SERVING STUDENTS WITH NEUROLOGICAL DISORDERS:

A MANUAL FOR EDUCATORS

By

Maryann Beal

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and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Education

_____ Date: 3/30/06
James C. Chalfant

_____ Date: 3/30/06
Margaret V. Pysh

_____ Date: 3/30/06
S. Mae Smith

Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copies of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

_____ Date: 3/30/06
Dissertation Director: James C. Chalfant

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DEDICATION

To all the students, families, school personnel, and professionals in the medical community I have worked with who continue to challenge and change the field of education.

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ABSTRACT

During the past 20 years, the number of children and youth with neurological disorders attending schools has increased dramatically. There are two reasons for this increase. First, medical advances have resulted in more children and youth with neurological disorders surviving. Second, in the past, children with disabilities and health care needs were cared for in hospitals and residential institutions. Since 1975, however, federal legislation has mandated that all children with disabilities be provided a free appropriate public education in the nation's schools and in general education classrooms whenever possible.

Unfortunately, school administrators and classroom teachers are not trained in how to accommodate students with neurological disorders. The medical literature provides information regarding the medical aspects of neurological disorders. However, neither the medical literature nor the educational literature provides the specialized knowledge and skills administrators and teachers need to plan for and provide appropriate educational and health related services to children with neurological disorders. This dissertation addresses the need to provide teacher and administrators with practical information about accommodating students with neurological disorders in schools.

The purpose of this project was to develop a resource manual which describes the impact of students' neurological disorders on their education. This "user-friendly" resource manual can be used by teachers, administrators, and support staff in developing individualized educational programs for children and youth with neurological disorders. The manual focuses on six neurological disorders about which school personnel have

limited knowledge. Section One includes a historical overview of the education of children with neurological disorders and the legislation which mandates that schools must provide all children with disabilities an appropriate education. Section Two describes each neurological disorder by presenting the definition of the disorder and its associated physical and cognitive conditions. Section Three addresses accommodations teachers can use in classrooms to meet the individual physical, cognitive and health care needs of these children.

CHAPTER 1

INTRODUCTION

Over the past twenty years, an increasing number of students with neurological disorders have been attending public schools (Best, Heller, & Bigge, 2005). A combination of medical advances, changing educational philosophies, legislation, and litigation has led to an increase in the number of children and youth who are assisted by medical treatment and technology and attend schools in their home communities (Heller, Fredrick, Best, Dykes, & Cohen, 2000). Chapter I is an introduction to the education of students with neurological disorders in public schools. The introduction includes an overview of the characteristics of students with neurological disorders, the components of educational programs to meet the needs of these students, and the challenges for public schools. A statement of the problem, the purpose of the project, and the limitations of the project are included.

Characteristics of Students with Neurological Disorders

Children with neurological disorders are an extremely varied population (Best, et al., 2005). Even if general terms were used, describing them with a single set of characteristics would be impossible. The physical disabilities range from mild to moderate to severe. Some children with neurological disorders are extremely restricted in their activities and intellectual functioning, others have no major limitations on what they can do or learn (Hill, 1999). Some appear entirely normal and others have highly visible disabilities. They may have a single impairment or a combination of disabilities and have lived with the disorder since birth, or have acquired the disorder recently. Some

disorders are always present, while others occur intermittently. The severity of disorder may increase, decrease, or remain the same over time (Heller, 2004; Cohen, 2000).

Components of Educational Programs

Students with neurological disorders are educated in general education classrooms, in special education classrooms located on general education campuses, and in special schools separate from general education classes (Best, Hemsley, & Best, 1986). Some students benefit from placement in general education classrooms, accessing the general education curriculum, with minimal educational accommodations or environmental modifications (Best et al., 2005). The complex health care and learning needs of other students often requires a coordinated array of multiple specialized instruction, therapy, and related services (Bigge, Stump, Spagna, & Silberman, 1999). Even after issues of where to deliver the educational services are addressed, many challenges exist for providing effective instruction. Careful planning involving administrators, teachers, support staff, and parents is needed to ensure the educational and health care needs of students with neurological disorders are met while attending school.

An appropriate educational program for students with neurological disorders often requires modifications to the classroom environment, use of specialized teaching techniques, assistive devices for communication and mobility, and the provision of health related services (Heller, 2004). In addition to access to the general education curriculum, students may need both a parallel curriculum and instruction on ways to cope with their disabilities. The parallel curriculum includes specialized teaching techniques and equipment to increase independence, the self-administering of health care routines, and

learning self-advocacy skills (Bowe, 2000). When developing educational programs to meet the needs of these students, the manner in which a particular condition may affect a child's development, learning, and behavior must be considered.

In addition to the educational and environmental accommodations and modifications, the school staff need to be aware of possible medical complications and emergencies which may arise in the classroom or on the school campus. School personnel need to know how to manage these situations effectively and when and how to seek assistance (Mukherjee, Lightfoot, & Sloper, 2000).

Challenges for Public Schools

Educators and administrators are challenged with developing appropriate programs to meet the educational and medical needs of students with neurological disorders. Teachers have basic curricular knowledge and strategies for effective instruction. Special and general education teachers and support staff, however, need additional specialized knowledge and skills to plan for and provide appropriate educational services and school health related services. Specialized knowledge and skills encompass understanding a variety of neurological disorders and the implications those impairments have on students' functioning. School personnel have knowledge of legal mandates for providing special education services, but also must understand the legal mandates for providing supplemental supports and services (Best et al., 2005). Teachers, administrators, and support staff benefit when they obtain skills used for interacting successfully with personnel from many disciplines, including therapists, doctors, nurses, specialists, and others within the school district and among community agencies (Bigge et al., 1999). It

is critical for educators to have the specialized knowledge required and empathy to work with families who may be coping with multiple sources of stress, frequent hospitalizations, multiple medical appointments, and perhaps with terminal outcomes (Best et al., 2005).

Heller, Forney, Alberto, Schwartzman, & Goeckel (2000) assessed the perceived competencies of special education teachers who taught students with physical and health impairments. Questions developed for this study were derived from the CEC standards in physical and health disabilities. Over 40% of the 503 certified special education teachers indicated they were not well trained on about half (11 of 23) of the competencies. Teachers reported they were not trained in: (a) developing assistive technology plans; (b) instructional modifications; (c) teaching medical self-management skills; (d) integrating health care plans into students' daily programming; (e) strategies for working with chronically ill and terminally ill students and families and; (f) participating in trans-disciplinary team activities.

Including students with neurological disorders in public schools has raised several controversial issues. These issues center on the extent of responsibility assumed by school districts, teachers, and support staff. Procedures such as tube feeding, suctioning, colostomy care, ventilator management, clean intermittent catheterization, administration of oxygen, and administration of medication are now commonly provided in schools (Heward, 2003). Some educators, support personnel, and administrators believe such services are medical and should not be the school's responsibility. In addition, the expense of such services, along with the training and supervision of school personnel

pose potential problems for school districts. Assistive devices and therapeutic services pose concerns similar to the issues surrounding health care procedures. The cost, responsibility for training, and supervision continue to be controversial issues in the education of students with neurological disorders (Heward, 2003).

Statement of the Problem

The number of children and youth with neurological disorders has rapidly increased over the last 20 years (Best et al., 2005). Unfortunately, the public education system in the United States has not been able to provide sufficient services to meet the educational and health care needs of students with neurological disorders. A shortage of specialists within the public schools trained to develop and implement education programs to meet the needs of students with neurological disorders continues to exist. General education teachers are not trained in how to accommodate students with neurological disorders in their classrooms (Hill, 1999).

Purpose of the Project

The purpose of the current project was to develop a manual for teachers, administrators, and support staff to utilize when developing education programs to accommodate students with neurological disorders within the general education classroom and school campus.

Rationale for the Project

Professional medical literature provides school staff with current information regarding the health conditions of students, but teachers, support personnel, and administrators are seldom provided with applied information which can easily be

translated into an education setting. School personnel need a manual which describes the impact of students' neurological disorders on their education and to assist in translating medical information into appropriate individualized educational programs. The manual will serve as a resource for teachers, support personnel, and administrators. School personnel can use the manual when developing and implementing individualized programs with accommodations to meet both the educational and medical needs of students with neurological disorders while attending school.

Limitations of the Project

Many children and youth with special health care needs confront educators in the public schools. This project, however, was limited to the physical cognitive, and education impact of six neurological disorders about which school staff have limited or no knowledge. Although the literature on the medical implications of these disorders is readily available, there is little or no information in the literature addressing the educational impact of these neurological disorders in children and youth in school. The writer's own experience as a special education teacher for 20 years and as an Education Specialist in a medical clinic is both a limitation and a strength of this project. In the absence of literature on educational strategies, the writer had to rely on her own knowledge of educational accommodations and adaptations. This manual is a beginning to developing a "user friendly manual" for school personnel.

Definition of Terms

Adaptive Equipment – specialized devices used to help an individual perform an activity. Such equipment can assist in providing the individual with proper positioning, mobility, movement, or to accomplish specific goals (Downing, 1996).

Augmentative and alternative communication device – specialized devices to promote communication through symbols, pictures, or words (Downing, 1996).

Individualized Education Program (IEP) – a written plan developed, reviewed, and revived for each student with a disability, ages three to twenty one, based on an evaluation of the student. The Federal law specifies the content of an IEP, the factors to consider when developing the IEP, and the members of the team who develop the IEP (Turnbull, Turnbull, Shank, & Leal, 2003; Individuals with Disabilities Education Improvement Act, 2004).

Individualized Health Care Plans (IHP) – a document which "outlines the special health care needs, goals and strategies needed to maintain and or improve student health, and increase student participation in education programs" (Porter, Haynie, Bierle, Caldwell, & Palfrey, 1997, p. 381).

Least Restrictive Environment – "to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and that special classes, separate schooling or other removal of children with disabilities from the regular education environment

occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (Individuals with Disabilities Education Improvement Act, 2004).

Medically fragile students – students who have a temporary medical crisis, students who are consistently fragile, or students whose health continues to deteriorate to a life threatening point (Caldwll & Sirvis, 1991).

Medical Services (in education settings)- services which are diagnostic and evaluative and provided by a licensed physician to determine a student's medically related disability which results in the student's need for special education and related services (Porter, et al., 1997; Individuals with Disabilities Education Improvement Act, 2004).

Multiple disabilities – term used to describe students with two or more disabilities which significantly affect their ability to function. The combination usually results in an interactional effect, rather than a simple additive one (Best, et al., 2005; Individuals with Disabilities Education Improvement Act, 2004).

Nurse Practice Act – regulations passed by each state legislature to address the power and authority of the practice of nursing. The Act addresses the definition and scope of nursing practice, qualifications for nursing specialists, accountability for nursing practice, and accountability for nursing tasks delegated but supervised by nurses (Porter et al., 1997).

Orthopedic Impairment – term used to describe an individual with a severe orthopedic impairment that adversely affects a child's educational performance. The orthopedic impairment can be caused by congenital anomaly, disease, and other causes such as cerebral palsy (Best, et. al., 2005; Individuals with Disabilities Education Improvement Act, 2004).

Other Health Impairment – term used by educators to describe individuals with "limited strength, vitality, or alertness including a heightened alertness to environmental stimuli, that results in limited alertness to the education environment due to chronic or acute health conditions such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle call anemia, hemophilia, epilepsy, lead poisoning, leukemia or diabetes that adversely affects education performance" (Individuals with Disabilities Education Improvement Act, 2004).

Related Services – services in schools which augment and support students' special education program. Such services include "transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education." Service areas identified under this term encompass speech pathology; audiology; psychological services; physical and occupational therapy; recreation, including therapeutic recreation; early identification and assessment of disabilities in children; counseling services, including rehabilitation counseling; medical services for diagnostic or evaluation purposes; school health services; social work

services; and parent counseling and training (Individuals with Disabilities Education Improvement Act, 2004).

Students with specialized health care needs- students requiring specialized health care procedures for life support and/or health support during the school day (Council for Exceptional Children, 1988).

Supplementary Aids and Services – "aids, services, and other supports that are provided in regular education classes or other education related settings to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate" (Individuals with Disabilities Education Improvement Act, 2004).

School Health Services – services provided by a school nurse or other qualified person (Porter et al., 1997).

School Nurse Services – services provided by a qualified school nurse, designed to enable a child with a disability to receive a free and appropriate public education as described in the child's IEP (Individuals with Disabilities Education Improvement Act, 2004).

CHAPTER 2

LITERATURE REVIEW

Introduction

A review of the literature was conducted regarding the education of students with neurological disorders. This chapter summarizes the literature relevant to the: (a) Historical Overview of Educating Students with Neurological Disorders; (b) Overview of Legislation for Individuals with Disabilities; (c) Overview of Litigation; (d) Regulations, Standards, and other Laws; and (e) Families of Children with Neurological Disorders.

Historical Overview of the Education of Students with Neurological Disorders

Many children with neurological disorders who in the past would have been cared for in hospitals or residential institutions are now living at home and integrated into local public schools (Hill, 1999). Until the 1990's, attendance at school was uncommon for most children and youth with neurological disorders. Walker and Jacobs (1985) traced the trends in providing services to such students and found two factors contributing to children and youth not receiving a public school education. The first factor was unsophisticated medical practices causing high mortality rates. In 1890, approximately 20% of children died before reaching the age of two and 50% did not live to adulthood. In addition to the high mortality rates, individuals who were different or disabled tended to be ostracized.

Throughout the first half of the 20th century, increasing numbers of children with neurological disorders, considered as mildly involved by today's standards, were able to return to school (Best et al, 2005). Childhood survival rates continued to rise due to medical advances in treatment and prevention of diseases and new surgical procedures (Connor, Scandary, & Tullock, 1988). Walker and Jacobs (1985) attributed this increase in educational opportunities with the outbreaks of tuberculosis and polio. Epidemics were so widespread that school systems were unable to ignore the survivors (p. 618).

As a result of the tuberculosis and polio epidemics, classrooms in hospitals and sanatoriums became common, as did homebound instruction. When children were allowed to attend their local public schools, the most common placement was in special classes for the "crippled" or "delicate" (Conner et al., 1988). Such classes were segregated from typical classes. At that time, educational placements were typically determined by the medical personnel not affiliated with school districts. Educational decisions to ignore, isolate, and institutionalize children were often based on assumed mental incompetence because of physical disabilities or health impairments (Conner et al., p. 6).

Until the 1950s, special classes, separate schools, instruction in hospitals, and the homes of the children still remained the most common placements for students with mild and moderate neurological disorders (Walker & Jacobs, 1985). Some students attended school in settings sponsored by specific organizations, such as United Cerebral Palsy Association. Often the public school would provide the teachers and the organizations

would provide the buildings and therapy services, such as physical therapy, occupational therapy, and speech therapy (Connor et al., 1988).

Major social changes occurred in the United States from 1960 to 1980 (Walker & Jacobs, 1985). Such changes included the civil rights movement, legislation requiring buildings to be accessible, court cases challenging the segregation of students with disabilities, deinstitutionalization, and the development of innovative rehabilitation programs. Unfortunately, the needs of students with neurological disorders were not addressed. By the 1970s, more children with neurological disorders were beginning to attend public schools, but not their neighborhood schools. Students with neurological disorders with physical disabilities and health care needs were bused to special schools designed to serve students from a wider geographic area (Conner, Scandary, & Tullock, 1988). In general, necessary treatment was provided at home or in hospitals. Schools were not considered responsible for the provision of direct physical or medical care (Caldwell & Sirvis, 1991).

Passage of P.L. 94-142, The Education for All Handicapped Children Act of 1975, changed the situation for many children with neurological disorders, especially those with increasingly more severe physical disabilities and health care needs. P.L. 94-142 mandated that all children ages 3-21 receive a free appropriate education in the least restrictive environment. The Education for All Handicapped Children Act of 1975 impacted educational placement decisions and services for children with orthopedic impairments, health impairments, and multiple disabilities. By providing school personnel with legal definitions of orthopedic impairment, other health impairment, and

multiple disabilities "school districts and school personnel were forced into previously uncharted territories" (Walker & Jacobs, 1985, pp. 615-616). In addition, this legislation defined medical services and school health services. Probably more than any other aspect of the law, "the related services provision transformed the educational environment and changed schools from scholastic institutions into therapeutic agencies" (Palfrey, 1995, p. 265).

In the last 20 years, a gradually increasing number of children and youth with complex neurological disorders have been integrated into public school systems (Heller, 2004). The 24th Annual Report to Congress on the Implementation of Individuals with Disabilities Education Act reported 291,850 students classified under the Other Health Impairment category in 2000-2001. These classified students represented a 397% increase from the total number of students attending public schools under the category of Other Health Impairment during the 1991- 1992 school year (U.S. Department of Education, 2002).

The increase in the number of children and youth with neurological disorders attending public schools has been due in a large part to litigation efforts by parents (Hill, 1999). Many children with neurological disorders who would have been cared for in hospitals and residential facilities in the past are now living at home. They attend their neighborhood schools and many students are integrated into general education classrooms. Current issues revolve around the responsibility being assumed by teachers and school districts in caring for the students' medical and physical needs. Many of the services required by children with neurological disorders currently supplied by school

personnel are the administration of medications, catheterization, and gastrostomy feeding. These services are considered by some school personnel as medical services rather than educational services (Heward, 2003). The extent of responsibility assumed by school personnel and school districts for providing services to meet the physical and health care needs of students with neurological disorders continues to be debated at both the school level and through court cases.

Overview of Legislation for Individuals with Disabilities

Since the early 1970s, numerous laws have been passed by the United States Congress to protect the civil rights and enhance the educational experience of students with disabilities. Major aspects of the pertinent federal laws are presented in chronological order from the time of their passage.

Rehabilitation Act of 1973

In 1973 Congress passed P.L. 93-112, known as the Rehabilitation Act of 1973. This is an important civil rights legislation for people with disabilities including children and youth attending public schools. The Rehabilitation Act of 1973 states in part that "no otherwise qualified handicapped individual shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance" (Rehabilitation Act of 1973). The law's wording identically matched the Civil Rights Act of 1964 which prohibited discrimination based on race, color, or national origin. The Rehabilitation Act of 1973 expanded services to children and adults with disabilities in education, employment, and other settings.

Section 504 of The Rehabilitation Act of 1973 is not a federal grant program like the Education for All Handicapped Children Act of 1975, as it does not provide federal money to assist people with disabilities. Instead, Section 504 imposes a responsibility on every recipient of federal funds not to discriminate against handicapped persons. Recipients of federal funds must provide appropriate accommodations and accessibility for individuals with disabilities to have an equal opportunity to achieve. Some specific accessibility considerations under Section 504 of the Rehabilitation Act of 1975 include removal of architectural barriers, provision of information in accessible formats, and use of augmentative communication and adaptive materials (Hill, 1999).

Students eligible under Section 504 are "individuals who have a physical or mental impairment which substantially limits one or more of the individual's major life activities, have a record of such impairment, or are individuals who are regarded as having such impairment" (Rehabilitation Act of 1975). Section 504 regulations define major life activities as "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working" (Rehabilitation Act of 1975). The definition of an individual with a disability under Section 504 is broader than the definition under education legislation. For a student to receive services in an educational setting under Section 504, the individual's disability does not have to limit the major life activity of learning. The student's educational performance may be at grade level. The student's disability could limit other major life activities such as caring for one's self, walking, or breathing (Janz, Beyer, Schwab, Anderson, Caldwell, & Harrison, 2003).

Education for All Handicapped Children Act of 1975

The Education for All Handicapped Children Act of 1975, also known as P.L. 94-142 is considered landmark educational legislation. The passage of P.L. 94-142 marked the culmination of efforts of numerous parents, advocates, educators, and legislators to bring together one comprehensive law regarding the education of children with disabilities (Heward, 2003). The Education for All Handicapped Children Act and subsequent reauthorizations affected every school in the country and continues to impact the roles of general and special educators, school administrators, parents, and students with disabilities.

P.L. 94-142 primarily impacts states, which are responsible for providing education to their citizens. The majority of the rules and regulations defining how the law operates are related to six major principles which have remained unchanged since 1975 (Turnbull & Turnbull, 2001). The first principle is the provision of a **free appropriate public education (FAPE).** All children with disabilities regardless of the type or severity of their disability shall receive a free, appropriate public education. Education must be available at public expense, without cost to the students' parents. An individualized education program (IEP) must be developed and implemented for each student with a disability. The IEP is individually designed to meet the student's unique needs (Education for All Handicapped Children Act of 1975).

The second principle is **nondiscriminatory identification and evaluation.** School personnel must use nonbiased, multi-factored methods of evaluation to determine whether a child has a disability and, if so, whether special education is needed. Testing

and evaluation procedures must not discriminate on the basis of race, culture, or native language, and tests must be administered in the child's native language. Identification and placement decisions cannot be made on the basis of a single test score (Heller, 2004).

The **least restrictive environment (LRE)** provision is the third principle. P.L. 94-142 mandates that students with disabilities be educated with children without disabilities to the maximum extent appropriate. Students with disabilities are only removed to separate classes or schools when the nature or severity of their disabilities prevents them from receiving an appropriate education in a general education classroom with supplementary aides and services (Heward, 2003). The principle of least restrictive environment created a presumption in favor of inclusion in the general education classroom. To ensure students with disabilities are educated in the least restrictive environment appropriate for their needs, school districts must provide a continuum of placement and service alternatives (Walker & Jacobs, 1985).

Zero reject is the fourth principle of P.L. 94-142. The zero reject provision requires school districts to educate all children with disabilities. This principle applies to all students with disabilities, regardless of the nature or severity of the disability. No child with disabilities may be excluded from a public education (Heward, 2003).

The fifth principle is **due process safeguards**. Schools must provide due process safeguards to protect the rights of children with disabilities and their parents. Parental consent must be obtained for the initial and all subsequent evaluations and placement decisions regarding special education. When the school personnel and parents disagree on the identification, evaluation, placement, or special education and related services for

the child, the parents may request a due process hearing. States are also required to offer parents the opportunity to resolve the matter through mediation by a third party before holding a due process hearing (Rapport, 1996).

Parent and student participation is the sixth and final principle of P.L. 94-142. Personnel in schools must collaborate with parents and students with disabilities in the design and implementation of special education services. The parents and, whenever appropriate, the students' input and wishes must be considered in the Individual Education Program (IEP) goals and objectives, related service, and placement decisions (Turnbull & Turnbull, 2001).

Passage of P.L. 94-142 changed the education situation for many children with neurological disorders, particularly those with an increased severity of physical and medical needs. The law and subsequent reauthorizations mandated services be provided for many groups of students, including those who were orthopedically impaired and other health impaired. P.L. 94-142 and subsequent reauthorizations emphasized the importance of the provision of related services to assist in the removal of potential barriers to the successful inclusion of students with neurological disorders into general education classrooms and campuses (Palfrey, 1995). Some of the possible related services include: transportation, speech, occupational and physical therapy, psychological services, counseling services, medical services for diagnostic and evaluation purposes, and school health services. In addition, P.L. 94-142 defined medical services and school health services (Education for All Handicapped Children Act of 1975).

Technology-Related Assistance for Individuals with Disabilities Act of 1988

The first federal legislation specifically addressing the assistive technology (AT) needs of individuals with disabilities was the Technology-Related Assistance to Individuals with Disabilities Act of 1988, P.L. 100-407, referred to as the Tech Act of 1988. P.L. 100-407 required states to develop statewide programs of technology related services for individuals with disabilities of all ages. The intent of The Tech Act of 1988 was to increase awareness of the needs of individuals with disabilities for both AT devices and services. Policies, practices, and procedures impacting the availability of AT devices and services were to be made available to individuals with disabilities. The Tech Act of 1988 provided funding to states to develop, fund, and deliver AT devices and services to individuals with disabilities (Julnes & Brown, 1993).

The Tech Act of 1988 offered the first federal definition of what constitutes AT services and an AT device. Assistive technology services were defined as "any service which directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device" (Technology-Related Assistance for Individuals with Disabilities Act of 1988). An AT device was defined as "any item, piece of equipment, or product systems, whether acquired commercially off the shelf, modified, or customized, used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Technology Related Assistance for Individuals with Disabilities Act of 1988).

The Tech Act of 1988 also incorporated the following services of: (a) functional evaluations of the needs of individuals with disabilities; (b) acquisition of AT devices;

(c) selecting designing, fitting customizing, adapting, applying, retaining, repairing or replacing of AT devices; (d) coordinating and using other therapies, interventions, or services with AT devices; (e) training or technical assistance for an individual with disabilities and the family and; (f) training or technical assistance for professionals (Smith & Jones, 1999).

Americans with Disabilities Act of 1990

Another civil rights legislation enacted by Congress was P.L. 101-336, also known as the Americans with Disabilities Act of 1990 (ADA). This legislation expanded the anti-discrimination and equal opportunity mandates of the Rehabilitation Act of 1973 by addressing discrimination in private sector employment, housing, education, transportation, communication, recreation, health services, voting, and access to public services (Hill, 1999). A person with a disability is defined by ADA as "a person with a mental or physical impairment which substantially limits a major life activity such as walking, talking, working and self care, or the individual can have a record of such impairment or is regarded as having an impairment" (Americans with Disabilities Act of 1990). People protected by ADA are individuals with impairments which substantially limit them in one or more life activity.

As an anti-discrimination and equal opportunity law, the ADA has far-reaching implications. ADA mandates reasonable accommodations and provisions for both public and private sector services. For school age individuals, reasonable accommodations must be provided for the students to benefit from their education. To accomplish these requirements, school districts may need to modify equipment or school buildings so

students with disabilities can physically access places where other students go and engage in the same or similar activities (Best et. al., 2005).

Individuals with Disabilities Education Act (IDEA) of 1990

In 1990, the reauthorization of P.L. 94-142, Education for All Handicapped Children Act of 1975 changed the title to the Individuals with Disabilities Education Act, or IDEA 1990. The authors of IDEA 1990 recognized the importance of first person language by using the phrase *individuals with disabilities* instead of *disabled individuals*. The IDEA 1990 amendment included the addition of traumatic brain injury and autism as separate federal disability categories. Related services of rehabilitation counseling and social work services were also added (Individuals with Disabilities Education Act of 1990).

Technology-Related Assistance Act Amendments of 1994

In 1994, Congress reauthorized the Tech Act of 1988 to address the barriers persons with disabilities experience in gaining access to assistive technology (AT) devices and services. In passing the Technology-Related Assistance Act of 1994, also known as P.L. 103-21, or the Tech Act of 1994, Congress attempted to mandate an infrastructure to improve access and timely acquisition of AT devices for persons with disabilities. Bryant, Seay, O'Connell and Comstock-Galagan (1996) noted congressional sentiment when they summarized: "Assistive technology offers persons with disabilities opportunities that heretofore have been largely inaccessible: however there currently exists systems which too often preclude timely acquisition of assistive technology devices and services – this system must be changed" (Technology-Related Assistance Act Amendments of 1994).

The Tech Act of 1994 required states to undertake six activities to ensure access to AT devices and services across school settings. All states were mandated to alter the current systems to better enable individuals with disabilities to access and use AT devices and services, and develop specific systems to change funding. In an attempt to ensure access to AT devices and services, agencies are mandated to collaborate to better serve individuals with disabilities receiving services. Agencies must now work with the disability community to empower individuals to be active participants in the process of accessing AT devices and services. Groups traditionally identified as underrepresented or located in rural geographic locations now must have access to AT devices and services (Technology-Related Assistance Act Amendments of 1994). The overall goal of the Tech Act of 1994 was for states to be responsible for the identification and implementation of procedures to ensure timely acquisition and delivery of AT devices and services to individuals with special needs (Smith & Jones, 1999).

Individual with Disabilities Education Act of 1997

IDEA 1990 was reauthorized by P.L. 105-17, The Individuals with Disabilities Education Act of 1997, or IDEA 97. When it reauthorized IDEA in 1997, Congress found the previous laws were successful in ensuring students with disabilities have access to a free appropriate public education. However, Congress concluded the implementation of both the Education for All Handicapped Children Act of 1975 and IDEA 1990 had been impeded by low expectations concerning students with disabilities and special education programs and there had been insufficient focus on applying research-based methods of teaching and learning (Turnbull, Turnbull, Shank, & Leal, 2003). Congress

based its conclusion upon the National Council on Disability's report (Council for Exceptional Children, 2004).

The authors of the National Council on Disability's report concluded the basic features of IDEA 1990 were valid, but the implementation needed to be improved. The National Council on Disability investigated a number of components of special education programs in public school settings. When investigating school buildings, the National Council on Disability found many school buildings were not accessible to students with physical disabilities. When examining identification and evaluation practices, they found school personnel evaluated students more for the purpose of classifying them, then determining what education services they need. The special education services being provided to students with disabilities were not sufficiently individualized, which resulted in students not benefiting from school. Special education had become an alternative for students who pose challenges to their teachers. The intent of IDEA 1990 was for special education to be a service which makes it possible for many more students to remain in general education programs. In addition to investigating special education programs and services, the National Council on Disability examined the parent school personnel relationships. The Council found parents were not real partners with educators in making decisions about their children's education.

IDEA 97 mandated both significant policy changes and influenced how children and youth with disabilities are educated. The amendment increased the alignment of special education to general education school improvement efforts. As a result, a general education teacher was mandated to be a member of the IEP team working with all team

members determining how each student with a disability will access the general education curriculum. A statement on how the student's disability impeded performance in general education programs along with an explanation of the extent to which the student would not be participating in general education programs was to be included on the IEP (Best et al., 2005). Students with disabilities were to participate in district wide assessments with accommodations as necessary. Alternative forms of assessment were to be available for students who could not participate in standardized assessments (Turnbull & Turnbull, 2001).

IDEA 1997 defined supplementary aids and services as "aids, services, and other supports provided in regular education classes or other education related settings to enable students with disabilities to be educated to the maximum extent appropriate with nondisabled students." The new definition clearly distinguished supplementary aids and services from related services. The definition of related services included "transportation and such developmental, corrective, and other supportive services required to assist a student with a disability to benefit from special education" (Individuals with Disabilities Education Act of 1997). Related services augment and support a student receiving special education services, while supplementary aids and services enable students with disabilities to be educated with nondisabled students to the maximum extent appropriate in regular education classes or other education related settings (Individuals with Disabilities Education Act of 1997). One new task of the IEP team was to consider the resources needed for general education teachers to provide an appropriate program for students with disabilities (Heumann & Hehir to Chief State School Officers, 1997). IEP

team members needed a process to discuss, determine, and document the supplemental aids and services the team members intend to provide for students and teachers (Etscheidt & Bartlett, 1999).

IDEA 97 modified the transition services requirements. The Individual Education Program (IEP) now included a statement of the transition services related to the student's course of study. In IDEA 1990, a statement of transition services needed to be included in the IEP by the time the student reached the age of 16. IDEA 1997 changed the transition services requirement on the student's IEP to when the student turns 14.

IDEA 97 contains provisions enabling school districts to discipline students with disabilities in the same manner as students without disabilities, with a few exceptions. If a school district changes a student's placement, by suspension or expulsion in excess of 10 days within a school year, the IEP team and other qualified personnel are to review the relationship between the student's misconduct and the student's disability. This review is called a manifestation determination (Heward, 2003). If the student's behavior is found not related to the student's disability, the same disciplinary procedures used with other students may be imposed. However, the school district is obligated to provide educational services in an alternative placement (Individuals with Disabilities Education Act of 1997; Turnbull et al., 2003).

Individuals with Disabilities Education Improvement Act of 2004

In December 2004, Public Law 108-446, The Individuals with Disabilities Improvement Act of 2004, was signed by President Bush. P.L. 108-446 reauthorized the Individuals with Disabilities Act of 1997. Many of the provisions became effective on

July 1, 2005. The changes and educational implications of the Individuals with Disabilities Improvement Act of 2004 are too numerous to discuss in detail. Two major sections of the Act impacted IEP requirements and changed the qualifications of special education teachers.

IDEA 2004 eliminated the requirement of short-term objectives and benchmarks from the IEP. The exception for this requirement is for students who take alternative assessments and receive instruction from an alternative curriculum. Transition requirements on the IEP have been changed from beginning at age 14 to beginning when the student is 16. Measurable postsecondary goals based on appropriate transition assessments are to be included on the IEP.

Attendance requirements for IEP team members at IEP meetings changed. IEP team members are not required to attend IEP meetings if their area of curriculum or related service is not to be discussed. When a curriculum area or related service is going to be discussed, the team member can be excused if they provide information to the parent prior to the meeting. Parents must have agreed in writing prior to the IEP meeting for team members not to participate in the meeting. In addition, parents and the local education agency can agree to make changes to an IEP in between annual reviews without convening an IEP meeting and without creating a new IEP (Weintraub, 2005).

The new law impacts special education teacher qualification requirements in several ways. First, experienced special education teachers are expected to meet the No Child Left Behind Act's (NCLB) highly qualified provisions. Special education teachers must have at least a bachelor's degree and hold a valid teaching license. In addition, they must

meet their state's requirements for being highly qualified in the core academic subjects they are solely responsible for teaching. Each state has its own methods and requirements for determining whether teachers are highly qualified. Such methods may require teachers to take a test, attend professional development, and/or meet observable standards.

Qualification requirements for special education teachers are similar to school improvement trends seen in general education over the past few years. The goal has been to ensure that highly qualified teachers are in classrooms. The Council for Exceptional Children (2004) has advocated for special education teachers to be competent in the academic content of all classes they teach. However, the Council for Exceptional Children's position states that the attempts to directly link highly qualified requirements of special educators to the subject matter requirements for general educators under No Child Left Behind provides a lack of recognition for the integrity of special educators. In school districts, special educators deliver services in multiple settings and perform diverse instructional roles. The highly qualified requirements for special educators do not take into consideration the diversity of the individuals special educators serve (Council for Exceptional Children, 2004, p. 4). The impact of the new special education teacher qualifications on school personnel and public school programs for students with disabilities is not yet known.

Overview of Litigation

Including students with neurological disorders into schools has raised several controversial issues. The issues are centered on the extent of responsibility assumed by

school staff and school districts for providing physical and health care services. Many educators and administrators believe services such as catheterization, tracheotomy care, and tube feeding are more medical than educational and should not be the school's responsibility (Heward, 2003). The expense associated with providing health related services in schools and training and supervision of school personnel pose potential problems for school districts. The responsibility for providing health services by school district personnel has been examined by the judicial system. The Supreme Court has established what are considered allowable school health services rather than deciding which services do not have to be provided by school districts. Two landmark court cases have made clear the court's position on health related support services.

Irving Independent School District v. Tatro (1984)

The first landmark court case to address the question of medical support services in schools is Irving Independent School District v. Tatro (hereafter Tatro). In this case, the Supreme Court addressed the question of catheterization as a related service under IDEA. Amber Tatro was an 8-year–old child, born with spina bifida, who needed clean intermittent catheterization (CIC) every 3-4 hours. Amber was eligible for special education and related services under IDEA because she had an orthopedic impairment and speech impairment which impacted her learning. The school district provided special classes and the related services of occupational and physical therapy. However, the district did not provide CIC as a related service because CIC was determined to be a medical service, not an educational service (Irving Independent School District v. Tatro, 1984).

The Irving Independent school district claimed the CIC procedure could only be performed by a physician or a nurse with a physician in attendance. The Supreme Court ruled catheterization was a related service under IDEA because the service was necessary for Amber to attend school. Without the CIC service, Amber would not be able to benefit from her special education program (Irving Independent School District v. Tatro, 1988). The court further ruled CIC was not a medical service because the services did not have to be performed by a physician (Katsiyannis & Yell, 2000). Lower courts and schools needed assistance in determining whether a particular service was a health care service covered by IDEA or a medical service excluded from IDEA coverage. The Court established a "bright-line test" with three criteria: (a) the student must be IDEA eligible; (b) the service must be necessary to assist the child to benefit from special education; and (c) the service must be performed by a nurse or other qualified person, but not by a physician (Irving Independent School District v. Tatro, 1984).

Cedar Rapids Community School District v. Garret F (1997)

The second landmark case addressing the question of school districts' responsibility to provide health related serves was Cedar Rapids Community School District v. Garret F (hereafter Garret F). This case involved a 12-year-old middle school student who was paralyzed from a motorcycle accident at the age of 4. Garret F's mother had used money from insurance and a settlement with the motorcycle company to hire a nurse to care for Garret F's medical needs while he attended elementary school. When Garret F entered middle school, his mother asked the school district to assume the cost of his physical care during the school day. The school district refused, believing it was not responsible under

IDEA for providing continuous nursing care. The services needed by Garret F were urinary bladder catheterization, tracheotomy suctioning, manual resuscitation, and blood pressure monitoring (Katsiyannis & Yell, 2000). The Administrative Law Judge (ALJ) relied on the Tatro "bright-line" standard and ruled the school district was required to pay for health related services. The ALJ ruled in favor of Garret F based on the distinction between health care services and medical services in the Education for All Handicapped Children Act of 1975 and subsequent reauthorizations. Medical services were defined as those services which can only be performed by a licensed physician and school districts cannot be held accountable for performing. The school district appealed and lost in both the district court and the U.S. Circuit Court of Appeals for the 8th circuit (Etscheidt & Bartlett, 1999). Cedar Rapids Community School District appealed to the Supreme Court. The Supreme Court agreed with the lower courts. The requested health related services were related services because Garret F could not attend school without them. The Court also concurred the services were not excluded as medical services because they did not need to be performed by a physician. Though the court acknowledged the school district may have had legitimate concerns about the financial burden of providing these services, the Court determined this issue fell outside its authority (Katsiyannis & Yell, 2000).

By reaffirming the standards adopted in Tatro, the Supreme Court clearly established the need for school districts to provide any and all necessary health care services to qualified students with disabilities. Until Garret F, the Courts held that a single health care procedure was deemed a related service. The Garret F ruling elaborated on the Tatro

ruling, by stating that as long as a doctor was not required to perform the health care procedure, any combination of services, regardless of the cost, should be the responsibility of the school district (Best et al, 2005).

Despite the Court's ruling in Tatro and Garret F, the controversy regarding school health services has continued. A number of lower courts departed from the standard of Tatro and ruled numerous and complex health services required for a particular student, even when not performed by a physician, were medical in nature and were, therefore, not required under IDEA (Hill, 1999).

Regulations, Standards, and Other Laws

State regulations, professional standards, and guidelines related to health care influence the education of students with neurological disorders in public school settings. Legislation and litigation supports the provision of health care procedures during the school day as a related service in the education of students with health care needs. The decisions regarding personnel who will provide the health care service is based on state and local regulations, guidelines, and school district policies (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000).

State legislatures pass licensure requirements for nurses and delegate the function of regulating the practice of nursing to a state board of nursing or board of nursing examiners. These boards regulate nursing practice, monitor nursing activities, determine the scope of practice, and set disciplinary standards (Janz et al., 2003). School districts need to be aware of and understand the specifics of medical and nursing practice legislations, regulations, and standards for their state. Each state's nursing practice act

includes a provision allowing the nurse to delegate certain procedures to unlicensed personnel (Heller, Frederick, Best, Dykes, & Cohen, 2000). In such situations, teachers and paraprofessionals work under the school nurses' supervision. The school nurse is accountable for the appropriateness of delegating the specialized health care procedure (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000).

In addition to federal and state legislation, many national organizations have produced publications, position statements, and or guidelines for the provision of health care services in schools. Such organizations include the National Association of School Nurses, the American Academy of Pediatrics, and the National Education Association. Guidelines are not law, but offer standards for high-quality practice and services.

Several state departments of health or education have produced guidelines and standards which affect the education of and services provided for students with neurological disorders. These guidelines are generally not adopted into federal or state laws, but are often incorporated into the district's policy and procedures. Guidelines may include infection control, universal precautions, medication administration, guidelines for nursing practice and school policy recommendations. School district policies and procedures also influence the quality of service provided to students with neurological disorders. Often school district's job descriptions, personnel qualifications, and staffing patterns of nurses and other school personnel are adopted from state and national standards and guidelines (Heller, Frederick, Best, Dykes, & Cohen, 2000).

Clinical, legal, and administrative issues related to the education of students with physical and health care needs in public school settings can be complex. School health

care and education personnel working together to educate each other, exploring all relevant issues, and developing plans to ensures quality care for each student with special health care needs is essential.

Families of Children with Neurological Disorders

All families are social systems from which all individuals establish roles and relationships which grow, develop, and change while interacting with each other (Fine & Nissenbaum, 2000). The family provides protection, physical care, support, and socialization for each individual, especially the children (Falvo, 2005). Each individual within the family plays a role in the everyday life of the family. The impact of a child with a neurological disorder is far-reaching. The impact extends beyond the child with the disorder. The impact extends to all those with whom the individual has contact, especially the family.

The Impact on Family Life

A child with a neurological disorder affects each family member and the family life. Family members may experience increased stress, disruption to relationships, and financial hardships. The health care needs or disability of one child can bring about changes in housing, careers, family life style, and the roles of family members (Turnbull & Turnbull, 2001).

Knoll (1992) found children with neurological disorders affect their families with respect to daily care issues. Approximately 50 percent of the families gave their child extensive assistance with toileting, bathing, and medical monitoring. One–fourth of the families indicated their child needed 24 hour a day monitoring. Slightly more than half

of the families reported they had experienced some sort of crisis requiring intervention within the last month. Each family with a child with a health impairment or physical disability created family routines taking into consideration the child's daily care needs. In addition to daily care needs, parents also deal with medical equipment, specialized procedures, medical appointments, and hospitalization (Turnbull & Turnbull, 2001; Harkins, 1994).

While most families receive federal, state, or private insurance assistance, many families pay thousands of dollars for medical treatments, therapies outside of school and equipment. In addition to the added expenses, families of children with neurological disorders often have reduced income because one parent works part time instead of full time or does not work at all to provide the time needed to care for the child (Heward, 2003).

Parental Stress

Parenting requires tremendous physical and emotional energy. Parents of children with neurological disorders experience added stress brought on by the child's physical, emotional, and financial demands (Turnbull & Turnbull, 2001). Different types of neurological disorders bring different kinds of challenges to families (Heward, 2003; Harkins, 1994).

Grieving Process: It is generally accepted that families, especially parents, go through a grieving process when their child is first diagnosed with a neurological disorder. Much of the literature related to the impact of a child with a disability on the family has been adapted from the work by Elisabeth Kubler-Ross (1969) who outlined the stages of grief

individuals go through in their response to the death of a loved one. Freitag-Koonz (1988) described five different stages parents of children with severe neurological impairments or a congenital malformation experienced in the process of accepting their child's condition. The stages included: (a) shock; (b) denial, disbelief, and bargaining; (c) sadness, anger, and anxiety; (d) establishing equilibrium; and (e) reorganization.

The stages parents experience in adjusting to a child with a chronic illness, as opposed to a disability, are dependent on the chronology of the illness. McCollum and Gibson (1970) outlined a four-stage process family's progress through when dealing with a child with chronic terminal health impairment. The first stage is the prediagnostic stage. This is the time period between when parents realize their child is ill and receiving a diagnosis of the child's medical condition. The second stage is the confrontational stage. During this time, parents mourn the loss of their normal healthy child and struggle with their own confirmation of the diagnosis. The third stage is the long-term adaptation stage when parents attempt to meet the physical and psychological needs of the child. In addition, they attempt to maintain a relationship with their dying child. The fourth stage is the terminal stage when parents accept the child is not going to survive.

Coping and Resiliency: Assuming all parents experience a grieving process and time is the most important variable to adjustment may be too simplistic an interpretation of the process. Recent research has shown parents react to a child with neurological disorders in many ways (Turnbull & Turnbull, 2001; Patterson & Leonard, 1994; Bruce & Schultz, 2001). For some parents, years may pass and they are still not comfortable with their child. Other parents have reported their lives have been strengthened by having a child

with a disability (Scorgie & Sobsey, 2000). Patterson and Leonard (1994) interviewed couples whose children required intensive home care routines because of chronic and complex health care needs. They found roughly equal numbers of positive and negative responses. Individual family members may experience different feelings, in various sequences, and at different times. Parents have reported many events in their daily life will trigger feelings of sadness. These events involve changes, such as a new diagnosis or medical need, using new technology and the child's transition to another grade or school. Milestones such as birthdays, graduation, and transition from elementary to middle to high school can also trigger feelings (Turnbull & Turnbull, 2001; Bruce & Schultz, 2001).

More recently, research has shifted to exploring how families manage and cope with the demands of caring for children with disabilities. In a study of families with medically fragile children, Youngblut, Brennan, and Swegart (1994) investigated the major coping strategies the families used. The coping strategies used by families included sharing their difficulties with relatives, neighbors, and friends. By sharing their difficulties, parents and caregivers allowed themselves the opportunity to receive support. These families also sought out information and advice from people who could be helpful in making decisions and solving problems. The families looked for advice and assistance with solving problems by turning to physicians, nurses, relatives, therapists, and religious leaders. Some families found support from professional counselors.

Patterson and Blum (1999) identified factors leading to resiliency in families. The resilient families showed a commitment to all family members including the child with

the disability. Family routines had been established taking in the needs of all family members. Parents were able to maintain clear family routines, but were able to be flexible with routines during a health care crisis or disruption to their daily routines. Parents could change their expectations and alter their roles and family rules as needed, but not at the expense of other family members. One parent was less likely to become overly involved with the child with the special health care needs.

Resilient parents had the skills required to access information and services. They were able to solve problems, make decisions, and resolve conflicts within a collaborative relationship with professionals. In the process of caring for the child, these parents developed and maintained supportive relationships with friends, relatives, and community members.

Families able to meet the needs of the child with a neurological disorder were able to acknowledge the positive contributions of the child to the family. Some parents reported their lives developed more meaning as a result of their child's special needs.

Siblings

Just as a child with a neurological disorder will impact his or her parents, the child's siblings will also be impacted (Stoneman, 1998). Research on the impact on siblings is contradictory. Research reports potential negative impacts on siblings such as over identification, embarrassment, guilt, isolation, loneliness and resentment (Turnbull & Turnbull, 2001). The negative impact can manifest itself in sibling's poor school performance, increased attention seeking behaviors, increased responsibility, and pressure to achieve (Faux, 1993). Research has also found the impact on siblings can

also be positive. Siblings of a brother or sister with a neurological disorder can exhibit enhanced maturity, more insight and tolerance, an increased sense of accomplishment and self-worth (Turnbull & Turnbull, 2001).

CHAPTER 3

MANUAL DEVELOPMENT PROCEDURES

Introduction

This chapter includes methods used to develop a manual for educators and support staff which will assist them in developing and implementing appropriate programs to meet the needs of students with neurological disorders. The methods used are listed sequentially in the order of completion. The time line for completion is also included.

Review of the Literature

The first task in developing a manual for teachers, support staff, and administrators was to review the literature to determine the current status of knowledge about public school students with neurological disorders. Education literature, legislation, and litigation related to educating children and youth with neurological disorders was reviewed and organized into the following categories: (a) the characteristics of students with neurological disorders; (b) the components of educational programs to meet the needs of these students; (c) the challenges public schools face when creating and implementing programs to meet the educational and health care needs of students with neurological disorders; and (d) the impact on families. The review of the literature began in January 2005 and was completed in May 2005.

Select the Neurological Disorders

The neurological disorders included in the manual were selected after the literature review was completed and the medical conditions frequently cited as challenging for staff in public schools were determined. The writer's own experience as a special education

teacher in both public and private schools for 20 years also was used to select the medical conditions. In addition, the writer's six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts were used in identifying the neurological disorders of children and youth the public schools are struggling to educate. This task was started in January 2005 and completed in April 2005.

Survey Existing Manuals

Existing manuals and textbooks available to teachers, administrators, and support staff were reviewed to identify the strengths and weaknesses of these manuals. The specific areas targeted were: (a) characteristics of each neurological disorder; (b) the impact the neurological disorder can have on the students' education; (c) classroom accommodations and strategies needed for the students to access their education; (d) legislation and litigation pertaining to educating students with neurological disorders; (e) resources available to school staff; and (f) the impact on families. The survey of existing manuals and textbooks was started in January 2005 and completed in June 2005.

Develop a Table of Contents for the Manual

The table of contents of the manual was originally determined after gathering data from the literature review, surveying the existing manuals and textbooks and the selection of medical conditions to be included. The areas in the table of contents included: (a) students with neurological disorders; (b) education of students with neurological disorders; (c) overview of legislation; (d) overview of litigation; (e) families of children with neurological disorders; (f) description and characteristics of neurological disorders;

(g) medical interventions; and (h) classroom accommodations. The preliminary table of contents was developed in April 2005 and continuously revised until March 2006.

Develop the Format for Each Section of the Manual

The format of the manual was developed after gathering data from the literature review and the survey of existing manuals and textbooks. Sample formats were reviewed by committee members, teachers, and administrators, who serve students with neurological disorders. The final format which was selected represents the consensus of all reviewers as the most "user-friendly" presentation style. The format for each section of the manual was completed in July 2005.

Write Each Section of the Manual

A draft of each section of the manual was completed using the data gathered and organized during the review of the literature and survey of available manuals and textbooks. All sections listed in the table of contents were written following the outline for the table of contents and the format determined in previous methodology sections. A draft of all sections of the manual was completed in September 2005.

Revise the Manual

Each section of the manual was reviewed by classroom teachers, support staff, and administrators. Revisions were made as needed. The first draft of the completed manual was delivered to the Dissertation Committee Members in September 2005. Revisions were made from November 2005 to March 2006.

CHAPTER 4

THE MANUAL

SERVING STUDENTS WITH NEUROLOGICAL DISORDERS:

A MANUAL FOR EDUCATORS

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PART ONE

BACKGROUND TO NEUROLOGICAL DISORDERS

SECTION ONE

INTRODUCTION TO STUDENTS WITH NEUROLOGICAL DISORDERS

Over the past twenty years, an increasing number of students with neurological disorders have been attending public schools (Best, Heller, & Bigge, 2005). A combination of medical advances, changing educational philosophies, legislation, and litigation has led to an increase in the number of children and youth who are assisted by medical treatment and technology, and are attending schools in their home communities (Heller, Fredrick, Best, Dykes, & Cohen, 2000).

Characteristics of Students with Neurological Disorders

Children with physical disabilities, health impairments, and multiple disabilities are an extremely varied population (Best, et al., 2005). Even if general terms were used, describing them with a single set of characteristics would be impossible. Physical disabilities range from mild to moderate to severe. Some students with health care needs are extremely restricted in their activities and intellectual functioning, others have no major limitations on what they can do or learn (Hill, 1999). Some appear entirely normal and others have highly visible disabilities. They may have a single impairment or a combination of disabilities and have lived with the health impairment or physical disability since birth, or have acquired the disability recently. Some disabilities are always present, while others occur intermittently. The severity of disability may increase, decrease, or remain the same over time (Heller, Frederick, Best, Dykes, & Cohen, 2000).

Components of Educational Programs

Students with neurological disorders are educated in general education classrooms, in special education classrooms located on general education campuses, and in special schools separate from general education classes (Best, Hemsley, & Best, 1986). Some students will benefit from placement in general education classrooms, accessing the general education curriculum, with minimal educational accommodations or environmental modifications (Best et al., 2005). The complex health care and learning needs of other students often require a coordinated array of multiple specialized instruction, therapy, and related services (Bigge, Stump, Spagna, & Silberman, 1999). Even after issues of where to deliver the educational services are addressed, many challenges exist for providing effective instruction. Careful planning involving administrators, teachers, support staff, and parents is needed to ensure the educational and health care needs of students are met while attending school.

An appropriate educational program for students with neurological disorders often requires modifications to the classroom environment, use of specialized teaching techniques, assistive devices for communication and mobility, and the provision of health related services (Heller, 2004). In addition to access to the general education curriculum, students may need both a parallel curriculum and instruction on ways to cope with their disabilities. The parallel curriculum includes specialized teaching techniques and equipment to increase independence, the self-administering of health care routines, and learning self-advocacy skills (Bowe, 2000). When developing educational programs to

meet the needs of these students, the manner in which a particular condition may affect a student's development, learning, and behavior must be considered.

In addition to the educational and environmental accommodations and modifications, the school staff need to be aware of possible medical complications and emergencies which may arise in the classroom or on the school campus. School personnel need to know how to manage these situations effectively and when and how to seek assistance (Mukherjee, Lightfoot, & Sloper, 2000).

Challenges for Public Schools

Educators and administrators are challenged with developing appropriate programs to meet the educational and medical needs of students with neurological disorders. Teachers have basic curricular knowledge and strategies for effective instruction. Special and general education teachers, and support staff, however, need additional specialized knowledge and skills to plan for and provide appropriate educational services and school health related services. Specialized knowledge and skills encompass understanding a variety of physical and health impairments and implications those impairments have on students' functioning. School personnel have knowledge of legal mandates for providing special education services, but also must understand the legal mandates for providing supplemental supports and services (Best et al., 2005). Teachers, administrators, and support staff benefit when they obtain skills used for interacting successfully with personnel from many disciplines, including therapists, doctors, nurses, specialists, and others within the school district and among community agencies (Bigge et al., 1999). It is critical for educators to have the specialized knowledge and empathy needed for

working with families coping with multiple sources of stress, frequent hospitalizations, frequent medical appointments, and perhaps with terminal outcomes (Best et al., 2005).

Heller, Forney, Alberto, Schwartzman, & Goeckel (2000) assessed the perceived competencies of special education teachers who taught students with neurological disorders. Questions developed for this study were derived from the Council for Exceptional Children standards for physical and health disabilities. Over 40% of the 503 certified special education teachers indicated they were not well trained on about half (11 of 23) of the competencies. Teachers reported they were not trained in: (a) developing assistive technology plans; (b) instructional modifications; (c) teaching medical self-management skills; (d) integrating health care plans into students' daily programming; (e) strategies for working with chronically ill and terminally ill students and families and: (f) participating in trans-disciplinary team activities.

Including students with neurological disorders in public schools has raised several controversial issues. These issues center on the extent of responsibility assumed by school districts, teachers, and support staff. Procedures such as tube feeding, suctioning, colostomy care, ventilator management, clean intermittent catheterization, administration of oxygen, and administration of medication are now commonly provided in schools (Heward, 2003). Some educators, support personnel, and administrators believe such services are medical and should not be the school's responsibility. In addition, the expense of such services, along with the training and supervision of school personnel pose potential problems for school districts. Assistive devices and therapeutic services pose similar concerns. The cost, responsibility for training, and supervision continue to

be controversial issues in the education of students with neurological disorders (Heward, 2003).

Purpose of the Manual

The number of children and youth with neurological disorders has rapidly increased over the last 20 years (Best et al., 2005). Unfortunately, the public education system in the United States has not been able to provide sufficient services to meet the educational and health care needs of students with neurological disorders. A shortage of specialists within the public schools trained to develop and implement education programs to meet the needs of students with neurological disorders continues to exist. General education teachers are not trained in how to accommodate students with neurological disorders in their classrooms (Hill, 1999).

Professional medical literature provides school staff with current information regarding the neurological disorders of students. However, teachers, support personnel, and administrators are seldom provided with applied information which can be easily translated into an education setting. School personnel need a manual describing the impact of students' health conditions on learning and behavior to assist in translating medical diagnoses into appropriate educational programs. This manual will serve as a resource for teachers, support personnel, and administrators.

Organization of the Manual

This manual is organized in four sections. Part One provides a background to students with neurological disorders. Part Two describes the six different neurological disorders. Part Three details both the typical medical interventions and specific medical

interventions for each disorder. Part Four provides recommendations for classroom and campus accommodations.

PART ONE: Background to Neurological Disorders

Part One includes five sections which provide an introduction to the education of students with neurological disorders in schools. The first section of the manual includes an overview of the characteristics of students with neurological disorders, the components of educational programs to meet the needs of the students, and the challenges for public school personnel. Section Two provides a historical overview of the education of students with neurological disorders. Section Three provides an overview of federal laws the United States Congress passed to protect the civil rights and enhance the educational experience of students with neurological disorders. Section Four presents an overview of the litigation surrounding the responsibility of school personnel and school districts for providing services to meet the needs of students with neurological disorders. Section Five includes an overview of the impact a student with a neurological disorder has on the family.

PART TWO: Neurological Disorders: Descriptions and Characteristics

Part Two provides an overview of six chronic pediatric neurological conditions which school personnel have limited knowledge of, but are frequently encountered in public school settings. The conditions include non-traumatic acquired brain injuries, cerebral palsy, muscular dystrophy, neurocutaneous syndromes, seizure disorders, and spina bifida. Each section contains the definition and description of the neurological condition

and an overview of the physical and cognitive complications associated with each condition. The sections conclude with a list of resources for school personnel.

PART THREE: Medical Interventions

Part Three addresses the medical management of students with neurological disorders. Section Thirteen describes the typical medical interventions many students encounter both at home and at school. Section Fourteen provides an overview of the specific medical interventions for the six chronic pediatric neurological conditions included in Part Two.

PART FOUR: Classroom Accommodations

The final section provides accommodations school personnel can use when developing and implementing individualized programs to meet both the educational and medical needs of students with neurological disorders while attending school. The six areas of accommodations include: academic, communication, furniture and equipment, health related, instructional, and mobility.

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SECTION TWO

HISTORICAL OVERVIEW OF THE EDUCATION OF STUDENTS WITH NEUROLOGICAL DISORDERS

Many children with neurological disorders, who in the past would have been cared for in hospitals or residential institutions, are living at home and are now being integrated into local public schools (Hill, 1999). Until the 1990's, attendance at school was uncommon for most children and youth with neurological disorders. Walker and Jacobs (1985) traced the trends in providing services to such students and found two factors contributing to children and youth not receiving a public school education. The first factor was unsophisticated medical practices causing high mortality rates. In 1890, approximately 20% of children died before reaching the age of two and 50% did not live to adulthood. In addition to the high mortality rates, individuals who were different or disabled tended to be ostracized.

Throughout the first half of the 20th century, increasing numbers of children with neurological disorders, considered as mildly involved by today's standards, were able to return to school (Best, Hemsley, & Best, 1986). Childhood survival rates continued to rise due to medical advances in treatment and prevention of diseases and new surgical procedures (Connor, Scandary, & Tullock, 1988). Walker and Jacobs (1985) attributed this increase in educational opportunities with the outbreaks of tuberculosis and polio. Epidemics were so widespread that school systems were unable to ignore the survivors (p. 618). As a result of the tuberculosis and polio epidemics, classrooms in hospitals and sanatoriums became common, as did homebound instruction. When children were

allowed to attend their local public schools, the most common placement was in special classes for the "crippled" or "delicate" (Conner et al., 1988). Such classes were segregated from typical classes. At that time, educational placements were typically determined by the medical personnel not affiliated with school districts. Educational decisions to ignore, isolate, and institutionalize children were often based on assumed mental incompetence because of physical disabilities or health impairments (Conner et al., p. 6).

Until the 1950s, special classes, separate schools, instruction in hospitals and in the homes of the children still remained the most common placements for students with mild and moderate neurological disorders (Walker & Jacobs, 1985). Some students attended school in settings sponsored by specific organizations, such as United Cerebral Palsy Association. Often the public school would provide the teachers and the organizations would provide the buildings and therapy services, such as physical therapy, occupational therapy, and speech therapy (Connor et al., 1988).

Major social changes occurred in the United States from 1960 to 1980 (Walker & Jacobs, 1985). Such changes included the civil rights movement, legislation requiring buildings to be accessible, court cases challenging the segregation of students with disabilities, deinstitutionalization, and the development of innovative rehabilitation programs. Unfortunately, the needs of students with neurological disorders were not addressed. By the 1970s, more children with neurological disorders were beginning to attend public schools, but not their neighborhood schools. Students with physical disabilities and neurological disorders were bused to special schools designed to serve

students from a wider geographic area (Conner et al., 1988). In general, necessary treatment was provided at home or in hospitals. Schools were not considered responsible for the provision of direct physical or medical care (Caldwell & Sirvis, 1991).

Passage of P.L. 94-142, The Education for All Handicapped Children Act of 1975, changed the situation for many children with neurological disorders, especially those with more severe physical disabilities and health care needs. P.L. 94-142 mandated that all children ages 3-21 receive a free appropriate education in the least restrictive environment. The Education for All Handicapped Children Act of 1975 impacted educational placement decisions and services for children with orthopedic impairments, health impairments, and multiple disabilities. By providing school personnel with legal definitions of orthopedic impairment, other health impairment, and multiple disabilities "school districts and school personnel were forced into previously uncharted territories" (Walker & Jacobs, 1985, pp. 615-616). In addition, legislation defined medical services and school health services. Probably more than any other aspect of the law, "the related services provision transformed the educational environment and changed schools from scholastic institutions into therapeutic agencies" (Palfrey, 1995, p. 265).

In the last 20 years, a gradually increasing number of children and youth with complex neurological disorders have been integrated into public school systems (Heller, 2004). The 24th Annual Report to Congress on the Implementation of Individuals with Disabilities Education Act reported 291,850 students classified under the Other Health Impairment category in 2000-2001. These classified students represented a 397% increase from the total number of students attending public schools under the category of

Other Health Impairment during the 1991- 1992 school year (U.S. Department of Education, 2002).

The increase in the number of children and youth with neurological disorders attending public schools has been due in a large part to litigation efforts by parents (Hill, 1999). Many children with neurological disorders who would have been cared for in hospitals and residential facilities in the past are now living at home. They attend their neighborhood schools and many students are integrated into general education classrooms. Current issues revolve around the responsibility being assumed by teachers and school districts in caring for the students' medical and physical needs. Many of the services required by children with neurological disorders currently supplied by school personnel are the administration of medications, catheterization, and gastrostomy feeding. These services are considered by some school personnel as medical services rather than educational services (Heward, 2003). The extent of responsibility assumed by school personnel and school districts for providing services to meet the physical and health care needs of students with neurological disorders continues to be debated at both the school level and through court cases.

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SECTION THREE

OVERVIEW OF LEGISLATION FOR INDIVIDUALS WITH DISABILITIES

Since the early 1970s, numerous laws have been passed by the United States Congress to protect the civil rights and enhance the educational experience of students with disabilities. Major aspects of the pertinent federal laws are presented in chronological order from the time of their passage.

Rehabilitation Act of 1973

In 1973 Congress passed P.L. 93-112, known as the Rehabilitation Act of 1973. This is an important civil rights legislation for people with disabilities including children and youth attending public schools. The Rehabilitation Act of 1973 states in part that "no otherwise qualified handicapped individual shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance" (Rehabilitation Act of 1973). The law's wording identically matched the Civil Rights Act of 1964 which prohibited discrimination based on race, color, or national origin. The Rehabilitation Act of 1973 expanded services to children and adults with disabilities in education, employment, and other settings.

Section 504 of The Rehabilitation Act of 1973 is not a federal grant program like The Education for All Handicapped Children Act of 1975, as it does not provide federal money to assist people with disabilities. Instead, Section 504 imposes a responsibility on every recipient of federal funds not to discriminate against handicapped persons.

Recipients of federal funds must provide appropriate accommodations and accessibility for individuals with disabilities to have an equal opportunity to achieve. Some specific accessibility considerations under Section 504 of the Rehabilitation Act of 1975 include removal of architectural barriers, provision of information in accessible formats, and use of augmentative communication and adaptive materials (Hill, 1999).

Students eligible under Section 504 are "individuals who have a physical or mental impairment which substantially limits one or more of the individual's major life activities, have a record of such impairment, or are individuals who are regarded as having such impairment" (Rehabilitation Act of 1973). Section 504 regulations define major life activity as "functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working" (Rehabilitation Act of 1973). The definition of an individual with a disability under Section 504 is broader than the definition under education legislation. For a student to receive services in an educational setting under Section 504, the individual's disability does not have to limit the major life activity of learning. The student's educational performance may be at grade level. The student's disability could limit other major life activities such as caring for one's self, walking, or breathing. A Section 504 Plan can provide accommodations for students whose disabilities adversely affect their educational performance. When a student's learning and educational performance are impacted, school teams will evaluate the student for either a 504 Plan with accommodations or special education services under other educational legislation (Janz, Beyer, Schwab, Anderson, Caldwell, & Harrison, 2003).

Education for All Handicapped Children Act of 1975

The Education for All Handicapped Children Act of 1975, also known as P.L. 94-142, is considered landmark educational legislation. The passage of P.L. 94-142 marked the culmination of efforts of numerous parents, advocates, educators, and legislators to bring together one comprehensive law regarding the education of children with disabilities (Heward, 2003). The Education for All Handicapped Children Act and subsequent reauthorizations affected every school in the country and continues to impact the roles of general and special educators, school administrators, parents, and students with disabilities.

P.L. 94-142 primarily impacts states, which are responsible for providing education to their citizens. The majority of the rules and regulations defining how the law operates are related to six major principles that have remained unchanged since 1995 (Turnbull & Turnbull, 2001). The first principle is the provision of a **free appropriate public education (FAPE).** All children with disabilities regardless of the type or severity of their disability shall receive a free, appropriate public education. Education must be available at public expense, without cost to the students' parents. An individualized education program (IEP) must be developed and implemented for each student with a disability. The IEP must be individually designed to meet the student's unique needs (Education for All Handicapped Children Act of 1975).

The second principle is **nondiscriminatory identification and evaluation.** School personnel must use nonbiased, multi-factored methods of evaluation to determine whether a child has a disability and, if so, whether special education is needed. Testing

and evaluation procedures must not discriminate on the basis of race, culture, or native language, and tests must be administered in the child's native language. Identification and placement decisions cannot be made on the basis of a single test score (Heller, 2004).

The **least restrictive environment (LRE)** provision is the third principle. P.L. 94-142 mandates students with disabilities be educated with children without disabilities to the maximum extent appropriate. Students with disabilities can only be removed to separate classes or schools when the nature or severity of their disabilities prevents them from receiving an appropriate education in a general education classroom with supplementary aides and services (Heward, 2003). The principle of least restrictive environment created a presumption in favor of inclusion in the general education classroom. To ensure students with disabilities are educated in the least restrictive environment appropriate for their needs, school districts must provide a continuum of placement and service alternatives (Walker & Jacobs, 1985).

Zero reject is the fourth principle of P.L. 94-142. The zero reject provision requires school districts to educate all children with disabilities. This principle applies to all students with disabilities, regardless of the nature or severity of the disability. No child with disabilities may be excluded from a public education (Heward, 2003).

The fifth principle is **due process safeguards**. Schools must provide due process safeguards to protect the rights of children with disabilities and their parents. Parental consent must be obtained for initial and all subsequent evaluations and placement decisions regarding special education. When the school and parents disagree on the identification, evaluation, placement, or special education and related services for the

child, the parents may request a due process hearing. States are also required to offer parents the opportunity to resolve the matter through mediation by a third party before holding a due process hearing (Rapport, 1996).

Parent and student participation is the sixth and final principle of P.L. 94-142. School personnel must collaborate with parents and students with disabilities in the design and implementation of special education services. The parents' and, whenever appropriate, the students' input and wishes must be considered in the Individual Education Program (IEP) goals and objectives, related service, and placement decisions (Turnbull & Turnbull, 2001).

Passage of P.L. 94-142 changed the education situation for many children with neurological disorders, particularly those with an increased severity of physical and medical needs. The law and subsequent reauthorizations mandated services be provided for many groups of students, including those who were orthopedically impaired and other health impaired. P.L. 94-142 and subsequent reauthorizations emphasized the importance of the provision of related services to assist in the removal of potential barriers to the successful inclusion of students with neurological disorders into general education classrooms and campuses (Palfrey, 1995). Some of the possible related services include: transportation, speech, occupational and physical therapy, psychological services, counseling services, medical services for diagnostic and evaluation purposes, and school health services. In addition, P.L. 94-142 defined medical services and school health services (Education for All Handicapped Children Act of 1975).

Technology Related Assistance for Individuals with Disabilities Act of 1988

The first federal legislation specifically addressing the assistive technology (AT) needs of individuals with disabilities was the Technology-Related Assistance to Individuals with Disabilities Act of 1988, P.L. 100-407, referred to as the Tech Act of 1988. P.L. 100-407 required states to develop statewide programs of technology related services for individuals with disabilities of all ages. The intent of The Tech Act of 1988 was to increase awareness of the needs of individuals with disabilities for both AT devices and services. Policies, practices, and procedures impacting the availability of AT devices and services were to be made available to individuals with disabilities. The Tech Act of 1988 provided funding to states to develop, fund, and deliver AT devices and services to individuals with disabilities (Julnes & Brown, 1993).

The Tech Act of 1988 offered the first federal definition of what constitutes AT services and an AT device. Assistive technology services were defined as "any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device" (Technology Related Assistance for Individuals with Disabilities Act of 1988). An AT device was defined as "any item, piece of equipment, or product systems, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Technology Related Assistance for Individuals with Disabilities Act of 1988).

The Tech Act of 1988 also incorporated the following services of: (a) functional evaluations of the needs of individuals with disabilities; (b) acquisition of AT devices;

(c) selecting designing, fitting customizing, adapting, applying, retaining, repairing or replacing of AT devices; (d) coordinating and using other therapies, interventions, or services with AT devices; (e) training or technical assistance for an individual with disabilities and the family and; (f) training or technical assistance for professionals (Smith & Jones, 1999).

Americans with Disabilities Act of 1990

Another civil rights legislation enacted by Congress was P.L. 101-336, also known as the Americans with Disabilities Act of 1990 (ADA). This legislation expanded the anti-discrimination and equal opportunity mandates of The Rehabilitation Act of 1973 further by addressing discrimination in private sector employment, housing, education, transportation, communication, recreation, health services, voting, and access to public services (Hill, 1999). A person with a disability is defined by ADA as "a person with a mental or physical impairment that substantially limits a major life activity such as walking, talking, working and self care, or the individual can have a record of such impairment or is regarded as having an impairment" (Americans with Disabilities Act, 1990). People protected by ADA are individuals with impairments which substantially limit them in one or more life activity.

As an antidiscrimination and equal opportunity law, the ADA has far-reaching implications. ADA mandates reasonable accommodations and provisions for both public and private sector services. For school age individuals, reasonable accommodations must be provided for the students to benefit from their education. To accomplish these requirements, school districts may need to modify equipment or school buildings so

students can physically access places where other students go and engage in the same or similar activities (Best, Heller, & Bigge, 2005).

Individuals with Disabilities Education Act (IDEA) of 1990

In 1990, the reauthorization of P.L. 94-142 The Education for All Handicapped Children Act of 1975 changed the title to the Individuals with Disabilities Education Act, or IDEA 1990. The authors of IDEA 1990 recognized the importance of first person language by using the phrase *individuals with disabilities* instead of using *disabled individuals*. The IDEA 1990 amendment included the addition of traumatic brain injury and autism as separate federal disability categories. Related services of rehabilitation counseling and social work services were also added (Individuals with Disabilities Education Act of 1990).

Technology-Related Assistance Act Amendments of 1994

In 1994, Congress reauthorized the Tech Act of 1988 to address the barriers persons with disabilities experience in gaining access to assistive technology (AT) devices and services. In passing the Technology-Related Assistance Act of 1994, also known as P.L. 103-21, or the Tech Act of 1994, Congress attempted to mandate an infrastructure to improve access and timely acquisition of AT devices for persons with disabilities. Bryant, Seay, O'Connell and Comstock-Galagan (1995) noted congressional sentiment when they summarized: "Assistive technology offers persons with disabilities opportunities that heretofore have been largely inaccessible: however there currently exists systems which too often preclude timely acquisition of assistive technology

devices and services – this system must be changed" (Technology-Related Assistance Act Amendments of 1994).

The Tech Act of 1994 required states to undertake six activities to ensure access to AT devices and services across school settings. All states were mandated to alter the current systems to better enable individuals with disabilities to access and use AT devices and services, and develop specific systems to change funding. In an attempt to ensure access to AT devices and services, agencies are mandated to collaborate to serve individuals with disabilities receiving services. Agencies must now work with the disability community to empower individuals to be active participants in the process of accessing AT devices and services. Groups that were traditionally identified as underrepresented or located in rural geographic locations now must have access to AT devices and services (Technology-Related Assistance Act Amendments of 1994). The overall goal of the Tech Act of 1994 was for states to be responsible for the identification and implementation of procedures to ensure timely acquisition and delivery of AT devices and services to individuals with special needs (Smith & Jones, 1999).

Individuals with Disabilities Education Act (IDEA) of 1997

IDEA 1990 was reauthorized by P.L. 105-17, The Individuals with Disabilities Education Act of 1997, or IDEA 97. When it reauthorized IDEA in 1997, Congress found the previous laws were successful in ensuring students with disabilities have access to a free appropriate public education. However, Congress concluded the implementation of both the Education for All Handicapped Children Act of 1975 and IDEA 1990 had been impeded by low expectations concerning students with disabilities and special

education programs and there had been insufficient focus on applying research-based methods of teaching and learning (Turnbull, Turnbull, Shank, & Leal, 2003). Congress based its conclusion upon the National Council on Disability's report (Council for Exceptional Children, 2004).

The authors of the National Council on Disability's report (2004) concluded the basic features of IDEA 1990 are valid, but the implementation needed to be improved. The National Council on Disability investigated a number of components of special education programs in public school settings. When investigating school buildings, the National Council on Disability found many school buildings were not accessible to students with physical disabilities. When examining identification and evaluation practices they found school personnel evaluated students more for the purpose of classifying them, then determining what education services they need. The special education services being provided to students with disabilities were not sufficiently individualized, which resulted in students not benefiting from school. Special education had become a place in schools for students who pose challenges to their teachers. The intent of IDEA 1990 was for special education to be a service which makes it possible for many more students to remain in general education programs. In addition to investigating special education programs and services, the National Council on Disabilities examined the parent school personnel relationships. The Council found parents are not real partners with educators in making decisions about their children's education.

IDEA 97 mandated both significant policy changes and influenced how children and youth with disabilities should be educated. The amendment increased the alignment of

special education to general education school improvement efforts. As a result, a general education teacher was mandated as a member of the IEP team to work with all team members to determine how each student with a disability will access the general education curriculum. A statement on how the student's disability impeded performance in general education programs along with an explanation of the extent to which the student would not be participating in general education programs was to be included on the IEP (Best et al., 2005). Students with disabilities were to participate in district wide assessments with accommodations as necessary. Alternative forms of assessment were to be available for students who could not participate in standardized assessments (Turnbull & Turnbull, 2001).

IDEA 1997 defined supplementary aids and services as "aids, services, and other supports provided in regular education classes or other education related settings to enable students with disabilities to be educated to the maximum extent appropriate with nondisabled students." The new definition clearly distinguished supplementary aids and services from related services. The definition of related services included "transportation and such developmental, corrective, and other supportive services required to assist a student with a disability to benefit from special education." Related services augment and support a student receiving special education services, while supplementary aids and services enable students with disabilities to be educated with nondisabled students to the maximum extent appropriate in regular education classes or other education related settings (Individuals with Disabilities Education Act of 1997). One new task of the IEP team was to consider the resources needed for general education teachers to provide an

appropriate program for students with disabilities (Heumann & Hehir to Chief State School Officers, 1997). IEP team members needed a process to discuss, determine, and document the supplemental aids and services the team intended to provide for students and teachers (Etscheidt & Bartlett, 1999).

IDEA 1997 modified the transition services requirements. The Individual Education Program (IEP) now included a statement of the transition services related to the student's course of study. In IDEA 1990, a statement of transition services needed to be included in the IEP by the time the student reached the age of 16. IDEA 1997 changed the transition services requirement on the student's IEP to age of 14.

The IDEA amendment of 1997 contains provisions enabling school districts to discipline students with disabilities in the same manner as students without disabilities, with a few exceptions. If a school district changes a student's placement, by suspension or expulsion in excess of 10 days within a school year, the IEP team and other qualified personnel are to review the relationship between the student's misconduct and the student's disability. This review is called a manifestation determination (Heward, 2003). If the student's behavior is found not related to the student's disability, the same disciplinary procedures used with other students may be imposed. However, the school district is obligated to provide educational services in an alternative placement (Turnbull et al., 2003).

Individuals with Disabilities Education Improvement Act of 2004

In December 2004, Public Law 108-446, The Individuals with Disabilities Improvement Act of 2004, was signed by President Bush. P.L. 108-446 reauthorized the

Individuals with Disabilities Act of 1997. Many of the provisions became effective on July 1, 2005. The changes and educational implications of the Individuals with Disabilities Improvement Act of 2004 are too numerous to discuss in detail. Two major sections of the Act impacted IEP requirements and changed the qualifications of special education teachers.

IDEA 2004 eliminated the requirement of short-term objectives and benchmarks from the IEP. The exception for this requirement is for students who take alternative assessments and receive instruction from an alternative curriculum. Transition requirements on the IEP have been changed from beginning when a student turns 14 to when the student is 16. Measurable postsecondary goals based on appropriate transition assessments are to be included on the IEP.

Attendance requirements for IEP team members at IEP meetings changed. IEP team members are not required to attend IEP meetings if their area of curriculum or related service is not to be discussed. When a curriculum area or related service is going to be discussed, the team member can be excused if they provide information to the parent prior to the meeting. Parents must have agreed in writing prior to the IEP meeting for team members not to participate in the meeting. In addition, parents and the local education agency can agree to make changes to an IEP in between annual reviews without convening an IEP meeting and without creating a new IEP (Weintraub, 2005).

The new law impacts special education teacher qualification requirements in several ways. First, experienced special education teachers are expected to meet the No Child Left Behind Act's (NCLB) highly qualified provisions. Special education teachers must

have at least a bachelor's degree and hold a valid teaching license. In addition, they must meet their state's requirements for being highly qualified in the core academic subjects they are solely responsible for teaching. Each state has its own methods and requirements for determining whether teachers are highly qualified. Such methods may require teachers to take a test, attend professional development, and/or meet observable standards.

Qualification requirements for special education teachers parallels school improvement trends seen in general education over the past few years. The goal has been to ensure highly qualified teachers are in classrooms. The Council for Exceptional Children (2004) has advocated for special education teachers to be competent in the academic content of all classes they teach. However, the Council for Exceptional Children's position states that the attempts to directly link highly qualified requirements of special educators to the subject matter requirements for general educators under No Child Left Behind provides a lack of recognition for the integrity of special educators. In school districts, special educators deliver services in multiple settings and perform diverse instructional roles. The highly qualified requirements for special educators do not take into consideration the diversity of the individuals for whom special educators serve (Council for Exceptional Children, 2004, p.4). The impact of the new special education teacher qualifications on school personnel and public school programs for students with disabilities is not yet known.

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SECTION FOUR

OVERVIEW OF LITIGATION

Including students with neurological disorders into schools has raised several controversial issues. The issues are centered on the extent of responsibility assumed by school staff and school districts for providing services to meet the needs of children with physical and health care needs. Many educators and administrators believe services such as catheterization, tracheotomy care, and tube feedings are more medical than educational and should not be the school's responsibility (Heward, 2003). The expense associated with providing health related services in schools and the training and supervision of school personnel pose potential problems for school districts. The responsibility for providing health services by school district personnel has been examined by the judicial system. The Supreme Court has established what are considered allowable school health services rather than deciding what services do not have to be provided by school districts. Two landmark court cases have clarified the court's position on health related support services.

Irving Independent School District v. Tatro (1984)

The first landmark court case to address the question of medical support services in schools is Irving Independent School District v. Tatro (hereafter Tatro). In this case, the Supreme Court addressed the question of catheterization as a related service under IDEA. Amber Tatro was an 8-year–old child born with spina bifida who needed clean intermittent catheterization (CIC) every 3-4 hours. Amber was eligible for special education and related services under IDEA because she had an orthopedic impairment

and speech impairment which impacted her learning. The school district provided special classes and the related services of occupational therapy and physical therapy. However, the district did not provide CIC as a related service on the basis of CIC being a medical service, not an educational service (Irving Independent School District v, Tatro, 1984).

The Irving Independent school district claimed that the CIC procedure could only be performed by a physician or a nurse with a physician in attendance. The Supreme Court ruled that catheterization was a related service under IDEA because the service was necessary for Amber to attend school. Without the CIC service, Amber would not be able to benefit from her special education program (Irving Independent School District v. Tatro, 1988). The court further ruled that CIC was not a medical service because the services did not have to be performed by a physician (Katsiyannis & Yell, 2000). Lower courts and schools needed assistance in determining whether a particular service was a health care service covered by IDEA or a medical service excluded from IDEA coverage. The Court established a "bright-line test" with three criteria: (a) the student must be IDEA eligible; (b) the service must be necessary to assist the child to benefit from special education; and (c) the service must be performed by a nurse or other qualified person, but not by a physician (Irving Independent School District v. Tatro, 1984).

Cedar Rapids Community School District v. Garret F (1997)

The second landmark case addressing the question of school districts' responsibility to provide health related serves was Cedar Rapids Community School District v. Garret F (hereafter Garret F). This case involved a 12-year-old middle school student who was paralyzed from a motorcycle accident at the age of 4. Garret F's mother had used money

from insurance and a settlement with the motorcycle company to hire a nurse to care for Garret F's medical needs while he attended elementary school. When Garret F entered middle school, his mother asked the school district to assume the cost of his physical care during the school day. The school district refused, believing it was not responsible under IDEA for providing continuous nursing care. The services needed by Garret F were urinary bladder catheterization, tracheotomy suctioning, manual resuscitation, and blood pressure monitoring (Katsiyannis & Yell, 2000). The Administrative Law Judge (ALJ) relied on the Tatro "bright-line" standard and ruled the school district was required to pay for health related services. The AJL ruled in favor of Garret F based on the distinction between health care services and medical services in the Education for All Handicapped Children Act of 1975 and subsequent reauthorizations. Medical services were defined as those services that can only be performed by a licensed physician and school districts cannot be held accountable for performing. The school district appealed and lost in both the district court and the U.S. Circuit Court of Appeals for the 8th circuit (Etscheidt & Bartlett, 1999). Cedar Rapids Community School District appealed to the Supreme Court. The Supreme Court agreed with the lower courts. The requested health related services were related services because Garret F could not attend school without the services. The Court also concurred the services were not excluded as medical services needed to be performed by a physician. Though the court acknowledged the school district may have had legitimate concerns about the financial burden of providing these services, the Court determined this issue fell outside its authority (Katsiyannis & Yell, 2000).

By reaffirming the standards adopted in Tatro, the Supreme Court clearly established the need for school districts to provide any and all necessary health care services to qualified students with disabilities. Until Garret F, the Courts held that a single health care procedure was deemed a related service. The Garret F ruling elaborated on the Tatro ruling, by stating that as long as a doctor was not required to perform the health care procedure, any combination of services, regardless of the cost, should be the responsibility of the school district (Best, Heller, & Bigge, 2005).

Despite the Court's ruling in Tatro and Garret F, the controversy regarding school health services has continued. A number of lower courts departed from the standard of Tatro and ruled numerous and complex health services required for a particular student, even when not performed by a physician, were medical in nature and were, therefore, not required under IDEA (Hill, 1999).

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SECTION FIVE

REGULATIONS, STANDARDS, AND OTHER LAWS

State regulations, professional standards, and guidelines related to health care influence the education of students with neurological disorders in public school settings. Legislation and litigation supports the provision of health care procedures during the school day as a related service in the education of students with neurological disorders. The decisions regarding personnel who will provide the health care service is based on state and local regulations, guidelines, and school district policies (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000).

State legislatures pass licensure requirements for nurses and delegate the function of regulating the practice of nursing to a state board of nursing or board of nursing examiners. These boards regulate nursing practice, monitor nursing activities, determine the scope of practice, and set disciplinary standards (Janz, Beyer, Schwab, Anderson, Caldwell, & Harrison, 2003). School districts need to be aware of and understand the specifics of medical and nursing practice legislations, regulations, and standards for their state. Each states' nursing practice act includes a provision where by the nurse can delegate certain procedures to unlicensed personnel (Heller, Frederick, Best, Dykes, & Cohen, 2000). In such situations, teachers and paraprofessionals work under the school nurses' supervision. The school nurse is accountable for the appropriateness of delegating the specialized health care procedure (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000).

In addition to federal and state legislation, many national organizations have produced publications, position statements, and or guidelines for the provision of health care services in schools. Such organizations include the National Association of School Nurses, the American Academy of Pediatrics, and the National Education Association. Guidelines are not law, but offer standards for high-quality practice and services.

Several state departments of health or education have produced guidelines and standards which affect the education of and services provided for students with neurological disorders. These guidelines are generally not adopted into federal or state laws, but are often incorporated into the district's policy and procedures. Guidelines may include infection control, universal precautions, medication administration, guidelines for nursing practice and school policy recommendations. School district policies and procedures also influence the quality of service provided to students with neurological disorders. Often school district's job descriptions, personnel qualifications, and staffing patterns of nurses and other school personnel are adopted from state and national standards and guidelines (Heller, Frederick, Best, Dykes, & Cohen, 2000).

Clinical, legal, and administrative issues related to the education of students with physical and health care needs in public school settings can be complex. School health care and education personnel working together to educate each other, exploring all relevant issues, and developing plans to ensures quality care for each student with special health care needs is essential.

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SECTION SIX

FAMILIES OF CHILDREN WITH NEUROLOGICAL DISORDERS

All families are social systems from which all individuals establish roles and relationships which grow, develop, and change while interacting with each other (Fine & Nissenbaum, 2000). The family provides protection, physical care, support, and socialization for each individual, especially the children (Falvo, 2005). Each individual within the family plays a role in the everyday life of the family. The impact of a child with a neurological disorder is far-reaching. The impact extends beyond the child with the neurological disorder. The impact extends to all those with whom the individual has contact, especially the family.

The Impact on Family Life

A child with a neurological disorder affects each family member and the family life. Family members may experience increased stress, disruption to relationships, and financial hardships. The health care needs or disability of one child can bring about changes in housing, careers, family life style, and the roles of family members (Turnbull & Turnbull, 2001).

Knoll (1992) found children with neurological disorders affect their families with respect to daily care issues. Approximately 50 percent of the families gave their child extensive assistance with toileting, bathing, and medical monitoring. One–fourth of the families indicated their child needed 24 hour a day monitoring. Slightly more than half of the families reported they had experienced some sort of crisis requiring intervention within the last month. Each family created family routines taking into consideration the

child's daily care needs. In addition to daily care needs, parents also deal with medical equipment, specialized procedures, medical appointments, and hospitalization (Harkins, 1994; Turnbull & Turnbull).

While most families receive federal, state, or private insurance assistance, many families pay thousands of dollars for medical treatments, therapies outside of school and equipment. In addition to the added expenses, families of children with neurological disorders often have reduced income because one parent works part time instead of full time or does not work at all to provide the time needed to care for the child (Heward, 2003).

Parental Stress

Parenting is an awesome responsibility requiring tremendous physical and emotional energy. Parents of children with neurological disorders experience added stress brought on by the child's physical, emotional, and financial demands (Turnbull & Turnbull, 2001). Different types of neurological disorders bring different kinds of challenges to families (Harkins, 1994; Heward, 2003).

Grieving Process: It is generally accepted that families, especially parents, go through a grieving process when their child is first diagnosed with a neurological disorder. Much of the literature related to the impact of a child with a disability on the family has been adapted from the work by Elisabeth Kubler-Ross (1969) who outlined the stages of grief individuals go through in their response to the death of a loved one. Freitag-Koonz (1988) described five different stages parents of children with severe neurological impairments or a congenital malformation experienced in the process of accepting their

child's condition. The stages included: (a) shock; (b) denial, disbelief, and bargaining: (c) sadness, anger, and anxiety; (d) establishing equilibrium; and (e) reorganization.

The stages parents experience in adjusting to a child with a chronic illness, as opposed to a disability, are dependent on the chronology of the illness. McCollum and Gibson (1970) outlined a four-stage process family's progress through when dealing with a child with chronic terminal health impairment. The first stage is the prediagnostic stage. This is the time period between when parents realize their child is ill and receiving a diagnosis of the child's medical condition. The second stage is the confrontational stage. During this time, parents mourn the loss of their normal healthy child and struggle with their own confirmation of the diagnosis. The third stage is the long-term adaptation stage when parents attempt to meet the physical and psychological needs of the child. In addition, they attempt to maintain a relationship with their dying child. The fourth stage is the terminal stage when parents accept the child is not going to survive.

Coping and Resiliency: Assuming all parents experience a grieving process and time is the most important variable to adjustment may be too simplistic an interpretation of the process. Recent research has shown parents react to a child with special health care needs and physical disabilities in many ways (Bruce & Schultz, 2001; Patterson & Leonard, 1994; Turnbull & Turnbull, 2001). For some parents, years may pass and they are still not comfortable with their child. Other parents have reported their lives have been strengthened by having a child with a disability (Scorgie & Sobsey, 2000). Patterson and Leonard (1994) interviewed couples whose children required intensive home care routines because of chronic and complex health care needs. They found

roughly equal numbers of positive and negative responses. Individual family members may experience different feelings, in various sequences, and at different times. Parents have reported many events in their daily life will trigger feelings of sadness. These events involve changes, such as a new diagnosis or medical need, using new technology and the child's transition to another grade or school. Milestones such as birthdays, graduation, and transition from elementary to middle to high school can also trigger feelings (Turnbull & Turnbull, 2001; Bruce & Schultz, 2001).

More recently, research has shifted to exploring how families manage and cope with the demands of caring for children with disabilities. In a study of families with medically fragile children, Youngblut, Brennan, and Swegart (1994) investigated the major coping strategies the families used. The coping strategies used by families included sharing their difficulties with relatives, neighbors, and friends. During these interactions, the family members allowed themselves the opportunity to receive support. Families also sought out information and advice from people who could be helpful in making decisions and solving problems. The families looked for advice and assistance with solving problems by turning to physicians, nurses, relatives, therapists, and religious leaders. Some families found support from professional counselors.

Patterson and Blum (1999) identified factors leading to resiliency in families. The resilient families showed a commitment to all family members including the child with the disability. Family routines had been established taking in the needs of all family members. Parents were able to maintain clear family routines, but were able to be flexible with routines during a health care crisis or disruption to their daily routines.

Parents could change their expectations and alter their roles and family rules as needed, but not at the expense of other family members. One parent was less likely to become overly involved with the child with the special health care needs.

These resilient parents had the skills required to access information and services. They were able to solve problems, make decisions, and resolve conflicts within a collaborative relationship with professionals. In the process of caring for the child with a health care need or physical disability these parents developed and maintained supportive relationships with friends, relatives, and community members.

Families able to meet the needs of the child with the health care needs or physical disabilities were able to acknowledge the positive contributions of the child to the family. Some parents reported their lives developed more meaning as a result of their child's special health care need or disability.

Siblings

Just as a child with a special health care need or with a physical disability will impact his or her parents, the child's siblings will also be impacted (Stoneman, 1998). Research on the impact on siblings is contradictory. Research reports potential negative impacts on siblings such as over identification, embarrassment, guilt, isolation, loneliness and resentment (Turnbull & Turnbull, 2001). The negative impact can manifest itself in sibling's poor school performance, increased attention seeking behaviors, increased responsibility, and pressure to achieve (Faux, 1993). Research has also found the impact on siblings can also be positive. Siblings of a brother or sister with a special health care

need or physical disability can exhibit enhanced maturity, more insight and tolerance, an increased sense of accomplishment and self-worth (Turnbull & Turnbull, 2001).

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PART TWO

NEUROLOGICAL DISORDERS:

DESCRIPTIONS AND CHARACTERISTICS

SECTION SEVEN

NON-TRAUMATIC ACQUIRED BRAIN INJURIES

An appropriate education program for students with non-traumatic acquired brain injuries requires modifications to the classroom environment, assistive devices for instruction and mobility, health related services, and social and emotional support. Education programs must provide students with access to the general education curriculum with accommodations to meet the individual and changing needs of each student. In addition to academic skills, the student needs to become as independent as possible with mobility, health care routines, and activities of daily living.

Careful planning involving administrators, teachers, support personnel, and parents is needed to ensure the changing educational and health care needs of students with non-traumatic acquired brain injuries are met in school. While developing educational programs to meet the needs of the students, how the non-traumatic acquired brain injury may affect a student's development, learning, behavior, and emotion, must be considered.

The medical and educational impact of non-traumatic acquired brain injuries is not stable and students may experience delayed complications. Deficits may emerge throughout childhood and adolescence as more demands are places on the students (Lash, Wolcott, & Pearson, 2000). School personnel must periodically monitor the students' present level of functioning and adjust the level of support and physical assistance provided to students to meet their changing physical, educational, and emotional needs.

This chapter contains a definition of and description of the causes of non-traumatic acquired brain injuries. An overview of the physical and cognitive conditions associated

with non-traumatic acquired brain injuries is included. Social, emotional, and behavioral complications are also discussed. The chapter concludes with resources for school personnel.

Definition and Description

An acquired brain injury is an injury to the brain which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain which has occurred after birth. Non-traumatic brain injuries occur at the cellular level within the brain. Therefore, the injury can impact cells throughout the entire brain instead of a specific area, as with traumatic brain injuries (Middleton, 2001). Non-traumatic brain injuries can cause a total or partial disability or impairment. Impairments may be temporary or long lasting and fall into three main categories: physical and sensory changes; cognition; and social, behavioral, and emotional problems (Savage, 2001). Students may exhibit any combination of difficulties to varying degrees. Brain injuries can affect all areas of a student's life and functioning.

Unlike many other types of students with special needs, students with acquired brain injuries defy easy categorization as brain injuries are not alike. The pattern of difficulties will be determined by where and what type of damage occurred and the student's age at the time of the injury (Savage & Wolcott, 2001). One striking difference in comparing most students receiving special education services and students having a non-traumatic acquired brain injury is the rate of change which occurs. Recovery within the first twelve to eighteen months following the injury is often rapid. Students can plateau for a time and suddenly make significant progress (Savage & Wolcott, 2000).

Classification of Non-traumatic Acquired Brain Injuries

Non-traumatic acquired brain injuries are caused by different types of medical conditions. The medical conditions most often responsible for non-traumatic acquired brain injuries are anoxic injuries, infections of the brain, strokes, and other vascular accidents.

Anoxic Injuries

Anoxic injuries are caused by partial or complete lack of oxygen supplied to the brain. Cells in the brain need oxygen to survive and function. Anoxic injuries include, but are not limited to, anesthetic accidents, choking, near-drowning accidents, electrical shock, lightening strike, infectious diseases, and severe blood loss (Middleton, 2001).

Infections of the Brain

The brain and spinal cord can become infected by a large spectrum of bacteria and viruses. These bacteria and viruses cause an inflammation of the areas of the brain which are invaded by the bacteria or virus. Depending on the location of the infection, the student may be diagnosed with either meningitis or encephalitis. Recovery depends on the student's age, the severity of the illness, and the type of invading bacteria or virus (Savage, 2001).

Meningitis occurs when the meninges or membranes surrounding the brain and spinal cord become infected. Meningitis most commonly affects infants and young children. About two-thirds of all cases of meningitis reported in the United States occur in children. Meningitis can be caused by either bacteria or viruses. Viral meningitis is relatively common and usually causes milder symptoms (Savage & Wolcott, 2001).

Bacterial meningitis is very serious and may result in death. One in five children with bacterial meningitis develop permanent disabilities, such as cerebral palsy (Middleton, 2001).

Encephalitis is an inflammation of the brain. It can be caused by either bacteria or a virus. The acute phase of the illness when symptoms are the most severe usually lasts up to a week. Recovery from the physical complications can take much longer, often several weeks or months (Savage & Wolcott, 2000).

Strokes and Other Vascular Accidents

The term "stroke" is used to describe the disruption of blood flow in the brain. Children and newborns can develop a stroke which is an interruption of blood to the brain. Brain cells in the immediate areas are damaged or destroyed. Cells in the surrounding areas are affected by the reduced blood flow. Once the brain cells are destroyed, their function will be impaired (Savage & Wolcott, 2000). The most common causes of strokes in children include heart disorders, blood disorders such as sickle cell disease, infections in the skull, and injury or trauma to the head (Middleton, 2001).

A cerebral hemorrhage is bleeding from a ruptured blood vessel inside the brain. A cerebral hemorrhage causes a collection of blood which will clot, putting pressure on nearby brain tissue. The collection of blood will restrict the delivery of oxygen and nutrients to the brain. A cerebral hemorrhage can be life threatening. Treatment depends on the location and severity of the hemorrhage (Savage, 2001).

Physical Conditions Associated with Acquired Brain Injuries

Most complications of non-traumatic acquired brain injuries are very similar to the outcomes of traumatic brain injuries (Savage & Wolcott, 2001). More severe and often more frequent patterns of difficulties occur with students with non-traumatic acquired brain injuries. Physical conditions associated with non-traumatic acquired brain injuries are effectively managed through the collaboration of physicians, school nurses, teachers, physical and occupational therapists, and support staff working directly with the student and their families (Lash, Wolcott, & Pearson, 2000).

Orthopedic Impairment

Orthopedic impairments are extremely variable in students with a non-traumatic acquired brain injury. During the early stages of recovery, the student may require a wheelchair or walker for mobility (Feenick & Judd, 2001). The student may experience Hemiplegia or weakness on one side of the body. This type of orthopedic impairment may require therapeutic rehabilitation and possibly future surgery (Middleton, 2001).

In addition to the apparent physical impairments, a student may have problems with coordination and balance. Motor planning, the ability to put together a sequence of movements, can also be a long-term complication of a non-traumatic acquired brain injury (Middleton, 2001).

Fatigue

Physical and mental fatigue is often apparent in the early stages of recovery. Endurance for performing both physical and mental activities can be significantly impaired (Feenick & Judd, 2001). For some students, fatigue will decrease as they

recover. For others, fatigue will be a life long complication of the brain injury. Fatigue is a very common long-term effect of an acquired brain injury. Fatigue can impact the student's physical, cognitive, and emotional skills (Savage & Wolcott, 2000).

Sensory Impairments

Some students with non-traumatic acquired brain injury may have impairments of vision and hearing. Visual acuity may be impacted for some students. Other students have adequate visual acuity, but are unable to interpret visual information (Lash, Wolcott, & Pearson, 2000). Some students will be unable to process information they see or hear when other noises or things are within their field of vision. In addition to a hearing or visual loss, students may be unable to feel portions of their extremities, be unable to differentiate one sensation from another, or be extremely sensitive to pain (Savage, 2001).

Seizures

Some children with non-traumatic acquired brain injuries will develop a seizure disorder. A seizure is a sudden occurrence of altered consciousness, behavior, sensation, and/or movement due to disruption of normal electrochemical activity in the brain (Clancy, 1990). See the chapter on seizure disorders for additional information.

Cognitive Conditions Associated with Acquired Brain Injuries

Non-traumatic acquired brain injuries can result in partial or total functional disability which can adversely impact student's educational performance. The non-traumatic acquired brain injury may result in mild, moderate, or severe impairments in one or more

areas. The areas impacted include attention, concentration, memory, cognition, communication, and executive functioning skills (Savage, 2001).

Attention and Concentration

The student's inability to concentrate may be due to distractibility. The student may not be able to divide attention between competing visual and auditory input. The student may also have a difficult time shifting their attention from one task to another (Savage & Wolcott, 2001).

Memory

Portions of a student's ability to remember may be impaired while other types of memory are intact. The students may be able to remember information and materials presented visually, but not auditory presentations, or the reverse. Memory of things which happened in the past may be easier to recall than current activities or events (Lash, Wolcott & Pearson, 2000).

Information Processing

Often students with a non-traumatic acquired brain injury are no longer able to process information as quickly as they could previously. Attention, concentration, memory, fatigue, and communication deficits will impact the students' ability to process information (Savage, 2001).

Communication

A wide range of speech and language difficulties may be experienced by students with non-traumatic brain injuries. Some students may lose the ability to communicate through speech. Others may have a difficult time articulating words clearly. Some students will

be able to articulate clearly, but have a difficult time formulating and expressing what they want to say (Savage & Wolcott, 2001). Lack of the skills needed to communicate can lead to frustration and anger for the students with the brain injury.

Executive Functioning Skills

Many students with a brain injury experience difficulty with executive function skills. These skills include the ability to plan, reason, set goals, organize an activity, and complete it following the correct sequence, with revisions as needed. These skills also include the ability to know which behavior is appropriate in different situations (Feenick & Judd, 2001).

Social, Emotional, and Behavioral Changes

Behavioral and personality changes may result directly from damage to areas of the brain or may be secondary effects of the acquired cognitive difficulties or the frustration of these impairments. Some common problems are: restlessness, lack of motivation, dramatic mood swings, aggressiveness, destruction, impulsivity, socially inappropriate behaviors, depression, obsessive-compulsive disorders, and frustration (Lash, Wolcott, & Pearson, 2000). The student may also develop fears and anxieties caused by the illness or injury and changes to their abilities (Savage & Wolcott, 2001).

Changes in the student's ability to control their emotions may result in temper flare-ups, yelling, swearing outbursts, and hitting or punching others. These behaviors may occur more frequently when noise and activity levels increase or during stressful periods. Feelings of sadness and loss are normal reactions to a brain injury (Feenick & Judd, 2001). These feelings can be caused by a direct injury to the brain resulting in altered

emotional functioning. Some medications can contribute to these feelings. Many times these feelings are a result of the student's feeling changed or not being the person they were before (Middleton, 2001).

The potential impact on social relationships cannot be underestimated. The student who has suffered non-traumatic brain injury has probably spent a considerable amount of time in the hospital, a rehabilitation setting, or at home. This extended absence may mean a loss of contact with some family members, peers, and classmates. Previous friendships may be strained if old friends have to adjust to a friend who may have changed (Feenick & Judd, 2001).

RESOURCES

Americans with Disabilities Act Accessibility Guidelines http://www.access-board.gov/adaag/html

American Occupational Therapy Association http://www.aota.org

American Physical Therapy Association http://www.apta.org

Disabilities Information Access Line 800-922-3425

Epilepsy Foundation of America http://www.efa.org

National Information Center for Children and Youth with Disabilities (NICHCY) 800-695-0285 http://nichcy.org

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SECTION EIGHT

CEREBRAL PALSY

An appropriate education program for students with cerebral palsy often requires modifications to the classroom environment, use of specialized teaching techniques, assistive devices for instruction, communication, mobility, and health related services. An appropriate education program provides students with access to the general education curriculum with accommodations to meet the individual needs of each student. In addition to learning academic skills, students with cerebral palsy need to become as independent as possible with health care routines and activities of daily living. Careful planning involving administrators, teachers, support personnel, and parents is needed to ensure the educational and health care needs of students with cerebral palsy are met in school. When developing an educational program to meet the needs of the student, how cerebral palsy may affect a student's development, learning, and behavior must be considered.

This chapter contains a definition and description of cerebral palsy and an overview of the physical and cognitive conditions associated with cerebral palsy. The chapter concludes with resources for school personnel.

Definition and Description

Cerebral Palsy is a disorder of movement and posture originating from damage to the central nervous system (CNS) which consists of the brain and spinal cord. The motor functions of individuals with cerebral palsy are affected. Manifestations may include paralysis, extreme weakness, lack of coordination and other motor disorders. In addition

to the physical impairments, cerebral palsy is often accompanied by sensory, communication, learning, and cognitive disabilities (Pellegrino, 2002).

Individuals with cerebral palsy have damage to the central nervous system which impacts motor development and function. In turn, motor dysfunctions can significantly impact development and learning. Researchers in human cognitive development have emphasized the importance of sensation and movement activities in the early years of life (Pellegrino, 2002). Through movement, infants learn about spatial relationships, limits, proportions of their own bodies and balance. Infants also learn properties of objects and mass by moving about in space and exploring, experimenting, and remembering consequences (Hill, 1999).

Cerebral palsy is different from conditions that are progressive or unstable. The brain damage that causes cerebral palsy does not heal, nor does it worsen. Cerebral palsy cannot be cured; it is not a disease, is not fatal or contagious (Heward, 2003). A diagnosis of cerebral palsy does not provide a description of how an individual is affected or how the individual will function. There is no typical individual with cerebral palsy or typical constellation of impairments (Best, Heller, & Bigge, 2005). The degree of physical impairment is not related directly to the individual's learning potential. Intellectual potential may range from giftedness to average to impaired.

Classification of Cerebral Palsy

A diagnosis of cerebral palsy is not descriptive of its effects on the individual. The condition may be mild for some individuals and severe for others. Cerebral Palsy can be classified either by the effects on movement or the location or body part. The

classification by specific motor patterns and its effects on movement are spastic cerebral palsy, athetoid cerebral palsy, and ataxic cerebral palsy (Best, et al., 2005).

Classification by Effects on Movement Patterns

Spastic cerebral palsy is the most common form of cerebral palsy. It is characterized by increased muscle tone and exaggerated reflexes. Spasticity results in tight contracted muscles and shortened ligaments. Students' movements may be jerky, exaggerated, and poorly coordinated. Muscle contractions can result in gradual limitations of joint mobility and restricted range of motion. Contractures can contribute to deformities of the spine, hip dislocation, and contractures of the hands, elbow, foot, and knee (Pellegrino, 2002).

Athetoid cerebral palsy consists of a group of disorders. It is characterized by involuntary, non-purposeful movement particularly in the arms, hands, and facial muscles. When movement is attempted, it overflows to other muscle groups resulting in uncontrolled overflowing movements, tremors, and shaking (Hill, 1999).

Ataxic cerebral palsy is associated with increased or decreased muscle tone. The main feature is lack of coordination in balance and equilibrium. The individual may appear dizzy and will fall easily if not provided with support. Difficulties include controlling the hand and arm during reaching along with controlling the timing of movements. Ataxic cerebral palsy can occur in conjunction with spastic cerebral palsy (Heward, 2003).

Classifications by Location or Body Part

The classification by location or body part provides a description of which limb is affected. The major classifications by location include:

Diplegia involves all four limbs with the legs being more involved then the arms.

Hemiplegia involves one side of the body.

Paraplegia involves impairment of the legs.

Quadriplegia involves all four limbs.

Physical Conditions Associated with Cerebral Palsy

In addition to orthopedic impairments and seizures, individuals with cerebral palsy frequently experience impairments in vision, hearing, and or speech. Physical conditions associated with cerebral palsy are most effectively managed through the collaboration of physicians, school nurses, teachers, physical and occupational therapists, communication specialists, support staff and all other staff who work directly with the student and their families (Heward, 2003).

Orthopedic Impairments

Continuing muscle tightness can cause skeletal deformities in the spine and extremities such as hips, legs, feet, arms, hands, fingers, etc. (Pellegrino, 2002). These orthopedic impairments may require corrective surgeries and therapeutic rehabilitation. Ongoing collaboration between physicians, therapists, school personnel, family members, and the individual with cerebral palsy is necessary to achieve optimal therapeutic outcomes (Heward, 2003).

Seizures

A seizure is a sudden occurrence of altered consciousness, behavior, sensation, and or movement due to disruption of normal electrochemical activity in the brain (Clancy 1990). It is estimated that between 25% and 50% of individuals with cerebral palsy have

a seizure disorder (Brown, 2002). See the chapter on Seizure Disorders for additional information.

Sensory Impairments

Individuals with cerebral palsy frequently experience impairments in hearing and vision. Between 5- 15% of individuals with cerebral palsy have a hearing loss (Heward, 2003). It has been estimated half to three-quarters of all children with cerebral palsy have some kind of visual impairment (Heward, 2003; Buultjens & McLean, 2003). Common visual impairments include myopia (nearsightedness), amblyopia (loss of vision related to disuse), strabismus (eyes crossed or turned in), and nystagmus (eyes that flicker back and forth). In addition to these visual impairments, the individual may have good visual acuity but be unable to visually track smoothly, focus on objects, recognize objects, or use their vision in all visual fields. These visual difficulties are often called cortical visual impairment, cerebral visual impairment, or CVI (Buultjens & McLean, 2003).

Students with cerebral palsy need to be evaluated to be sure they have adequate vision and hearing. If a sensory impairment is present, services from specialists in vision or hearing impairments and orientation and mobility specialist will provide strategies for enhancing educational achievement. Assistive technology devises and services should be made available to enhance function when a sensory impairment that impacts learning is present.

Speech Impairments

Speech is a motor act that occurs through coordinated efforts of breathing and movement of muscles that control the mouth, tongue, and lips (Hill, 1999). When an

individual's muscles are affected, their speech may be slurred, distorted or absent. If speech and language are issues for the individual with cerebral palsy, the individual may have trouble understanding what is said, formulating a response, and using speech to communicate.

Cognitive Conditions Associated with Cerebral Palsy

Cognitive abilities of individuals with cerebral palsy may range from giftedness to average intelligence, a specific learning disability, or mental retardation (Best, et. al., 2005). It is often difficult to assess intelligence in individuals with cerebral palsy using standardized measures. Many tasks required in these assessments are based on motor or verbal responses that are impossible for some individuals with cerebral palsy to reproduce. Care should be taken never to infer intellectual deficits solely on the basis of motor and or speech disabilities (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000).

RESOURCES

Americans with Disabilities Act Accessibility Guidelines http://www.access-board.gov/adaag/html

American Occupational Therapy Association http://www.aota.org

American Physical Therapy Association http://www.apta.org

Disabilities Information Access Line 800-922-3425

Epilepsy Foundation of America http://www.efa.org

National Easter Seals Society http://www.seals.com

National Information Center for Children and Youth with Disabilities (NICHCY) 800-695-0285 http://nichcy.org

National Scoliosis Foundation, Inc. 800-673-6922

Scoliosis Association 800-800-0669 http://www.spine-surgery.com

United Cerebral Palsy 800-872-5827 http://www.ucpa.org/html/index.html

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SECTION NINE

MUSCULAR DYSTROPHY

An appropriate education program for students with muscular dystrophy requires modifications to the classroom environment, assistive devices for instruction and mobility, health related services, and social and emotional support. Education programs must provide students with access to the general education curriculum with accommodations to meet the individual and changing needs of each student. In addition to academic skills, the students must stay as independent as possible with mobility, health care routines, and activities of daily living. Careful planning involving administrators, teachers, support personnel, and parents is needed to ensure the educational and health care needs of students with muscular dystrophy are met in school. While developing educational programs to meet the needs of the students, how muscular dystrophy may affect a student's development, learning, behavior, and emotion, must be considered. Since muscular dystrophy is a progressive disease, school personnel must periodically monitor the students' present level of functioning and adjust the level of support and physical assistance provided to students to meet their changing physical needs.

This chapter contains a definition and description of muscular dystrophy and an overview of the physical and cognitive conditions associated with muscular dystrophy. Psychosocial development is also discussed. The chapter concludes with resources for school personnel.

Definition and Description

At birth, children with muscular dystrophy appear typical. During early childhood, they develop muscle weakness. By 12-14 years of age, many children with muscular dystrophy are no longer able to ambulate. In many cases, students with muscular dystrophy have a shortened life expectancy. Over the years, the life expectancy of children with muscular dystrophy has consistently been revised upward due to advances in scoliosis treatment and pulmonary care (Hill, 1999).

Classification of Muscular Dystrophy

A diagnosis of muscular dystrophy is not descriptive of its effects on the individual. Symptoms progress at varying rates with the symptoms being mild for some individuals and severe for others. There are actually 13 different types of muscular dystrophy and three are seen in children. Four criteria are used to classify the types of muscular dystrophy. Criteria used are: mode of inheritance; age of onset; muscles involved; and severity and degeneration of muscle tissue (Hill, 1999). Three major types of muscular dystrophy typically seen in children are Duchenne muscular dystrophy (DMD), facioscapulohumeral (FSH), and mytonic muscular dystrophy (MMD).

Duchenne Muscular Dystrophy (DMD)

Duchenne muscular dystrophy (DMD) is the most common type of muscular dystrophy. DMD is a sex-linked disease which affects one in every 3500 live male births. DMD is the second most common lethal genetic disorder, second to cystic fibrosis. Females transmit the condition to 50% of their sons, but they are not affected by the disease (Hill, 1999).

Students with DMD have a different physical development experience than typically developing children. Physical development is initially normal and the student can remember the experience of walking and running as they physically deteriorate. Symptoms of DMD are observable between the ages of two and six years, although symptoms progress at varying rates. Weakness usually begins in the lower legs and with pelvic muscles which cause difficulty with running and climbing. Lower legs of students with DMD appear muscular when in fact muscle tissue is being replaced with fat and fibrous tissue (Hill, 1999). Eventually ambulation is no longer possible and the student will need a wheelchair. Muscle control becomes limited to the use of the fingers, even after the ability to hold up the head is lost. Individuals often live until adolescence or young adulthood. Death is usually caused by respiratory failure due to weakness of the chest muscles or heart failure due to weakened heart muscles (Leet, Dormans, & Tosi, 2002).

Facioscapulohumeral (FSH)

FSH Muscular Dystrophy is a group of neuromuscular syndromes which differ from each other in extent of symptoms. Symptoms of FSH usually occur during adolescence, but may occur as early as age seven. Symptoms include upper arm and shoulder weakness, impaired eye and lip closure, and eventually foot drop. Muscle involvement in eye movement and chewing are spared and ambulation is often preserved (Sandoval, 1999).

The child's mother or father can carry the defective gene and either can pass it on to their son or daughter. FSH has a slower progression than Duchenne muscular dystrophy

(Best, Heller, & Bigge, 2005). More than half of those affected have a normal life expectancy due to FSH being a slowly progressive, but chronic disease (Hill, 1999).

Mytonic Muscular Dystrophy (MMD)

Myotonic muscular dystrophy is an inherited disorder with varied symptoms affecting more males than females. Symptoms include the inability of muscles to relax after contraction, loss of muscle power and bulk in the face and neck, flat facial expression, swallowing difficulties and weakness of the extremities. About half of the individuals with MMD develop mild scoliosis and contractures at the ankles (Leet et al., 2002).

MMD is usually first noted in adolescence, but progressive general muscle weakness can be seen at birth or shortly thereafter (Sandoval, 1999). MMD is a progressive condition, but the deterioration is usually slower with MMD than with DMD. Many students with MMD have mild muscle weakness. For some students, the muscle involvement is severe and the student will become incapacitated (Hill, 1999).

Physical Conditions Associated with Duchenne Muscular Dystrophy

Students with DMD experience typical physical development. Initial physical mastery of many skills is followed by slow progressive loss of function. Over a period of time ranging from months to years, students with DMD deteriorate physically as their muscles waste away. As students physically deteriorate, ambulation becomes difficult and they develop orthopedic complications and curvature of the spine (Hill, 1999). Although students with DMD may appear to have only physical disabilities associated with maintaining active upright mobility, the condition is complex and can affect other systems of the body. Over time, the students, their families, and school personnel will

need to manage respiratory and cardiac complications both at home and at school (Best et al., 2005). Physical conditions associated with muscular dystrophy are most effectively managed through the collaboration of physicians, school nurses, teachers, physical and occupational therapists, respiratory therapists, support staff, social workers, psychologists and all other staff who work directly with students and their families (Heward, 2003).

Orthopedic Impairments

Continuing muscle atrophy and lack of mobility can cause contractures or tightening of the joints. Students with muscular dystrophy often develop contractures of the hips, knees, ankles, shoulders, elbows, and feet (Hill, 1999). Therapeutic rehabilitation, exercise programs, use of orthotics, and corrective surgeries are used to prevent and treat contractures.

Scoliosis

As students with muscular dystrophy become less mobile and spend more time in a wheelchair, they develop scoliosis, a curvature of the spine. Usually scoliosis will develop within 2 years of the student using a wheelchair (Sandoval, 1999). Scoliosis is a major concern as maintaining a straight spine slows the progression of breathing difficulties. Medical teams treating students with muscular dystrophy monitor the scoliosis and prescribe therapeutic rehabilitation and corrective surgeries.

Respiratory Complications

As the chest muscles weaken, students with muscular dystrophy are unable to take a deep breath or cough properly. Minor colds and chest infections frequently lead to pneumonia. Often students with muscular dystrophy will work with a respiratory

therapist or pulmonologist who will provide the student with breathing exercises to facilitate breathing and prevent infections (Hill, 1999)

Cognitive Conditions Associated with Muscular Dystrophy

Research indicates that cognition is impaired in some males with DMD, especially in verbal performance (Leet et al., 2002). Poor school performance may be a result of low expectations, frequent school absences due to illness, or psychological stress (Hill, 1999). Although there are no cognitive studies available for children with FSH, adults with FSH generally fall in the normal range of intelligence. More than 20% of children with MMD present with mild to moderate mental retardation (Sandoval, 1999).

Psychosocial Development of Students with Muscular Dystrophy

Students with DMD experience the psychosocial impact of living with a terminal illness. In addition to dealing with decreased physical limitations, increased dependency on others for care, they eventually realize that their prognosis for a long life is not realistic (Leet et al., 2002). Students with DMD often become passive and withdrawn as the disease progresses (Hill, 1999). Many parents, in an attempt to protect their child, will allow their child to stop attending school. Students with DMD can become socially isolated from friends, peers, and family members (Best et al., 2005)

RESOURCES

Americans with Disabilities Act Accessibility Guidelines http://www.access-board.gov/adaag/html

American Occupational Therapy Association http://www.aota.org

American Physical Therapy Association http://www.apta.org

Disabilities Information Access Line 800-922-3425

Muscular Dystrophy Association (DMA) 800-572-1717

National Information Center for Children and Youth with Disabilities (NICHCY) 800-695-0285 http://nichcy.org

National Scoliosis Foundation, Inc. 800-673-6922

Scoliosis Association 800-800-0669 http://www.spine-surgery.com

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SECTION TEN

NEUROCUTANEOUS SYNDROMES

An appropriate education program for students with neurocutaneous syndromes often requires modifications to the classroom environment, use of specialized teaching techniques, health related services, and social and emotional support. Educational programs must provide students with access to the general education curriculum with accommodations to meet the individual needs of each student. Careful planning involving administrators, teachers, support personnel, and parents is needed to ensure the educational and health care needs of students with neurocutaneous syndromes are met in school. While developing educational programs to meet the needs of the students, how neurocutaneous syndromes may affect a student's development, learning, behavior, and emotions, must be considered.

This chapter contains a definition and description of neurocutaneous syndromes along with the definition and description of the three most common neurocutaneous syndromes. An overview of the physical and cognitive conditions associated with each neurocutaneous syndrome is discussed. The psychosocial implications are included. The chapter concludes with resources for school personnel.

Definition and Description of Neurocutaneous Syndromes

Neurocutaneous syndromes are a group of neurological disorders characterized by skin lesions and abnormalities of the central nervous system (Cross, 2005). The disorders cause tumors to grow inside the brain, spinal cord, organs, skin, and bones. All neurocutaneous disorders are congenital and present with varying degrees of symptoms.

The disorders are life long conditions which are not curable (Phelps, 1999). Treatment for each condition focuses on preventing or minimizing deformities and maximizing independence. The three most common neurocutaneous syndromes are neurofibromatosis (NF), tuberous sclerosis complex (TS), and Sturge-Weber disease (SWS).

Neurofibromatosis (NF)

Neurofibromatosis is an unpredictable disorder affecting the skin and nerves. It varies widely in severity from one individual to the next, even between two individuals in the same family (Phelps, 1999). Some individuals have mild symptoms while others have major cosmetic and medical complications.

Neurofibromatosis encompasses two separate disorders, classified as Neurofibromatosis type I (NF I) and Neurofibromatosis type II (NF II). They are both genetic conditions which cause tumors to form around nerves, but otherwise they are distinct conditions (Phelps, 1999). This chapter contains information about NF I because NF II is rare and seldom appears among school age students.

Half of all individuals with NF I inherited the disease from one of their parents. A parent with NF I has a 50% chance of passing the condition to their child. NF I may also result from a non-inherited mutation of a new gene. The incidence of NF I is 1 in 3000 births. Males and females are equally affected and it occurs in all races and ethnic groups (Cross, 2005).

Physical Conditions Associated with Neurofibromatosis Type I

Neurofibromatosis type I is a complex disorder with a number of diverse features. Students with NF I may have some or all of the following features: café-au-lait spots; neurofibromas; Lisch nodules; optic gliomas; and skeletal abnormalities (Cross, 2005). Café-au-lait spots are light brown patches of pigment in the skin and are usually the first feature to appear. Neurofibromas are small visible benign tumors growing on the nerves under the skin and in various organs. While most of these tumors are benign, 10 to 15% of individuals with NF I will experience malignant (cancerous) changes in the neurofibromas. Lisch nodules are small benign tumors on the iris, the colored part of the eye. Optic gliomas are tumors on the optic nerve. Lisch nodules and optic gliomas usually do not cause symptoms, but need to be monitored for changes. Skeletal abnormalities can develop, including bowing of the legs and a curvature of the spine. In addition to these features, many students with NF I may experience migraine headaches (Phelps, 1999).

Cognitive Conditions Associated with Neurofibromatosis Type I

Intelligence in individuals with NF I spans the entire range from below average to well above average. It has been estimated about half of individuals with NF I have some degree of cognitive or behavioral involvement (Cross, 2005). While mental retardation is rare, a wide range of learning disabilities are seen in students with NF I. Studies have shown 63% of individuals with NF I will have learning disabilities in the areas of visual spatial dysfunction and delays in reading comprehension, math, and written language (Phelps, 1999).

Psychosocial Issues Related to NF I

Students with NF I are at high risk for developing academic, behavioral, and social emotional difficulties. Parents of children with NF I report their children experience significant social-emotional difficulties. Seventy-seven percent of 63 families interviewed report their children had problems at school (Benjamin, Colley, Donnai, Kingston, Harris, & Kerzin-Storrar, 1993). Issues at school included difficulties with schoolwork, teasing related to physical symptoms, and difficulties with making friends. Behavioral problems associated with NF I may include similar problems related to attention deficit disorder or hyperactivity. In addition, forty-eight percent of students with NF I experience anxiety disorders which impact their daily lives (Phelps, 1999).

Tuberous Sclerosis Complex

Tuberous sclerosis complex (TSC) is the most common neurocutaneous syndrome. It is a multi-system syndrome involving the nerves and the skin. The characteristics of this genetic disorder appear by the age of five (Riccio, & Harrison, 1999). TSC is associated with a number of health, learning, and behavioral problems. There is great variation in the severity of the features associated with TSC.

Tuberous sclerosis complex is often inherited. If one parent is affected with TSC, there is a 50% chance for each child to be affected. In addition to inheritance, about 66% of cases of TSC are a result of a spontaneous gene mutation. The prevalence is unknown, but the incidence has been estimated to be 1 in 6,000 live births. Approximately 50,000 individuals in the United States and more than 1 million worldwide have TSC. It occurs in both males and females and in all races and ethnic groups (Riccio & Harrison, 1999).

Physical Conditions Associated with Tuberous Sclerosis Complex

The extent and severity of the characteristics of Tuberous Sclerosis Complex varies in individuals. The most common characteristic of TSC is flesh colored marks on the skin around the nose which resemble acne. These marks increase in number and size as the student ages (Riccio & Harrison, 1999). Growths called tubers are often found growing inside the brain and retinal areas of the eyes. Tubers can also affect many organs of the body. Seizures and mental retardation are also considered characteristics of TSC, especially in individuals with a more severe presentation of TSC (Cross, 2005).

Cognitive Conditions Associated with Tuberous Sclerosis

There is no typical cognitive profile of individuals with TSC. Studies of children with TSC indicate a wide variation of deficits ranging from severe cognitive, sensory, and motor problems to mild problems. The variation is attributed to the location of the tubers within the brain. There is a frequent occurrence of learning problems with 48 – 83% of individuals with TSC also identified as learning disabled (Hunt, 1995). The occurrence of mental retardation in individuals with TSC is estimated at 47 – 60% and ranges from mild to profound (Riccio & Harrison, 1999).

Individuals with TSC with less severe seizures often have average intelligence and fewer learning and behavioral problems. These individuals may have speech and language delays, memory difficulties, aggression, anxiety disorders, hyperactivity, and attention deficits (Cross, 2005).

The estimated prevalence of autism in individuals with TSC has been found to be one in four individuals with TSC. This increases to one in two individuals with mental

retardation and tuberous sclerosis (Hunt, 1995). Although there is some speculation about the occurrence of autism and tuberous sclerosis being related to the location of tubers in the brain, additional research in this area is needed (Smalley, Tanguary, Smith, & Gutierrez, 1992).

Behavioral Challenges Associated with Tuberous Sclerosis Complex

Three basic types of behavioral challenges have been identified in individuals with TSC. In reviewing case reports, Smalley, Tanguary, Smith, and Gutierrez (1992) identified the following behavioral problems: autism or autistic like behaviors (36%), hyperactivity or impulsive behaviors (26%), and aggressive and destructive behaviors (36%). These behavior problems were more often reported for males than for females with TSC.

Sturge-Weber Syndrome (SWS)

Sturge-Weber Syndrome is a congenital neurocutaneous syndrome typically characterized by a unilateral port wine stain on the face. Clinical variations are common and make incidence figures difficult to calculate. SWS occurs less frequently than neurofibromatosis and tuberous sclerosis. It affects both sexes and all races and ethnic groups. There is no known genetic cause (Cody & Hynd, 1999).

Physical Conditions Associated with Sturge-Weber Syndrome

Sturge-Weber Syndrome (SWS) is typically characterized by a unilateral port wine stain birthmark on the face near or around the eye and forehead areas. The port wine stain is present at birth and varies in color from red to dark purple. This type of birthmark is caused by a mass of tumors chiefly composed of tiny blood vessels under the

skin (Cody & Hynd, 1999). Although the facial port wine stain birthmark is the most characteristic of this syndrome, other associated features are also present, including seizures (55 -97%), hemiparesis or weakness of muscles on one side of the body (30 - 50%), and glaucoma (40%). Abnormal brain tissue caused by calcium deposits are often found on the same side as the port wine stain (Thomas-Sohl, Vaslow, & Maria, 2004).

At birth, children with SWS are neurologically intact, but become impaired with the acute onset of seizures. Approximately 90% of children with SWS have an onset of seizures in the first year of life, and almost always by the second year. Some children develop frequent seizures while others have only occasional episodes. As the child ages, the seizures increase in severity and frequency (Cross, 2005).

Students with SWS are at risk for developing visual complications. The most common is glaucoma. It usually presents on the same side as the port wine stain facial birthmark. Students whose birthmark lies close to the eye are at greater risk. Approximately 40% of children with SWS will develop glaucoma in childhood (Cody & Hynd, 1999).

Cognitive Conditions Associated with Sturge-Weber Syndrome

Students with SWS will present with a variety of neurological abnormalities including epilepsy, mental retardation, and attention deficit hyperactivity disorder. Although seizures are the most common feature presenting along with the port wine stain, mental retardation is present in approximately 75% of children with seizures (Cody & Hynd, 1999). The degree of developmental delay and mental retardation in children with SWS is dictated by the extent of the neurological involvement (Thomas-Sohl et al., 2004).

Often multiple anticonvulsant medications are used to control seizures. The medication may result in behavioral or cognitive side effects. Behavioral side effects include drowsiness, irritability, aggressiveness, or hyperactivity. Cognitive side effects include impaired memory, decreased attention span, and mental confusion (Cody & Hynd, 1999). These side effects can impact the behavior and academic performance of students with SWS.

RESOURCES

Children's Tumor Foundation
800-323-7938
http://www.clf.org

National Neurofibromatosis Foundation
95 Pine Street
16th Floor
New York, NY 10005
800-323-7938
http://www.nfinc.org

National Organization for Rare Disorders
800-999-6673
http://www.pcnet.com

National Tuberous Sclerosis Association
800-225-6872
http://www.ntsa.org

Neurofibromatosis, Inc
800-942-6825

Neurofibromatosis Resources
http://neurosurgery.mgh.harvard.edu/nfr

The Sturge-Weber Foundation
800-627-5482
http://www.inforamp.net

Tuberous Sclerosis Association
http://ourworld.compuserve.com/homepages/tassn/tsa.htm

Tuberous Sclerosis International
http://crystal.feo.hvu.nl/Groepen/tsi/tsi.htm

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SECTION ELEVEN

SEIZURE DISORDERS

Appropriate educational programs for students with seizure disorders often require modifications to the classroom environment, use of specialized teaching techniques, and health related services. Appropriate education programs provide students with access to the general education curriculum with accommodations to meet the individual needs of each student. In addition to learning academic skills, students with seizure disorders may need programs to address behavioral and social emotional issues. Careful planning involving administrators, teachers, support personnel, and parents is needed to ensure the educational and health care needs of students with seizure disorders are met in school. When developing an educational program to meet the needs of the student, how seizures may affect a student's development, learning, behavior, and emotions must be considered.

This chapter contains a definition and description of seizure disorders and an overview of the cognitive conditions associated with seizure disorders. The chapter concludes with resources for school personnel.

Definition and Description

A seizure is a sudden excessive disorderly discharge of electrical activity in the brain. The result of the discharge is impairment to consciousness, sensation, memory, movement, or behavior (Clancy, 1990). The diagnosis of a seizure disorder is given when an individual has chronic, recurrent episodes of seizures, unaccompanied by fever or illness. Historically called epilepsy, a seizure disorder is a chronic condition, not a

disease, or a mental illness. Seizure disorders are considered to be the most prevalent neurological disorder of childhood (Epilepsy Foundation of America, 2005).

Even though the exact prevalence of seizure disorders is unknown, approximately 2% of children under the age of 20 are believed to have a seizure disorder. Seizure disorders occur in 5 out of 1,000 children (Teeter & Semrud-Clikeman, 1998). The Epilepsy Foundation of America has estimated 50,000 children develop a seizure disorder every year in the United States. Seizure disorders generally develop before 20 years of age and the incidence rates increase dramatically for children with other disabilities (Best, Heller, & Bigge, 2005). Children with cerebral palsy, mental retardations, brain injury, and autism have been known to have increased rates of seizure disorders (Heller, Forney, Alberto, Schwartzman, & Goeckel 2000). In addition to children with these disabilities, children who experience serious traumatic injuries as a result of vehicular accidents, sports accidents, or gunshot wounds have an increased risk of developing a seizure disorder (Teeter & Semrud-Clikeman, 1998).

Classification of Seizure Disorders

Previous classifications systems, including grand mal, petit mal, and psychomotor seizures have generally been replaced. Current classification of seizure disorders consists of descriptive terms. The general classifications used are partial seizures (simple partial and complex partial seizures), and generalized seizures (tonic-clonic and absence seizures) (Teeter, Semrud-Clikeman, 1998).

Partial Seizures

The seizure activity of partial seizures is limited to one hemisphere or portion of the brain. Partial seizures usually occur as a result of some underlying damage to a specific portion of the brain (Hill, 1999). Partial seizures are divided into simple partial or complex partial seizures. With simple partial seizures, the student will not experience an impairment of consciousness. Students with complex partial seizures will experience a loss of consciousness (Teeter & Semrud-Clikeman, 1998).

Simple Partial Seizures differ from individual to individual, but the pattern is often consistent from one episode to the next. Generally, there is no forewarning the seizure is going to occur. However, the individual does not lose consciousness, and in most cases, can resume the activity they were engaged in prior to the seizure (Weinstein, 2002).

The student's manifestations will depend on the area of abnormal electrical activity in the brain. If the partial seizure originates in the motor areas of the brain, the student will experience twitching of a particular muscle group such as hand and arm or foot and leg. If the oral motor area of the brain is affected, the student may make chewing, lip-smacking, and swallowing movements. When the seizure originates in the area of the brain controlling eye movements, the student may suddenly turn their eyes or both head and eyes to one side (Teeter & Semrud-Clikeman, 1998).

Simple partial seizures originating in the sensory areas of the brain occur more commonly in adults and children over the age of eight. If the simple partial seizure originates in the sensory area of the brain, the first symptom is usually a feeling of numbness or tingling, or feeling of warmth or coldness in a specific body part. In most

cases, the site of onset is the lips, fingers, or toes. The sensation quickly moves to adjacent parts of the body such as face, hands, and feet (Weinstein, 2002). When the occipital lobe of the brain is affected, the student may report seeing flickering lights or spots. In some cases, the student may see colors or experience darkness. Seizures originating in the temporal lobe may cause the student to complain of ringing, roaring, or buzzing in their ears. In some cases, students who have simple partial seizures experience psychic symptoms. The symptoms can include hallucinations and extreme fear (Teeter & Semrud-Clikeman, 1998).

Complex Partial Seizures, in contrast to simple partial seizures, always present with impairment of consciousness. Complex partial seizures may last for up to several minutes. However, in some cases the period of unconsciousness may be so brief that no one but the student will be aware the seizure has occurred (Weinstein, 2002). Complex partial seizures have in the past been referred to as psychomotor seizures. This type of seizure can be mistaken for some type of emotional disability as the student appears to be in a state of altered consciousness and can carry out complex coordinated activities (Teeter & Semrud-Clikeman, 1998).

Some students with complex partial seizures may be aware a seizure is going to occur within the next few hours or within the next day or two. The student may experience mood or behavior changes such as irritation, anxiety, apathy, depression or decreased concentration. Sometimes the seizure is preceded by a headache (Weinstein, 2002). Immediately before the complex partial seizure begins, the student may experience an

aura, a specific sensation which is remembered on regaining consciousness. The student may feel fear, excitement, anxiety, embarrassment, or light-headedness (Hill, 1999).

As the seizure starts, the student may appear in a dreamlike state or trance. When spoken to, the student makes no response. Typically, involuntary motor movements appear and seem to have no purpose. Some of the common motor movements are: lip chewing, spitting, gagging laughing, eye blinking, staring blankly, waving, clapping, scratching, and running (Weinstein, 2002). In addition to motor movements, the student may experience vomiting, nausea, sweating, dilated pupils, and bowel and bladder incontinence. After a complex partial seizure, the student may be confused and drowsy for minutes to hours. The student may want to sleep. Often the student will have no memory of the seizure and wonder why they are tired (Teeter & Semrud-Clikeman, 1998).

Generalized Seizures

A common characteristic of generalized seizures is involvement of both hemispheres of the brain. Generalized seizures also always involve a loss of consciousness. The two types of generalized seizures are tonic-clonic seizures and absence seizures.

Tonic-Clonic Seizures were formerly referred to as grand mal seizures. Generalized tonic-clonic seizures occur in approximately 75% to 80% of children with seizure disorders (Weinstein, 2002). Tonic-clonic seizures are the most dramatic and often the most frightening to observe (Hill, 1999). Often the student has no warning the seizure will occur and there is an immediate loss of consciousness (Teeter & Semrud-Clikeman, 1998).

The tonic-clonic seizure is divided into the tonic (rigid) and clonic (jerky) sub-phases. During the initial part of the tonic phase the student may fall to the ground, or if sitting, they may slump over. Typically, the body becomes stiff. The tonic phase generally lasts from 10 seconds to 20 seconds. The rigid tonic phase is followed by the clonic phase. During this phase, the student's muscles will begin to twitch and eventually there will be a convulsion of some or all of the body. This phase can be as brief as a few seconds or as long as 30 minutes. Usually this phase lasts for less than 5 minutes. As the seizure progresses, the movements become less intense and less continuous until they stop altogether (Weinstein, 2002). Bowel and bladder incontinence typically occurs after the last clonic jerk (Hill, 1999).

After the tonic-clonic seizure ends, the student may be drowsy, confused, and disoriented. Some students may fall into a deep sleep which may extend for 5 to 10 minutes or up to 3 to 4 hours. Upon wakening, the student may be uncoordinated and have a difficult time with fine motor tasks. In addition, the students' speech may be slurred and a headache and nausea may be present (Thuppal & Sobsey, 2004).

Tonic clonic seizures which are continuous and persist for long periods of time are often diagnosed as status epilepticus. If the student has status epilepticus or experiences a tonic-clonic seizure for an extended period of time, immediate medical attention is required (Hill, 1999).

Absence Seizure formerly referred to as petit mal seizures, are generalized seizures without convulsion. An absence seizure is an abrupt loss of consciousness. Once the seizure ceases, the student will resume their activity as if nothing unusual happened

(Thuppal & Sobsey, 2004). Absence seizures occur as a series of isolated absence spells. When these seizures occur, the student will typically stare into space without moving. The student may appear dazed, stop talking, and maintain their posture and balance. When the seizure is over, the student will resume their previous activity and will be unaware of the interruption. If absence seizures occur frequently, the student may be described as dreamy or unmotivated and their learning can be disrupted (Thuppal & Sobsey, 2004).

Cognitive Conditions Associated with Seizure Disorders

Students with seizure disorders will range in cognitive abilities from retarded to average or to superior intelligence (Dreisbach, Ballard, Russo, & Schain, 1982). The relationship between seizure disorders and lower cognitive functioning is complicated. Studies with students and adults with seizure disorders have found intelligence to be weakly correlated with seizure disorders (Teeter & Semrud-Clikeman, 1998).

Not all students with a seizure disorder will be affected the same way by seizures. Some students will struggle with learning and others will not be affected. The duration and frequency of seizures, the drugs used to control seizures, the brain damage caused by the seizures, related behavior problems, and attention deficits can impact students' learning (Thuppal & Sobsey, 2004). In addition, the confusion, mental impairment, headaches, or fatigue following a seizure can also interfere with learning (Weinstein, 2002). Medication can help some students with these issues. For some students, the medication may result in sluggishness, lethargy, depression, irritability, or behavior

problems, all of which can impact the students' learning (Teeter & Semrud-Clikeman, 1999).

The most frequently associated disabilities in students with epilepsy are mental retardation (31.4%), speech disorders (27.5%), and specific learning disabilities (23.1%) (Sachs & Barrett, 1995). Deficits in reading, written language, and spelling were also found with students with seizure disorders. Reading comprehension is often more impaired than word recognition skills and may impact a variety of subject areas.

When comparing intellectual potential with academic performance in students with seizure disorders, a consistent pattern of under-achievement has been found. Family factors, parental attitudes, and cultural variables have been significantly correlated with underachievement in students with seizure disorders (Teeter & Semrud-Clikeman, 1999). The student with a seizure disorder faces a number of social problems related to the disorder. The attitudes of parents, family members, educational personnel, and peers contribute to the student acceptance and adjustment to the seizure disorder (Dreisbach et al., 1982).

RESOURCES

Disabilities Information Access Line 800-922-3425

Epilepsy Foundation of America http://www.efa.org

National Information Center for Children and Youth with Disabilities (NICHCY)
800-695-0285 http://nichcy.org

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SECTION TWELVE

SPINA BIFIDA

An appropriate education program for students with spina bifida often requires modifications to the classroom environment, use of specialized teaching techniques, assistive devices for mobility, and health related services. Education programs provide students with access to the general education curriculum with accommodations to meet the individual needs of the students. In addition to mastering academic skills, students must become as independent as possible with health care routines and activities of daily living. Careful planning involving administrators, teachers, support personnel, and parents is needed to ensure the educational and health care needs of students with spina bifida are met in school. While developing educational programs to meet the needs of the students, teams need to consider how spina bifida may affect students' development, learning, and behavior.

This chapter contains a definition and description of spina bifida and an overview of the physical and cognitive conditions associated with spina bifida. Medical management of spina bifida can be found in Section Fourteen. The chapter concludes with a list of resources for school personnel.

Definition and Description

Neural tube defects are congenital malformations of the brain, spinal cord, or vertebrae (Heward, 2003). The most common neural tube defect is spina bifida. In general terms, spina bifida refers to the abnormal development of the spine. During the first month of pregnancy, the backbone fails to form properly leaving an opening along

the spine. As a result, a portion of the spinal cord and the nerves that control muscles and feeling in the lower body, pass through the opening into a fluid filled sac (Hill, 1999). Once the infant is born, the opening must be closed up to prevent spinal cord infections and to protect spinal nerves. The level of disability associated with spina bifida depends on several factors. These factors include the extent of the bony opening, the degree of the nerve involvement, and the location of the abnormality in the bony structure (Best, Heller, & Bigge, 2005). The primary neurological abnormalities are paralysis, loss of sensation, hydrocephalus, and Chiari malformations explained later in this chapter (Liptak, 2002)

Spina bifida is the most frequently occurring and permanently disabling of all birth defects. Spina bifida occurs in about one in every 1000 live births in the United States. About 4000 children are born with spina bifida each year. More children are affected by spina bifida than muscular dystrophy, multiple sclerosis, and cystic fibrosis combined (Hill, 1999).

Classification of Spina Bifida

Spina bifida is classified on the basis of severity. The three types of spina bifida are spina bifida occulta, meningocele, and myelomeningocele.

Spina Bifida Occulta

Spina bifida occulta is the mildest form of spina bifida. In this form of spina bifida, there is no protrusion or herniation of the spinal cord beyond the vertebrae. The defect is usually not visible externally. Students with spina bifida occulta usually do not

experience paralysis or loss of sensation. It is estimated that up to 10% of the general population may have spina bifida occulta (Liptak, 2002).

Myelomeningocele

Myelomeningocele is the most common and most serious form of spina bifida. This condition is often referred to as "open spine" and is visible. The vertebra column is not completely closed over and a sac containing all or some of the contents of the spinal cord protrudes outward through the spinal column (Hill, 1999). In some cases, the sacs are covered with skin, in others, the tissue and nerves are exposed. About 6 in 10,000 live births in the United States result in myelomeningocele (Liptak, 1997).

Meningocele

Meningocele is the least common form of neural tube defects. Students with meningocele have intact spinal cords. Meninges or protective covering around the spinal cord has pushed out through the opening of the vertebrae into a sac. Meningocele can be repaired with little or no damage to the nerve pathways (Hill, 1999).

Physical Conditions Associated with Spina Bifida

Physical conditions associated with spina bifida vary widely, from student to student. The extent of functional disability is associated with the type of spina bifida and its location. The location of the defect on the spinal column has a direct impact on the extent of muscle paralysis and loss of sensation. Some students will present with minor physical involvement and others are totally paralyzed below the site of the defect. Although students with spina bifida may appear to have only physical problems

associated with mobility, the condition is complex and can affect many of the systems of the body (Hill, 1999).

Students with spina bifida face ever-changing challenges. Maximum ambulation is seen in students around nine years old. Students may gradually deteriorate physically as they gain weight and muscle weakness increases (Shine, 1998).

Paralysis

The extent of motor paralysis and sensory loss depends on where the defect occurs in the spinal cord. All motor functions below the point of the defect will be impaired (Charney, 1992). The vertebral column is divided into neck (cervical), chest (thoracic), back (lumbar), and lower back (sacral) vertebrae regions. Spina bifida most commonly affects the thoracic and lumbar regions. The higher the lesion on the student's vertebral column, the greater the impairment in ambulation (Liptak, 2002).

Skeletal Abnormalities

As a result of the muscle imbalance that occurs along with paralysis, bone deformities are common in individuals with myelomeningocele. These skeletal abnormalities include clubfeet, dislocated hips and spinal curvatures or scoliosis. Over time, the students may develop contractures of the hip, knee, and ankle joints. Contractures occur as a result of the muscle imbalance and in some cases because of improper positioning (Hill, 1999). Surgery, orthotics, and braces are used to correct or prevent deformities.

Individuals with spina bifida who ambulate using braces and crutches or use a wheelchair do not bear weight fully on their legs. This leads to weak bones that can break with even minor injury. Due to the decreased or absent feeling in the legs,

individuals with spina bifida may not be aware of the injury. Swelling and deformity may be the only indication of a broken bone (Shaer, 2001).

Hydrocephaly

Hydrocephalus is the accumulation of cerebrospinal fluid in tissues surrounding the brain due to blockage to the flow or drainage of the fluid (Heward, 2003). Left untreated, hydrocephaly can lead to head enlargement, brain abnormalities, seizures, and severe brain damage. About 80 to 90% of children born with myelomeningocele develop hydrocephalus (Best et al., 2005). In some cases, infants develop symptoms the first two to three weeks of life, others develop symptoms later.

Tethered Cord

A tethered cord is caused by crowding of the spinal cord by tissue not removed during the initial surgery or by scar tissue around the spinal cord in the areas of the initial surgery. A tethered cord can occur any time in childhood or early adulthood. If untreated, a tethered cord can cause additional damage to the spinal cord or nerves. Tethered cords are surgically corrected (Shaer, 2001).

Arnold-Chiari Malformations

The majority of students with myelomeningocele have Arnold-Chiari malformations. An accumulation of cerebrospinal fluid causes a downward displacement of the cerebellum, parts of the brain stem, and the fourth ventricle into the upper cervical canal (Hill, 1999). Arnold-Chiari malformations can result in swallowing problems, breathing difficulties, eye problems, and poor eye hand coordination. For many students this condition does not cause any major problems. Other students experience severe pain in

the neck and head, stiffness in the arms, dizziness, and loss of tongue movement (Shaer, 2001). Surgical intervention may be required to relieve the pressure on the brain stem.

Seizure Disorders

Students with myelomeningocele often experience increased cranial pressure and are likely to develop a seizure disorder. A seizure is a sudden occurrence of altered consciousness, behavior, sensation, and or movement due to disruption of normal electrochemical activity in the brain (Clancy, 1990). Epilepsy develops in as many as 15% of all persons with myelomeningocele (Brown, 2002). See the chapter on Seizure Disorders for additional information.

Urinary Dysfunction

Many students with spina bifida are challenged with life long incontinence. Lack of bladder control is common in about 95% of all children with myelomeningocele (Liptak, 2002). Problems with either storage or emptying the bladder lead to incontinence and infections. Incontinence is the inability for normal toileting with urinary control. Some students may experience a constant dribbling of urine due to an overly full bladder. Medication is used to enhance storage of urine (Hill, 1999).

Some students with spina bifida use medication and clean intermittent catheterization (CIC) to achieve continence. CIC is a procedure where urine is removed by means of a tube inserted into the bladder to drain urine, and is removed when the bladder is emptied (Shaer, 2001). CIC is usually performed every two to four hours. Using a combination of CIC and medication, continence is achieved in about 85% of students with bladder dysfunctions due to myelomeningocele (Bratshaw & Perret, 1992). CIC increases the

risk of urinary track infections. It is vital infections be treated because untreated urinary track infections can lead to more serious infections of the kidney (Heller, et al., 2000).

Some students with spina bifida may have a vesicostomy, an artificial site used to drain urine. The stoma, or opening for the vesicostomy, is on the abdomen. The student may catheterize using the stoma or urine may drain into a pouch or bag (Porter, Haynie, Bierle, Caldwell, & Palfrey, 1997).

Bowel Dysfunction

Many students with spina bifida are challenged with both bowel and bladder incontinence. Poor anal sphincter control, lack of rectal sensation, and uncoordinated actions of the intestines may result in bowel incontinence (Liptak, 1997). Bowel incontinence can lead to soiling. Bowel management may include a daily rectal suppository, medication, and special diets. Diets often include adequate fluids, fiber, and natural laxatives. Students with spina bifida often experience constipation, fecal impactions, and diarrhea. Symptoms can be a result of insufficient movement, lack of physical exercise, inadequate hydration, and an inadequate diet (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000).

Skin Sores

Skin sores or decubital ulcers often occur in children with myelomeningocele. Many students are not sensitive to pain on their weight bearing surfaces such as their feet and buttocks. Students may sustain an injury they do not feel. Inadequate circulation increases the problem because the wounds do not heal properly (Liptak, 2002).

Latex Allergy

Allergic reactions to latex containing items have frequently been reported in children and adults with spina bifida. Allergic reactions to latex include watery eyes, wheezing, rash, hives, swelling, and, in severe cases, life threatening anaphylactic shock. Allergic reactions can occur when items made with latex touch the skin, enter the blood stream, are inhaled, or ingested from food handled by latex gloves (Giardina & Psota, 1997).

Latex containing items are found in many medical products used in hospitals, clinics, and school settings. Latex items are also commonly found in non-medical objects used in the home, school, and community. Medical equipment that may contain latex include: gloves, catheters, tape, bandages, wheelchair cushions, and tires. Non-medical items that may contain latex include balloons, rubber balls or toys, baby bottles, art supplies, diapers and clothing with elastic. Alternative non-latex products for most of the previously mentioned items are available. Lists of latex products and alternative products are available from the Spina Bifida Association of America. These lists are updated twice a year.

Cognitive Conditions Associated with Spina Bifida

Cognitive abilities of individuals with spina bifida may range from mental retardation to gifted (Heller et al., 2000). Approximately two-thirds of students with myelomeningocele and shunted hydrocephalus have intelligence within the normal range (Bratshaw & Perret, 1992). Care should be taken never to infer intellectual deficits solely on the basis of motor impairments (Best et al., 2005).

Research studies with students with spina bifida and hydrocephalus have found the higher the level at which the spinal cord is affected, the greater the possibility intelligence and academic skills will be lower. Verbal skills are usually significantly better than nonverbal and performance skills. Students often have poor perceptual motor abilities which affect their eye-hand coordination. In addition, students may have deficits in memory, comprehension, attention, impulsivity, sequencing, organization, and reasoning (Bratshaw & Perret, 1992; Shaer, 2001).

RESOURCES

Americans with Disabilities Act Accessibility Guidelines
http://www.access-board.gov/adaag/html

American Occupational Therapy Association http://www.aota.org

American Physical Therapy Association http://www.apta.org

Disabilities Information Access Line 800-922-3425

Epilepsy Foundation of America http://www.efa.org

National Easter Seals Society http://www.seals.com

National Information Center for Children and Youth with Disabilities (NICHCY)
800-695-0285 http://nichcy.org

National Scoliosis Foundation, Inc. 800-673-6922

Scoliosis Association 800-800-0669 http://www.spine-surgery.com

Spina Bifida Association of America 800-621-3141 http://www.sbaa.org

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PART THREE:

MEDICAL INTERVENTIONS

SECTION THIRTEEN

TYPICAL MEDICAL INTERVENTIONS

Medical management of students with neurological disorders may involve multiple surgeries, orthopedic interventions, medication, physical and occupational therapy, and speech therapy (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000). School personnel need to be aware of each student's current and previous medical treatments along with the physical and academic implications of these treatments. Continuous communication with family members is imperative for school personnel to adapt the school program to the student's changing physical, academic, and emotional needs.

Orthopedic Surgery

Orthopedic Surgery is used as a treatment method for individuals with physical disabilities to improve function and prevent deformities which affect motor skills. Surgery is used to prevent or release contractures and correct muscle imbalances (Sprague, 1992). Surgery is often used in conjunction with other techniques such as bracing and positioning. School staff must provide appropriate physician directed care for students who return to school following surgery. All school personnel need to accommodate excused absences due to medical appointments, hospitalizations, and recovery at home after a surgery.

Mobility Equipment

Some students with physical disabilities will be able to master mobility skills without the need for devices and equipment. Others will need various types of equipment to assist with mobility and independence. A walker may be used to allow the student to

have functional mobility without the need for physical support from an adult (Best, Heller & Bigge, 2005). Commercially available walkers provide different types and levels of support. Some students are unable to ambulate without support, but do not require the level of support provided by a walker. These students may use canes or crutches. For each student, the goal for mobility should be to use the least amount of equipment possible, and promote functional independence (Heller et al., 2000).

Some students have physical disabilities which make standing and walking not physically practical. These students will use a wheelchair as their primary means of mobility. There are many types of wheelchairs currently available. Each student's physical, sensory, and cognitive strengths and weaknesses should be considered when selecting a wheelchair. Taking these into consideration, the wheelchair can be customized to meet different individual needs. The frames, backs, seats, armrests, leg rests, and wheels can be customized. There are two basic types of wheelchairs, manual and power chairs. A manual wheelchair requires the student or someone else to propel it. A power wheelchair allows the student to propel the chair by using a switch device attached to the wheelchair (Pellegrino, 2002).

Orthotics

Orthotics are devices that include braces, splints, and other appliances which support weak or inefficient muscles (Best et al., 2005). Orthotics are used so students can be positioned correctly to prevent contractures and the need for surgery. Some students wear splints on their hands to reduce tone and hold fingers in a more relaxed position or to improve their grip. It is important for students to use their orthotics at home and at

school as prescribed by the physician. Orthotics are custom made and must be replaced when the student outgrows the brace, splint or appliance. Family members, school personnel, and students need to check the skin daily for swelling, bruises, redness, and blisters.

School personnel must learn how to position students correctly while using their orthotics. Physical and occupational therapists and family members can instruct teachers and support personnel on the use of orthotics. It is imperative for all individuals who work with the student to communicate regularly to share information, solve problems, and coordinate the use of orthotics for students with physical disabilities and special health care needs.

Physical Therapy

The physical therapist is a licensed professional who works with students in schools and medical facilities. Physical therapists evaluate students and develop individualized programs to increase each student's gross motor functions, posture, balance, and to prevent deformities (Pellegrino, 2002). The physical therapist may provide the individual, school personnel, and family members with exercises for the individual to perform daily. The physical therapist will monitor positioning equipment, orthotics, and casts. The overall goal of physical therapy is to maximize the student's independence and functioning.

Many students work with a physical therapist at school and in the community. The school therapist addresses classroom and campus functioning while the community therapist will address postoperative rehabilitation, fitting and monitoring positioning

equipment, orthotics, and casts along with physical functioning. The therapists, the individual with cerebral palsy, and family members need to share information, problem solve issues that arise, and adapt programs to meet the changing physical needs of the student, to optimize the outcome of physical therapy.

Occupational Therapy

The occupational therapist is a licensed professional who works with students within schools and medical facilities. The occupational therapist evaluates the student and develops programs to increase the student's eye hand coordination, perceptual skills, and the use of arms and hands for self-help skills, activities of daily living, and classroom activities such as using materials and handwriting. The occupational therapist evaluates the student's sensory integration skills and recommends activities to aid the student in responding appropriately to sensory information. In addition to therapy, the occupational therapist is involved in adapting materials and obtaining equipment to increase the student's independence (Hill, 1999).

Many students work with an occupational therapist at school and in the community. The school therapist will address the students' academic, classroom, and campus functioning. Community therapists will concentrate on postoperative rehabilitation, fitting and monitoring positioning equipment, orthotics, and casts along with physical functioning. The therapists, the individual with cerebral palsy, and family members need to share information, problem solve issues that arise, and adapt programs and equipment to meet the changing physical needs of the student to maximize the individual's functioning and independence.

Speech and Language Therapy

A speech language pathologist is a licensed professional who works with students in schools and medical facilities. The speech therapist evaluates the student to develop a program or activities which will enhance the student's ability to express their ideas and communicate with others. The speech therapist may work on articulation skills, breath control or understanding and using language. If the student has limited speech, the speech therapist will design and develop appropriate communication devices. These devices include communication boards or books and augmentative communication devices. In addition to communication skills, the speech therapist is a team member who works on a student's oral motor activities, chewing and swallowing (Downing & Demchak, 1996).

Many students work with a speech therapist at school and in the community. Typically, the school therapist concentrates on communication for academic, classroom, and campus functioning while the community therapist will address communication for the home and the community. The community therapist may also assist the family in obtaining an appropriate assistive technology device for the student. Family members and school personnel will need training on operating, programming, and maintaining the device. The therapists, the individual, and family members need to share information, problem solve issues that arise, and adapt programs and augmentative communication devices to meet the changing communication needs of the student.

Activities of Daily Living

Learning personal care and daily living skills is an important goal for everyone. For some students, activities such as eating, dressing, and bathing take considerable practice and often require adapted equipment. Even with practice, a student may not achieve independence with activities of daily living at the chronological age usually expected (Heward, 2003). Teachers are faced with the competing demands of addressing academic goals versus scheduling time to work on daily living skills, mobility with a walker, wheelchair, or power chair during class times.

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SECTION FOURTEEN

SPECIFIC MEDICAL INTERVENTIONS BY DISORDER

Cerebral Palsy: Medical Management

Medical management of individuals with cerebral palsy may involve orthopedic surgeries, the use of orthotics and equipment, medication, physical, and occupational therapy (Heller, Forney, Alberto, Schwartzman, & Goeckel, 2000). School personnel need to be aware of the student's current and previous medical treatments along with the physical and academic implications of these treatments. Continuous communication with family members is imperative for school personnel to adapt the school program to the students' changing physical, academic, and emotional needs.

Medication

Medication may be used to relax muscles. Medications may cause drowsiness, increase drooling, muscle weakness, and upset the stomach. One intervention is the use of Botulinum Toxin (Botox). Botox is injected into spastic muscles of students with cerebral palsy to reduce muscle tension (Pellegrino, 1997). A recent innovation is intrathecal baclofen therapy**.** Baclofen is delivered through a tube into the cerebral spinal fluid in the lower back. A pump is worn externally or placed below the skin in the abdomen. The baclofen pump bypasses the need for repeated injections, ensures the correct dosage, and reduces medication side effects (Albright, 1996). The baclofen pump is used to reduce spastic tone in the lower limbs, to enhance activity, and improve range of motion (Butler & Campbell, 2000).

Nutrition and Feeding

Students with cerebral palsy often have problems with eating and swallowing. A comprehensive evaluation of the individual's oral motor, feeding, swallowing, and respiratory functions can determine the cause of the eating or swallowing problem. The evaluation will provide information which will indicate the most appropriate interventions needed to manage activities such as snack time, mealtime, tooth brushing and other oral motor activities (Heward, 2003). Speech language pathologists can provide training to school personnel and assist with the implementation of appropriate nutrition and feeding programs into the school day.

Students with cerebral palsy will expend higher levels of energy to maintain balance and to ambulate. Consequently, they may have a difficult time gaining weight. When a student's eating capability is limited due to motor impairments in the mouth area or in swallowing, the individual may receive nutritional supplements by mouth or via a device known as a gastrostomy tube (G-tube). A G-tune is a flexible catheter used to administer foods and fluids directly into the stomach. The method is used to bypass the usual route of feeding (Porter, Hayne, Bierle, Caldwell, & Palfrey, 1997).

Additional medical interventions for students with cerebral palsy include orthopedic surgery, use of orthotics and equipment, physical, speech, and occupational therapy. Additional information on these medical treatments can be found in Section Thirteen.

Muscular Dystrophy: Medical Management

Medical management of students with muscular dystrophy may involve orthopedic surgeries, medication, and the use of orthotics and equipment, respiratory therapy and counseling (Heller et al., 2000). There is no cure for DMD. Medical management is aimed at maintaining function and slowing the progression of symptoms. Goals of treatment for students with DMD are: (a) maintaining function of unaffected muscles for as long as possible; (b) keeping the student as independent as possible; (c) facilitating ambulation for as long as possible; (d) managing respiratory and cardiac complications; and (e) supporting the student and their family (Sandoval, 1999). School personnel need to be aware of the student's current and previous medical treatments, the physical and emotional implications of these treatments, and the changing treatment goals for the students. Continuous communication with family members is imperative for school personnel to adapt the school program to each student's changing physical, academic, and emotional needs.

Medication

The primary pharmacologic treatment of muscular dystrophy is the use of steroids. This type of medication is used to slow the loss of muscle function. These types of medications have been reported to produce side effects with students with muscular dystrophy. Side effects can include significant weight gain, loss of bone and muscle tissue. These side effects will impact the student's ambulation and independence.

Surgery

Orthopedic surgery is used as a treatment method for students with muscular dystrophy. The goal is to improve functioning and prevent deformities affecting motor skills by preventing or releasing contractures (Sprague, 1992). Surgery is often used in conjunction with other techniques such as bracing and positioning. Families face the challenge of making difficult decisions about surgeries. Often scoliosis surgery will improve a student's respiratory function but will decrease mobility. In addition to looking at the potential outcomes of a surgery, families must also consider the student's overall health and the risk of anesthesia (Leet, Dormans, & Tosi, 2002).

Respiratory Therapy

As the weakness of the student's chest muscles progresses, the respiratory therapist will assist the student and family with using a ventilator. The ventilator is a machine which delivers air to the student with each breath. Often the student will start out using the ventilator while sleeping. A nasal or facemask is worn by the student when they sleep. As the students' respiratory complications progress, the student will use a ventilator during the day, including at school.

Additional medical treatments for students with muscular dystrophy include use of orthotics and equipment, physical, occupational, and speech therapy. Additional information on these medical treatments can be found in Section Thirteen.

Neurocutaneous Syndromes: Medical Management

Individuals with neurocutaneous syndromes will need lifelong medical monitoring and treatment as symptoms appear. The goal of medical treatment is to prevent or minimize deformities and maximize independence. School personnel need to be aware of each student's current and previous medical treatments along with the physical, academic, behavioral, and emotional implications of these treatments. Continuous communication with family members is imperative for school personnel to adapt the school program to each student's changing physical, academic, behavioral, and emotional needs.

Diagnostic Procedures

Students with neurocutaneous syndromes are monitored by a variety of medical personnel including neurologists, pediatricians, genetic counselors, nutritionists, psychologists, psychiatrists, and neurosurgeons who may prescribe a variety of medical tests. The typical tests will include blood tests, x-rays, genetic testing, and eye exams. The students may also have magnetic imaging (MRI), computed tomograhy (CT scan) to monitor tumor growth, electroencephalogram (EEG) to monitor seizures, and the surgical removal of tissue samples from tumors or skin lesions (Cross, 2005).

Medication

Students with neurocutaneous syndromes may be treated with a variety of medications depending upon the physical symptoms and their severity. Medication may also be prescribed for behavioral issues. Some medications are used short term and others are taken for extended periods of time. School personnel may be asked to monitor the

students while at school for possible side effects and impact on their learning and behavior (Cody & Hynd, 1999; Phelps, 1999).

Medication is also used to control seizure disorders. Management of recurrent seizures associated with other medical conditions applies to seizure management of students with tuberous sclerosis complex and Sturge-Weber syndrome (Cross, 2005). See the section on medical management of seizure disorders which contains information on seizure management.

Surgery

Surgery can be used as a treatment method for students with neurocutaneous syndromes. Surgical intervention often consists of removing tumors causing medical complications. Orthopedic surgery may also be used in the treatment of scoliosis and other orthopedic complications (Phelps, 1999). See the section of orthopedic surgery in Section Thirteen for additional information.

Seizure Disorders: Medical Interventions

Medical management of students with seizure disorders includes multiple diagnostic procedures, anticonvulsant drugs, surgeries, special diets, and behavioral interventions. School personnel need to be aware of the student's current and previous medical treatments along with the academic implications of these treatments. Continuous communication with family members is imperative for school personnel to adapt the school program to each student's changing medical, academic, and emotional needs.

Diagnostic Procedures

The most common diagnostic test for seizure disorders is an Electroencephalogram (EEG). Electrical impulses in the brain are measured and recorded by electrodes attached to the outside of the skull (Freeman, 2003). The EEG records the brain waves in specific areas of the brain. Many students with a seizure disorder will have abnormal brainwave patterns between seizures which will be recorded by the EEG. Some students may enter the hospital for a 24-hour EEG. This provides the medical team with a recording of the student's brain waves for a prolonged period of time. Recording of the students' brain waves is completed while they are awake, asleep, and after sleep deprivation. A persistently normal EEG recording usually rules out the possibility of a seizure disorder, but an EEG cannot always rule out seizure disorders.

CT (computer tomography) scans and MRI (magnetic resonance imaging) of the head are often used to get clear images of the interior sections of the student's brain. PET (positron emission tomography) scans are used to study the actual functioning of the

different regions of the brain. All of these diagnostic tools are used to detect structural changes in the brain which can lead to seizures (Thuppal & Sobsey, 2004).

Medication

The primary treatment for seizure disorders is the use of antiepileptic drugs (AED). Many of the current AEDs available have proven effective in the treatment of seizure disorders, but not without side effects. These medications have been reported to impact cognitive functioning, activity levels, behaviors and moods of students (Sachs & Barrett, 1995). Some AEDs have dangerous side effects which require close medical monitoring, including regular blood tests and frequent appointments with the neurologist. Despite the side effects, the need for controlling seizure activity will usually override side effect concerns (Sachs & Barrett, 1995). As new drugs become available, they are being incorporated into treatment plans as the goal is to control the seizure activity with the smallest number of medications with the fewest side effects.

Non-pharmacologic Interventions

The goal of all medical treatments for students' seizures is minimizing the number of seizures. For some students, anti-epileptic drugs are inadequate in controlling seizures. Non-pharmacologic alternatives are frequently used for these students. Non-pharmacologic treatments include surgery, the ketogenic diet, and the use of vegus nerve stimulation (Wheless, 2004).

Surgery is used in a small percentage of students with intractable seizures. Surgical intervention mainly consists of removing a lesion from the student's brain which has been identified as the cause of the seizures. A total or partial hemispherectomy may be

performed to control seizures in students with hemispheric disease and medically intractable seizures (Farley, 1996). Corpus colostomy is another surgical procedure used to control medically intractable seizures involving both hemispheres of the brain. The corpus callosum is the connecting bridge between the two hemispheres of the brain. A corpus colostomy will partially or completely sever the bridge between the two hemispheres to decrease the seizure activity (Farley, 1996).

Ketogenic Diet: Dietary intervention has also been used to treat seizure disorders. The ketogenic diet was developed in 1921 to control seizures in children. The diet involves a brief period of fasting, followed by a carefully controlled high fat, low carbohydrate and low protein diet. For some students, the ketogenic diet will result in ketosis which has an antiepileptic effect. Why ketosis brings about this effect is not completely understood (Wheless, 2004). As awareness of problems related to high fat intake increased and more drugs became available, the ketogenic diet was used less frequently. In the 1970s, a new version of the ketogenic diet came into use and has been prescribed by medical professionals and used with children despite the availability of more AED options. A dietitian or nutritionist often works closely with the neurologist and family to monitor this dietary intervention.

Vegal Nerve Stimulation (VNS) is a newer treatment for intractable seizures. A programmable signal generator powered by a lithium battery is implanted in the student's brain. Stimulating electrodes connected to the vagus nerve send electrical currents from the generator to the vagus nerve. VNS has been reported to have minimal side effects and is a safe procedure for students with intractable seizures (Wheless, 2004).

Spina Bifida: Medical Management

Medical management of individuals with spina bifida may involve multiple surgeries, orthopedic interventions, physical and occupational therapy and medication (Heller, 2004). School personnel need to be aware of the current and previous medical treatments of the student along with the physical and academic implications of these treatments. Continuous communication with family members is imperative for school personnel to adapt the school program to the students' changing physical, academic, and emotional needs.

Students with spina bifida often require multiple surgeries. These students have on the average 8.2 surgeries by the time they are twelve years old (Shine, 1998). The first surgical treatment of myelomeningocele is initiated shortly after birth. Removal of the protruding sac is completed so the open area along the spinal column can be closed. Surgery is performed to protect the exposed nerves from injury and to prevent infection. Frequently this surgery is followed by another one to place a shunt in the brain. A shunt is a plastic tube inserted into the ventricles to drain the fluid from the brain into the abdominal cavity. Without the surgery to correct the hydrocephalus, infants with myelomeningocele may suffer brain damage as the fluid pushes the brain against the side of the skill (Best, Heller, & Bigge, 2005).

Additional medical treatments for students with spina bifida include orthopedic surgery, use of orthotics and equipment, physical, occupational, and speech therapy. Additional information on these medical treatments can be found in Section Thirteen.

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PART FOUR

CLASSROOM ACCOMMODATIONS

SECTION FIFTEEN

ACADEMIC ACCOMMODATIONS

While developing an educational program to meet the individual needs of students, how neurological disorders may affect each student's development, learning, and behavior must be considered. The curriculum school personnel implement to meet the individual needs of students will include the knowledge and skill domains needed to maximize each student's functioning and increase independence. Curriculum school personnel implement to meet the individual needs of students with neurological disorders are:

- The general education curriculum with accommodations includes curriculum specified by state and district standards for typical students. Curriculum is not modified or changed. Accommodations are provided for accessing and participating in the general education curriculum. Students are held accountable for mastery of state and district standards.
- The general education curriculum with accommodations and modifications provides students access to the general education curriculum which has been changed or adapted. Students access the general education curriculum at a level below their grade level. They are expected to master predetermined sections of state and district standards.
- Functional academics are academic skills needed for daily life activities. This curriculum covers skills needed to function as independently as possible. Functional academics may include reading functional words, balancing a

checkbook, writing your name and understanding basic science and social studies concepts.

- Daily living skills curriculum includes skills the student will need to function as independently as possible. Daily living skills include personal care and health care routines. For some students with neurological disorders an appropriate education program will include daily living skills and access to the general education curriculum.

True educational integration for students with neurological disorders is a matter of providing support which matches the level of need, as well as adapting curricula for access and function. Many students are given the task of scorekeeper or encouraged to provide cheers for classmates during physical education activities and are not given the opportunity to participate in the activities. They may be told to watch their peers complete a science experiment or art activity. Motor deficits should not be allowed to interfere with meaningful participation in educational experiences. It is essential education personnel work together to educate each other, problem solve when issues arise, and develop and implement programs which ensure academic progress for students with neurological disorders.

The section which follows delineates situations which can be challenging for school personnel, along with the accommodations to address the situation. The writer has 20 years of experience as a special education teacher in both public and private schools and six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts. The

accommodations which follow each problem are taken from the writer's experience working with children and youth (Beal, 2006).

Problem – Pencil and paper tasks are physically difficult for the student to complete.

Accommodations

- Worksheets may need to be adjusted. Fewer items, more time, and reduced complexity of content can be used as alternatives.
- Materials may need to be provided in larger print or other altered formats such as extra spacing between words or letters and color contrast as needed.
- Occupational therapists can provide adaptive equipment such as pencil grips, book holders, raised line paper, page-turners, and technology that offers alternative input methods.
- Alternative access materials, such as screen reading software, tape recorders, and talking books may be used to increase independence.

Problem - Students are physically unable to take notes during class lectures.

Accommodations

- Teachers can provide students with a copy of the notes or a copy of another student's notes.
- Class lecture can be taped for the student to listen to later in the day or at home.
- Students can be given an outline of the material presented in class. During or after class, students can fill in the outline with the information from the class. This can be done using a scribe, tape recorder, or on the computer.

Problem – Students are unable to use textbooks.

Accommodations

- If the textbook is the primary instructional tool used by the general education teacher, the textbook needs to be examined to determine if it is appropriate for individual students.

- Alternative materials or textbooks can be used when the current textbook being used is determined to be inappropriate for an individual student.

- Textbooks can be provided to the student on tape to be used in the classroom and also at home. This allows the student to listen to the text while looking at the page.

- Chapters of textbooks or important sections of the chapters can be scanned into the computer. Computer software can be used to highlight the important sections and present information in both an auditory and visual format.

- Textbooks may be made more accessible to students by highlighting important content so that the student will focus on the important concepts and skip the other information.

- Study guides containing the important concepts for each chapter should be developed prior to instruction and provided to the students at the start of each new chapter or unit. Study guides provide the student with important concepts in an organized and concise format.

- In addition to study guides, visual displays identify important information. Visual displays can be graphic organizers, discussion webs, and mapping charts.

Problem - The student is physically unable to complete tests using pencil and paper.

Accommodations

- Scribes can record the student's answers to the test questions.

- Test questions can be given to students using a tape recorder. Students listen to the questions and answer the questions by verbally responding on the tape.

- Tests can be scanned into the computer. Students can listen to the test and answer the questions on the computer, using a keyboard, mouse or whatever means they have to input their answers.

- Additional time may be needed for the alternative methods being used by the student.

- Frequent breaks may be needed to reduce fatigue and increase endurance.

SECTION SIXTEEN

COMMUNICATION ACCOMMODATIONS

Many students with neurological disorders have speech which is difficult to understand. These students may require augmentative and alternative communication (ACC) devices and strategies to meet their individual communication needs. Augmentative and alternative communication devices promote communication through symbols, pictures, or words. ACC devices include communication boards and books and computer based devices. The types of communication a student uses will depend upon the student's physical, sensory, and cognitive abilities and the environment in which communication is occurring.

It is essential for education personnel to work together to inform one another and problem solve issues that arise. School personnel will interact with personnel from many disciplines, including therapists, doctors, nurses, and specialists from a variety of community agencies when obtaining communication devices, and determining how and when this device will be integrated into the school setting to maximize functioning and increase the independence of students.

The section which follows presents the accommodations needed for students who use alternative communication systems. The writer has 20 years of experience as a special education teacher in both public and private schools and six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts. The accommodations which follow each

problem are taken from the writer's experience working with children and youth (Beal, 2006).

Problem – Preparing to use an alternative communication system.

Accommodations needed prior to the student using the alternative communication system

- Family members and the speech therapist can provide classroom personnel with training on how to communicate effectively with a student who uses ACC devices.
- Cafeteria workers, bus drivers, playground monitors, office staff, support personnel, and administrators need to learn how to communicate effectively with the student.
- Make time to explain to the classmates of the student who uses an ACC device, the purpose of the device and what they need to do.
- Communication devices need to be programmed with concepts related to academic content and materials being discussed in class so students can contribute to discussions and ask questions.
- Communication devices also need to be programmed with words, phrases, and sentences that allow the student to interact with peers.
- Team members working with students using augmentative communication devices need to determine who is responsible for the programming and maintenance of the device.

Problem – Students use alternative communication systems.

Accommodations for the student using the alternative communication system.

- Speech therapists should work with the classroom staff so the alternative communication devices can be incorporated into the student's day, within the classroom and on the school campus.
- If communication devices are used by students, they should be used for conversations between the student and teachers, support staff, and with other students.

- If students are able to answer verbally or by using a device, teachers and other students in the classroom need to wait for the students to respond and refrain from finishing the sentence for students or speaking for them.

SECTION SEVENTEEN

FURNITURE AND EQUIPMENT ACCOMMODATIONS

Students with neurological disorders may use special furniture, assistive equipment, and adapted materials to maximize functioning and increase independence. This can include wheelchairs, orthotics, assistive technology, augmentative and alternative communication devices, and adapted materials. It is essential education personnel work together to educate each other and problem solve when issues arise. School personnel will interact with personnel from many disciplines, including therapists, doctors, nurses, and specialists from a variety of community agencies when obtaining equipment and furniture, and determining how and when this equipment and furniture will be integrated into the school setting to maximize functioning and increase the independence of students.

The section which follows delineates situations that can be challenging for school personnel, along with the accommodations to address each situation. The writer has 20 years of experience as a special education teacher in both public and private schools and six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts. The accommodations which follow each problem are taken from the writer's experience working with children and youth (Beal, 2006).

Problem – Students are unable to sit in a classroom chair or use a student desk.

Accommodations

- Adapted or alternative furniture is used to meet the unique seating and positioning needs of the student. A simple accommodation is using a table instead of a desk to accommodate a wheelchair.

- Physical and occupational therapists who work with students can provide appropriate seating and positioning equipment for students to use in the classroom.

- If students work in multiple classrooms, the correct equipment needs to be available in all learning environments.

- Students unable to sit in a classroom chair might need seating modifications. This can range from sophisticated seating systems to using a rolled towel or a security strap. A chair with arms may provide the additional support they need.

Problem - Students use walkers, canes, or crutches to ambulate.

Accommodations

- Students and school personnel need to be trained on the safe handling of crutches, canes, or walkers.

- Students need to be shown how to stand and sit safely using the devices. Team members need to assist students with mastering these skills.

- Team members need to determine the appropriate location for a student to place their device when not being used.

- Students need training on using these devices to navigate corners and tight spaces and stairs.

- Students need many opportunities to use crutches, canes, or walker on various surfaces.

- Physical therapists need to provide all team members with information on the student's progress so that all team members are aware of the student's abilities and limitations, and the current mobility goals.

Problem - Students use positioning equipment during the school day.

Accommodations

- Classroom personnel should consult with occupational physical therapists to develop schedules for equipment use.

- Teachers and paraprofessionals need to work closely with the occupational and physical therapists to determine the correct positioning of students in equipment.

- Sitting all day in one position can decrease alertness and impact the students' learning. Using equipment to stand, if appropriate, is an alternative positioning method.

- School personnel who assist in the physical management of students with cerebral palsy are at risk for injuring themselves or the student. Therapists must instruct all staff on how to use proper body mechanics for transferring, lifting, and carrying students.

- Storage areas are needed for the equipment when not in use.

Problem - Students use equipment and adapted materials throughout the school day.

Accommodations

- Adaptive equipment used by the student needs to be available in all learning environments.

- Modified locations for storage and retrieval of personal learning and study materials need to be developed and accessible to the student.

- Students must learn as early as possible how to use the equipment as independently as possible or how to instruct others to assist them in using the equipment.

- Teachers need to become familiar with the function of orthotics, wheelchairs, and augmentative and alternative communication devices and equipment and how to incorporate these devices into the student's day.

- Assistive technology devices and alternative communication devices need to be incorporated into the classroom routines. Teams working with students need to collaborate to determine how and when devices and equipment will be used and who is responsible for the programming and maintenance of the devices.

- It is not unusual for school personnel to assist students too much because it is faster and easier to provide help rather than watch the students struggle. School personnel need to remember the goal for all students with neurological disorders is independent functioning.

SECTION EIGHTEEN

HEALTH RELATED ACCOMMODATIONS

Educators and administrators are challenged with developing appropriate programs to meet both the educational and medical needs of students with neurological disorders. It is essential for the school health care and educational personnel to work together to educate each other, solve problems which arise and develop and implement a program which ensures quality care for each student. School personnel will interact with personnel from many disciplines, including therapists, doctors, nurses, and specialists from a variety of community agencies.

The section which follows delineates a number of common problems school personnel face along with possible accommodations. The writer has 20 years of experience as a special education teacher in both public and private schools and six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts. The accommodations which follow each problem are taken from the writer's experience working with children and youth (Beal, 2006).

Problem – Students who must leave the classroom during academic instruction to receive health care or therapy.

Accommodation

- Careful planning by team members needs to be done prior to students entering a school program and at the start of each school year.
- Schedule times for the student to use the bathroom and go to the healthcare office during breaks in instruction.

- Students' schedules need to be reviewed and modified as needed to meet the changing needs of the students and classroom routine.

- Break times and rest periods outside the classroom may need to be built into students' daily schedule to reduce fatigue.

- School nurses provide training for staff and monitor some of the health care procedures. Some procedures can only be performed by the nurse.

- Qualified personnel need to be available to provide specialized health care routines within the school setting. Contingency plans need to be developed which include backup personnel who are qualified to provide health care services.

Problem – Students who are absent from school for extended periods of time, arrive late or leave school early.

Accommodation

- All school personnel need to accommodate for excused absences due to medical appointments, hospitalizations, and student illness.

- Break times and rest periods outside of the classroom may be built into a student's daily schedule to reduce fatigue and increase the time the student can attend school.

- Reduced assignments or additional time to complete assignments are two simple ways to accommodate excused absences.

- Students can be given assignments ahead of time to work on at home.

- Alternative assignments offer students the opportunity to master the academic content.

- School personnel need to be aware of changes in students' schedules and make accommodations with classroom and homework assignments.

SECTION NINETEEN

INSTRUCTIONAL ACCOMMODATIONS

Instructional accommodations are individualized accommodations and modifications which allow students to access the curriculum. When determining the accommodations and modifications for students, how physical disabilities and special health care needs have affected the students' development, learning, and behavior must be considered. It is essential for school personnel to work together, to educate each other, solve problems which arise, and develop and implement accommodations and modifications for students.

The section which follows delineates challenging situations for school personnel, along with accommodations to address the situation. The writer has 20 years of experience as a special education teacher in both public and private schools and six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts. The accommodations which follow each problem are taken from the writer's experience working with children and youth (Beal, 2006).

Problem – School team members who are new to developing and implementing a program for students with physical disabilities and special health care needs.

Accommodations

- General and special education teachers need to work together and plan in advance the content that will be covered during classroom instruction.
- Major concepts along with the level each student is expected to master needs to be determined prior to instruction.
- Primary instructional tool used by the general education teacher needs to be examined to determine if it is appropriate for individual students.

- Information may need to be presented in multiple formats: visual, auditory, and tactile, depending on the individual needs of the student.

- Instructional accommodations and modifications need to be determined prior to instruction.

- Team members responsible for developing or obtaining instructional materials for individual students need to be determined prior to instruction.

- Instruction may need to be broken down into smaller steps and clustered into short learning segments with breaks in between.

Problem - Students who become overly excited or withdrawn during instruction.

Accommodations

- School personnel working with the students need to adjust the sensory input as appropriate for each student to calm their over excitable nervous system, reduce their fear of falling, and help them attend to motor tasks.

- Occupational and physical therapists can instruct all staff on when and how to use alerting and calming activities.

- Weighted toys and vests, beanbags or clay are often used to prepare a student for an activity. These materials can be used to calm an excited student or prepare them to participate in an activity.

- Opportunities to change position can also prevent fatigue and increase attending skills. Using a variety of equipment for seating and opportunities to stand, if appropriate, need to be part of the student's schedule.

Problem - Students who struggle with concepts taught in previous grades.

Accommodations

- Many students with physical and health impairments lack the background knowledge needed to master new concepts. Some students will have missed previous opportunities to learn concepts due to high absenteeism.

- Prior to instruction, a students' knowledge of the content and concepts needs to be assessed to provide teachers with a better understanding of what the students know.

- If the student does not have the prerequisite skills for the new concepts, the skills need to be taught.

- Communication devices need to be programmed with concepts and vocabulary related to academic content so students can participate in discussions and ask questions.

Problem - Students with visual impairments who are having a difficult time with classroom instructional materials.

Accommodations

- Team members who work with students need to consult with the teacher of the visually impaired to determine appropriate instructional materials to use, the positioning of these materials, and techniques to use to decrease the student's visual fatigue.

- Routines and activities should be explained to the students. The explanation should include what will happen, when, and with whom.

- The same language and sequence of actions should be used each time an activity is conducted.

- Most students with Cortical Vision Impairment (CVI) will need a longer time to process visual information. Allow extra time for students to respond to visual materials.

- Activities should be demonstrated slowly and carefully.

- Visual tasks can be tiring. Visual tasks may need to be broken down into 10-minute segments with breaks in-between.

- Allow the students to handle the materials as the students will position the materials where they can see it best.

- Activities that involve motor movements should be demonstrated to students with a "hand under hand" approach. The student's hand should rest on top of the person demonstrating the activity so students can learn the motor pattern required.

- Use of quiet distraction free areas may help the student use their vision more effectively.

- Materials should be used with a clear color contrast so the student can clearly see them.

- Materials may need to be presented on a slanted surface.

Problems - Students who are unable to organize materials and assignments.

Accommodations

- Typical students gain organization, problem solving skills, and study skills through day- to-day experiences or teacher modeling. Students may need direct instruction in these skill areas.

- Students need daily assistance with developing strategies to organize materials and assignments until they have mastered organizational skills.

- Many types of assignment books and notebooks can be introduced to students to organize assignments and materials.

- A small hand held tape recorder can be used to record assignments and reminders.

- Study skills may need to be taught. Study guides, visual displays, graphic organizers, mapping charts, and discussion webs need to be introduced with instruction on how to use each tool and opportunities to practice the skills.

- Because of physical and medical needs, students may not have had many opportunities to solve problems. A problem-solving model can be taught along with opportunities to use the model with support as needed.

- Students may benefit from a list of the sequential steps needed to complete a task. Sequential steps provide students a way to complete a task without having to ask for assistance or wait for directions. Sequential steps can be presented in pictures, symbols, sentences or on audio tape.

SECTION TWENTY

MOBILITY ACCOMMODATIONS

Struggle for balance and movement control may deplete energy needed for attending to tasks and completing assignments. Poor postural control also interferes with breathing and alertness which may impact handwriting, drawing, holding books and utensils, listening and responding to questions. Navigating with mobility equipment around furniture, materials, and other students in a classroom is often challenging for students with neurological disorders. Teachers and paraprofessionals should not be expected to fill the role of the therapist in developing interventions in the classroom. Nevertheless, teachers and paraprofessionals spend a lot time in close proximity to each student during the school day and often follow through on therapy programs.

This section identifies challenging situations for school personnel with examples of accommodations to address these problems. The writer has 20 years of experience as a special education teacher in both public and private schools and six years of experience as an Education Specialist in a medical clinic, working with parents, educators, administrators, and support staff in public school districts. The accommodations which follow each problem are taken from the writer's experience working with children and youth (Beal, 2005).

Problem - Students who have a difficult time maneuvering around classrooms.

Accommodations

- Arrange the classroom so that students can get to all areas of the room without complex maneuvering.

- Place a line of tape on the floor to facilitate maneuvering of walkers and wheelchairs. This will also remind other students in the classroom to keep the area free of furniture and other materials.

- Desks and furniture should be moved to create wider aisles.

- Students' work area should be placed in an area which will increase access.

- Students need to be instructed in how to move the wheelchair forward, backward, and maneuvering around corners and tight spaces with crutches, canes or walkers.

Problem - Students who use manual and/or power wheelchairs at school.

Accommodations

- Physical therapists can provide school personnel with general guidelines for correct and safe wheelchair procedures.

- Team members need to work with physical therapists to determine activities appropriate for individual students.

- School personnel need to be trained on how to assist students with transfers in and out of the wheelchair to chairs, the floor, and other equipment in the classroom and in the bathroom.

- All team members need to be trained in how to position and adjust wheelchair straps, brakes, footrests, armrests, and other customized adaptations to the wheelchair.

- All school personnel need to be aware of the plan for evacuation of students in wheelchairs when there is an emergency.

- A contingency plan needs to be developed for students who use a power wheelchair, if the power wheelchair becomes inoperable.

- All school personnel who provide assistance to students need to understand each student's individual needs and personal preferences.

- Pushing a student's wheelchair without permission is not acceptable. Always ask permission to move the student's wheelchair.

- Let the student know when you are going to start moving the wheelchair.

- Let the student know what you plan to do before doing it. This would include going up and down curbs and ramps and the final destination.

- Students should face forward while being pushed up a ramp.

- When pushing a wheelchair down a steep or long slope the wheelchair should go down backwards.

- While pushing a wheelchair, talk to the students as you would while walking with students who is ambulatory.

- A manual wheelchair is a mobility device, not exercise equipment. Propelling the wheelchair should never be considered a means of exercise for the student.

- Classmates of students who use wheelchairs may be curious and have questions about the wheelchair. Students in the class should be given time to ask questions and, if possible, have the opportunity to sit in and propel a wheelchair.

Problem – Students who are unable to access all areas of the school campus in their wheelchair or when using their walker.

Accommodations

- ADA Accessibility Guidelines should be reviewed. The guidelines are available on line at http://www.access-board.gov/adaag/html

- Bathrooms on the school campus need to be wheelchair accessible.

- Doors into classrooms, the library, cafeteria, and school office need to be wheelchair accessible.

- Outside areas and playground areas where students congregate need to be wheelchair accessible.

- Ramps are required for students to access rooms only accessible by stairs.

- Students using wheelchairs may not be able to open doors. Someone needs to be available to open the doors or buttons can be installed to assist with opening doors.

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