

Cerebral Palsy Grown Up

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CASE VIGNETTE

Scott was diagnosed with severe cerebral palsy (CP) in infancy. He had difficulty sucking and swallowing shortly after birth and failed to meet motor milestones on time, but his cognitive skills were normal. He was educated in a regular classroom with special educational support but often missed school due to illness and frequent doctor visits for his CP. He has never walked, but he can sit in a wheelchair, and his language is average. He recently graduated from high school but does not have a job. He would like to work in graphic design but lacks eye-hand coordination because of cortical visual impairment, and his fine motor skills are below average. Scott has few friends, mostly because he cannot organize or carry out meeting other people without assistance. The friends he has are similarly impaired and have the same barriers. He is dependent on his aging parents for all activities of daily living. Their income is below the poverty line, and they have their own health problems.

Throughout infancy and childhood, Scott attended a specialty clinic at a large pediatric hospital for children with CP staffed by a team of physical and occupational therapists, developmental pediatricians, a pediatric physiatrist who administers Botox injections, a team of pediatric neurosurgeons and nurse practitioners who manage his baclofen pump, a pediatric orthopedic surgeon for his dislocated hips and contractures, a pediatric ophthalmologist, a pediatric anesthesiologist and pain specialist, social workers, and a special team of hospitalists for the medically complex to care for him when he requires admission to the hospital. Scott's extensive medical records and team of specialists are readily available to help care for him until he turns 23 years, the age at which his children's hospital stops seeing patients. Unfortunately, Scott is 22 years. All of the specialists who have cared for him from birth will soon no longer be available.

On the eve of graduation from his state-of-the-art pediatric hospital, Scott's physicians are very concerned about his future. He will likely continue living with his parents who are dependent on the Social Security benefits that come to them for Scott's care. For financial

reasons, they are not motivated to find an alternative living situation for him. Scott's mother is worried about his health because he has worsening chronic hip pain, but, right now, she is more preoccupied with her own health concerns. Despite repeated discussions about transitioning to adult providers in the community, his family has made no effort to meet a new provider.

In contemplating the future and in a state of relative isolation, Scott wonders if he will die young or suffer an adult life of pain. As a teen he felt invincible, but now, on the eve of his 23rd birthday, he is aching more and is less able to sit in his wheelchair. Finally, one day, he summons the courage to ask what he has always wanted to ask of his long-time physician. "What will my life be like? How long will I live?"

The problems Scott faces are common. Transitioning to adult care providers is complicated and daunting. Concerns about the transition plague patients, parents, and professionals involved in the care of children and young adults with CP. What is the prognosis for a young person like Scott teetering on the precipice of adulthood? No professional can precisely answer this question for every individual with CP because each patient is unique with his or her own type and severity of CP, set of personality strengths and weaknesses, talents, and temperament. Comorbidities like intellectual disability (ID), communication impairment, presence of seizures, and behavioral disorders certainly play an important role in prognosis as well. Each person presents with their own family and that family's attitude, belief system, financial situation, intellectual capability, and priorities. In addition, environmental factors like the availability of adult-oriented providers, local programs, state policies, and local resources can significantly impact outcomes.

The goal of this article is to inform physicians and other providers about the challenges young adults with CP face when transitioning to adulthood to help them understand the issues concerning future needs and prognoses. The goal is to help health care providers to ease this transition, to encourage providers caring for these individuals to start planning early for this challenging process, and to advocate on a policy level.

DIAGNOSTIC CRITERIA AND FUNCTIONAL CLASSIFICATION

The definition of CP is the same for adults as for children. Bax and other CP experts around the world revised the official definition of CP by consensus in 2005. The term *cerebral palsy* describes a group of disorders of movement and posture causing activity lim-

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itation attributed to nonprogressive disturbances that occur in the developing fetal, neonatal, infant, or toddler brain. The motor disorders of CP are often accompanied by disturbances of sensation, cognition, communication, perception, and behavior.¹ Hallmark features of CP include abnormalities of tone (such as spasticity and dystonia), weakness, delayed motor milestones, difficulty with mobility, problems with selective motor control, and difficulties with balance. It is important to note that spasticity may worsen as individuals with CP age and mobility may decrease, especially if activity decreases as it often does in adulthood. However, the underlying cause of CP is, by definition, nonprogressive (static encephalopathy), and young children should not lose skills or regress. In other words, while a person's clinical and functional situation may worsen, the original cause of the CP does not continue to damage the brain.

Features associated with CP, but not part of the definition, include seizures, ID, learning disabilities, behavior problems, cortical visual impairment and other visual deficits, hearing loss, language/articulation problems, and disturbance of sensations. These associated features can dramatically affect outcomes such as employment, education, and living situation.

The severity of a person's CP also affects outcomes. CP severity is now traditionally classified by the Gross Motor Functional Classification System (GMFCS).² The use of this scale based on ability to move has revolutionized the way we discuss CP in that it allows clinicians, researchers, therapists, and families to use common language to describe severity. Previously, the term *severe cerebral palsy* meant different things to different people and was not precise enough to be clinically useful. The GMFCS not only gauges current severity but also helps to predict level of function in the future. Those with GMFCS Level 1 CP are expected ultimately to be fully ambulatory. Those with GMFCS Level 2 CP, typically will walk with use of aids like a cane. Household ambulation is expected of those with GMFCS Level 3 CP. Those at Level 4 will typically remain wheelchair dependent, but will hold up their own head. People with GMFCS Level 5 CP cannot hold their head up independently.

Barring environmental deprivation, by age 5 years, children with CP reach 90% of their motor function (as measured by the Gross Motor Function Measure. Certainly by age 7 years, they will have declared themselves with regard to their ultimate level of motor skill. More specifically, GMFCS Level 1 children achieve 90% of their motor skills potential by age 4.8 years. Level 2 individuals do so by 4.4 years, and Level 3 children by 3.7 years, Level 4 children by 3.5 years, and Level 5 by age 2.7 years.³

Families of young children newly diagnosed with CP often ask, "Will my child walk?" The positive predictive value of GMFCS for answering this questions is excellent. Specifically, a study by McCormick showed that if a child was not able to walk at age 12 years, they were 96% likely not to walk at age 17 to 38 years too. If they were

walking at age 12 years, then they were 88% likely to walk at 17 to 38 years as well.⁴ The use of the GMFCS by all health care providers who care for individuals with CP is strongly encouraged by members of the American Academy of Cerebral Palsy and Developmental Medicine, the most prominent professional society dedicated to improving the care of those with CP. The GMFCS can be accessed for free by internet via the following website: www.canchild.ca/en/measures/gmfcs.asp.

PREVALENCE OF CP

It is estimated that between 765,000 and 1,000,000 children and adults (~0.3% of the population) in the United States are living with CP. Most recent estimates of prevalence of CP in the United States resulted from a cross-sectional survey of 8 year olds. Data were collected from 3 sites across the country: metropolitan Atlanta, southeastern Wisconsin, and northern Alabama, using record review from multiple sources in 2002. This survey revealed a prevalence ranging from 3.3 to 3.8 cases per 1000.⁵ In comparison, the Surveillance of Cerebral Palsy European Network has reported a prevalence of CP of 2 to 3 per 1000 live births. The number of individuals with the disorder is increasing, likely because of the increasing survival rates of very low birth weight infants and increasing longevity of adults with the disorder.^{6,7}

Longevity

Longevity in adults with CP is improving, although still lower than in the general population.⁶ It is unusual for a person with CP to die in childhood unless they have multiple, severe disabilities or congenital anomalies in addition to CP.⁸ Mortality in CP is highly concentrated in infancy and is associated with severe brain injuries.⁶

Recent data on persons with CP born between 1940 and 1960 indicate that 86% were alive at age 50 years in the United States compared with 96% in the United Kingdom.⁹ Among children with CP studied in the United Kingdom, 99% with CP and no other severe impairment survived to age 30 years compared to 95% with 1 additional severe disability. Among those with 2 additional disabilities, 59% reached adulthood. Similar studies in California revealed that among children with CP aged 4 to 14 years, 98% survived to 20 years if their CP was described as "not severe," versus 85% with "severe" CP.⁶ In one very large, population-based study of over 3100 individuals with CP in British Columbia, Canada, 30-year survival was ~87%. Factors adversely affecting survival included the type of CP (spastic quadriplegia had the worst prognosis), epilepsy, and severe or profound mental retardation.⁸ Cooper et al.,¹⁰ in a study on physical activity and health among people with disabilities, found that activity level was highly positively correlated with years of survival in adults with CP.

CHANGE IN FUNCTION WITH AGE

CP is a dynamic disorder. Research indicates that from 1 to 7 years of age, motor skills almost always improve.

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From 10 to 15 years, they generally plateau. From 15 to 25 years, individuals with CP may stay the same, get better, or worsen. From 25 to 40 years, decline is expected, but not certain. Activity level and physical therapy intervention may play important roles in mobility and wellness.¹¹⁻¹³

Numerous studies from the United States, Canada, Japan, and Europe indicate that, as with typically developing individuals, adults with CP tend to become more sedentary with age. There is a general trend toward decreasing ambulation with age. For example, 1 study in California of adults with CP living independently from parents reported that 75% stopped walking by choice by the age of 25 years.¹⁴ Possible explanations for this motor decline are increased body size, decreased activity, and changes in spinal alignment.⁶ Adults with CP often experience age-related changes earlier in life than peers without CP. A vicious cycle of decreased activity, deconditioning, and loss of muscle mass leads to contractures, fatigue, pain, and less ambulation in many people with CP.⁷

As activity decreases, musculoskeletal tightness and muscle tone increase and the consequences of contractures accumulate. This results in decreased functional ability in numerous activities of daily living. New problems related to abnormal mechanics present over time. Examples of these include osteoarthritis of hips and knees, patella alta, cervical stenosis, over-use syndromes, scoliosis, osteoporosis, and subsequent fractures. In fact, adults with CP are more likely than nondisabled adults to have at least 4 to 5 chronic health conditions.^{11,15-24} CP patients of all ages need to be monitored for vision, hearing, seizures, and dental concerns across the life span.²⁵

There are unique health concerns associated with extrapyramidal (athetoid) CP in adulthood. One study from Japan indicated that cervical instability is one such problem. The cervical spinal canals of those with athetoid CP are narrower than typically developing subjects. Significantly earlier and more severe disc degeneration with loss of function in the arms and hands can result in such patients.²⁶

The current community standard in the United States is for physical therapy services to be offered in the public school system through age 12 years. This policy of curtailing therapy by age 13 years is based on earlier research indicating that the brain is most plastic and susceptible to influence from outside stimuli early in life. For example, maturation of the spinal cord to an adult phenotype with no uncrossed axons in the corticospinal tract is typically complete by age 13 years.²⁷ However, more recent data suggest that the brain continues to be plastic across the life span and that physical and occupational therapies can refine motor control after age 13 years.²⁸ Because repetition drives plasticity, discontinuance of motor therapy at age 13 years may contribute to overall decline in ambulation and movement with age.⁷

FUNCTIONAL OUTCOMES AND PREDICTORS/ MEDIATORS OF OUTCOMES IN ADULTHOOD

Over the past 50 years, there have been dramatic improvements in the opportunities and supports available to individuals with CP in the United States and other industrialized nations. Changes in legislation have substantially broadened options regarding where people with CP are educated, where they can visit easily, where they can work, and where they can live. Two examples of this are the Individuals with Disability in Education Act and the Americans with Disability Act. Individuals with Disability in Education Act requires public schools to make available to all eligible children with disabilities a free, appropriate public education in the least restrictive environment appropriate to their individual needs.^{29,30} The Americans with Disabilities Act prohibits discrimination on the basis of disability in employment, state and local government. For example, this law calls for accommodations with regard to commercial facilities, public transportation, and telecommunications that will allow those who want to work to have the opportunity to work.^{31,32} Despite these legal protections, as our Case Vignette illustrates, laws can change opportunities, but disparities still exist that make realizing those opportunities a separate concern. In this section, we will summarize the outcomes of education, employment, independent living, health, and relationships among adults with CP.

Education

In the United States, vocational education starts early in high school and involves job training if the student has cognitive skill to benefit from it. Extra time to take tests and adaptive equipment like communication boards can be very helpful accommodations for those with CP attending school. Individualized Education Plans and Section 504 plans include official documentation for such accommodations to be provided at school; individuals with Individualized Education Plans also can receive therapy services like speech and language therapy and occupational therapy. Community college can be used to supplement job training after the young adult with CP leaves high school. Studies have shown that if young people with CP have the opportunity to enroll in postsecondary school experiences (such as auditing courses or participating in certificate programs), their chances for improved employment opportunities are greatly enhanced.^{33,34} In the absence of ID, people with CP can successfully complete postsecondary education, depending on their support system.^{33,34} One study from Israel revealed that 79% of those with CP completed 12 years of education.³⁵ Special education high school ends at age 21 years for those who have developmental disabilities.

Employment

There are various levels of employment in industrialized nations now including competitive or transitional

employment with or without a job coach, flexible working arrangements, sheltered employment, and specifically created jobs. In addition, the number of venues utilizing various supported employment strategies has increased in most communities.

Studies of employment in individuals with CP indicate that a minority of all adults with CP are employed.^{6,19,36-39} Estimates of employment of those with CP are muddled by the use of different samples, which include differences in intellectual abilities and other characteristics. In Sweden, Andersson and Mattsson⁴⁰ reported that nearly 25% worked full time, 10% worked part time, and 50% received full or partial disability pension. O'Grady et al⁴¹ performed a records review in a CP clinic in the United States in which 49% were working, 38% full-time.

Predictors of employment include higher IQ, higher education including job training, better mobility (specifically ability to walk), an emotionally supportive family, better physical health, less pain, being female, not having seizures, having been in regular high school, better speech ability, a more positive attitude, and more normal hearing and vision.^{6,14,42,43} One study of 948 people with CP in a Danish registry concluded that motor impairment among those with CP who could walk had only minor influence on employment. Only half of the participants in that study who had attended mainstream school were employed.³⁷ The highest estimate of employment has come from one study of 101 adults with CP in California who were living independently. Fifty-three percent of that select population were competitively employed, a much higher estimate than reported in other studies from the United States, England, and Scandinavia over the last 4 decades. It may be that employment rates are rising as technology and supportive programs enhance independent mobility and place a higher value on mental rather than physical ability.¹⁴

Living Arrangements

Living arrangements in adulthood vary widely among individuals with CP. Independent living is the norm among those with very mild CP but group homes and supported living arrangements where a caregiver checks in on the client with CP for varying numbers of hours per day are also options in industrialized countries. Many young people, however, experience difficulty becoming liberated from their family and achieving independent life.⁴⁴ Parents can facilitate or be a barrier to independent living at times. Murphy et al¹⁴ surveyed 101 adults with CP who were living independently in California. Eighty-five percent felt that their parents over-protected them in childhood. Sometimes parents receive compensation for caring for their adult child with CP and that funding is crucial to the family's budget. Perhaps more importantly, parents are often fearful that no one can care for their child like they can. Individuals with CP are often quite fearful of venturing out on their own, especially when parents send the message that their child

could never manage without them. This type of enmeshed interaction is very challenging for the physician to address and requires teamwork, ample preparation time, and skill to manage well as the young adult comes of the age where leaving home can facilitate further development. Although the types and modifications of supported living opportunities have substantially increased in most communities, they are still unavailable to many who could benefit from increased independence.

The majority of adults with CP live independently. One study of 221 CP patients without ID surveyed by mail in Sweden who were aged 20 to 58 years revealed that 61% of participants were living alone in an apartment. Fourteen percent lived with a partner and 13% lived with parents. Forty-one percent of respondents received support, and 33% had >60 hours/week service.⁴⁰ Another study of 101 adults with CP found that 67% lived independently.¹⁴ As expected, living independently occurs more among those who have more mild forms of CP than among those with more severe forms such as spastic quadriplegia.¹⁴

Health

A sample of 81 youth from Seattle with GMFCS Levels 1 through 3 (mild to moderate) CP self-reported significantly lower health status than age- and sex-matched typically developing youth.⁴⁵ In general, engaging in less physical activity, being less physically fit, experiencing more pain, and having lower muscle mass and bone density are associated with less robust health among persons with CP. Being less mobile and having worse nutritional status are associated with having more health problems, more hospital admissions, and more frequent doctor visits.^{20,46}

A 2011 article by Rimmer et al on obesity and overweight prevalence among adolescents with disabilities revealed that those with cognitive and physical disabilities have higher rates of obesity (17.5%) compared with nondisabled youth (13.0%). Eighteen year olds were more likely to be obese than younger children with disabilities, suggesting that this is particularly problematic at the transition to adulthood.⁴⁷

Rimmer⁴⁸ has reported at length on the positive impact of physical activity on health and function in persons with disabilities. Investigators studying exercise in CP have frequently concluded that there is evidence that adults with CP might not be engaging in sufficient physical activity to produce the improvements in fitness that would be required to experience associated health benefits.⁴⁹

A study of 335 young adults with CP in Australia revealed that 75% had bodily pain, of which 29% reported moderate to severe impact on daily work. Bodily pain was significantly associated with motor impairment, unemployment, and poorer quality of life.⁴² Studies of pain in persons with CP in the United States have similar conclusions.⁵⁰

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Among individuals with CP, marriage or long-term partnership is certainly possible. Twenty-five percent of one sample of adults with CP were married at one point in their lives.¹⁴ Better motor skills and having more friends predicted dating and sexual activity.⁵¹ Unfortunately, studies also indicate that loneliness and social isolation are greater among adults with CP compared with those without CP.⁵² Twenty-four percent of adults with developmental disabilities (including CP) reportedly either had no one to talk with about personal things or often felt lonely.²³ Some adults with CP face additional barriers with communication, poor eating skills, vision, transportation, and lack of acceptance in the community that limit community participation.^{6,23,52-54} Recent data confirm that employment, higher socioeconomic status, higher education, and independent living are all associated with better social functioning and greater community interaction.⁵¹

A recent extensive review from Canada emphasizes the importance of psychosocial issues in overall function of adults with CP. Its three major conclusions are the following: (1) adults with CP experience negative psychosocial issues, often together with secondary biomedical concerns related to their disability; (2) psychosocial issues associated with aging with CP include the need for social support, self-acceptance, and acceptance by others; and (3) adult rehabilitation and/or social programs that include essential aspects of "sense of well-being" as part of the socialization process could enhance the coping potential of adults aging with CP.⁵⁵

CARE COORDINATION DIFFERENCES IN ADULTHOOD

One major difference between the care of adults and children with CP is that multidisciplinary care is more typical and more available for children than for adults. Across the globe, access to specialty care dwindles as children with CP become adults. A recent Canadian study reported that children attend outpatient visits 1.9 times more than peers without CP and adults with CP visit 2.2 times more.²⁰ However, there is a difference in where these children and adults with CP receive care. While children with CP often see physicians who specialize in CP, adults with CP are much more likely to go to the emergency room or to a general practitioner. This difference reflects a lack of specialists available for adults with CP.²⁰ Health care professionals who care for adults with CP may be less knowledgeable and less familiar with the standard evaluations and treatments of adults with CP. Adult patients with CP often realize that their physicians know less than they do about CP. In the end, they seek treatment for pain less often, use fewer preventive and rehabilitative services and use the emergency room more.²⁰

Adults with CP need care from practitioners of adult medicine who can deal with the comorbidities associ-

ated with CP and who can respond to the crises that may occur in adults but are rarely seen in children (e.g., osteoarthritis). One such model of care has already been established in St Paul, MN, called the Gillette Lifetime Specialty Healthcare clinic. Gillette is a multidisciplinary clinic for persons with CP with 2 main stated goals: (1) maximizing function, and (2) preventing secondary complications like contractures and pressure sores. It is equipped with adaptive feeding and toileting equipment, a therapy gym, and educational tools to prevent skin breakdown. Social workers guide patients through legal guardianship questions and restrictions on insurance coverage that present at age 18 years. The facility is staffed by a multidisciplinary team of providers (therapists, developmental pediatricians, and internists) that creates an environment in which professionals learn from each other and care for patients with CP of all ages.⁵⁶ Although Gillette is held up as an ideal model, the question of who pays for the care remains. Should the cost fall to patients, insurance companies, governmental grants, foundations, or a combination of these? Few, if any, multidisciplinary care clinics can have a neutral revenue stream without outside funding because the care per patient is so expensive.

SUMMARY AND IMPLICATIONS FOR CURRENT PRACTICE

How can a physician answer the question that the patient in our vignette, Scott, asked, "What will my life be like?" And what can a physician say to the parents of newly diagnosed children with CP about how to improve long-term outcomes for their child? Adults with CP have told and shown us that physicians can encourage hope for the future. Physicians should recommend functional therapies and exercise as soon as possible after diagnosis and continuing into adulthood to maximize mobility, prevent pain, and keep the patient connected with other people. Education geared toward achieving independence is key to enhancing the likelihood of employment and independent living that are associated with better medical care and better overall quality of life. The physician would be wise to encourage parents to help their child establish lasting friendships with others to guard against loneliness and social isolation.

The patient presented at the beginning of this article did not receive the ideal preparation needed to transition comfortably from childhood to adulthood. He was not prepared for living in a group home, so he remained with his parents. He was not prepared for a job by the time he graduated from high school, so he remained unemployed and spent his days watching television. As a young adult, he began seeing the physician closest to home who did not know him well and did not have any medical records to review by the time of the first visit. But it is not too late for Scott. All of these things can still happen.

It will be important for future practice for there to be formal mechanisms for information exchange between

pediatricians and internists. Clinicians will benefit from training about techniques and resources available to support the young persons with CP as they grow. Preparation of an individualized plan for adult care of the person with CP should start in early adolescence and continue to the point of transition at 22 years and beyond.⁵⁷ Part of the preparation for adult care, for example, should be addressing who will maintain the patient's baclofen pump. An individualized transition plan could include social service systems (like Social Security Income case workers, community services centers, and vocational rehabilitation centers), educational opportunities (community or traditional colleges), legal concerns (like guardianship), career counseling to formulate realistic and concrete goals for employment and independent living, and methods for achieving those goals. Ideally, multiple people would participate in the development of this plan including the young adult themselves, parents, physicians, physical and occupational therapists, social workers, teachers, community service providers, and potential employers.^{56,58} These approaches provide the greatest likelihood of altering the trajectory that leaves far too many adults with CP underemployed and living alone with their parents, isolated from social relationships.

We close with the success story of Kristin Rytter, nonambulatory and nonverbal PhD graduate of the University of Washington. At age 41 years, Rytter uses a communication system and a specially equipped computer to research communication disorders in children. She has a personal staff to translate her own communication code into language and she types on a laptop computer by moving her head against sensors. It took Rytter 17 years to finish her PhD in developmental psychology.⁵⁹ Three years later, she finished her first book on living with CP.⁶⁰ In a commencement speech, Rytter encouraged graduates not to underestimate the abilities of people with disabilities like CP. She spoke of how important it is to listen to and learn from people with disabilities and their support systems.⁵⁸ Her early health care providers underestimated her potential, which is not uncommon. Her story emphasizes the importance of Assistive Technology and Augmentative and Alternative Communication systems. She embodies all that is possible with community and family supports for individuals with CP transitioning to adulthood.

Our hope is that this article will serve as inspiration to physicians and patients with CP alike. Physicians should keep in mind that it is not enough to advocate at an individual (patient) level for those with CP. Our ultimate goal should be to improve systems of care including insurance coverage and public policies so that Kristin Rytter's story will become the norm.

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REFERENCES

- Bax M, Goldstein M, Rosenbaum P, et al. Proposed definition and classification of cerebral palsy. *Dev Med Child Neurol*. 2005;47:571-576.
- Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*. 1997;39:214-223.
- Rosenbaum PL, Walter SD, Hanna SE, et al. Prognosis for gross motor function in cerebral palsy: creation of motor development curves. *JAMA*. 2002;288:1357-1365.
- McCormick A, Brien M, Plourde J, Wood E, Rosenbaum P, McLean J. Stability of the Gross Motor Function Classification System in adults with cerebral palsy. *Dev Med Child Neurol*. 2007;49:265-269.
- Yeargin-Allsopp M, Van Naarden Braun K, Doernberg NS, Benedict RE, Kirby RS, Durkin MS. Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: a multisite collaboration. *Pediatrics*. 2008;121:547-554.
- Haak P, Lenski M, Hidecker MJ, Li M, Paneth N. Cerebral palsy and aging. *Dev Med Child Neurol*. 2009;51(suppl 4):16-23.
- Tosi Laura L, Maher N, Moore DW, Goldstein M, Aisen M. Adults with cerebral palsy: a workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population. *Dev Med Child Neurol*. 2009, 51(suppl 4):2-11.
- Crichton JU, Mackinnon M, White CP. The life-expectancy of persons with cerebral palsy. *Dev Med Child Neurol*. 1995;37:567-576.
- Paneth N, Kiely J. *The Frequency of Cerebral Palsy: A Review of Population Studied in Industrialized Nations Since 1950*. Oxford, England: Blackwell Scientific Publications; 1999:46-56.
- Cooper RA, Quatrano LA, Axelson PW, et al. Research on physical activity and health among people with disabilities: a consensus statement. *J Rehabil Res Dev*. 1999;36:142-154.
- Shortland A. Muscle deficits in cerebral palsy and early loss of mobility: can we learn something from our elders? *Dev Med Child Neurol*. 2009;51:59-63.
- Turk MA. Health, mortality, and wellness issues in adults with cerebral palsy. *Dev Med Child Neurol*. 2009;51(suppl 4):24-29.
- Day SM, Wu YW, Strauss DJ, Shavelle RM, Reynolds RJ. Change in ambulatory ability of adolescents and young adults with cerebral palsy. *Dev Med Child Neurol*. 2007;49:647-653.
- Murphy KP, Molnar GE, Lankasky BA. Employment and social issues in adults with cerebral palsy. *Arch Phys Med Rehabil*. 2000;81:807-811.
- Vogtle L.K. Pain in adults with cerebral palsy: impact and solutions. *Dev Med Child Neurol*. 2009;51(suppl 4):113-121.
- Krach LE. Intrathecal baclofen use in adults with cerebral palsy. *Dev Med Child Neurol*. 2009;51(suppl 4):106-112.
- Sandstrom K. The lived body—experiences from adults with cerebral palsy. *Clin Rehabil*. 2007;21:432-441.
- Turk MA, Germiski CA, Rosenbaum PF, Weber RJ. The health status of women with cerebral palsy. *Arch Phys Med Rehabil*. 1997;78(12 suppl 5):S10-S17.
- Murphy KP, Molnar CE, Lankasky R. Medical and functional status of adults with cerebral palsy. *Dev Med Child Neurol*. 1995;37:1075-1084.
- Young NL, Gilbert TK, McCormick A, et al. Youth and young adults with cerebral palsy: their use of physician and hospital services. *Arch Phys Med Rehabil*. 2007;88:696-702.
- Horstmann HM, Hosalkar H, Keenan MA. Orthopaedic issues in the musculoskeletal care of adults with cerebral palsy. *Dev Med Child Neurol*. 2009;51(suppl 4):99-105.
- Murphy KP. Cerebral palsy lifetime care—four musculoskeletal

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- conditions. *Dev Med Child Neurol*. 2009;51(suppl 4):30-37.
23. Havercamp SM, Scandlin D, Roth M. Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Rep*. 2004;119:418-426.
 24. Sheridan KJ. Osteoporosis in adults with cerebral palsy. *Dev Med Child Neurol*. 2009;51(suppl 4):38-51.
 25. Zaffuto-Sforza CD. Aging with cerebral palsy. *Phys Med Rehabil Clin N Am*. 2005;16:235-249.
 26. Harada T, Ebara S, Anwar MM, et al. The cervical spine in athetoid cerebral palsy. A radiological study of 180 patients. *J Bone Joint Surg*. 1996;78:613-619.
 27. Nezu A, Kimura S, Uehara S, Kobayashi T, Tanaka M, Saito K. Magnetic stimulation of motor cortex in children: maturity of corticospinal pathway and problem of clinical application. *Brain Dev*. 1997;19:176-180.
 28. Wittenberg GF. Neural plasticity and treatment across the lifespan for motor deficits in cerebral palsy. *Dev Med Child Neurol*. 2009;51(suppl 4):130-133.
 29. Apling RN, Jones NL. *The Individuals with Disabilities Education Act (IDEA): Overview and Selected Issues*. The Congressional Research Service Report for Congress. Order Code RS22590. Updated January 14, 2008.
 30. U.S. Department of Justice. Civil Rights Division. Disability Rights Section. *A Guide to Disability Rights Laws*. Washington, DC: U.S. Department of Justice; 2005:15.
 31. U.S. Department of Justice. Civil Rights Division. Disability Rights Section. *A Guide to Disability Rights Laws*. September Washington, DC: U.S. Department of Justice; 2005:1.
 32. *Americans with Disabilities Act. A Guide for People with Disabilities Seeking Employment*. Social Security Administration. Equal Employment Opportunity Commission. U.S. Department of Justice. Civil Rights Division; 2000.
 33. Hart D, Zafft C, Zimbrich K. Creating access to college for all students. *J Vocat Spec Needs Educ*. 2001;23:19-31.
 34. Hart D, Mele-McCarthy J, Parker D, Pasternack R, Zimbrich K. Community college: a pathway to success for youth with learning, cognitive, and intellectual disabilities in secondary education. *Educ Train Dev Disabil*. 2004;39:54-66.
 35. Mesterman R, Leitner Y, Yifat R, et al. Cerebral palsy—long term medical, functional, educational, and psychosocial outcomes. *J Child Neurol*. 2009;25:36.
 36. Walker W, Johnson CP. Cognitive Adaptive Disability Individuals with disabilities Education Act of 1990. In: Wolraich ML, Drotal DD, Dworkin PH, Perrin EC, eds. *Developmental-Behavioral Pediatrics: Evidence and Practice*. Philadelphia: Mosby Elsevier, 2008:405-443.
 37. Michaelson SI, Uldall P, Keja AM, Madsen M. Education and employment prospects in cerebral palsy. *Dev Med Child Neurol*. 2005;47:511-517.
 38. Ingram TTS. *Paediatric Aspects of Cerebral Palsy*. Edinburgh: ES Livingston; 1964.
 39. Hansen E. *Cerebral Palsy in Denmark*. Copenhagen: Munksgaard; 1960.
 40. Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol*. 2001;43:76-82.
 41. O'Grady RS, Crain LS, Kohn J. The prediction of long-term functional outcomes of children with cerebral palsy. *Dev Med Child Neurol*. 1995;37:997-1005.
 42. Jiang B, Davis E, Walstab J, McLinepi R, Lanigan A, Reddinough O. Pain experience in young adults with cerebral palsy [abstract]. *Dev Med Child Neurol*. 2009;51(suppl 5):11.
 43. Cohen P, Kohn JG. Follow-up study of patients with cerebral palsy. *West J Med*. 1979;130:6-11.
 44. Kokkonen J, Saukkonen AL, Timonen E, Serlo W, Kinnunen P. Social outcome of handicapped children as adults. *Dev Med Child Neurol*. 1991;33:1095-1100.
 45. Bjornson KF, Belza B, Kartin D, Logsdon RG, McLaughlin J. Self-reported health status and quality of life in youth with cerebral palsy and typically developing youth. *Arch Phys Med Rehabil*. 2008;81:121-127.
 46. Liptak G. Health and well-being of adults with cerebral palsy. *Curr Opin Neurol*. 2008;21:136-142.
 47. Rimmer JH, Yamaki K, Davis BM, Wang E, Vogel LC. Obesity and overweight prevalence among adolescents with disabilities. *Prev Chronic Dis*. 2011;8:A41.
 48. Rimmer JH. Exercise and physical activity in persons aging with a physical disability. *Phys Med Rehabil Clin N Am*. 2005;16:41-56.
 49. Thorpe D. The role of fitness in health and disease: status of adults with cerebral palsy. *Dev Med Child Neurol*. 2009;51(suppl 4):52-58.
 50. Engel JM, Peterina TJ, Dudgeon BJ, McKernan KA. Cerebral palsy and chronic pain: a descriptive study of children and adolescents. *Phys Occup Ther Pediatr*. 2005;25:73-84.
 51. Wiegerink D, Roebroek M, Stam H, Cohen-Kettenis P. Importance of peers and dating in development of romantic and sexual relationships among young adults with cerebral palsy [abstract]. *Dev Med Child Neurol*. 2009;51(suppl 5):11.
 52. Balandin S, Berg N, Waller A. Assessing the loneliness of older people with cerebral palsy. *Disabil Rehabil*. 2006;28:469-479.
 53. Ballin L, Balandin S. An exploration of loneliness: communication and the social networks of older people with cerebral palsy. *J Intellect Dev Disabil*. 2007;32:315-326.
 54. Jones G. Aging with cerebral palsy and other developmental disabilities: personal reflections and recommendations. *Dev Med Child Neurol*. 2009;51(suppl 4):12-15.
 55. Horsman M, Suto M, Dudgeon B, Harris SR. Ageing with cerebral palsy: psychosocial issues. *Age Ageing*. 2010;39:294-299.
 56. Linroth R. Meeting the needs of young people and adults with childhood-onset conditions: Gillette Lifetime Specialty Healthcare. *Dev Med Child Neurol*. 2009;51(suppl 4):174-177.
 57. Palfrey JS, Foley SM, Sharma N. Developmental and behavioral disorders grown up. *J Dev Behav Pediatr*. 2008;29:524-531.
 58. Stewart D. Transition to adult services for young people with disabilities: current evidence to guide future research. *Dev Med Child Neurol*. 2009;51(suppl 4):169-173.
 59. Frey C. Cerebral palsy couldn't stop Kristin Rytter's drive for PhD. *Seattle Post Intelligencer*. January 2007. <http://seattlepi.com/local/298906-rytter09.html>. Accessed on October 25, 2010.
 60. Seattle scholar overcomes cerebral palsy to publish first book. *King 5 News*. December 6, 2010. www.king5.com/news/local. Accessed on December 20, 2010.