

Preface

Dr. Sherwood Best has written this chapter on the topic of cerebral palsy for the third edition of *Medical, Psychosocial, and Vocational Aspects of Disability*, edited by Dr. Martin Brodwin.

CEREBRAL PALSY

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INTRODUCTION

Most people recognize the words “cerebral palsy” but few are able to describe this heterogeneous and complex disorder. The first descriptions of cerebral palsy were made by Dr. William John Little (1810-1894), who described “spastic rigidity” in a group of children who had suffered brain damage at the time of their births. Called “Little’s Disease” for decades, the term cerebral palsy was first used in 1937. There is no “typical” person with cerebral palsy, and their clinical, educational, rehabilitative, and vocational needs and outcomes are not easily predictable.

Cerebral palsy cannot be cured by medical or educational interventions. As children with cerebral palsy grow into adulthood, they will be faced with a variety of challenges related to physical and emotional maturation. Fortunately, the advent of assistive technology has done much to improve the quality of life of persons with cerebral palsy. The physical limitations imposed by cerebral palsy should no longer define their educational or career aspirations and outcomes.

DEFINITION AND CLASSIFICATION

Definition

Cerebral palsy is defined as “the term for a range of non-progressive syndromes of posture and motor impairment that results from an insult to the developing central nervous system” (Koman, Smith, & Shilt, 2004, p.1619). The components of this definition contain the following features: (1) aberrant control of movement and/or posture; (2) early onset; and (3) no recognized underlying progressive pathology (Taylor & Kopriva, 2002). Cerebral palsy is not a disease but the result of damage to the developing brain. The disorders of movement and posture are due to damage to areas of the brain that control motor function. The damage is referred to as “static”; it does not get worse. However, the dysfunction that results from muscle imbalance over time, combined with secondary characteristics of cerebral palsy, can contribute to more severe disability as the person grows older (Benda, McGibbon, & Grant, 2003). Persons with cerebral palsy may develop scoliosis (curvature of the spine), hip dislocation, uneven bone growth, and/or chronic pain. These all contribute to reduced functionality and quality of life.

In addition to the posture and motor abnormalities just described, persons with cerebral palsy may have secondary outcomes of brain damage, including epilepsy, mental retardation, sensory and cognitive impairments, and orthopedic complications (Best & Bigge, 2005; Odding, Roebroek, & Stam, 2006). Disorders of speech, such as dysarthria (slurred speech due to muscle tightness, weakness, or incoordination) and aphasia

(impairment in the ability to communicate through speech or writing) are frequent impairments (Taylor & Kopriva, 2002). However, not every person with cerebral palsy will experience every one of these impairments.

In the past three decades, the prevalence of cerebral palsy has risen to over 2.0 per 1000 live births (Odding, Roebroek, & Stam, 2006). Increases in both incidence and prevalence of cerebral palsy have been attributed to improved documentation, advances in obstetrics and medical interventions that save the lives of infants and children while failing to prevent central nervous system damage, and other factors. A recent phenomenon has been the occurrence of multiple births resulting from assisted reproduction (Blickstein, 2002, 2003; Sutcliffe & Derom, 2006). Children who are the products of multiple births, or who are very premature, are much more likely to have cerebral palsy than children who do not experience these intrauterine and birth conditions (Sutcliffe & Derom, 2006).

Classification

Cerebral palsy is generally classified in one of several ways: (1) area of brain damage (neuroanatomical); (2) type of movement disorder (spastic, dyskinetic, ataxic, and mixed); (3) limb involvement (topographical); and (4) function. Neuroanatomical classification of cerebral palsy describes the location of brain damage, and is associated with the type of movement disorder. If damage occurs in the cerebral cortex and pyramidal tracts (nerve fibers that originate in the nerve cells in the cerebral cortex and descend to the limbs to provide voluntary control of muscles), the outcome is a movement disorder called spasticity. In spastic cerebral palsy, limb muscles contract (tighten) abnormally, resulting in movement that is stiff and jerky. Over time, spastic muscles become shorter and exert differential pull around joints. The result is skeletal deformity, as the limbs, pelvis, and spine become mis-aligned. If damage occurs in the extrapyramidal tracts (cells in the deep structures of the brain called the basal ganglia), the outcome is a movement disorder called dyskinesia. In dyskinetic cerebral palsy, purposeful movement is distorted and muscles move random and involuntarily, especially in the arms, hands, and face. Movement may range from writhing to jerking to tremor, depending on the type of dyskinesia. Muscle tone may be more normal when the individual is asleep. Finally, if damage occurs in the cerebellum (tissue at the base of the brain that controls balance and coordination), the outcome is a movement disorder called ataxia. Persons with ataxia may have great difficulty stabilizing their gait, and walk with feet wide apart while holding the arms out for balance. It is important to remember that rarely do these types of cerebral palsy exist in “pure” forms. Frequently, for example, persons may have both spasticity and dyskinesia. This is referred to as mixed cerebral palsy. In addition to classification by neuroanatomy and type of movement disorder, cerebral palsy is also classified by the location of limb involvement, as follows:

Figure 1: Classification of Cerebral Palsy by Location (Topography)

Limb Involvement	Description
Monoplegia	Single limb involvement. Uncommon in cerebral palsy
Paraplegia	Legs only are involved.
Hemiplegia	Limbs on one side of the body are

	involved. The arm is usually more involved than the leg.
Triplegia	Three limbs are involved, usually both legs and one arm
Quadriplegia	All four limbs are involved. The trunk is also often involved.
Diplegia	Greater involvement of the lower limbs than the upper limbs
Double Hemiplegia	More involvement in the upper limbs than the lower limbs. One side of the body may also be more involved than the other.

Classifying cerebral palsy by location of damage and quality of movement may not help the practitioner to understand the capabilities of the persons with cerebral palsy, which is more apparent when using functional classification. Descriptions for mild, moderate, and severe levels of functional limitation are provided in Figure 2.

Figure 2: Classification of Cerebral Palsy by Function

Mild Functional Impairment

1. Ambulation and speech are present
2. Head and neck control are present
3. Limitation of activity is slight to unimpaired

Moderate Functional Impairment

1. Impairments affect ambulation and speech
2. Head and neck control are affected
3. Limitation of activity is moderate to severe
4. Activities of daily living or other useful physical activity are limited without assistive technology

Severe Functional Impairment

1. Impairments are incapacitating
2. Head and neck control are absent or severely limited
3. Physical deformities and contractures are present
4. Individuals are unable to complete activities of daily living or other useful activity without assistive technology

[Adapted from Heller, K. W., Alberto, P. A., Forney, P. E., & Schwartzman, M. N.(Eds.) (1996). *Understanding physical, sensory, and health impairments: Characteristics and educational implications*. Pacific Grove, CA: Brooks/Cole].

Adding functional limitation description to other types of classification systems provides a clear picture of the person and assists practitioners to communicate about what levels of support are needed. For example, a diagnosis of “severe spastic quadriplegia” suggests that the individual has tight, contracted muscles in all four limbs, probably uses a wheelchair or some other type of mobility device, and may have additional needs in performing daily living activities. However, even if the description reflects severe

impairment, this is no indicator of intellect or learning potential (Best & Bigge, 2005). Appearances can be deceiving!

ETIOLOGY

Many factors contribute to a diagnosis of cerebral palsy. The neurological damage that causes cerebral palsy can occur before birth, during delivery, or as a result of insult to the brain before the age of two (Koman, Smith, & Shilt, 2004; Lin, 2003). The range of factors that contribute to an outcome of cerebral palsy, including the cause, location, time, and severity of damage helps to explain why this condition is so complex and varied.

Prenatal Causes of Cerebral Palsy

Approximately 5,000 infants are born with cerebral palsy every year (Heller, Alberto, Forney, & Schwartzman, 1996). Brain malformation, genetic syndromes, maternal infection, and anoxia (lack of oxygen) have been identified as causes of cerebral palsy during the prenatal (pre-birth) period. Recent advances in neuroimaging have improved understanding of prenatal causes of cerebral palsy (Folkerth, 2005; Hoon, 2005). Prenatal brain malformation resulting in cerebral palsy may be caused by genetic syndromes, acquired injuries from infections such as cytomegalovirus, or mutations. Premature infants whose birthweight is very low are at risk for cerebral palsy from injury to white matter in their brains. As the brain matures, it is less susceptible to white matter injury and may be more vulnerable to focal injury. Asphyxia (loss of oxygen) during the later prenatal period may do damage to deep structures in the brain, leading to dyskinetic cerebral palsy (Hoon, 2005). Finally, multiple births place stress on the uterine environment and heighten the possibility of preterm birth, with increased risk for cerebral palsy (Blickstein, 2002, 2003; Sutcliffe & Derom, 2006). Blickstein (2003) reported an 800% increase in high-order multiple pregnancies (triplets and above) since the 1970's.

Perinatal Causes of Cerebral Palsy

The birth process itself can result in cerebral palsy. Risk factors such as maternal bleeding, problems with the placenta, maternal infection (such as herpes), and obstetrical complications such as prolonged labor, use of forceps, prolapsed cord, and abnormal presentation of the infant can all result in brain injury either from direct insult to the brain or from anoxia. Although modern obstetrics have done much to eliminate birth injuries, parents must still seek proper prenatal care to support their child's development.

Postnatal Causes of Cerebral Palsy

After birth, the brain can be damaged through direct injury or lack of oxygen (Best & Bigge, 2005). Infections to the central nervous system from encephalitis, poison, near drowning, suffocation, electrocution, and other traumatic events can all result in cerebral palsy. One entirely preventable cause of postnatal cerebral palsy is physical abuse. Infants and young children can suffer severe head injury from shaking and hitting, resulting in cerebral palsy and necessitating special educational and vocational services (Karandar, Coles, Jayawant, & Kemp, 2004). Another preventable cause of brain injury occurs when infants and children are not properly secured in automobiles. Safety and

supervision are important in avoiding preventable accidents that can result in brain damage.

DIAGNOSIS

Due to the complexity of causes and risk factors associated with cerebral palsy, many infants may not be diagnosed for several years. To make a diagnosis of cerebral palsy, physicians rely on clinical judgment and comparison of infant function to their knowledge of typical infant development (Hamilton, 2006). Most scales of early development are heavily focused on motor skills, which are almost always absent, delayed, or distorted in persons with cerebral palsy. Physicians and other professionals look for the presence of certain reflexive motor behaviors to assist them in a diagnosis of cerebral palsy. These reflexive behaviors, common to all infants, appear and disappear at predictable times during the course of development. They are involuntary and largely mediated through the brain stem. As infants mature, these motor behaviors are subsumed by higher order brain development and become controlled by voluntary movement. Since human development is logical and predictable, the presence of these reflexive motor behaviors past the time when they should no longer be predominant is a strong indicator of brain damage and possible cerebral palsy.

It is almost impossible to predict developmental outcomes in young children with cerebral palsy. Physicians and other professionals should work collaboratively with parents for information that will assist them in providing optimal treatment. Because there are many treatment options for persons with cerebral palsy, it is easy to feel confused and even overwhelmed when making treatment decisions. A thorough understanding of available treatments and their efficacy for treating the symptoms of cerebral palsy is therefore necessary.

TREATMENT

Persons with cerebral palsy have been the recipients of a variety of medical and therapeutic treatments. It is important to remember that these treatments do not “cure” cerebral palsy, but are employed to manage symptoms. Because these symptoms range in severity, location, and form among different persons with cerebral palsy, treatments may be more useful for some persons than for others. Close communication with health providers as well as patient and caregiver attention to treatments ensure the best outcomes.

Medications

Medications for persons with cerebral palsy are used to treat associated conditions such as epilepsy or more direct treatment of muscle spasticity. Two of the more recent medications are intramuscular botulinum A toxin (Botox) and intrathecal baclofen (Lioresal)(Reading, 2004). Both medications have been used successfully with children and adults. However, as with all medications, caution is needed for correct use and expectation for results should be appropriate.

Botulinum A toxin is injected into spastic muscles to release tension in the feet, upper limbs, pelvis, and back, which assists in more functional walking and sitting (Koman, Paterson, & Balkrishnan, 2003). It has also been found to be effective in reducing back pain and muscle spasms in adults with cerebral palsy (Bergfeldt, Borg,

Kullander, & Julin, 2006; Gallien, Nicolas, Petrilli, Kerdoncuff, Lassalles, Le Tallec, & Durufle, 2004). Although botulinum A toxin acts to paralyze muscles, the effect is not permanent. Pain at the injection site is a negative outcome of this therapy (Rosigno, 2002). In addition, botulinum A toxin may complicate other procedures, such as casting to correct certain deformities associated with cerebral palsy (Kay, Rethlefsen, Fern-Buneo, Wren, & Skaggs, 2004). Botulinum A toxin is not recommended for persons with excessive spasticity, are allergic to this medication, whose contracted muscles are fixed in deformity (immobile), or who take other medications for neuromuscular function (Koman, Paterson, & Balkrishnan, 2003). It is important to understand that botulinum A toxin provides symptom relief but is not a permanent solution to muscle spasticity and its effects.

Baclofen acts to inhibit spinal reflexes, and is administered orally or via a pump that is worn externally or inserted under the skin. Oral baclofen can cause drowsiness and is therefore more efficiently delivered from the pump through a catheter to the cerebral spinal fluid in the lower back (intrathecal space). The pump regulates the amount of baclofen needed to reduce spasticity and also bypasses the need for repeated injections (Best & Bigge, 2005). Baclofen has been successful in reducing spasticity in the legs and also improving intelligible speech (Awaad, Tayem, Munoz, Ham, Michon, & Awaad, 2003; Leary, Gilpin, Lockley, Rodriguez, Jarrett, & Stevenson, 2006). Caregivers have been enthusiastic about the decrease in spasticity and resulting reduction of physical caregiving effort afforded by this medication (Gooch, Oberg, Grams, Ward, & Walker, 2004). In addition, intrathecal baclofen has been successful in reducing spasticity in older individuals who have quadriplegic limb involvement and are not good candidates for other procedures (Von Koch, Park, Steinbok, Smyth, & Peacock, 2001). However, patient, family, and teacher education is critical in detecting complications of this procedure, including disconnection of the catheter that carries the baclofen from the pump to the injection site and mechanical problems with the pump (Gooch, Oberg, Grams, Ward, & Walker, 2003). Although it is reversible, implantation of the pump is a surgical procedure and requires visit to refill and adjust the pump.

Surgical Treatments

The goals of surgical intervention are to correct defects, reduce deformity, and increase functionality. A variety of surgical procedures can be used to treat cerebral palsy symptoms. These may include neurosurgery to reduce hydrocephalus (fluid collecting in the brain), remove benign tumors, and eliminate intractable seizures from epilepsy (Taylor & Kopriva, 2002, p. 393). A recent neurosurgical breakthrough in treating spasticity is selective dorsal rhizotomy. The best candidates for rhizotomy are young persons with spastic diplegia who have ambulation before surgery (Hagglund, 2002; Von Koch et al., 2001). In this procedure, the spinal cord and nerve rootlets are exposed and electrical stimulation is applied to dorsal nerve rootlets. If the muscle that is activated by a specific rootlet reacts to electrical stimulation with contraction and then relaxation, that rootlet is not selected for cutting. If the muscle reacts with contraction but fails to relax, the rootlet that activates that muscle is severed. Between 25 to 50% of dorsal rootlets may be severed in this procedure. After surgery the patient receives physical therapy to maintain the reduced spasticity and improved function (Flett, 2003; Hagglund, 2005). Fine motor skill improvement has also been observed after rhizotomy (Sandeep, Farmer,

Al-Atassi, Montpetit, Gervais, Poulin, Cantin, & Benaroch, 2002). It appears that selective dorsal rhizotomy is most successful when it is performed early in life, is followed up with intensive physical therapy, and is restricted to persons with mild to moderate spasticity. Because this procedure is relatively new, it is impossible to evaluate its long-term effects.

Orthopedic surgery is complementary to surgical treatment of underlying causes of cerebral palsy, such as selective rhizotomy or intrathecal baclofen. Orthopedic surgery is frequently performed on persons with cerebral palsy to “release” contracted muscles and improve standing and walking, as well as reduce pain, stabilize joints, enhance comfort, and ease caregiver burden (Gormley, 2001; Gormley, Krach, & Piccini, 2001). Hip displacement is common in children with cerebral palsy (Soo, Howard, Boyd, Reid, Lanigan, Reddihough, & Graham, 2006). Soft-tissue release surgery can be used to prevent hip dislocation (Presedo, Oh, Dabney, & Miller, 2005), but may be less warranted in older persons unless there is pain and severe contractures (Noonan, Jones, Pierson, Honkamp, & Levenson, 2004). Another critical surgery for young children is muscle release for strabismus, a condition where the eyeball is pulled inward or outward by stronger contraction of one of the muscles that rotate the eye. If surgery is not performed in a timely manner, sight in the eye may be permanently lost (Gormley, 2001).

Surgical management of symptoms of cerebral palsy is complex and has short and long-term effects. Many treatments are complimentary, must be goal-oriented and functional, and should be reasonable based on such factors as family support and severity of disability (Boop, Woo, & Maria, 2001; Gormley, 2001). Surgical management is usually supported with a variety of ongoing therapies to optimize functional outcomes. As is the case with surgical and medication options, there are many therapeutic treatment options for managing symptoms of cerebral palsy.

Occupational Therapy and Physical Therapy

Occupational and physical therapists work with physicians to facilitate motor development and management in persons with cerebral palsy. Physical therapists work to normalize the quality of patient movement through program planning for posture and balance, deformity prevention, and gross motor function, including walking. They work to align the spine, legs, and feet, provide postoperative rehabilitation, assist with physical management at home, and are responsible for fitting and monitoring positioning equipment, braces, prostheses, and/or casts (Best & Bigge, 2005, p. 93). Occupational therapists focus on development of functional skills for performance of activities in daily life (Steultjens, Dekker, Bouter, van de Nes, Lambregts, & van den Ende, 2004). They work on eye-hand coordination skills, use of hands and arms for functional activities such as keyboarding feeding, and/or writing, assess and remediate perceptual skills, evaluate the ability to organize and respond to incoming sensory information, and perform prevocational assessments (Best & Bigge, 2005; Steultjens et al., 2004). While physical therapists are more focused on motor abilities in the lower extremities, occupational therapists are more focused on abilities in the upper extremities. However, the disciplines are meant to complement each other.

Many systems of treatment have developed in physical and occupational therapy. Two of the most widely recognized approaches are neurodevelopmental treatment (NDT) and sensory motor integration (SMI). Neurodevelopmental treatment is based on the

work of Karel and Bertha Bobath from the 1940's (Bly, 1991). It features the use of positioning to inhibit inappropriate reflexive movements and enhance postural control. In this way, movement potential is maximized while musculoskeletal complications are reduced. Therapy is applied within the context of functional activities that promote motivation and participation.

Sensory integration “refers to both a theory, originally developed by Ayres and a neurological process that enables the individual to take in, interpret, integrate, and use the spatial-temporal aspects of sensory information from the body and the environment to plan and produces organized motor behaviour” (Bumin & Kayihan, 2001, p. 394). Children with cerebral palsy may have dysfunction of sensory-motor integration because they lack normal motor control and therefore do not experience what normal movement “feels like”. Occupational therapists engage children with cerebral palsy in activities such as climbing, puzzle completion, ball-related games, and many others that supply sensory input, enhance body awareness, stimulate the vestibular system, and support perceptual and fine motor skills (Bumin & Kayihan, 2001).

A critical aspect of therapy support is assessment and use of orthotic devices, which include custom-made braces, splints, and other appliances. Orthotic devices are prescribed after surgery to hold muscles in correct positions and keep them from becoming contracted. They also support weak muscles and aid the person in walking. It is critical that orthotic devices are worn for the amount of time prescribed by the physician. Therapists will assist family members and professionals to check orthotic devices for correct fit and function. Children are taught to care for their orthotic devices as early as possible. Today's orthotic devices are lightweight plastic and can often be worn with regular shoes, which is a distinct improvement over the heavy, metal and leather “Forrest Gump” braces that many people associate with cerebral palsy.

In addition to assisting with orthotic devices, physical and occupational therapists assess and recommend equipment for positioning and mobility (Best & Bigge, 2005). This equipment is selected for function, comfort, durability, safety, acceptance to the individuals with cerebral palsy and his/her family (Hong, 2005). Equipment to assist with sitting, standing, and lying on the side may all be prescribed. Physical therapists assess and recommend mobility equipment, including wheelchairs, walkers, canes, and crutches. Options for mobility equipment have grown tremendously in recent years. Wheelchairs are customized for every individual and even activity, including wheelchairs for street mobility, road racing and beach use. Along with improvements in speed, weight, and functionality, today's wheelchairs can make a statement about their user that includes color choices and monograms.

Exercise is an area of physical activity that is often limited for persons with cerebral palsy. It is planned and structured, which differentiates it from general energy expenditure that would occur through walking or other movement. Exercise is beneficial because it strengthens muscles, supports physical fitness, and provides opportunities for social interaction (Kelly & Darrah, 2005). Strength training and aquatic exercise are good forms of exercise for persons with cerebral palsy (Kelly & Darrah, 2005; Morton, Brownlee, & McFadyen, 2005). Strength training has enhanced outcomes for walking, running, and jumping (Morton et al., 2005). Aquatic exercise is especially appealing because it eliminates pressure on joints and reduces the influence of gravity. The results are freer movement and better postural control. The resistance offered by water promotes

aerobic and strengthening outcomes (Kelly & Darrah, 2005). Water should be kept at a therapeutic temperature to keep muscles relaxed and keep the swimmer comfortable. Physical and occupational therapists understand the value of these functional and enjoyable forms of exercise.

Other Therapies

Many therapies have been used to treat the symptoms of cerebral palsy. Some are not commonly used in the United States, but have gained popularity in other countries (Rosenbaum, 2003). These are categorized as examples of complimentary and alternative medicine (CAM), defined as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (Liptak, 2005, p. 156). Complimentary therapies add a therapeutic component to activities that children would otherwise normally perform, like riding a horse, swimming, and skiing (Rosembaum, 2003). Alternative therapies are separate from traditional therapies and are frequently based on different and “unusual ideas of the biology of the condition to which they are being applied” (Rosembaum, 2003, p. s91). Among others, these treatments include patterning, conductive education, the Adeli suit, equine therapy, therapeutic electrical stimulation, conductive education, and hyperbaric oxygen therapy.

Patterning. Also called the Doman Delacato Method, patterning has been popular since the 1950's. The premise of patterning is to put children through a series of repetitive motor sequences, which are repeated through each day. Sometimes several people are needed to move the child's limbs and head. No studies have confirmed the claims of patterning experts regarding the long-term changes in motor ability of children with cerebral palsy. The adverse effects of this approach include parental effort in complying with the patterning regimen, expense of special training, and neglect of typical siblings who do not receive adequate parental attention (Liptak, 2005).

Conductive Education. Conductive education has existed in Europe since the 1940's, but has only recently become popular in the United States. The goal is more independent functioning through repetitive movements supported by specific verbal guidance by a “conductor”. The combinations of motor repetitions and active cognitive participation, coupled with simple adaptive equipment, makes conductive education an appealing therapy. Results of research on the efficacy of conductive education are mixed (Liptak, 2005; Odman & Oberg, 2005; Wright, Boschen, & Jutai, 2005).

Adeli Suit. The Adeli suit was originally developed from 1960's Russian technology for maintaining physical fitness in a weightless environment (Bar-Haim, Harries, Belokopytov, Frank, Copeliovitch, Kaplanski, & Lahat; 2006; Liptak, 2005; Rosenbaum, 2003). The tight-fitting Adeli body suit provides complete trunk stability (postural support) to allow better use of the legs, arms, and hands. The deep pressure provided by the suit on limb joints is alleged to promote coordination. The suit is uncomfortable and expensive, the therapy that accompanies its use is extensive and fatiguing, and there is no conclusive evidence that it provides lasting change in muscle tension and coordination (Liptak, 2005; Rosembaum, 2003).

Equine Therapy. Hippotherapy, or horse-assisted therapy, works to improve balance, posture and coordination in persons with cerebral palsy as they adjust to the movement of the horse beneath them. Riders must keep the head and trunk controlled

while astride the horse, and the condition of horseback riding provides incentive for these tasks. Several studies have found improvements in muscle symmetry and activity (Benda, et al. 2003), and walking, running, and jumping (Cherng, Liao, & Leung, 2004). This activity is fun and fits the criterion for complimentary medicine, since it is not contraindicated by more traditional therapies and is something that typical persons would enjoy.

Therapeutic Electrical Stimulation. This procedure involves applying subthreshold electrical stimulation is applied on top of or through the skin to affected muscles of persons with cerebral palsy. The stimulation is purported to increase blood flow to the affected muscle, which helps it to increase in bulk (Liptak, 2005). A study by Sommerfelt, Markstad, & Berg (2001) found no benefit to ambulation after two years of therapeutic electrical stimulation therapy. Dali, Hansen, Pedersen (2002) found similar lack of improvement in range of motion, muscle growth, degree of spasticity, or motor function in a group who received therapeutic electrical stimulation treatment and a matched group who received a placebo treatment. Parents of treated children, however, reported significant improvement. It must be remembered that family perception of therapeutic gain is often a potent factor in demand for a particular treatment.

Hyperbaric Oxygen Therapy. While not categorized as a CAM, hyperbaric oxygen therapy is another therapy approach for persons with cerebral palsy. The assumption of this therapy is that areas of the brain close to damaged areas can be “re-awakened” with oxygen added in increase concentrations via a hyperbaric chamber (Rosembaum, 2003, p. s92.). Evaluation of this therapy have not resulted in any lasting results other than the positive effect of being involved in a clinical trial (Rosenbaum, 2003). Adverse effects include ear drum perforation due to changes in atmospheric pressure created by receiving treatment in the pressurized the oxygen chamber, changes in the eyes, and oxygen-induced convulsions (Liptak, 2005).

It is important for educators and rehabilitation experts to thoroughly research the efficacy of complimentary and alternative therapies before endorsing them. Complimentary therapies, while maybe not effecting permanent change, are enjoyable and have useful components for function, children’s self-esteem, and promoting a sense of access and participation. Any therapies that promote a “cure” for cerebral palsy, purport to apply to persons with a wide range of disabilities, and are supported by testimonial evidence in the absence of rigorous scientific study should be viewed with caution (Rosenbaum, 2003).

EDUCATIONAL AND PSYCHOSOCIAL IMPLICATIONS

Early Intervention

Whatever medication, surgical, and therapeutic experiences the child encounters is secondary to the fact that the typical experiences of childhood are necessary for growth and development. Early intervention provides many opportunities for development for the young child with cerebral palsy. Supported by federal law since 1986, early intervention is available for families of infants and young children with cerebral palsy. It provides opportunities for the child to develop in the domains of gross/fine motor, self-care, social/emotional, communication, and cognition while receiving services in the home, at a center for children with special needs, or with typically developing peers. In

addition to specific structured activities, many skills in early intervention programs are promoted through play.

Play is a critical activity that enhances learning in children. Many fine and gross motor skills are practiced and refined during play. Children engage in symbolic play when they “practice” adult activities such as cooking and fantasy play such as “dress up”. Play fulfills social needs as children learn to take turns, explore roles, and learn to cooperate. Because it is intrinsically motivating, play is a joyous activity that is undertaken for its own value rather than for a particular outcome.

Many children with cerebral palsy cannot play in typical ways. Their motor impairments prevent them from grasping and manipulating toys. If they have visual or auditory deficits their interactions with toys may be even more limited. The intensity of their motor needs may prevent others from engaging them in play activities because there seems to be no way to do so. The outcomes of reduced play experiences affect not only the child’s motor development but also increases dependency, motivation, self-esteem, and self-competence (Miller & Reid, 2003).

Therapists, educators, and care providers must be creative at adapting toys for play. Two examples are object modification and environmental control (Best, Reed, & Bigge, 2005). Figure 3 provides some examples of object modification:

Figure 3: Object Modification for Physical Use

Object Stabilization

1. Secure bases of play items to table tops with clamps, adhesive tape, or two-sided foam tape
2. Use suction cups on bases of toys to secure them to table tops of wheelchair tray tables

Boundaries

1. Create tracks to confine rolling or pull toys
2. Place play items inside shallow containers so they won’t move away when the child interacts with them
3. Build an edge around the lip of the wheelchair tray so objects don’t fall off
4. Place the child within an enclosed area to play

Grasping and Manipulation Aids

1. Enlarge items such as paint brushes by wrapping tape or plumbers foam around the handles
2. Put knobs on toys, puzzles pieces, and other flat objects to make them easier to pick up
3. Put foam tape between book pages to make page turning easier

(Adapted from Best, Reed, & Bigge. (2005, p. 215). *Assistive technology*. In Best, Heller, & Bigge, J. L. *Teaching individuals with physical or multiple disabilities*. (5th ed.). Upper Saddle River, N. J.: Prentice Hall.

Another way that children with cerebral palsy can have a satisfying play experience is through the use of environmental control. Any toy that is operated electronically can be attached to a switch that the child controls. These switches can be operated by hands, feet, and even the lips. By using switch interface with a battery-operated car, for example,

the child with cerebral palsy can control the car to perform all the activities that any other child could do with this toy.

Elementary and Secondary School Programs

In recent years, assistive technology has opened new worlds of exploration and interactions for children and youth with cerebral palsy. Assistive technology is defined as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability” (20 U.S.C., 1401, § 602[1]). This means that assistive technology can be as simple as a pencil with a fatter handle for easier grasp, a book podium to adjust height and angle of reading materials, or as complex as a computer and all its peripheral elements.

Children with cerebral palsy can learn to operate computer software using switch interface to replace the hand-controlled mouse. Even a “head mouse” is available that can be mounted on spectacles. Head movement controls the cursor, and maintaining the head in a steady position acts to “click” the mouse. Computer programs are available that are voice controlled for the individual whose speech is adequate but hand use is not.

An exciting variation of environmental control for older children and adolescents is virtual reality play (Miller & Reid, 2003; Reid, 2004). Virtual reality (VR) technology immerses the child in an experience and allows levels of interaction otherwise prevented by the disability. For example, a child engaged in a virtual reality artistic experience can draw, play paintball or sports, or even play a musical instrument. Miller and Reid (2003) state that “Virtual reality applications have the potential of improving life skills, social participation, mobility, and cognitive abilities, while creating a motivating experience for children with disabilities” (p. 624). In their research, children and adolescents in who engaged in virtual reality experiences in sports/games, artistic activities, and technology/computer assisted activities reported increased belief in their ability, creativity, and competence. Some even reported feeling safer during VR games because they could not really get hurt!

Although breakthroughs in technology have liberated persons with cerebral palsy from the constraints of their motor and speech impairments, they remain at risk for less satisfactory social interactions with peers. Nadeau & Tessier (2006) found that children with cerebral palsy differed from their typical classmates across factors of reciprocal friendships, social status, sociability/leadership, social isolation behavior, and verbal and physical victimization (p. 334). Females with cerebral palsy were more at risk for these negative interactions than males with cerebral palsy. A similar gender-based outcome was reported by Shields, Murdoch, Loy, Dodd, & Taylor (2006), who found that females with cerebral palsy had lower self-concept than able-bodied peers in the areas of physical appearance, athletic competence, and scholastic competence.

In research on affective quality of school life, Best (1995) found that children with visible physical disabilities (including cerebral palsy) evaluated themselves more negatively than non-disabled peers in areas of social competence, perception of acceptance by others, school attitude, and self-concept. This dynamic was more pronounced for children in mainstream settings than for children attending special day class programs. While these findings should not be interpreted to mean that children with cerebral palsy should receive their education in separate environments from their typical

peers, efforts must be made to assist them to manage social interactions, cope with teasing, and develop leadership and other social competence skills.

REHABILITATION AND VOCATIONAL OUTCOMES

Rehabilitation

Persons with cerebral palsy do not acquire their disability as a result of disease, accident, or other experience later in life. Since cerebral palsy is defined as a developmental disability, it is a condition that begins before or shortly after birth or during early childhood. Therefore, the concept of rehabilitation is actually one of “habilitation”, with professionals, family members, and the person with cerebral palsy focused on maximizing potential physically, intellectually, emotionally, and socially from the time of diagnosis. Previous discussion of medical and therapeutic treatments for cerebral palsy indicates the need for early intensive intervention. Although beneficial for physical outcomes, medical and therapeutic interventions can complicate the attainment of an appropriate and complete educational experience. Surgery recuperation, therapy sessions, and other necessities such as orthotics evaluations and medication regimens all contribute to time lost from school.

In the educational setting itself, continuation of occupational and physical therapy services, with additional services such as speech/language therapy, may distract the student from academic achievement. Lack of adequate school-based vocational preparation represents an additional hurdle to successful employment. Poor preparation of teachers to adequately address the needs of students with cerebral palsy results in underestimation of academic potential and poor application of critical supports such as AAC. Finally, family members who have shouldered the majority of caregiving may find themselves exhausted and unmotivated to act as advocates for their children. If they have spent considerable effort struggling for services and have lost trust in the professional institutions that provide services for their children, their involvement may be further reduced (Best, 2005). For conditions as complex as cerebral palsy, communication, cooperation, and mutual respect among all parties is necessary to achieve a balanced and successful outcome.

Vocational Potential and Outcomes

The vocational potential for persons with cerebral palsy is broad and as varied as the disabilities that are associated with this condition (Taylor & Kopriva, 2002). Becoming employed and staying employed is a strong indicator of successful rehabilitation and adult achievement (Mitchell, Adkins, & Kemp, 2006). Unfortunately, proportionately fewer adults with cerebral palsy are employed than their non-disabled counterparts (Michelsen, Uldall, Kejs, & Madsen, 2005; Murphy, Molnar, & Lankasky, 2000). When they are employed, the rate of employment drops when persons with disabilities are in their 40's (Mitchell et al., 2006). Changes in health status associated with age, increased fatigue and need for medical services, and pain may account for workplace loss. Persons without a college education had the lowest employment rates throughout their life spans. Unfortunately, disability entitlements (Social Security, Medicare, and Medicaid) received by non-working persons with disabilities may eclipse the wage rate for unskilled employment. In addition, lower paying jobs are more physical

in nature and not possible for persons with cerebral palsy. Maintaining people in the workplace could include knowledge about age-related physical changes, anticipation of changes with appropriate accommodations, and improved workplace and job efficiency to reduce such factors as fatigue (Mitchell et al., 2006).

The research on disability and employment strongly suggests that higher education can do much to mediate the factors that result in early employment loss (Mitchell, Adkins, & Kemp, 2006). However, not all persons with cerebral palsy will be successful in college. For this reason, the implementation of supported employment programs for persons with cerebral palsy and cognitive impairment is a positive addition to school programs (Gilmore, Schuster, Timmons, & Butterworth, 2000). Social skill development should also be considered as part of a “life skills” or formal vocational preparation program.

Interactions among educational and adult service delivery systems personnel assist adolescents with cerebral palsy to transition to work and other aspects of adult living. These interactions can occur in formal meetings such as those to evaluate the Individual Education Program (IEP) and Individual Transition Program (ITP) while the person with cerebral palsy is still in school. Connections to Departments of Rehabilitation, post-secondary vocational training programs, and job placements can be made at this time. Carryover of services that aid in daily living, such as transportation, equipment provision and maintenance, leisure activities, and health care, must be maintained even when the service provider shifts from schools to community and state agencies (Ko & McEnery, 2004). In all of these service areas, adolescents with cerebral palsy and their family members state that caring and supportive professionals, clear communication and ready information, reduced struggle for services, and awareness of the needs created by disability were the strongest indicators of satisfaction with service delivery.

Unfortunately, persons with cerebral palsy may be judged more on physical appearance and motor limitation than either intellectual potential or vocational motivation. Although cognitive limitations frequently accompany cerebral palsy, they are not synonymous conditions. The severity of cerebral palsy is not a predictor of either intellectual ability or limitation. Unfortunately, while physical barriers can be eliminated through legislation and its enforcement, attitude is less simple to manage (Darrah, Magil-Evans, & Adkins, 2002). McNaughten, Light, & Gulla (2003) note that tangible benefits can be derived from hiring a person with cerebral palsy that far outweigh the effort made to provide accommodations. The key lies in believing that the individual can make a valuable workplace contribution.

An even more important re-adjustment in attitude is one that places responsibility for making accommodations in the community rather than viewing the person with cerebral palsy as someone who needs to “meet the challenge” of disability (Darrah, Magil-Evans, & Adkins, 2002). Incorporating concepts such as “universal design” into living and work spaces is one example of adaptation that meets the physical needs of all persons, including persons with cerebral palsy. When all people benefit from physical barrier reduction such as incorporation of ramps, elevator, etc. into physical structures, or less tangible accommodations such as flexible work schedules and cyber-commuting, the partition between disability and able-bodied is removed (Darrah et al., 2002).

Augmentative and Alternative Communication

The role of assistive technology (AT) in providing educational and vocational access for persons with cerebral palsy is clear. Within the broad arena of AT is a sub-category known as augmentative and alternative communication (AAC). AAC attempts to compensate (either temporarily or permanently) for the impairment and disability patterns of individuals with severe expressive communication disorders. It can augment speech that is present but difficult to understand or be an alternative for speech that is absent. Not every person with cerebral palsy requires AAC, but it is a revolutionary breakthrough for persons who previously were unable to express their thoughts and feelings. AAC systems can be simple, such as two-dimensional picture-based communication boards that are accessed by pointing. They can also be complex electronic, dedicated communication devices that store and retrieve entire messages and output them through synthesized voice. These high tech devices frequently interface with computers, PDA's, and other systems so that messages can be downloaded and placed into word processing documents. The current communication possibilities with AAC are almost limitless.

Persons who use AAC face unique issues of employment and co-worker interaction. Discussion with a group of AAC users who were fully employed in competitive job situations included three themes: (1) barriers to employment; (2) necessary supports for employment; and (3) recommendations for improving employment outcomes for persons who use AAC (McNaughton, Light, & Arnold, 2002). Barriers to employment activities included negative attitudes of others, poor educational attainment, lack of technological training, policy and funding shortfalls, inadequate personal care/support services, and problems with transportation (pp. 66-67). Supports for employment included the user's personal characteristics, education and experience, family assistance for transportation and personal care, ability to use technology, the presence of workplace mentors, and legislative supports such as the ADA (p. 67-68). Recommendations for improving employment outcomes included strengthened vocational training and job search skills in educational systems, personal persistence and use of available resources, changes in AAC systems such as better portability, enforcement of zero tolerance for workplace discrimination, more stringent enforcement of the ADA, and tax relief for consumers in the areas of attendant care and technology equipment and services. (pp. 69-71). Examination of the factors that emerged from this research provides clear direction for professionals who facilitate the education and employment of persons with cerebral palsy.

Both AT and AAC are specifically legislated rights for children with cerebral palsy through the PL 100- 407: Technology-Related Assistance for Individuals with Disabilities Act (also called the Tech Act Amendments of 2000) and the IDEIA (2000). The Americans with Disabilities Act (1990) and Section 504 of the Rehabilitation Act (1972) can also be used to support AT and AAC equipment and services for adults with cerebral palsy. Many avenues of funding exist for the assessment and purchase of AAC systems. Children with cerebral palsy may be eligible through their school, therapy providers, or private insurance, while adults can work with their Departments of Rehabilitation

Quality of Life

It is difficult to define and yet desired by all. It encompasses the opportunity to be an active part of one's community and to engage in interactions critical to personal wellbeing (Best, 2005). In addition to objective factors such as physical health and material security, it includes subjective factors such as personal satisfaction and feelings of competence and empowerment (Schalock, 1990). People call it "Quality of life".

Like anyone else, persons with cerebral palsy have interests in life fulfillment beyond a good education and work satisfaction. Attainment and maintenance of physical and material wellbeing, social relations, participation in community and civic activities, personal development and fulfillment, and recreation all indicate good life quality (Schalock, 1990). These more inclusive outcomes should be the goal for any educator, rehabilitation counselor, or other professional who strives to assist persons with cerebral palsy to reach their potential.

CASE STUDY

Justin is a 20 year-old male who graduated high school last year. At two years of age, he was diagnosed with cerebral palsy. The cerebral palsy involvement was later diagnosed as quadriplegia (involving all four limbs), and of Class III degree of severity (moderate to great limitation of activity). In his early years of school, Justin was enrolled in a special class for students with orthopedic impairments. During the four years from kindergarten through third grade, Justin was frequently hospitalized for respiratory problems and other illnesses associated with his physical impairments. This led to his falling further and further behind in school. While he was not unhappy in the environment, his parents felt that Justin would be challenged to excel at a higher level, both academically and socially, if he were transferred to general education classes with his non-disabled peers. His teachers agreed.

From the third grade (which he repeated) until graduation from high school, Justin was included in age-appropriate general education classes with support from special education. Primarily, Justin's special education support involved the provision of physical therapy to assist him in increasing his mobility, and speech and language therapy using augmentative communication devices to help in developing communication skills. Special education teachers provided assistance in developing his computer skills and learning to use special switches as well as other assistive technology to access his computer and, thus, the academic curriculum.

Despite undergoing numerous surgical procedures (thereby missing school) as part of the orthopedic management of his contractures and deformities related to cerebral palsy, Justin maintained average achievement from elementary through high school. Since elementary school, Justin has been non-ambulatory and has used a motorized wheelchair. The wheelchair has a special tray designed to carry a lap top computer. With support from a paraprofessional assistant who helps him with his personal care and eating, Justin is able to perform all the learning activities required in school.

Justin is sure he will be able to succeed in the world of work. His goal is to obtain a job in the computer field and work while attending university classes part-time until he graduates with a degree in computer science. Using several different assistive technology devices, Justin has developed a high level of proficiency with the computer. Throughout school, he was a member of a group of young men and women who frequently met

during high school to play computer games. Justin not only excelled at the games but was able to alter many of them to make them more challenging and entertaining.

In the past year, one of Justin's friends from the group found a position with a computer game manufacturer as a programmer in research and development. This friend has assured Justin that the company would be interested in hiring him also. The pay is excellent and includes benefits; Justin feels that he is even more knowledgeable than his friend in this particular area. Justin could not think of a single reason not to seek employment with this company – until he spoke to his parents.

His parents explained that, while they wanted to join him in his excitement, they were very concerned that Justin complete college before becoming employed. They reminded him that technology is developing at a phenomenal pace and many technology companies are unable to keep pace and have layoffs or declare bankruptcy. Without a college degree, Justin could find himself out of work with no prospects for finding a new job. They asked Justin if he knew the expectations of the company for work output and whether they expect employees to be able to work at a certain pace.

This individual knows what he wants to do. The Americans with Disabilities Act provides some workplace protections against discrimination based on disability, and Justin is aware of this. Although he respects his parents and knows they have his best interests at heart, he believes this job is an opportunity of a lifetime. Justin reaches a compromise with his parents by agreeing to speak to his rehabilitation counselor at the Department of Rehabilitation and seek the counselor's advice. Both Justin and his parents agreed to seriously consider the counselor's ideas.

Questions

1. The vocational rehabilitation counselor needs to have basic information about the client to recommend a realistic vocational goal. What is this information?
2. Where does the counselor obtain this information?
3. As the counselor, identify how you will handle the dilemma regarding Justin's potential job and his completion of college.
4. Are the career goals of Justin and those of his parents realistic and compatible with his capabilities and limitations?
5. Identify other possibilities open for Justin as a client of the Department of Rehabilitation.
6. What obstacles to employment may Justin face? How limiting is his disability and society's perception of him, including potential employers? Include a discussion of the concept of a "disabling environment."

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