It is estimated that 1.5-2 million children and adults have cerebral palsy in the United States, with two to three children per 1,000 diagnosed in the United States each year. The Centers for Disease Control and Prevention (CDC) estimates 10,000 babies and infants are diagnosed with the condition each year. The United Cerebral Palsy Foundation estimates an additional 1,500 preschool age children are recognized each year to have cerebral palsy.

Impact on Society
Cerebral palsy (CP) is a group of chronic developmental conditions, not a disease, affecting body movement and muscle coordination. It is characterized by an inability to fully control motor function, particularly muscle control and coordination, and is caused by brain damage occurring before, during, or shortly after birth, or during infancy. The brain damage associated with cerebral palsy and the resulting impairments affecting the neurologic and musculoskeletal systems are not progressive. However, the secondary conditions, such as muscle weakness or incoordination, may get better, get worse, or remain the same over the life span of the individual.

The average lifetime cost to meet the unique medical and health care needs of an individual with cerebral palsy is estimated to be $921,000. Lifetime costs for all people with cerebral palsy born in 2000 will total $11.5 billion. This figure accounts for private and public funds associated with lifetime care, but it does not include out-of-pocket expenses used to cover hospital visits, emergency room visits, residential care, and other necessary items, such as:

• Adaptive equipment (e.g. adaptive bikes and toileting chairs)
• Orthotics and braces for feet and legs, walkers, or wheelchairs
• Medication
• Housing modifications to enable improved mobility (e.g. wheelchair access).

Individuals With Cerebral Palsy
Depending on which areas of the brain have been impacted by cerebral palsy, one or more of the following muscular changes may be present: muscle tightness or spasticity; involuntary movement; problems walking or an inability to walk; difficulty in swallowing; and problems with speech. In addition, individuals with cerebral palsy may have:

• Intellectual disability – Two-thirds of individuals with cerebral palsy will have a cognitive impairment.
What Causes Cerebral Palsy?

Cerebral palsy is a disorder with multiple causes. In the past, if physicians could not identify another cause, they attributed most cases of congenital cerebral palsy to problems or complications during labor that caused asphyxia (a lack of oxygen) during birth. However, research by National Institute for Neurological Disorder and Stroke (NINDS) scientists and others has shown that few babies who experience asphyxia during birth develop cerebral palsy or any other neurological disorder. Birth complications, including asphyxia, are now estimated to account for only 5-10% of the babies born with congenital cerebral palsy. As outlined by recent reports from the CDC, there are multiple prenatal (before birth) and postnatal (after birth) causes of cerebral palsy:

- Prenatal causes – include genetic conditions, infections such as bacterial meningitis, bleeding in the brain, severe jaundice, and even an elevated temperature during pregnancy.
- Postnatal causes – include infections such as meningitis, child abuse, stroke, and head injury due to trauma, such as a car accident.

Before the mid-twentieth century, few children with cerebral palsy survived to adulthood. Now, up to 90% of children with cerebral palsy live to adulthood. Adults with cerebral palsy have additional challenges, including:

- Premature aging with early heart and lung diseases;
- Daily work challenges and the need for assistive technology for work performance;
- Higher than average rates of depression (3-4 times higher than the general population);
- Post impairment syndrome, which is a combination of pain, fatigue, and weakness due to abnormal stress on the body;
- Arthritis and other chronic pain conditions; and
- Higher than normal rates of other medical conditions secondary to their cerebral palsy, such as hypertension, incontinence, bladder dysfunction, and swallowing difficulties.

The prevention and treatment of certain causes of cerebral palsy continues to advance. Improvements in medical management have resulted in more infants surviving the newborn period. Physical therapists play an important role to ensure that people with cerebral palsy are able to be as independent and/or as functional as possible.

The Physical Therapist’s Role in Treatment

Physical therapists evaluate and treat infants, children, and adults with in a variety of settings and across the lifespan. While physical therapy cannot prevent the brain damage that results in cerebral palsy, physical therapy can help children and adults reach their fullest potential and prevent secondary conditions.

Physical therapy for infants and young children with cerebral palsy focuses on maximizing the infant’s potential for recovery through neuroplasticity and developmental experience. Direct physical therapy services and family education encourages practice of efficient movement and developmentally appropriate play activities. Engaging families in these activities enhances the infant’s participation in the family, increases the infant’s opportunities to practice, and can advance the developmental skills such as reaching for toys, food, and other common objects. Under the Individuals with Disabilities Education Act (IDEA), Part C, very young children and their families may receive early intervention services to assist the child in his/her development. In addition, children may benefit from Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services if they qualify for Medicaid health insurance benefits.

School-aged children and adolescents with cerebral palsy may receive physical therapy both in the school setting and in the community. School-based physical therapy is two-fold. It includes services under IDEA which focus on maximizing each child’s capacity to benefit from his/her individualized education program through his/her ability to participate in the educational environment. School-based physical therapy services offered under state Medicaid programs address and treat disabilities and functional limitations to ensure that the child is receiving the proper medical attention while in the school setting. Physical therapists are vital in the prescription of appropriate adaptive equipment such as wheelchairs, classroom chairs, and walkers in this setting. The use of appropriate adaptive equipment prevents excess fatigue and improves arm function and classroom attention. As a “related service provider” within IDEA, physical therapists may provide recommendations and education to classroom teachers and aides.
on ways to support the development of independent mobility and/or safely assist a child with his/her mobility and positioning needs. Independent mobility and functional gain made at school translate into greater participation in both the school and the community. At the same time, many children also may have additional health needs that will be met through federal and private insurance.

Many children with cerebral palsy will undergo orthopedic surgery or procedures to reduce muscle tone. Physical therapists play an important role in evaluating the functional abilities of children, as well as in working with medical teams to recommend specific interventions based on the child’s abilities and goals. Likewise, physical therapy is vital to aid in recovery from surgery, and capitalizes on the child’s improved skeletal alignment and/or muscle tone. Activities such as strength and gait training have been shown to improve gait efficiency and speed.

Along with the increasing lifespan of people with cerebral palsy may come a host of secondary complications, such as the early onset of arthritis, joint and back pain, and impaired mobility. Physical therapists provide services for adults with cerebral palsy to reduce joint pain, improve function, promote joint and skeletal alignment, and encourage strengthening and fitness. Physical therapists are increasingly playing a vital role in the design and implementation of physical fitness programs for children and adults with cerebral palsy, with a primary goal of reducing the secondary conditions in adulthood. Participation in physical fitness programs has been shown to improve fitness, functional abilities, and quality of life in individuals with cerebral palsy.

**Current Funding and Policy Challenges**

While children and adults with cerebral palsy may receive many health care and medical services, they continue to have unmet needs that could be better addressed by a number of federal publicly funded programs. Several federal programs could also provide needed financial support for the education of physical therapists, which will allow the profession to better meet the needs of individuals with cerebral palsy throughout the lifespan and across multiple settings.

**IDEA**

The Individuals with Disabilities Education Act (IDEA) supports the provision of free and appropriate public education (FAPE) for all children, regardless of their disability. IDEA includes guidance to states on provision of early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities. Many medical services, including physical therapist services, are provided to children in schools as a result of IDEA under the category of “related services.” Physical therapists are an essential part of IDEA, furnishing services to children to maximize their function and participation in the classroom. The American Physical Therapy Association’s (APTA) advocacy efforts focus on ensuring that physical therapy and related services are implemented by qualified providers. APTA also supports efforts to create a special office within the US Department of Education to specifically address the needs of children and school-based providers covered under IDEA.

The financial burden of implementing IDEA programs is often shifted to state, local, and institution education budgets because IDEA is routinely underfunded through federal appropriations. The American Recovery and Reinvestment Act, abbreviated ARRA (Public Law No: 111-5), included a short term funding boost to IDEA. APTA supports efforts that seek to fully fund IDEA over the long term and improve access to physical therapists for individuals with disabilities. Advocacy is focused on the periodic reauthorization of IDEA, as well as the annual appropriations process for the Department of Education and IDEA programs.

**Medicaid**

Under Medicaid, there are certain services that are “optional benefits,” which means that a state may choose whether or not a set of services will be covered under its state Medicaid program. Physical therapy falls into this category of “optional benefits,” and currently is covered in 37 states throughout the United States. Currently, states are struggling to fund their Medicaid programs, and physical therapy has, unfortunately, been deleted or severely restricted in several state programs.

To aid states, ARRA included extensive provisions for Medicaid state fiscal relief. Specifically, Congress enacted a 1-year increase of 6.2% to the Federal Medical Assistance Percentage (FMAP) rate which provided many states with critically needed revenue to subsidize their state Medicaid program. Increasing funding via the FMAP is an ongoing federal priority for APTA advocacy efforts, given its impact on such programs as those that are provided to children.

Secondly, ARRA included an extension of moratoria on several Medicaid final regulations that could prove detrimental to access and coverage of rehabilitative services under several state Medicaid plans. Among these regulations are policies related to optional case management services, as well as school-based administration and transportation services.

APTA’s efforts on Medicaid reform are three-fold: 1) to
make physical therapy a mandated benefit under the Medicaid and the Children’s Health Insurance Program (CHIP) with the appropriate reimbursement levels under state Medicaid fee schedules and reimbursement methodologies; 2) to develop and implement minimum documentation standards under Medicaid for therapy services; and 3) to ensure that physical therapy services are provided by licensed and qualified professionals.

**Improving Access in Underserved Areas**

APTA supports efforts to encourage more physical therapists to practice in rural and urban underserved areas. The Physical Therapist Student Loan Repayment Eligibility Act would make physical therapists who choose to practice in rural and urban underserved areas eligible to participate in the National Health Service Corps loan repayment program. Currently physical therapists are not eligible to participate in this important program.

**Higher Education Act Funding**

The Higher Education Opportunity Act (Public Law No: 110-315) included a loan forgiveness provision for physical therapists who work in areas of national need, specifically including those who serve children, adolescents, and veterans. Before the program can be implemented for physical therapists, the Department of Education needs to develop regulations for eligibility and application. Federal funding is also needed for this program, as student loan debt load is a significant concern for many physical therapists.

**Support for National Institutes of Health**

The annual appropriation bill for the Departments of Labor, Health and Human Services, and Education includes funding for the National Institutes for Health (NIH). The National Institute of Neurological Disorders and Stroke (NINDS) and the Eunice Kennedy Shriver National Institute of Child Health and Development (NICHD) conduct important research on cerebral palsy. APTA advocates for increased funding for these institutes and other NIH rehabilitation research programs.

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**References:**


**Additional Web Resources:**

March of Dimes Foundation, www.marchofdimes.com
United Cerebral Palsy, www.ucp.org
National Institute for Neurological Disorders and Stroke (NINDS), www.ninds.nih.gov

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