major categories of content and strands (e.g., Reading and Literature) and substrands (e.g., Word Recognition, Analysis and Fluency, Comprehension, etc.).

Content Standards

"[State academic] content standards refer to what gets taught, the subject matter, the skills and knowledge, and the applications" (Nolet & McLaughlin, 2005, p. 5). Every student is expected to show what they know and can do relative to their state/district's academic content standards for the grade level appropriate for their age. A sample fourth-grade content standard is as follows: "Students understand the structure, functions, and powers of the United States local, state and federal governments as described in the U.S. Constitution" (California Grade-Level History/Social Science Content Standard 4.5, www.cde.ca.gov/be/st/ss/hstgrade4.asp). States may provide frameworks (also called strands) and even substrands that assist educators in "unpacking" the standard into units and subunits of study.

Achievement Standards

Achievement standards (also called performance standards) parallel content standards and specify "How good is good enough?" (Marzano & Kendall, 1996, p. 64). State achievement standards set the targets or levels of performance that students must achieve in the content standard. Using the example of the fourth-grade level content standard related to history and social science, a related performance standard is as follows: "Explain the structures and functions of state governments, including the roles and responsibilities of their elected officials" (California Grade-Level History/Social Science Content Standard 4.5, achievement standard 4, www.cde.ca.gov/be/st/ss/hstgrade4.asp).

State achievement standards may be either grade-level achievement standards, modified academic achievement

standards, or alternate academic standards. Modified academic achievement standards are based on grade-level content of the grade in which the student is enrolled and must be aligned with the state's academic content standards for that grade. Alternate achievement standards are reserved for those students with the most severe cognitive disabilities.

Benchmarks Toward Meeting State Standards

Benchmarks assist teachers in determining what students at the various grade levels need to know and be able to do at specified points of times during their grade-level program and at its end and represent milestones that measure students' progress. In some states, benchmarks are used to identify the specific knowledge and skills that students should acquire for that standard by the end of the grade level. Other states use benchmarks to identify milestones in sequences of what students should know and be able to do by a specific point in time.

Indicators/Objectives

Indicators define the various skills and knowledge subcomponents that a student is expected to master. Multiple indicators usually are provided for each benchmark, and separate benchmarks and indicators usually are developed for each grade level.

Assessments

State assessments are divided into two groups: (1) general state assessments in which most of the student body participates, and (2) alternate assessments for those unable to participate in the general assessments. Within the federal regulations (IDEA, NCLB), each state determines guidelines for those students who should participate in alternate assessments. Individual Education Program (IEP) teams identify which students should be included in which state assessment, based on the achievement standards they used for instructional practice. State frameworks provide information and guidance in matters of assessments for IEP teams. Chapter 5 presents curricular options to guide program planning for individual students with physical or multiple disabilities.

Although legislation provides civil rights protections and mandates for educational experiences of individuals with disabilities, it cannot address all concerns. The following section describes issues that are especially important for individuals with physical, health, or multiple disabilities.

CRITICAL ISSUES FOR INDIVIDUALS WITH PHYSICAL, HEALTH, OR MULTIPLE DISABILITIES

The issues of alike/different, visible/invisible, acute/ chronic, service intensity, and educational goals and expected outcomes are especially important for individuals with physical, health, or multiple disabilities. Each of these issues is explored briefly, followed by its implications for teachers. Remember that not all aspects of each issue will apply to every individual, nor can all important issues be addressed in this chapter.

Alike and Different

In most respects, people with disabilities have many of the same interests and life goals as people who do not have disabilities. These goals include education, personal relationships, satisfying careers, and community contributions. However, the presence of disability may have an impact on these goals, necessitating adjustment and adaptation for their successful attainment. Smith (2001) noted that the overemphasis on "sameness" when applied to educational and social needs of persons with disabilities may obscure the supports that are necessary for them to achieve best outcomes (p. 7). Teachers who work with individuals with physical or multiple disabilities need to recognize and appreciate similarities and differences, which will allow them to experience the person without either applying stereotypes or ignoring vital individual needs.

Visible and Invisible

Disability may be obvious or invisible to the observer. When disability is apparent to others, either through some aspect of the body or through use of equipment, the individual with a disability is confronted with the meaning others attach to the disability. The visibility of physical disability necessitates acknowledgment, as well as adjustment to changes in social interaction patterns related to acknowledgment of difference. In his classic work on disability and social identity, Goffman (1963) noted that disability visibility had a profound impact on social encounters. Individuals with visible disabilities have no choice regarding concealment and must make immediate decisions about responding to reactions of others.

Visible disability may generate inappropriate perceptions and reactions by others. For example, individuals with cerebral palsy who may not be able to walk or to use speech for communication may be treated as chronologically younger or intellectually less able by persons who do not know them well. Another factor to consider is disability relevance. Although the disability itself may have no relevance to a particular social encounter, it may become the focus of perception simply because it is *there*. The individual with a visible disability is therefore frequently confronted with managing the reactions of others in social situations.

Goffman (1963) noted that a different series of personal decisions and social encounters occur when a disability is invisible. For example, a person who has epilepsy may choose not to reveal this condition in a casual conversation, either because this disclosure is irrelevant to the interaction or because the individual does not wish to be exposed to potential explanations and possible rejection by acquaintances. In the event of a seizure, however, every participant will be confronted with the condition in an immediate fashion and with no preparation. It is true that knowledge of a disability condition may result in appropriate easing of expectations (restricted physical activity for a person with asthma, for example). However, if the condition remains invisible (e.g., an individual with a cardiac condition does not wish to disclose this condition), the individual may be subjected to unhealthful expectations ("You will run a lap around the track or receive a demerit") or risk rejection by peers ("You are a slacker"). The individual with an invisible disability is challenged by decisions about whether to reveal information that may be held against him or her or not disclose and be subjected to inappropriate expectations.

Teachers who work with individuals with physical or multiple disabilities must not only be sensitive to the dynamics of visibility/invisibility; they must also actively assist students to develop effective social interaction strategies. Effective strategies for managing stress and coping with potentially negative social interactions should be part of a specialized curriculum plan for individuals with physical or multiple disabilities.

Acute and Chronic

When most people think of illness, they conceptualize a period of discomfort and certain symptoms, such as nausea, loss of appetite, gastrointestinal upset, rash, and fever. These conditions are acute. After a period of time (and sometimes with medication or hospitalization), the illness dissipates and the person recovers. Although some acute illnesses can be very serious, they are characterized by resolution in some form. Some conditions do not resolve. These conditions are referred to as *chronic*.

By its definition, chronic illness is not curable. Toombs, Barnard, and Carson (1995) stated that chronic illness is "not simply a discrete episode in the course of a life narrative but rather a permanent feature of that narrative. To live with chronic illness and disability is to live a certain kind of life" (p. xi). Perrin, Bloom, and Gortmaker (2007) define a chronic health condition as a "condition that lasts ≥ 12 months at the time of diagnosis and is likely to have a duration of \geq 12 months" (p. 2755). The impact of chronic illness extends to family, educational experiences, social adjustment, career functioning, and overall quality of life in ways that are profound and lasting. Persons with chronic illness must cope with issues related to the impact of the illness, which may include altered growth and development, managing the trajectory of the illness, illness roles, stigma, altered mobility, pain, social isolation, body image, compliance with medical regimens, coping with fear and grief, receiving care, and sexuality (Lubkin, 1995).

Chronic illness includes conditions such as asthma, diabetes, congenital heart disease, epilepsy, cystic fibrosis, sickle cell anemia, cancer, HIV infection, rheumatoid arthritis, and kidney disease. It is estimated that approximately 7% of children in the United States (more than 5 million children and youth) have chronic conditions (National Center for Health Statistics, 2006). Increases in pediatric chronic conditions stem from the appearance of relatively new chronic conditions such as HIV, improved survival rates in individuals with conditions such as cystic fibrosis and leukemia, and dramatic increases in pediatric asthma (Perrin et al., 2007) and diabetes (Lipton, 2007). Clearly, chronic illness poses major concerns at individual, community, and national levels.

Teachers will encounter the challenges of chronic illness experienced by individuals with physical, health, or multiple disabilities. They must be alert to changes in physical condition that may signal the need for medical treatment. They may need to alter the intensity or amount of coursework to match the fatigue caused by a chronic condition, medication, or medical regimen. Close communication with parents is a necessity. Students may become so ill that they die, at home or even at school. Teachers must be able to support other students, school personnel, and themselves in the grief and coping that follow death. Parallel to all the physical, psychological, and social alterations created by chronic illness, the teacher must strive to provide a learning environment that is as typical and predictable as possible.

Appropriate Accommodation

Federal law mandates that reasonable accommodation be provided for individuals with physical, health, or multiple disabilities in order for them to gain access to those aspects of their lives that may be altered by disability. Accommodations may need to be provided on a longterm or permanent basis. Three types of accommodations especially important for individuals with physical, health, or multiple disabilities are assistive technology, universal design, and illness accommodation.

Assistive Technology. Assistive technology is a critical form of accommodation. The definition of *assistive technology* from the Tech Acts of 1988 and 1994 was incorporated into IDEA as "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability" (20 U.S.C., 1401 § 602 [1]). Assistive technology encompasses many areas, including positioning and mobility, augmentative communication, visual aids, computer access, physical education, leisure, play, self-care, and environmental control.

Although assistive technology is a critical accommodation for individuals with physical or multiple disabilities, Malouf (2001) warned that "introducing technology into education gives the impression of innovation and effectiveness for no other reason than technology is involved" (p. 1). This means that technology used to enhance the lives of individuals with disabilities must be carefully tailored to meet individual needs and not applied in a one-size-fits-all manner. Teachers who provide services to students with physical or multiple disabilities must therefore develop expertise in assistive technology that extends beyond more traditional pedagogy.

When teachers examine all the areas addressed by assistive technology, they will be tempted to wonder whether assistive technology isn't really the specialty of a related-service provider such as a physical or occupational therapist, rehabilitation engineer, adaptive physical education specialist, or speech-language specialist. Although the contributions of these professionals are crucial to successful outcomes for individuals with disabilities, it is the teacher with specialized expertise who provides the instructional link that focuses assistive technology on classroom applications. Because of its importance to meeting the needs of individuals with physical or multiple disabilities, assistive technology is addressed in a separate chapter in this text, and examples of assistive technology are infused throughout all text chapters.

Universal Design for Learning. The key to equal access and participation in society by persons with disabilities is embedded in the concept of **universal design** (UD). The concept of universal design originated in the field of architecture with the goal of designing physical features that simplified life through enhanced usability for all people, not just accommodations for a few. The concept of universal design is contained in seven basic principles:

Principle One: Equitable Use The design is useful and marketable to people with diverse abilities.

Principle Two: Flexibility in Use The design accommodates a wide range of individual preferences and abilities. *Principle Three: Simple and Intuitive Use* The design is easy to understand and, regardless of the user's experience, knowledge, language skills, or current concentration level.

Principle Four: Perceptible Information The design communicates necessary information effectively to the user, regardless of ambient conditions of the user's sensory abilities.

Principle Five: Tolerance for Error The design minimizes hazards and the adverse consequences of accidental or unintended consequences.

Principle Six: Low Physical Effort The design can be used effectively and comfortably and with a minimum of fatigue.

Principle Seven: Size and Space for Approach and Use Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility. (Mace, Principles of Universal Design, version 2.0, Center for Universal Design, North Carolina, 1997)

Although universal design is intended to apply to all people, it has special value for persons with disabilities, and is embedded in legal mandates that prevent discrimination and enhance accessibility (Council for Exceptional Children, 2005). A key component of the Vocational Rehabilitation Act of 1973 was elimination of physical barriers to access and participation by disabled citizens in the United States. Universal design addressed barrier removal for persons with disabilities while creating benefit for all citizens. The Americans with Disabilities Act of 1990 further extended the concept of access to the private sector through the mandate of **reasonable accommodation**.

The concept of UD is embedded in legal mandates for FAPE and the IEP process. Free, appropriate, and public education (FAPE) guarantees that children cannot be denied appropriate and free public education in the least restrictive environment. In IDEA 2004, the concept of appropriate education has been specified to mean access to the general education curriculum that is made available to nondisabled children. The alignment of special education with general education curriculum content further underscores the mandate of zero-reject from the outcomes of independence, participation, and productivity that are achieved through participation in general education (Jackson, 2005). The Individual Education Program (IEP) is used to align general curriculum with specially designed instruction and other supports necessary to enable access to curriculum. The following principles of universal design can be applied to teaching and learning:

- 1. Students with disabilities fall along a continuum of learner differences, like other students.
- 2. Teachers can and do make adjustments for all students, not just those with disabilities.
- 3. Curricular materials should be as varied and diverse as the needs in the classroom.
- 4. Rather than adjust students to learn a specific curriculum, the curriculum should be flexible to accommodate a range of student differences. (Male, 2003, p. 21)

By building accommodations into the design of instructional materials, teachers are provided with "flexible, equitable, and accessible ways to teach" (Council for Exceptional Children, 2005, p. 2). Figures 1.6 and 1.7 show how UD principles and the influence of legislation lead to univeral design for learning (UDL).

Illness Accommodation. One area that requires programmatic sensitivity is illness accommodation. Many situations contribute to decreased school participation, including student absenteeism, pain management, fatigue, and the necessity of following medical regimens during school hours. Although virtually all students occasionally miss school due to illness or doctor appointments, students with physical, health, or multiple disabilities may have multiple and/or prolonged absences that result in the need for special accommodation to maintain school performance. Some conditions are associated with increased pain and/or fatigue. If their disability is invisible, students may be perceived as healthy even when they feel bad or experience fatigue. For example, a student with a severe cardiac condition may appear healthy but experience chest pain and exhaustion after even mild exercise. Reduced performance related to illness, pain, and/or fatigue may result in teacher perception that students are inattentive to activities at school. Finally, some students must follow very strict medical treatments that require absence from class. An example would be the student with diabetes who must test for blood glucose levels

FIGURE 1.6 Part One: Universal design for learning and bringing about change.



Note. From R. Orkwis (2003). "Part One: Universal Design for Learning and Bringing About Change." In Universal Design for Learning: A Guide for Teachers and Education Professionals (2005), p. 16. Council for Exceptional Children. Arlington, VA: Author.

and then administer insulin. Another example would be the student with paralysis who must be excused from class to receive bladder catheterization.

Absenteeism, pain, fatigue, and other situations can all result in reduced performance. Appropriate accommodations include modifying homework assignments, reformulating school absence and grading policies, scheduling rest periods, rescheduling academic instruction or allowing a peer to take notes while a student is out of class, and providing home/hospital instruction. It is important to remember that not all students require all of these accommodations all of the time. Support through accommodations must be individually determined to be effective.

Service Intensity and Personal **Independence** Issues

Individuals with physical or multiple disabilities receive education and related services from many persons. Although the roles of educators, therapists, nurses, and others frequently overlap, services should be provided or supervised by specifically assigned and trained professionals. Consistency of assistance provides important reassurance to students that the persons who assist them are familiar with physical routines and will not harm them. Any of you who have experienced prolonged hospitalization will appreciate the efficiency and security afforded by consistent assistance from a trusted individual.

Peer Assistance. Occasionally a recommendation is made to assign a classroom peer to provide assistance to a student with a disability. Although peers can be very helpful in areas such as note-taking, obtaining materials, and other classroom activities, using peers to feed a friend, push a wheelchair, or provide instruction should be undertaken only after specific training and under adult guidance and for a specified, limited time period. Accidents can happen quickly and leave persistent feelings of guilt and blame. Even under carefully controlled circumstances, peer assistance is not always advisable. When peers are used in the role of assistants, their social interaction changes and may alter friendships available to student with disabilities. In Figure 1.8, a student receives assistance from a peer during an art project. Although she cannot squeeze the glue bottle independently, she can give directions. Taking charge of learning situations is an





Note. From R. Orkwis (2003). "Part Two: Universal Design for Learning in the Changed Environment." In Universal Design for Learning: A Guide for Teachers and Education Professionals (2005), p. 16. Council for Exceptional Children. Arlington, VA: Author

especially important self-advocacy tool for students with disabilities who require physical assistance.

FIGURE 1.8 Self-advocacy is supported when students take charge of learning situations.



Support for Personal Independence. In the area of selfcare, individuals with physical or multiple disabilities may require services beyond developmental and social expectations. For example, assistance may be required in the bathroom or for dressing. The need for intensive and personal assistance means that the person who is disabled must take intellectual and emotional control of situations in which physical control is lacking. This dynamic extends into areas of life management, including experiences such as managing personal assistants, negotiating medical treatment, and so on (Heller, Forney, Alberto, & Schwartzman, 2000). For example, a child may be unable to pull up his or her pants but can tell an assistant when and how this task should be accomplished. If it is not necessary for the assistant to take control (as would be the case with very young children), allowing the child to make decisions supports positive emotional growth.

The issues of service intensity and personal independence have important implications for teachers. First,

18 Part I Impact and Implications of Physical, Health, and Multiple Disabilities

teachers must acquire collaboration skills with personnel representing many disciplines. They must frequently coordinate their educational schedules with others who provide service and assistance. Scheduling must be accomplished with minimal disruption for students and their families and without compromising classroom learning experiences. Second, whoever is assigned to assist students with self-care must do so with the greatest respect for personal dignity and privacy. When physical care must be provided on a level that is more typical for very young children (e.g., wiping the nose, assisting with toilet paper, feeding) it is important not to conceptualize reduced physical performance with immaturity.

As stated earlier, individuals who require personal assistance should receive it from adults specifically assigned and trained for that purpose and upon the request of the individual needing assistance. Besides the need for continuity of assistance and maintenance of dignity, receiving physical assistance and being handled by many different adults can break down boundaries of appropriate and inappropriate handling and place the student at risk for physical injury or sexual exploitation.

TEACHING AND LEARNING ENVIRONMENTS

Teachers who serve individuals with physical or multiple disabilities provide support in a variety of educational systems and must possess specific knowledge and skills. In addition, their roles continue to evolve to include increased collaboration and consultation within education and related disciplines. Finally, they must function as a resource beyond the field of teaching for families and professionals. Contemporary teachers do more than instruct; they are learners, leaders, and advocates.

Educational services for students with physical or multiple disabilities traditionally were aligned with a medical model, which emphasized physical care and attention to specialized health needs. This position was reflected in the locations for their educational service delivery, including hospitals, convalescent homes, and residential facilities for "delicate" children with conditions such as diabetes, poliomyelitis, or pre-tuberculosis (Best, Bigge, & Sirvis, 1990). Segregation of students in separate classes and schools was justified on the basis of centralized therapy and related services, architectural accessibility, and social acceptance by a peer group with disabilities.

Current educational service delivery trends for students with physical, health, or multiple disabilities have broadened to include an array of placement options. Educational service delivery decisions should be made after consideration of the unique needs of students and may involve more than one placement at a time (e.g., general education classes plus specific support in a specialized program or with an assistant). *Special education is what and how teaching occurs, not where teaching occurs.* Sometimes the impact of a disability dictates educational placement, as happens in hospitalization or home instruction. However, instruction must represent the least restrictive educational environment for the specific student in relation to his or her unique needs, abilities, and goals.

Education Service Delivery Systems

Most students with physical or health disabilities are educated in general education class (inclusive) settings with supplementary aids and services as appropriate. General education teachers may be supported through collaborative and consultative services from a special education teacher in order to implement a variety of specific instructional strategies. Students may receive direct services from an itinerant special education instructor, who goes to different schools and provides direct instruction to students in the general education classroom. In a third model, the special education teacher may provide resource services to students with physical, health, or multiple disabilities, either in the general education classroom ("clustering"), or by providing intensive educational support in a separate area ("pull-out") (see Figure 1.9).

FIGURE 1.9 This teacher tries a variety of strategies to stabilize materials so her student can be more independent.



Some students require an educational environment outside of general education classes. They may be taught in **special day programs**, which are classes located on general education campuses with provisions for inclusion with same-age peers. In some cases, students are educated on **special sites** that are separate from general education campuses. Every effort should be made to ensure interaction with non-disabled peers.

With the exception of special sites, the models just described are part of the general education service system. One unique aspect of educating students with physical, health, or multiple disabilities is the existence of options for instruction that are not typical in general education. Students with acute or chronic illnesses may receive instruction in **hospital-based programs**. Hospital-based educators provide direct services in classrooms located in the hospital. For students whose physical conditions makes classroom attendance impossible, teachers work with students at their bedsides. Hospital instruction may require that universal precautions be used, including the use of physical barriers such as surgical gowns, gloves, and masks. If children are in the process of bone marrow transplantation or other procedures that suppress their immune systems, the teacher must scrub before providing services, and educational materials must be sterilized before use. Figure 1.10 describes the experiences of a teacher in a large metropolitan hospital.

Students who are recuperating from recent surgery, or whose condition prohibits school attendance, may be educated through special **itinerancy services at home**. Home teachers are itinerants with a student caseload who maintain contact with students and their assigned classroom teachers to foster successful educational progress and reintegration into the general education program after their health stabilizes.

Instructional systems for students unable to attend a classroom-based program have been changed by the rapid advances in technology and the availability of alternative learning environments. One alternative to home instruction is **distance education**. The teacher makes contact with several students through a school site-based telephone system, e-mail, or the Internet. This model eliminates the travel time and one-to-one

FIGURE 1.10 Thoughts on hospital teaching: Where everything else seems more important than learning.

Hospital teaching fascinates many observers. I can work on a one-to-one basis with my kids, choose my own books and often the classes I teach, develop a close relationship with every student, and fulfill many of their individual needs. I have time to build rapport with families and have access to full medical records. This all leads to quality teaching where individualization, task analysis, and a humanistic approach can flourish.

And then there's the flip side to all this merriment. These kids are sick. That's why they are hospitalized. They often don't feel good and cannot work during the allotted time set aside for them. They may be on strong medication and feel drowsy. Often they are not in the room when you arrive—books, puzzles, laptop in hand. Where are they? They're having a bone scan or an X-ray, perhaps they're getting a new cast, or an MRI, or an EEG. A common phrase I hear is "Come back in a few hours."

Flexibility, empathy, and sensitivity to individual needs are the hallmarks of hospital teaching. If a teacher has an issue with "being in control," hospital teaching is not the place to be. When working in a hospital, the teacher is always in the way. In I walk, materials in hand. I may have to go hunting for something to sit on, seat myself on the side opposite the blood pressure cuff, and watch out for the IV tubing. If the child is in isolation, a mask, gloves, and gown may be in order. Finally, I'm nestled next to the bed with all my equipment and we begin the lesson. All of a sudden a telephone rings, the nurse comes in, the social worker arrives, and the child is transported to whirlpool. "Come back later, Teacher."

The essentials for the traveling classroom vary with the students. If the child is able to write, pens, pencils, markers, paper, and a clipboard are necessities. I cannot leave textbooks with students in case they are discharged and take them home, never to be recovered. Younger and more developmentally delayed children benefit from manipulatives. This can present a transportation problem, and disinfectant spray must be used on toys and books to make this system safe. I try to plan all lessons in conjunction with the child's general education teacher.

In the sad event of a child's passing away, we call the student's home school and communicate with staff personally. I have stopped asking "Why?" and take the attitude that if I can bring a little relief and sunshine to these kids while helping them learn, my role is complete.

As you can see, my milieu is vastly different from the typical classroom setting. Bulletin boards, yard duty, parent conferences, and group lessons do not exist for the bedside hospital teacher. The core knowledge and values for the teaching profession remain the same. Commitment to educational excellence, sensitivity to the needs of individual students, and interpersonal skills assist me to be the best teacher to the children I serve.

Note. Adapted from "Thoughts on Hospital Teaching: Where Everything Else Seems More Important Than Learning," by E. Raikhy, 1998, DPHD Newsletter, pp. 2, 7. Reprinted with permission.

20 Part I Impact and Implications of Physical, Health, and Multiple Disabilities

requirements of home teaching while retaining the advantage of multistudent service and direct, immediate contact. The use of e-mail and the Internet (including school Web postings) adds print output to visual interaction. Students must have corresponding systems to send and receive e-mail, receive and download Internet information, and be down-linked for distance education services. Systems for individual students may be provided by the family, school district, a communication company or agency, or a combination of resources.

Finally, some models of educational service include a primary emphasis on the **community as an educational setting**. For many students with physical or multiple disabilities, the career and vocational aspects of curricula, daily living skills, and leisure pursuits would most appropriately occur in the community.

Educational placement decisions should *always* be based on the unique needs of individual students. It is inappropriate to presuppose that specific service delivery options are linked to disability severity. For instance, one cannot assume that a student with multiple disabilities must be educated in a special day class or separate site. Neither is it appropriate to assume that all students with health impairments are best served in general education settings. Some students are educated in more than one service placement at a time, and placement should change as student need changes. Family members play an integral part in making education placement decisions.

Challenges to Effective Service Delivery

Even after issues of educational service delivery are successfully addressed, many barriers or challenges exist for providing effective education. These may be broadly conceptualized as architectural, tangible, philosophical, and training-based. These barriers are not mutually exclusive, and they can be interactive. For example, renovating bathroom facilities to meet architectural accommodation requirements is a positive step toward physical integration, but it does not address the need for appropriately trained personnel who provide physical assistance to use adapted facilities. Furthermore, if such adaptations are perceived as an encroachment on available bathroom space (as happens when two toilet stalls are combined to provide one wider space or the faculty rest room is used for particular students because it is more accessible), fully adapted bathroom facilities and trained personnel still do not address resentment and possible backlash against integration attempts.

1. Architectural barriers. Architectural and other tangible barriers may be easy to remove if they are obvious and correctable. Installing a ramp, lowering a drinking fountain, and widening a doorway are basic examples. Although federal and state regulatory codes and uniform accessibility requirements provide guidance, and legislation such as the ADA adds legal reinforcement, identifying an architectural accommodation is only an initial step.

2. Tangible barriers. Lack of adequate equipment and lack of service provision are examples of tangible barriers that are logistical. Even when all parties have agreed on materials and services, significant time may elapse before materials arrive or repairs occur. Stories abound in which a wheelchair or other equipment had been ordered but was finally delivered after it was outgrown or a wheelchair had been broken for a year before agency funds were made available for its repair.

Failure to schedule and deliver services when and where they are most needed results in ineffective education. Consider the following situations:

- A general education teacher takes students for an out-of-classroom excursion and fails to leave a message for related-services or special education personnel who were scheduled to work with a student during that time.
- A special education teacher has pulled out students from general education classrooms at the teacher's convenience and ignored the goals of the general education program.
- A student who is fully included and uses a wheelchair for mobility misses an educational excursion because no one remembers to schedule a bus with a lift.
- A teacher has scheduled appointments with parents and others who then failed to honor those appointments.

The consequences of these experiences are wasted time and effort, abandonment of a collaborative education effort, and reduced learning time for students.

Material portability is another tangible barrier to successful school experiences. Augmentative communication devices, mobility devices, therapy equipment, adapted classroom furniture, and other equipment may consume considerable classroom space. In addition, if the student moves between classrooms, such equipment must be moved or duplicated. Some equipment is transported from home to school and back again daily. Equipment must be maintained in proper working order, be moved carefully, and be available where and when it is needed. Preplanning and ongoing communication are key elements in successful use of adapted materials.

Finally, individuals themselves must be able to move through their environments. Students who use wheelchairs must be able to access all parts of the classroom at an equal level to other students. Students may be seated closest to the exit door to decrease class disruption if they must exit the class frequently for health procedures. However, seating in the back of the class should not be a default situation because it is easier for the teacher and does not interfere with furniture arrangement. This constitutes teacher excuses and does not represent accommodations in the best interest of the student.

Accessibility must be provided to all areas of the classroom and the larger school environment. Materials must be placed at a height to facilitate independent access and manipulation. Extra space may be necessary for specialized equipment. If the student moves among classrooms, sufficient passing time must be allowed to avoid tardiness. Failure to provide opportunities for independent movement fosters a sense of failure and helplessness.

3. *Competing philosophies*. Competing philosophies regarding effective educational service delivery can present another barrier. If strong opinions exist about issues such as appropriate educational placement, curricula, discipline, and so on, the immediate educational, social, and vocational needs of the student may be sacrificed to ideology. Development and maintenance of open communication, willingness to come together to listen and compromise, and mutual appreciation of differences form the basis for making effective changes.

Individuals with disabilities require support and services from families and personnel whose tasks and job requirements overlap, but whose goals for the individual may be in conflict. For example, a child may be receiving feeding instruction from an occupational therapist who has established a goal of transition to varied textures and finger feeding. The parent may wish for the child to remain on pureed foods to ensure adequate nutritional intake and ease of feeding. The parents may have developed feeding techniques that the therapist believes are inappropriate. At school, the child is primarily fed by an instructional assistant, who receives conflicting input from both sources. Inevitably, issues of turf arise in multiperson systems and must be resolved through respectful communication and the ability of those involved to look beyond their particular professional roles and activities. Often the teacher must act as a case manager in bringing together all parties for mutual problem solving.

4. *Appropriate training*. After architectural and philosophical barriers are addressed, there remains the critical need for well-trained instructional personnel. Although it is impossible in this text to fully describe the training requirements of all personnel who provide services to individuals with physical, health, or multiple disabilities, teacher competencies merit detailed attention.

TEACHER COMPETENCIES AND EVOLVING ROLES

Teachers who instruct individuals with physical, health, or multiple disabilities must possess specific competencies that encompass instruction, physical management of students and the educational environment, health maintenance, use of assistive technology and augmentative communication, and curricular adaptation (Best, Heller, & Bigge, 2005; Council for Exceptional Children, 1998; Heller, Fredrick, Dykes, Best, & Cohen, 1999; Heller & Swinehart-Jones, 2003). In a national competency survey, special education teachers who lacked concentrations or disability-specific credentials to teach in the physical/ health disabilities area reported that they did not feel well trained or comfortable in providing direct services (Heller et al., 1999). This uncertainty regarding training was shared by special education directors and university personnel. The fact that students with orthopedic disabilities, health impairments, and multiple disabilities are increasingly served in general education programs places greater pressure on teachers who do not have specialized certification to meet the unique educational needs of this population (U.S. Department of Education, 2000).

The evolution toward inclusive educational environments, increased school attendance of children with severe and complex health needs, and the rising prevalence of students with physical disabilities support the importance of teachers having specific competencies for meeting the needs of students with physical, health, or multiple disabilities (Heller et al., 1999; Heller & Swinehart-Jones, 2003). These knowledge and skill areas are related to direct instruction and competencies that allow teachers to fulfill many roles in the field of special education.

Knowledge and Skills

With a growing trend toward less disability-specific teacher certification in special education and increasing placement of individuals with physical, health, or multiple disabilities into general education classrooms, specialist teachers report pressure from their colleagues to respond to questions about curriculum adaptation, assistive technology, postsecondary supports and services, and development of skills for self-determination. Review the 2003 edition of *What Every Special Educator Must Know: Ethics, Standards, and Guidelines for Special Educators*, which is available online from the Council for Exceptional Children (CEC) at www.cec.sped.org. Click on Professional Standards to find this document in pdf format. The CEC standards document includes a common core of essential knowledge and skills for special education teachers, plus specialized knowledge and skills related to disability categories.

In 2003 Heller and Swinehart-Jones grouped the specialized knowledge and skills in the area of physical and health disabilities from the CEC Special Education Content Standards into the following categories:

- Physical and health monitoring and maintaining a safe, healthy environment
- Adapted and specialized assessment and evaluation
- Modifications and assistive technology
- Specialized instructional strategies
- Disability-specific core curricula
- Setting the affective and learning environment

Several of these specialized knowledge and skills are addressed in Chapter 5, where they are called Essential Knowledge and Skill Domains for Personal Self-Reliance.

Professional Roles

Teachers of individuals with physical or multiple disabilities must be prepared to fulfill several educational and service roles. Not only do they provide direct instruction, they frequently collaborate with relatedservices personnel in the implementation of goals and objectives that are derived from their assessment. An increasingly important role is consultation to teachers in general education, where specialist teachers are perceived as the necessary link for specialized instruction, resources, and information.

Direct Instruction and Collaborative/Consultant Roles.

This text devotes several chapters to adaptations and instructional strategies for teaching core academic subjects and essential knowledge and skills to students with physical or multiple disabilities. In addition to providing direct instruction to students, teachers must be prepared to provide other direct and indirect services. For example, the specialist teacher might be asked to adapt assessments and provide information about making accommodations and/or modifications regarding the student's learning environment. Figure 1.11 highlights questions that teachers with specialized training in physical or multiple disabilities might be asked by other personnel.

Collaboration and a transdisciplinary approach are necessary for effective service provision. Figure 1.12 shows students receiving services from a physical therapist, a school nurse, and an adapted physical education specialist. These services may be provided by professionals who work at the school site where students receive their services or who travel to several different school sites. In some cases, the students may be transported to another school site to receive therapy. If students must receive therapy services away from their school sites, it is more desirable to do so on an outpatient basis before or after school hours rather than travel during the school day.

FIGURE 1.11 Questions to ask the consultant/teacher specializing in physical, health, or multiple disabilities.

Consultant/Teacher in Physical/Health Disabilities: This consultant/teacher has specialized knowledge in meeting the educational needs of students with physical and health disabilities. Some areas of expertise include: curriculum modification and design; assessment and evaluation adaptations; instructional techniques and modifications; arranging and adapting the learning environment; use of assistive technology and augmentative communication systems; instructing students in physical health care procedures; implications and implementation of the student's individual health plan; and interpreting, relaying, and implementing information from medical and related service reports.

GENERAL QUESTIONS REGARDING THE AREA OF PHYSICAL/HEALTH DISABILITIES What is the current educational definition of students with physical or health disabilities? What are the criteria for a student to be considered to have a physical or health disability? What are the service delivery options for students with physical or health disabilities? What are the laws and policies related to providing specialized health care in educational settings? What are the roles and responsibilities of all the team members? What additional resources and information are available to address the needs of students with physical/health disabilities?

(continued)

FIGURE 1.11 Continued

IGURE 1.11 Continued
QUESTIONS REGARDING THE CHARACTERISTICS OF THE PHYSICAL/HEALTH DISABILITY What do I need to know about the student's physical/health condition? Is the physical/health condition progressive or terminal? Are there possible emergency situations that can occur? What do I need to watch for and do? Are there any activity or diet restrictions? Are there any medication side effects or treatment effects that will affect the student's learning? Will the student fatigue easily and need rest breaks? Will the student faction predispose him or her to frequent absences? Will the student need assistance to do certain activities or require assistive devices? Does the student have any additional disabilities (e.g., cognitive, sensory)?
QUESTIONS REGARDING THE IMPACT OF THE PHYSICAL/HEALTH DISABILITY ON LEARNING Has the physical/health condition impacted the student's quantity and quality of life experiences? Has the physical/health disability affected concept development? How does the physical/health condition impact the student's learning? How can I enhance the student's learning? What types of technology and assistive devices does the student require to enhance learning?
QUESTIONS REGARDING STUDENT EVALUATIONS What pertinent information do I need to know from the medical evaluation(s) and related service evaluation(s)? Could the student's physical/health disability interfere with the accuracy of certain educational and psychological evaluations? Does the student require an alternate form of response (e.g., AAC device, pointing, eye gaze)? What are the following specialized assessments and their implications for instruction: adaptive technology assessment? augmentative/alternative communication assessment? movement and mobility assessment?
QUESTIONS REGARDING THE LEARNING ENVIRONMENT How does the learning environment need to be adapted to accommodate the needs and abilities of students with physical or health disabilities? How do I promote a positive environment for the student with a physical/health disability? What are the implications of the individual health care plan and how is it integrated into daily programming? How are the activities of the related service personnel coordinated to maximize direct instruction time? What are the optimal positioning options for the student and the material? How is the adaptive equipment used to facilitate positioning, mobility, communication, and learning? How do I maintain universal precautions in the classroom? How do I address the needs of a student with a chronic illness or terminal illness?
QUESTIONS REGARDING CURRICULUM CONTENT AND INSTRUCTIONAL STRATEGIES What type of curriculum is being provided for the student (e.g., identical, parallel, lower grade level, functional)? Will the student's curriculum include expanded content areas in addition to the regular curriculum? Does the student require modifications to instruction, material, or curriculum? What instructional techniques will be most helpful to this student? What adaptations and assistive devices are needed for the student to benefit from the lesson? How can the instructional lesson be adapted to minimize physical exertion? How can the instructional lesson be adapted to allow the student to actively participate? How will the student ask questions?
QUESTIONS REGARDING ASSIGNMENTS AND TESTS How do I modify tests for the student? How do I modify assignments for the student? How do I grade the student's work?

Note. From "Questions to Ask the Consultant/Teacher Specializing in Physical and Health Disabilities," by K. W. Heller, in Including Learners with Special Needs Related to Hearing, Physical/Health, or Vision in All Classrooms, by M. R. Byrne, S. R. Easterbrooks, A. R. Powers, M. K. Dykes, K. W. Heller, S. J. Best, C. Holbrook, R. C. Davidson, and A. L. Com. Presentation at the conference of the Council for Exceptional Children, Salt Lake City, Utah, April 1997. Reprinted with permission.

24 Part I Impact and Implications of Physical, Health, and Multiple Disabilities

FIGURE 1.12 Children receive related services from (a) a therapist, (b) a school nurse, and (c) an adapted physical education specialist.



(a)



(b)



Bigge and Stump (1999) have provided an extensive description of personnel who typically provide services for students with disabilities in educational and community settings (see Figure 1.13). Descriptions of several of these professionals (e.g., occupational therapist, physical therapist, augmentative and alternative communication specialist, inclusion specialist) reveal the complementary nature of their roles. Therefore, it is important to compare the roles of related-services personnel with that of educators who serve individuals with physical or multiple disabilities.

Therapists cannot take the place of professional educators, even though they assist in equipment modification and training that increases functional skills in educational settings. Conversely, educators cannot provide direct therapy services, although they frequently follow through on therapeutic management regimens established by occupational therapists and physical therapists. The emphasis on collaboration is particularly critical for meeting support in all areas of functioning for individuals with physical, health, or multiple disabilities.

The personnel descriptions listed in Figure 1.13 are not presented in order of their importance, but to illustrate the intensity of service needs. Certain service providers may at some times play a greater role than others, depending on student needs. Figure 1.14 identifies key questions specific to the needs of individuals with physical or multiple disabilities that general and specialist teachers could ask select members of the educational team.

Resources. Teachers who serve individuals with physical, health, or multiple disabilities must possess critical skills in direct service and interaction with other personnel. However, they cannot reasonably expect to master all aspects of education and support. Filling the gap between one's current knowledge base and needed information can be met through resourceful exploration and lifelong learning. Being resourceful means that teachers need to think beyond the classroom, and educate themselves and others through information related to disability, parent resources, education, community agencies, and other services. Teachers have many opportunities to gain additional expertise through resources provided by expanding technology. One of the most useful resources available to educators is the Internet. At the conclusion of every chapter, several specific organizations are profiled in the section titled "Focus on the Net." However, teachers and others should use caution when gathering information from Web sites, because not all Web-based material is accurate. It is best to consult sites that are current, valid, and professionally supervised, such as those from recognized health agencies or governmentsponsored institutions.

FIGURE 1.13 Related services personnel in education systems.

- **Special Education Teacher.** An educator who is qualified to design and provide instruction to students with disabilities and "has met . . . approved or recognized certification—that applies to the area in which he or she is providing special education" (34 C.F.R. §300.15).
- **Resource Room Teacher.** An educator who provides resource room instruction for individuals with disabilities by either pulling students out of a general education class for one or more hours/periods a day to receive this support in a special education resource classroom, or by working in general education classrooms; may also serve as collaborator with general education teachers for arranging modifications in general education classrooms.
- Itinerant Teacher. "A teacher or resource consultant who travels between schools or homes to teach or [to] provide instructional materials" (Esterson & Bluth, 1987, p. 148) to students with disabilities.
- **Speech-Language Pathologist.** "A professional who evaluates and develops programs for individuals with speech or language problems" (Anderson, Chitwood, & Hayden, 1990, p. 220).
- Occupational Therapist. A professional who delivers "activities focusing on fine motor skills and perceptual abilities that assist in improving physical, social, psychological, and/or other intellectual development; e.g., rolling a ball, finger painting" (Anderson, Chitwood, & Hayden, 1990, p. 218).
- Augmentative and Alternative Communication Specialist. A specialist who is qualified to meet the needs of individuals who have communication difficulties and who will benefit from special educators and speech-language pathologists providing services that prepare them to use augmentations and alternatives to speaking and writing.
- **Physical Therapist.** A professional "primarily concerned with preventing or minimizing [motor] disability, relieving pain, improving sensorimotor function, and assisting an individual to his or her greatest physical potential following injury, disease, loss of body part, or congenital disability" (Esterson & Bluth, 1987, p. 79).
- Audiologist. "A nonmedical specialist who measures hearing levels and evaluates hearing defects" (Esterson & Bluth, 1987, p. 147).
- Educational Psychologist. A professional with expertise in test administration and interpretation; may also have expertise in counseling and working with students in crisis situations.
- District Special Education Administrator or Coordinator. A professional who oversees special education programs in a school district; may assist with assessment, attend IEP/ITP meetings, and provide teacher support.
- **Diagnostician.** A professional with expertise in test administration and interpretation; the term may be used interchangeably with *educational psychologist*, although an educational psychologist's role generally requires skills beyond assessment and its interpretation.
- Inclusion Specialist/Inclusion Facilitator. A professional prepared in a special education field (e.g., learning disabilities) who manages programs of students participating in inclusion programs; responsibilities range from consulting with general education teachers to team planning and co-teaching with general education teachers in inclusion settings.
- Educational Therapist. A professional who works with individuals who exhibit learning problems and is also skilled in formal and informal assessment procedures, synthesizing assessment findings, developing and implementing remedial programs and strategies for addressing social and emotional aspects of learning problems. The educational therapist also serves as a case manager, and builds and supports communication links among the individual, family, school, and other professionals (Association of Educational Therapists, 1982).
- Orientation and Mobility Specialist. A specialist who prepares individuals who are visually impaired or blind to "orient themselves to their environments and move about independently" (Hazekamp & Huebner, 1989, p. 113).
- Adapted Physical Educator. A person who designs and carries out "a physical education program that has been modified to meet the specific needs" of students with disabilities (Anderson, Chitwood, & Hayden, 1990, p. 211).
- Social Worker. "In an educational context, a school social worker provides a link between school personnel and the families of . . . children [with disabilities] through activities such as individual pupil evaluation, parent interviews, and contact with community support services" (Anderson, Chitwood, & Hayden, 1990, p. 220).
- **Counselor[s].** "Qualified social workers, psychologists, guidance counselors, or other qualified personnel [who work to] . . . generally . . . improve a child's behavioral adjustment and control skills in order to make the child more available for participation in the educational program" (Esterson & Bluth, 1987, p. 27).
- Rehabilitation Counselor. An accredited counselor who assists individuals with disabilities in making transitions from school to work.

Note. From *Curriculum, Assessment, and Instruction for Students with Disabilities* (1st ed.), by J. L. Bigge and C. S. Stump, © 1999, Belmont, CA: Wadsworth. Reprinted with permission of Wadsworth Publishing, a division of Thomson Learning. Fax 800 730–2215.

FIGURE 1.14 Questions to ask select members of the educational team for students with physical, health, or multiple disabilities.

CONSULTANT/TEACHER IN PHYSICAL AND HEALTH DISABILITIES

This consultant/teacher has specialized knowledge in meeting the educational needs of students with physical and health disabilities. (See earlier description).

PHYSICAL THERAPIST (PT)

The physical therapist provides essential information regarding the optimal physical functioning in instructional activities, especially as they relate to gross motor skills and mobility.

Types of questions to ask the physical therapist:

Is the student properly positioned for this activity?

Is the adaptive positioning equipment being used correctly?

How do we safely help the student to move from area to area?

Are we using correct lifting and transferring techniques?

Are the splints/orthosis being properly applied?

OCCUPATIONAL THERAPIST (OT)

The occupational therapist provides essential information regarding physical functioning in instructional activities, particularly as they relate to fine motor skills, visual-motor skills, and self-care activities.

Types of questions to ask the occupational therapist:

How can we improve the student's handwriting?

What is the best placement of this material?

How can we best promote dressing skills?

What feeding techniques are most appropriate to encourage eating and feeding?

Are the hand splints being properly applied?

What is the most appropriate adaptive equipment for this activity?

SPEECH AND LANGUAGE PATHOLOGIST (SLP)

The SLP provides essential information in speech and language. Depending upon the SLP's background, the SLP may also have expertise in augmentative communication and feeding skills.

Types of questions to ask the speech and language pathologist:

What forms of communication does the student have?

Will the student's speech improve?

What do I do if I cannot understand what the student is saying?

Are alternative forms of communication being used?

How do you program the augmentative communication device for instruction?

NURSE

The nurse provides vital information for the educational team concerning students' physical and medical conditions and their effects on the students' educational programs. The nurse can also provide information on specialized health procedures. Types of questions to ask the nurse:

What type of physical/health condition does the student have?

What do I need to know about the student's physical/health condition?

What are the side effects of the medications the student is taking?

What is the individualized health plan for the student?

What health care procedures are being done at school?

PARENT AND CHILD

The parent(s) and child are critical members of the educational team who provide important information regarding history, goals, and objectives.

Types of questions to ask the parent and/or child:

What do we need to know about your child's (or your) condition?

How has your child (or how have you) liked school so far?

What has worked well for your child (or you) in school?

What are some of the problems found by your child (or you) at school?

How do you think these problems could be eliminated?

What goals are most important for your child (or you) to learn?

Does the physical or health disability interfere with doing homework?

Are there typically a lot of absences due to the physical/health disability?

Note. From "Questions to Ask the Consultant/Teacher Specializing in Physical and Health Disabilities," by K. W. Heller, in *Including Learners with Special Needs Related to Hearing, Physical/Health, or Vision in All Classrooms,* by M. R. Byrne, S. R. Easterbrooks, A. R. Powers, M. K. Dykes, K. W. Heller, S. J. Best, C. Holbrook, R. C. Davidson, and A. L. Corn. Presentation at the conference of the Council for Exceptional Children, Salt Lake City, Utah, April 1997. Reprinted with permission.

Chapter 1 Understanding Individuals with Physical, Health, and Multiple Disabilities 27