Clinical Therapy Services for Adults with Cerebral Palsy

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Optimizing Health and Well Being Across the Lifespan

Mary Gannotti and David Frumberg

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Abstract

In this chapter, we review the state of the science about health and rehabilitation needs of aging individuals with cerebral palsy (CP) and suggest goals, environments, effective techniques, and future directions for clinical management. Health and rehabilitation needs of adults with CP are similar to their aging peers but magnified by the biological and metabolic consequences of lack of physical activity during critical periods of development and throughout the life span. Standardized, validated measures of health, pain, function, participation, and well-being are recommended, as well as a review of the state of the science for effective rehabilitation techniques to address the needs of adults with CP. Synthesis of the literature about children with CP and adults with chronic disability was done to fill gaps that exist in evidence-based techniques and dosing. Recommendations for clinical practice and research are provided.

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Introduction

Most children with cerebral palsy (CP) have a life expectancy similar to their peers; hence, about 75% of all individuals with CP alive today are over the age of 18 years (Howden and Meyer 2011). Impairments experienced from CP in childhood persist into adulthood, increasing risk for poor health, function, and well-being with aging (Sullivan et al. 2011). Although adults with CP are the largest demographic, we know very little about how to optimize health, function, and well-being in adulthood. Likewise, little is known about biological and functional changes that occur with aging in adults with CP (Lungu et al. 2016). Comprehensive, multidisciplinary life span clinical and rehabilitation management has historically not been part of the service delivery model for individuals with CP. The costs of secondary conditions among adults with CP to society, the family, and the individuals have only begun to be realized (Kancherla et al. 2012).

There is a growing awareness from consumers, clinicians, and third party payers of the clinical and rehabilitation needs of adults with CP (Lungu et al. 2016; Gross et al. 2018). This increased awareness has resulted from changes in social attitudes and biases, as well as improvements in technology and the survival of very premature infants. For both social justice and economic reasons, preventative and chronic care management across the life span is imperative (Gross et al. 2018).

CP as a diagnostic category incurs some of the highest healthcare expenditures (Kruse et al. 2009; Kancherla et al. 2012), as well as high costs to family and individual (e.g., chronic stress and loss of employment). Given the associated comorbidities across the life span, person-centered care (Morgan and Yoder 2012) that emphasizes self-management is the most effective healthcare model for individuals with CP (Wagner et al. 2001). Preventative and directed interventions can optimize health and well-being as individuals age with CP. Clinicians, families, and individuals should be aware of available care for aging adults with CP.

The International Classification of Functioning, Disability, and Health (ICF) (World Health Organization 2001) provides a theoretical framework for understanding the interrelationships among individuals, environments, health, activities, interventions, and participation. Adults with CP are adults first, and experience all the same consequences of aging on body structures and function as compared to adults without CP. Among researchers there are multiple viewpoints on how to conceptualize the aging process including using chronological age, biomarkers for diseases with high mortality, physiological systems changes, and the reactions to changes in individual homeostatic regulatory processes (Lungu et al. 2016, Health 2016). Life course theory and the concept of accumulation of disability with age is a useful framework when discussing aging with a chronic disability (Sullivan et al. 2011). As individuals with CP increase in chronological age, there is evidence to support more rapid physiological changes than their peers without disability (Peterson et al. 2013; Peterson et al. 2012a). In this chapter, we review the state of the science about health and rehabilitation needs of aging individuals with CP and suggest goals, environments, effective techniques, and future directions for clinical management.

Health Needs

Adults with CP are adults first and require, at minimum, the same level primary and preventative care that all adults do. Adult Preventive Health Care Schedule: Recommendations from the USPSTF (American Family Physicians 2018) should be followed. Adults with CP need a primary care physician who is able to manage screenings for cancer, hypertension, high cholesterol, bone density, blood glucose, and mood disorders – and refer to specialists as needed. Unfortunately, many adults with CP may have difficulty finding a primary care physician to manage their care, and basic health and dental screenings may not occur on a regular basis (Turk 2009). Adults with CP who do not have regular basic health screenings are at risk for some chronic illnesses, such as cancer or hypertension that may not be detected in early stages. Issues like frequent urination, loose bowel movements, unexplained vomiting, stomachaches, or generalized back pain can be signs of short-term issues like viral infections. However, it is often reported that cancers of the bladder, stomach, colon, and breast are found in later stages in adults with CP (Turk 2009). Having a physician and caregivers who know the health status of the individual with CP is imperative to providing timely, relevant healthcare.

The National Institute of Health Care and Excellence in the United Kingdom has published Guidelines for the Care of Adults with CP which aims to improve health, well-being, function, and participation (National Institutes of Health Care and Excellence 2019). The Guidelines cover broad topics concerning excellence in care for adults from mental health to spasticity.

Despite the shortage of research to track lifelong health and chronic disease trajectories in this population, there is ample evidence demonstrating that individuals with CP have significant and progressive motor impairment, excessive sedentary behavior profiles, inadequate muscle and bone development, increased visceral and musculoskeletal adiposity, impaired glucose tolerance, and insulin resistance (Peterson et al. 2013; Peterson et al. 2012a; Peterson et al. 2012b; Peterson et al. 2019). Other reports suggest increased psychological morbidity, progressive issues with incontinence, gastrointestinal reflux, issues with sleep, dysmenorrhea, and reports of fatigue (Turk 2009). In fact, because ectopic fat is present in muscle and bones (which may make it difficult to obtain an accurate length of the body or height), body mass index is not recommended as the most accurate measure of adiposity (Benner et al. 2019). Waist-to-hip ratio has been suggested as a more accurate measure, with DEXA the gold standard to measure lean body mass to fat ratio (Benner et al. 2019).

Indeed, as individuals with CP age, a range of secondary and tertiary conditions arise at an accelerated rate as compared to adults without CP, prompting the widespread notion and clinical hypothesis that individuals with CP are prone to “premature aging” for chronological age. Yet, 150 years ago someone who was 50 years old would be considered elderly, when in today’s society 50 years old is considered “middle-aged.” It has been postulated that certain lifestyles (e.g., regular physical activity, healthy dietary habits) may produce these effects by altering typical aging trajectories of chronic disease that undermine functional status into older adulthood, and ultimately longevity. If this conjecture is correct, it would have substantial ramifications for the health and well-being of adults with CP.

Emerging evidence suggests that there may be different physiological processes in children and adults with CP in glucose utilization, muscle oxygenation, muscle physiology, and vascular structure that place them at higher risk for cardiovascular disease, functional decline, depression, and painful musculoskeletal disorders with aging (O’Connell et al. 2019; Peterson et al. 2019; Whitney et al. 2019). Until the physiological processes can be identified, potential modifying factors can be explored to alter these and healthy lifestyle and physical activity hold great promise to optimize the health and well-being of adults with CP.

Skeletal health has significant implications for well-being in adulthood. Osteopenia and fat infiltration in bone is documented in adolescents with CP (Whitney et al. 2018); hence, they enter adulthood without optimal bone mineralization. With aging and continued lack of regular physical exercise, osteopenia can progress into osteoporosis. There is not sufficient information about the trajectory of bone loss during early, middle, and young adulthood among individuals with CP (Health 2016). With abnormal biomechanical forces, over time progressive deformity of the hips, lower limbs, and feet can occur or reoccur, and musculoskeletal conditions may become painful. Three orthopedic conditions common in adults with CP that directly impact function are: patella alta, hip dysplasia, and cervical and lumbar stenosis (Murphy 2009). Patella alta can be painful and limit ambulation in adults who walk with flexed knees (Murphy 2009). Adults with who ambulate or transfer with hip dysplasia may develop pain and require surgery (Hwang et al. 2016).

Spondylolysis and lumbar stenosis, particularly at the L5-S1 level, and other types of low back pain may also contribute to functional decline. Cervical stenosis appears to be more prevalent in adults with spastic quadriparesis and dystonia and can also benefit from surgical (Lee et al. 2008) or physical therapy interventions. Onset of cervical and/or lumbar stenosis is *insidious*, and it has been suggested that screening should begin early before symptoms arise which is at approximately 50 years of age (Hung et al. 2017). The experiences of an adult with CP documented in a magazine article (https://www.eparent.com/exceptional-blog/the-surprise-of-cervical-spinal-stenosis/) demonstrates the urgency of the issue.

Muscle architecture in adults with CP, similar to bone, demonstrates differences compared to peers without CP (Mathewson and Lieber 2015). Muscles of individuals with CP present with more fat infiltration, smaller muscle bundle cross-sectional area, and less muscle bulk (Mathewson and Lieber 2015). Although these muscles have higher endurance, (Moreau et al. 2008), have more Type II fibers, they produce less force, are smaller, present with fat infiltration, and have a slower rate of force production (Moreau and Gannotti 2015). As a result of a slower rate of force production when moving, adults with CP expend more energy to function. Adults with CP complaints of subjective fatigue may be a result of the lack to generate force quickly enough and the extra energy expenditure needed for functional mobility.

Lack of mobility, spasticity, and joint contractures also put individuals with CP at risk for somatic or visceral pain (Vogtle 2009). Abnormal muscle tone may impact digestion, elimination, and menstruation (Turk 2009). Individuals with dystonia may experience spasms at night that interfere with sleep. Contractures may overstretch nerves and create neuralgia (Murphy 2009). Given the increased risks for nociceptive and neuropathic pain, it is likely that adults with CP may have increased risk for idiopathic or psychogenic pain. At this time, there is little information on the types of pain and its impact experiences by adults with CP.

Reported rates of chronic pain in small samples of adults with CP are 2–4.5 times higher than the general population (Brunton et al. 2016). Small studies suggest that adults with CP have more chronic pain, pain interference, pain intensity, (Jensen et al. 2006) fatigue, and depressive symptoms than peers without CP (Van Der Slot et al. 2012). Other reports suggest chronic pain and fatigue are main reasons for adults with CP to cease walking or lose other functional abilities (Jahnsen et al. 2004; Jahnsen et al. 2003). Loss of function and depression as a result of pain reduces quality of life.

Health issues become more complicated with adults with CP who have more severe physical disability. Evidence suggests with increasing physical disability there is an increased difference in muscle and bone architecture – increasing risk for neuralgia, chronic pain, and other secondary and tertiary conditions. Common health issues such as respiratory and urinary tract infections may lead to hospitalization and spiraling decline in health and function. Hospitalization for any reason, fractures, infection, or the flu may result in a decrease in functional skills. *Individuals with CP should be monitored for the need for additional rehabilitation services upon discharge from acute hospitalization.*

Some adults with CP who are dependent for self-care activities may reside in long-term care facilities (e.g., group homes or skilled nursing facilities). Guardians should be aware of the risks of bed entrapment, physical risks of transfers with untrained caretakers, and risks for not seeking follow-up on health symptoms. For example, guardians should be aware of the standards for the use of bed rails as published by the Food and Drug Administration (https://www.fda.gov/medical-devices/consumer-products/bed-rail-safety) and ensure facilities adhere to these guidelines to prevent death by entrapment.

Some adults with CP who are in chairs prefer to stand pivot transfer for weight bearing and exercise. However, untrained caregivers may not know how or when to pivot, resulting in falls and increasing risk for fractures. Use of mechanical lifts may be a safer alternative. Using a standing frame or another piece of equipment can substitute for the exercise of transferring.

Finally, adults with developmental disabilities are at greater risk for physical, emotional, and sexual abuse than their peers without disabilities (Platt et al. 2017). Knowledge of signs of physical and emotional abuse may be subtle or go undetected, and guardians should educate themselves on how to identify potential signs (http://apd.myflorida.com/zero-tolerance/common-signs/). This may be very difficult given any other behavioral, cognitive, communication, or emotional features of the individual with CP. Adults who have difficulty with expressive and receptive communication may face the greatest risk for bed entrapment, injuries with transfers, and missed health signs.

Box 1 Clinical Pearls – Examination

- Screen early for cervical stenosis, lumbar stenosis, and cardiovascular disease and loss of bone from age 21
- Screen for adiposity; waist-to-hip ratio more accurate than body mass index
- Early screenings for cancers – may be missing patient-reported signs and symptoms
- Screen for physical abuse and neglect – **non-verbal at risk**
- Equipment for safety – **Bed entrapment** is a life-threatening issue!

Rehabilitation Needs and Environment

The rehabilitation needs of adults with CP encompass the ICF domains of body structures and function, activity and participation, and contextual factors (Table 1). These needs are similar to the needs of adults without CP; however, they are magnified. The first tenant of physical rehabilitation is that everyone needs a lifelong fitness program, especially people with chronic physical disabilities, like CP. Physical Activity Recommendations for Americans (second Edition) recommends all adults with disabilities engage in at least 150–300 min of moderate to vigorous physical activity weekly (U.S. Department of Health and Human Services 2018) and some sort of muscle strengthening program 2–3 times a week. For people with more severe mobility disorders who are unable to exercise at high levels of intensity, the minutes of physical activity may be increased to obtain same effect (U.S. Department of Health and Human Services 2018). Meeting the need for physical activity for adults with CP and other mobility disorders should be the long-term goal of any rehabilitation program.

Plasticity, plasticity, plasticity! Despite early brain injury and subsequent sequelae from lack of movement, adults with CP have the same potential for plasticity of the muscles, bones, and brain, as other individuals. Specific interventions must be aimed at specific structures at an intense enough dose to induce change. Rehabilitation interventions should be aimed at harnessing the plasticity in the adult brain, cardiovascular, and musculoskeletal system. In studies of children with CP and adults with other neurologic diagnoses, there is a large body of evidence to support changes in structures (e.g., of the brain or muscle and an individual's ability to function). These changes occur for specific exercises given at specific doses. Rehabilitation interventions should be dosed given best evidence in the literature, which exists for children with CP (Gannotti 2017) but is lacking specifically for adults with CP. The ACSM's Exercise Management for People with Chronic Diseases and Disabilities (Moore et al. 2016) is a baseline to start with dosing for adults with CP. It should be augmented with what is known about dosing and exercise responses in children with CP, and individuals with stroke or multiple sclerosis, until more evidence emerges.

Plasticity can be induced through interventions directed at contextual factors, including personal and environmental features. Personal characteristics associated with change or achievement of goals across populations of individuals who face challenges include readiness to change, self-determination, self-efficacy, and mindset or "grit" (Dweck 2007). Education and self-awareness about readiness to change may be a part of the rehabilitation assessment. Rehabilitation professionals can use motivational interviewing techniques, use of consumer driven goals, and building a program for success to enhance these attributes.

Environmental supports or changes to the environment can also enhance participation. In fact, participation driven interventions are those interventions that change the task or the environment, and do not change the impairments of the individual (Darrah et al. 2011). Context-based interventions can provide more time for practice, more engagement, and movement that is self-initiated; all features that promote plasticity changes. If movement is repeated enough, there is the potential for changes in body structures and function (e.g., brain, muscle, or bone). Interventions can be performed in the home, school, or general community– and occur outside of the therapy session. Examples of context-based interventions are use of adapted sports equipment and participation on these teams, accessible gyms, video exercise programs with household objects (see Strategies: Table 1). The social and physical community (environment) influence the frequency and intensity of movement (Gannotti et al. 2014), and environmental modifications can provide additional opportunities for movement.

Service delivery models and inclusive public health initiatives are also part of context, or environment. Service delivery models effective for care coordination utilize multidisciplinary teams with a primary care physician who coordinates or directs care. This is ideally a local physician, or the consumer's medical home. However, use of the medical home or the local primary care physician is often unsatisfactory for consumers. There is much that remains unknown about aging and CP. Many specialty centers around the world have now developed life span clinics where developmental pediatricians; physiatrists; orthopedic surgeons; biomedical engineers; endocrinologists; physical, occupational, and speech therapist, psychologists; exercise physiologists; and others have special expertise in life span management of CP. Multidisciplinary teams are not possible in all areas, and telemedicine and the ease of sharing medical health records electronically opens possibilities to create "virtual" coordinated rehabilitation interventions to promote health and wellness.

Rehabilitation service delivery models based on best evidence suggest an annual physical therapy assessment for adults with chronic lifelong disability (Sullivan et al. 2011) and identifying person-centered goals for short episodes of therapy, usually ranging from 6 to 12 weeks depending on intervention type. Public health initiatives and community places by law should be inclusive of people with disabilities. However, most communities lack wheelchair accessible locker rooms, bathrooms, and equipment in gyms, recreation centers, town parks, beaches, schools, churches, restaurants, bike trails access points, and martial art centers. Some gyms and recreation centers will not let adults with disabilities work out with a helper due to liability issues. With the increase in age and decrease in mobility of the general US population, along with building of new structures in compliance with universal design guidelines, many architectural barriers can be eliminated in the future.

Assessing Rehabilitation Needs

Assessing the needs of adults with CP can be done comprehensively with a combination of patient reported and clinical measures. The National Institutes of Health of the United States has identified Common Data Elements (http://www.commondataelements.ninds.nih.gov/) for all research projects that include children with CP age 0–18 years of age, with a taxonomy of core, supplemental, and exploratory measures for research studies. These measures are reliable, valid, widely used and should be adopted by clinicians if not already in use. Most of the tests of measures of physical performance CDE for children are applicable to adults with CP.

Table 1 Rehabilitation needs by domains of International Classification of Functioning, Disability, and Health (ICF)

ICF domain	Needs by subdomain	Strategies
Body structures and function	Pain management	Application/instruction in therapeutic exercise and movement Application/instruction of analgesic modalities Assessment of bracing and equipment needs
	Subjective complaints of fatigue	Energy conservation Planned rest and physical activity Sleep assessment
	Cardiovascular and respiratory performance	Improve aerobic fitness Improve cardiovascular fitness Reduce waist size
	Muscle performance	Building strength reserve Increase lean muscle to fat ratio Improving flexibility Increasing rate of force development
	Skeletal health	Building bone Preventing bone loss
	Flexibility	Joint range of motion Prevention/minimize deformity
	Motor control	Gait training Balance training Reaching training
Activity and participation		
	Physical activity	Adaptive sports Adaptive aquatics Structured gym programs Video-instructed programs
	Locomotion	Wheelchair training and sports Aquatic locomotion Robotic locomotion
	Manual dexterity	Constraint-induced therapy Robotic reaching
	Fall prevention	Assessment of equipment for different environments Education; compensation Multimodal exercise training for balance Strategy specific training balance
	Activities of daily living	Assessment of equipment for different environments Referrals to urology for assessment of treatment options Ability to train caregivers
Contextual factors		
	Personal factors	Readiness to change Self determination Self efficacy Mindset or “grit”
	Environmental factors	Yearly rehabilitation assessments Episodic treatment sessions Accessible community gyms and recreation centers Social support for activities of daily living and transportation

The National Institutes of Health of the United States has created the Patient Reported Outcomes Measurement Information System (http://www.healthmeasures.net/explore-measurement-systems/promis) which contains computer adapted, standardized, norm-referenced measures of health, well-being, function, and satisfaction for children, caregivers, adults, and adults with neurologic disability. Using these measures provides norm-referenced values for clinicians and consumers to assess status and change over time. Table 2, Assessing Rehabilitation Needs, provides a list of reliable valid measures that have been demonstrated to be useful with adults with CP, adults with neurologic dysfunction, or have content validity for individuals with CP. Measures are part of the CDE for CP, PROMIS®, or other widely used assessments. (Table 2 is arranged by ICF subdomains, similar to how Rehabilitation Needs are listed in Table 1.)

Classification of gross motor, communication, manual, and, if appropriate, eating abilities is useful in identifying appropriate goals, techniques, and prognosis for health and wellness. The Gross Motor Functional Classification System (GMFCS) (Palisano et al. 2008), Communication Functional Classification Scale (CFCS) (Hidecker et al. 2011), and Manual Ability Classification System (MACS) (Eliasson et al. 2006) provide a comprehensive overview of consumers' functional abilities. The classification levels are stratified by level of physical and cognitive severity levels.. Additionally, the Eating and Drinking Classification Scale (EDCS) (Tschirren et al. 2018) and Bimanual Fine Motor Function Scale (BFMFS) (Elvrum et al. 2016) provide specific information about oral and fine motor abilities.

PROMIS® measures are suggested for pain interference and pain intensity to provide standardized norm-referenced scores. The Brief Pain Inventory (BPI) (Cleeland 1991) also measures pain intensity, interference, and location and is used by many large chronic pain studies. The Faces, Legs, Activity, Cry, Consolability Scale (Merkel et al. 1997) is useful with consumers who cannot communicate. PROMIS® Fatigue and the Sleep Disruption scales are recommended to assess fatigue impact and sleep quality. The 6-min walk test can assess endurance for locomotion (Maher et al. 2008). A consensus statement has been published recommending 9 measures of cardiometabolic risk including a continuous incremental measure of endurance and waist/hip circumference (Benner et al. 2019). The 10 m shuttle run, modified shuttle run, or wheelchair shuttle run (Verschuren et al. 2011; Verschuren et al. 2006; Verschuren et al. 2013) are appropriate continuous incremental measures of endurance for adults with CP. There are age referenced values up to age 20 for both GMFCS I and II for the 10 m shuttle run (Verschuren et al. 2010).

Functional strength of the lower extremities can be measured using the five repetition sit to stand (Wang et al. 2012), which is a test that is used with a variety of populations. The NIH CDE for CP recommends manual muscle testing along with Selective Control of the Lower Extremities (Fowler et al. 2009) and/or Selective Control of the Upper Extremities (Wagner et al. 2016), if needed. Measures of tone, such as the Hypertonia Assessment of Tool (Jethwa et al. 2010) or Modified Ashworth Scale (Ghotbi et al. 2011) are useful to monitor changes in tone that may occur with aging or as a result of interventions.

Joint and skeletal integrity are of upmost importance for pain prevention and optimizing function. Working closely with an orthopedist and endocrinologist is needed to assess bone health (density and strength), joint integrity of the extremities, spinal health (rule out stenosis), and manage progressive deformity. Joint range of motion, palpation, inspection, and testing of ligamentous integrity is essential, as is testing for sensory loss secondary to peripheral neuropathy (Turk 2009). Consultation regarding results of bone mineral density scans, magnetic resonance scans of the spine, or other types of diagnostic information is needed (Turk 2009). A team approach is needed to manage musculoskeletal health, as it is a combination of nutrition, genetics, physical activity, strengthening activities, lifestyle habits, and other factors.

Both patient reported and clinical examination measures can measure functional skills and participation in daily life. The PROMIS® physical activity, sedentary behavior, and strength impact

Table 2 Rehabilitation assessment measures by domains of International Classification of Functioning, Disability, and Health (ICF)

Subdomain	Test and measure	Domains assessed	Type	Time to administer
Pain				
	Brief pain inventory	Pain location Pain type Intensity Interference	Patient reported	10 min
	PROMIS® pain intensity	Pain intensity	Patient reported	5 sec
	PROMIS® pain interference	Pain interference	Patient reported	3–5 min
Fatigue				
	PROMIS® fatigue	Fatigue intensity Fatigue interference	Patient reported	3–5 min
	PROMIS® sleep disturbance	Sleep continuity, attainment, and quality	Patient reported	3–5 min
	6 min walk[a] test or 1 min walk test[a]	Endurance	Clinical measure	6 min or 1 min.
Cardiovascular and respiratory				
	Waist-to-hip ratio	Adiposity	Clinical measure	3 min
	Modified shuttle run or wheelchair shuttle run	Aerobic capacity	Clinical measure	5–10 min
Muscle performance				
	5 repetition sit to stand timed	Functional strength	Clinical measure	
	Manual muscle testing[a]	Strength	Clinical measure	10 min
Joint integrity				
	Review of Radiographs[a] and DEXAs (refer if needed) screen for stenosis	Bone health; skeletal integrity	Clinician chart review	3–5 min
	Joint range of motion and integrity[a]	Goniometer; inspection and palpation	Clinical exam	3–5 min
Motor control				
	Selective control assessment of lower extremities[a]	Isolated motor control of lower extremities	Clinical exam	10 min
	Selective control of the upper extremity	Isolated motor control of upper extremities	Clinical exam	10 min
	Hypertonia assessment tool[a]	Classification of type of hypertonia	Clinical exam	2–3 min
	Modified Ashworth scale[a]	Grading severity of hypertonia	Clinical exam	1–2 min
Activity and participation				
	Jebsen-Taylor hand function test[a]	Upper extremity dexterity	Clinical examination	10 min
	Gross motor function measure[a]	Gross motor skills	Clinical examination	10–20 min
	1 min walk test[a]	Gait speed	Clinical examination	1–2 min
	TUG[a]	Functional ability to move sit to stand and walk	Clinical examination	1–2 min

(continued)

Table 2 (continued)

Subdomain	Test and measure	Domains assessed	Type	Time to administer
	Segmental assessment of trunk control[a]	Trunk control	Clinical examination	5 min
	Berg balance Scale[a]	Static and dynamic balance	Clinical examination	10–15 min
	PROMIS® physical activity, sedentary behavior, and strength impact	Physical activity, sedentary behavior, and strength impact	Patient reported measure	3–5 min
	Neuro-QOL upper extremity function	Upper extremity function	Patient reported measure	3–5 min
	Neuro-QOL LE function	Lower extremity function	Patient reported measure	3–5 min
	PROMIS® satisfaction with social roles	Satisfaction with social roles	Patient reported measure	3–5 min
Contextual factors				
	Goal attainment scale[a]	Person-centered goals	Consumer and provider developed	10 min
	PROMIS® self-efficacy for managing chronic conditions	Self-efficacy for managing: Daily activities, symptoms, medications and treatments, emotions, and social interactions	Patient reported	7–10 min
	PROMIS® depression	Depression	Patient reported	3–5 min
	Barriers to physical activity questionnaire for people with mobility impairments	Environmental barriers to physical activity	Patient reported	10 min
	Social support services referral	Activities of daily living and transportation	Determined by clinician referral	
Cross ICF measures				
	CPChild[a]	Activities of daily living/personal care Positioning, transferring, and mobility Comfort and emotions Communication and social interaction Health Overall quality of life	For caregivers of dependent adults who cannot communicate their needs	10 min
	CPGOAL	ADLS GMF Pain Use of braces Use of wheelchair Treated by others	Patient reported	10 min
	Life-H[a]	ADLS: Nutrition, fitness, personal care, communication, housing, mobility Social roles: Responsibilities, interpersonal relationships, community life, education, employment and leisure Ability, use of assistance, and satisfaction	Patient reported	20 min

[a] Listed on the National Institutes of Health Common Data Elements for Cerebral Palsy https://www.commondataelements.ninds.nih.gov/CP.aspx#tab=Data_Standards

and satisfaction with social roles along with the Neuro-QOL measure of upper extremity and lower extremity function provide important patient reported information about function with norm referenced values. The Gross Motor Function Measure (Russell et al. 2000), the 1 MWT & the TUG (Hassani et al. 2014), and the Segmental Assessment of Trunk Control (Butler et al. 2010) have reference values for various Gross Motor Functional Classification Levels. The Berg Balance Scale and the Jebsen-Taylor Hand Function Test are two widely used tests with adults patients with neurologic dysfunction that have content validity for adults with CP (https://www.commondataelements.ninds.nih.gov/CP.aspx#tab=Data_Standards).

PROMIS® Self-Efficacy of Management of Chronic Conditions and Depression Scales capture emotional and functional coping skills of the individual. Barriers to Physical Activity Questionnaire for People with Mobility Impairments (Vasudevan et al. 2015) can identify environmental barriers to overcome and to promote more daily physical activity. These assessments can identify the need for social services referrals.

Goals

Two tenets of the disability rights movement (and many current adults with CP are baby boomers and from this era) are "Nothing for me, without me" and "Don't try and change me, you change." These tenets reflect a response to behaviors such as *people with disabilities are not often included in the discussion about their care* and misperceptions *that there is something inherently wrong with people with disabilities that needs to be fixed***.** Rehabilitation professionals should be sensitive to this perspective, and respectful of the points of view of the adult with CP. Hence, the individual with CP and/or caregivers should drive health and rehabilitation goal setting and care provided should be person-centered and designed to meet the needs of the individual. Person-centered care is holistic, individualized, respectful, and empowering (Morgan and Yoder 2012). It also is associated with improved quality of care, increased satisfaction with care, and improved health outcomes (Morgan and Yoder 2012).

The Goal Attainment Scale (Turner-Stokes 2009) is useful in capturing and measuring individualized goals. However, developing person-centered goals may be a challenge without having the consumer reflect and prioritize their needs and goals. Patient reported measures that cross several ICF domains might be more useful given the needs of the consumer and clinician. The CPCHILD (Narayanan et al. 2006) is designed for caregivers of children with CP who are dependent for all care (e.g., GMFCS IV and V) and may be useful with caregivers of adults who are dependent. The Gait Outcomes Assessment List (Thomason et al. 2018) is designed for children GMFCS I, II, and III; and it may also be useful with assessment of adults. The Life Habits Questionnaire (Noreau et al. 2004) asks ability, assistance needed, and satisfaction with activities of daily living and social roles in the home and community, providing a broad view of overall function.

Techniques

Eligibility for therapy services through private and public services is available for maintenance or once a functional decline is detected. Besides, everyone needs a physical activity program, especially people with physical disabilities, and they may need assistance to exercise.

Therapy techniques may target prevention, plasticity, or participation. Techniques will vary on the goals and the most effective way to reach them. Dosing has been identified as a key factor in treatment effectiveness, especially when linking structural and functional change (Gannotti et al. 2014). Dosing parameters for muscle performance, motor control, and skeletal health that produce both structural and functional change in children have been established for children with CP (Gannotti 2017), but not for adults with CP. At this time a synthesis of the recommendations of the Physical Activity Guidelines for Americans, second edition (U.S. Department of Health and Human Services 2018), the American College of

Table 3 Summary of dosing parameters and optimal timing to maximize plasticity and health for adults with cerebral palsy

Type	Load	Repetitions	Speed	Frequency	Rest	Duration	Timing
Strength resistance training	85% of 1RM	Build to 3 sets of 6–10	Slow to moderate; controlled	2–3 x/week (non-consecutive)	1–2 min between sets; 24 h btw sessions	8–20 weeks	Age 5 years of age and above
Velocity training	40–80% of 1RM	Build to 6 sets of 5–6	Concentric part “as fast as possible” Return, slow and controlled	2–3 x/week (non-consecutive)	1–2 min between sets; 24 h btw sessions	8–20 weeks	Age 5 years of age and above
Bone mass and structure	High ground reaction force	50–100	High strain	3–6 x/week (non-consecutive)	1–10 s btw reps; 4–8+ h btw sessions	9–12 months (min 3 months)	Pre-puberty; presence of growth hormones
Motor learning	Mental engagement beneficial; Time 20 min. 2 h, total time more than 90 h	Dozens to hundreds	Task dependent	Task dependent, more than competing movement pattern?	Needed for consolidation	Months	First year of life; again first 6–8 years of life; ongoing
Physical activity, aerobic exercise	Moderate-vigorous activity	150–300 min	Moderate to vigorous	Spread across a week	As needed	Lifespan	Lifespan
	Vigorous activity	75–150 min	Vigorous	Spread across a week	As needed	Lifespan	Lifespan
Flexibility	Prolonged positioning	30 min or more	Static	3 times a week	As needed	Lifespan	Lifespan
	Dynamic stretching	10–20 min	Slow and controlled	2–3 times a week	As needed	Lifespan	Lifespan

Table 4 Effective rehabilitation techniques by subdomains of International Classification of Functioning, Disability, and Health

ICF subdomain	Technique and conclusions	Source of synthesis of best evidence	Population
Pain			
Chronic low back pain (CLBP)	Cognitive behavioral therapy, supervised exercise therapy, brief educational interventions, and multidisciplinary (bio-psycho-social) treatment can each be recommended for nonspecific CLBP. Back schools (for short-term improvement), and short courses of manipulation/mobilization can also be considered The most promising approaches seem to be cognitive behavioral interventions encouraging activity/exercise	European guideline for the management of chronic nonspecific low back pain (Airaksinen et al. 2006)	Adults with CLBP
	For patients with chronic low back pain, clinicians and patients should initially select nonpharmacologic treatment with exercise, multidisciplinary rehabilitation, acupuncture, mindfulness-based stress reduction (moderate-quality evidence), tai chi, yoga, motor control exercise, progressive relaxation, electromyography biofeedback, low-level laser therapy, operant therapy, cognitive behavioral therapy, or spinal manipulation (low-quality evidence) (grade: Strong recommendation)	Noninvasive treatments of acute, sub-acute, and chronic low back pain: a Clinical Practice Guideline from the American College of Physicians (Qaseem et al. 2017)	Adults with CLBP
	There is limited evidence of improvement in pain severity as a result of exercise. There is some evidence of improved physical function and a variable effect on both psychological function and quality of life The evidence suggests that physical activity or exercise is an acceptable intervention in people with chronic pain, with minimal negative adverse effects	Physical activity and exercise for chronic pain in adults: an overview of Cochrane reviews (Review) (Geneen et al. 2017)	Adults with CLBP
Fatigue			
Chronic fatigue syndrome (CFS)	Patients with CFS may generally benefit and feel less fatigued following exercise therapy, and no evidence suggests that exercise therapy may worsen outcomes. A positive effect with respect to sleep, physical function, and self-perceived general health has been observed, but no conclusions for the outcomes of pain, quality of life, anxiety, depression, drop-out rate, and health service resources were possible The effectiveness of exercise therapy seems greater than that of pacing but similar to that of CBT. Randomized trials with low risk of bias are needed to investigate the type, duration, and intensity of the most beneficial exercise intervention	Exercise therapy for chronic fatigue syndrome (Larun et al. 2017)	Adults with CFS
Cardiovascular and respiratory			
Cardiovascular disease (CVD)	We conclude that the evidence to date is entirely limited to small studies in terms of sample size, short-term follow-up, and high-risk of methodological bias, which makes it difficult to derive any conclusions on the efficacy or safety	Exercise for people with high cardiovascular risk (Seron et al. 2014)	Adults with CVD

(continued)

Table 4 (continued)

ICF subdomain	Technique and conclusions	Source of synthesis of best evidence	Population
	of the exercise carried out in the included trials on total cardiovascular risk, mortality, or cardiovascular events. It is necessary to conduct high-quality clinical trials that evaluate the effect of exercise on people with increased cardiovascular risk		
Hypertension (HTN)	Exercise remains a cornerstone therapy for the primary prevention, treatment, and control of HTN. The optimal training frequency, intensity, time, and type (FITT) need to be better defined to optimize the BP lowering capacities of exercise, particularly in children, women, older adults, and certain ethnic groups. Based upon the current evidence, the following exercise prescription is recommended for those with high BP: Frequency: On most, preferably all, days of the week. Intensity: Moderate-intensity (40–<60% VO2R). Time: > or =30 min of continuous or accumulated physical activity per day. Type: Primarily endurance physical activity supplemented by resistance exercise	American College of Sports Medicine position stand. Exercise and hypertension (Pescatello et al. 2004b)	Adults with HTN
Endurance			
	Progressive resistive exercise	Effectiveness of exercise on functional mobility in adults with cerebral palsy: a systematic review (Lawrence et al. 2016)	Adults with CP
	Conventional physical therapy	Lawrence et al. (2016)	Adults with CP
	Whole body vibration	Lawrence et al. (2016)	Adults with CP
Bone health			
	Our results suggest a relatively small statistically significant, but possibly important, effect of exercise on bone density compared with control groups. Exercise has the potential to be a safe and effective way to avert bone loss in postmenopausal women	Exercise for treating osteoporosis in postmenopausal women (Howe et al. 2011)	Women >55
Activity and participation			
Gait speed			
	Treadmill training	Lawrence et al. (2016)	Adults with CP
	Conventional physical therapy	Lawrence et al. (2016)	Adults with CP
	Rhythmic auditory stimulation	Lawrence et al. (2016)	Adults with CP
	Balance activities	Lawrence et al. (2016)	Adults with CP
	Seated yoga, tai chi, mediation, relaxation	Lawrence et al. (2016)	Adults with CP
Gross motor function			
	Treadmill training	Lawrence et al. (2016)	Adults with CP
	Conventional physical therapy	Lawrence et al. (2016)	Adults with CP
	Whole body vibration	Lawrence et al. (2016)	Adults with CP
Balance			
	Video gaming	Lawrence et al. (2016)	Adults with CP

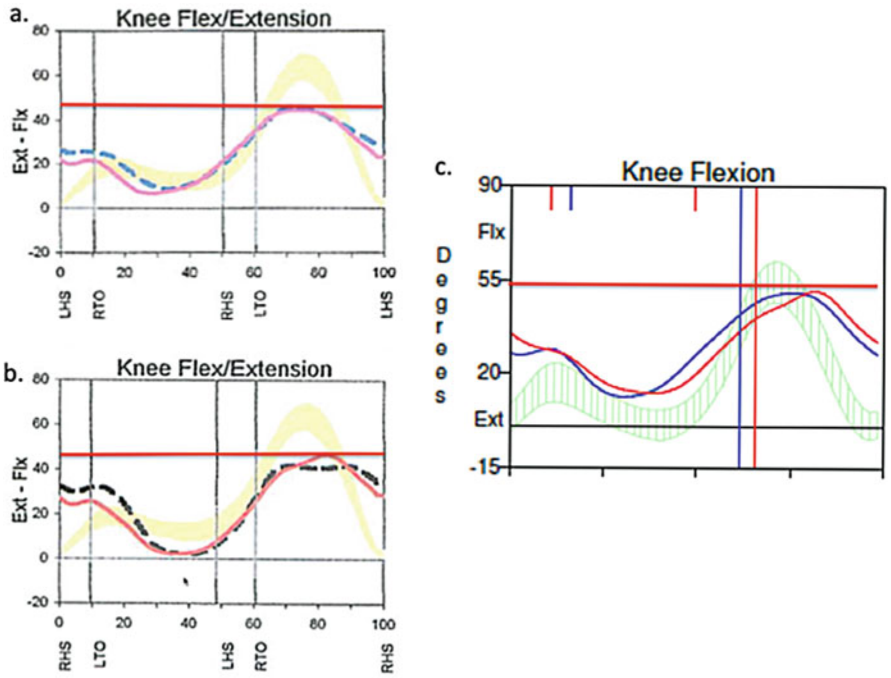

Fig. 1 (**a**) At 27 years of age, left peak knee flexion range of motion in swing at ~45–50 degrees, similar to pre- and postoperative values post rectus femoris transfer as a child. Yellow band is normal. (**b**) At 27 years of age, right peak knee flexion range of motion in swing at ~45–50 degrees, similar to pre and postoperative values post rectus femoris transfer as a child. Yellow bland is normal. (**c**) At almost 35 years of age, right (red) and left (blue) knee flexion peak knee flexion range of motion in swing is ~55 degrees. Green band is normal

Sports Medicine (ACSM) Exercise Management for People with Chronic Disease and Disability (Moore et al. 2016), and known dosing parameters for children with CP (Gannotti 2017) is best evidence for dosing parameters for adults with CP (see Table 3).

Combining rehabilitation strategies listed in Table 1 with rehabilitation techniques listed in Table 4 provides a variety of options for a rehabilitation plan that is individualized and person centered. Table 4 lists the best evidence to support rehabilitation techniques. In some instances, the best evidence has been not determined for adults with CP, specifically but for adults with chronic pain, fatigue, or cardiovascular disease. One systematic review synthesizes interventions published to date with effectiveness for adults with CP (Lawrence et al. 2016). Exercise and physical activity are the cornerstone of any rehabilitation program for adults with chronic disease and disability (Pescatello et al. 2004a). Using dosing parameters of adequate frequency, intensity and time, a variety of forms of exercise, physical activity, and rehabilitation techniques show promise for adults with CP. Forms of aerobic exercise such as treadmill training or conventional therapy have improved endurance, gait speed, and gross motor skills in adults with CP (Lawrence et al. 2016). Clinicians and consumers are challenged to find the type of exercise or physical activity that is best suited for each individual and their social context.

Conclusion

Clinical registries, patient reported registries, and more intervention research is needed to better meet the needs of adults with CP (Lungu et al. 2016). Nonetheless, there is ample evidence from the general population and other populations from which rehabilitation needs, assessments, strategies, and techniques can be developed. Consumers and clinicians should be aware of the possibilities and potential of rehabilitation interventions to improve the health, function, well-being, and quality of life of adults with CP and advocate for physical activity programs for all people with mobility disorders.

Case Studies

Andrew is 40 years old and has spastic diplegic CP, GMFCS II. He was fortunate to have some of the best care available when he was young. He had three-dimensional gait analysis and single event multilevel surgery when he was 9 years old. He walked with bilateral ankle foot orthoses, walked more slowly than other kids, and walked noticeably different. He had difficulty climbing stairs without using rail and could not run very well. He had the derotational osteotomy on the left femur (femoral derotational osteotomy), and soft tissue surgery on bilateral hamstrings, rectus femoris muscles, and heel cords. He had intense physical therapy after his surgery, and had postoperative gait analysis that demonstrated improvement in foot progression and toe clearance, but no change in the amount of knee flexion in swing. In middle school or high school, he rarely saw a physical therapist. He went to college and tried to keep up with his peers. After graduating and moving

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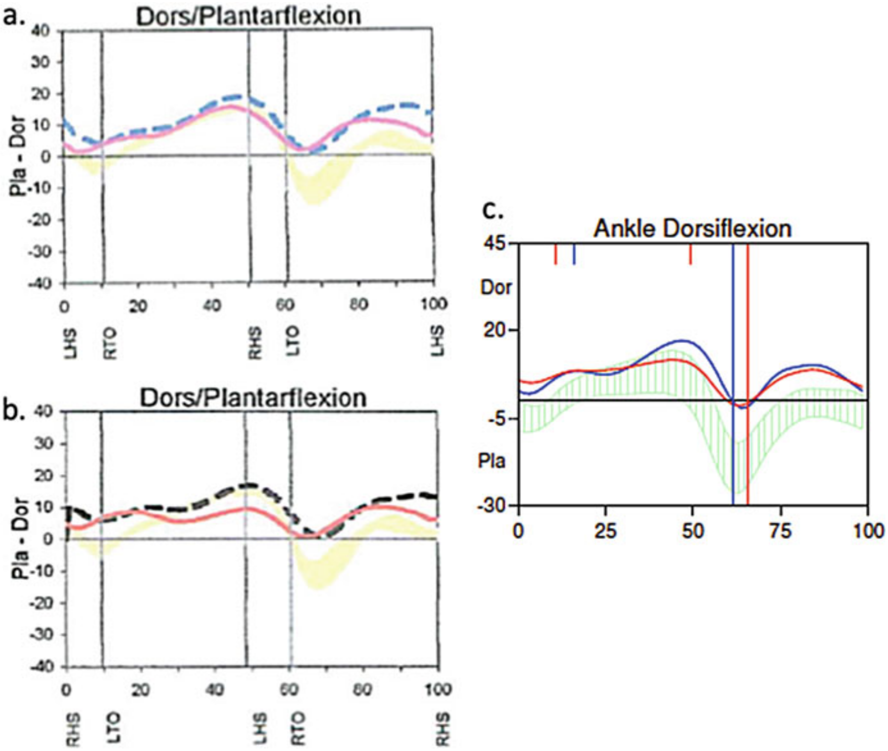

Fig. 2 (**a**) At 27 years of age, left ankle kinematics. Yellow band is normal. (**b**) At 27 years of age, right ankle kinematics. Yellow bland is normal. (**c**) At almost 35 years of age, right (red) and left (blue) ankle kinematics. Green band is normal. No changes in kinematics between two evaluations

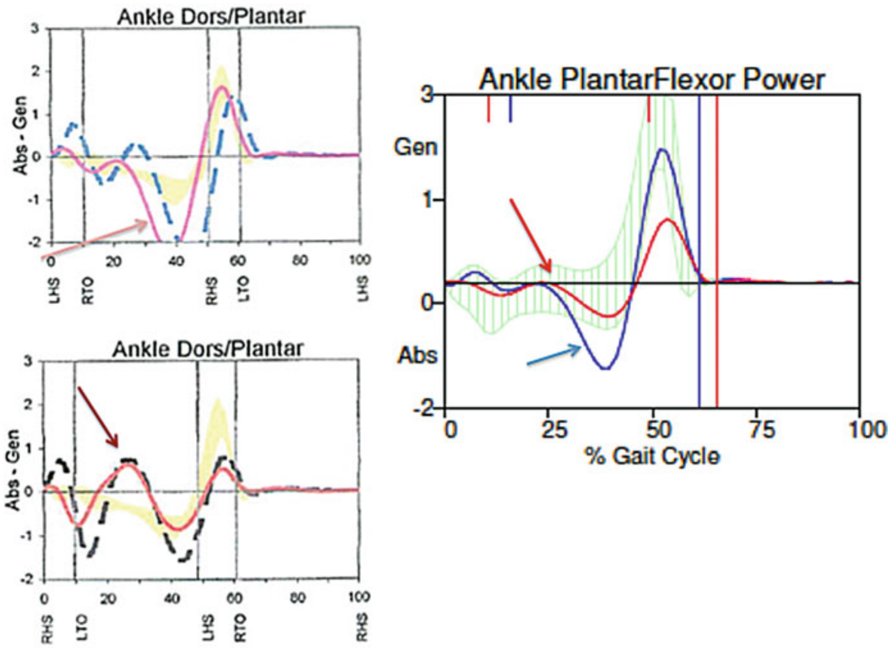

Fig. 3 (**a**) At 27 years of age, left ankle kinetics- solid line barefoot; dotted line shoes. Yellow band is normal. Arrow indicates excessive absorption. (**b**) At 27 years of age, right ankle kinetics- solid line barefoot; dotted line shoes. Yellow bland is normal. Arrow indicates power generation timing off. (**c**) At almost 35 years of age, right (red) and left (blue) ankle kinetics, barefoot Green band is normal. Timing and amount of power absorption on left and generation on right more normalized

out to the West Coast to start a business, at age 27, he began to trip and fall as he began to have difficulty clearing his right foot. He had a follow-up gait analysis that identified changes in range of motion at the hip, knee, and ankle, decreased gait speed, poor foot clearance bilaterally. Andrew began an intensive 2–3 week physical therapy program that consisted of a multimodal approach – strengthening, motor control, core stability, and vestibular training. The program transitioned after a year or so to an athletic trainer, who began to train Andrew like an athlete. He asked Andrew to identify a sport that he desired to do. Andrew had never done a sport, he was interested literature and science, and picked something he thought was unattainable. He said rock climbing. The athletic trainer and Andrew worked on this goal of gradually leaving the training program with the athletic trainer and moving to a gym where he could rock climb and exercise independently. After several years of work, Andrew joined a rock climbing gym. He currently engages in his own exercise program of resistance training, core stability, vestibular training, and power training. Additionally, he rock climbs, and he teaches children to rock climb. He had a repeat gait analysis after several years of his current lifestyle change, and he improved his peak knee flexion in swing and his foot clearance, by improving control of the timing and amplitude of his ankle power burst in push-off (see Figs. 1, 2, and 3). His rock climbing

(continued)

Photo C1.1 Andrew begins the climb and his calf muscles are in an elongated position and generate power to lift him up the wall. (photography by Devan Perez)

Photo C1.2 Continued ascent up the wall requires positioning of the foot and ankle and generation of muscle power to continue to climb. (photography by Devan Perez)

Photo C1.3 Ankle balance and positioning are key to staying on the route. (photography by Devan Perez)

Photo C1.4 Total body strength and coordination required to ascend. Although asymmetrical positioning of the body is a challenge persons with bilateral spastic diplegia, the position is functional on the rock wall! (photography by Devan Perez)

Photo C1.5 Andrew made it to the top! (photography by Devan Perez)

Photo C1.6 Ian's spine at 15 years old with greater than 70 degrees of scoliosis, osteopenia, and chronic pain. He was not a good candidate for surgery due to his fragile health

carried over to functional changes in his gait (see Video C1.1).

Ian is 30 years old, and he has spastic quadriplegia, GMFCS IV, with a more than 70° scoliosis. Ian's case study is well described elsewhere (Gannotti et al. 2015). Ian became disenchanted with traditional school and medical physical therapy services as a teenager and beseeched

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his parents to provide him with the opportunity to become a boxer, a wheelchair boxer. Ian's engagement in his sport changed a young man with a G-tube, failure to thrive, poor grades, incontinence, and upper extremity contractures, into a more vibrant, confident, healthy person. After working out aggressively two times a week from age 15 years until age 23, Ian was able to increase his appetite and eliminate his G-tube, regulate his bowels and form stools, attend college, improve his upper extremity speed of movement and range of motion, and decrease his back painzation with people with and without disabilities. His exercise program has been a vital part of keeping him healthy. He has avoided spine surgery, kept active and managed his pain, avoided pneumonia or other respiratory infections, and is able to enjoy life living with his romantic partner and working part time ￼(see Photos 1, 2, 3 and 4; Video C1.2, heavy bag and Video C1.3 – pull-ups)￼.

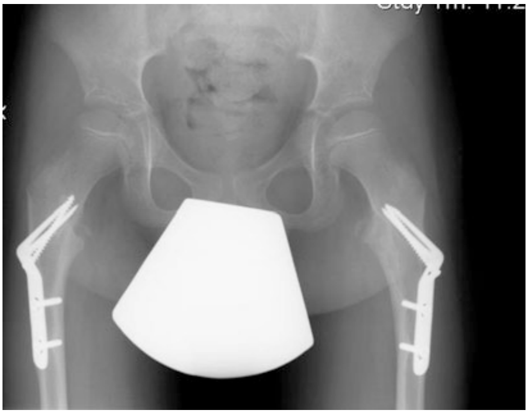

Photo C1.7 Ian's hip x-ray after bilateral hip osteotomies reveal osteopenia at an early age

Photo C1.8 (left upper corner) Ian shadow boxing in preparation to hit the heavy bag. (lower left corner) Home adaptation of lazy Susan with foam to assist with trunk rotation with punching. (Right) Ian performing knee extension with assist of Tyrone Burris, his personal care assistant. (photography by Pete Pyzik)

Cross-References

- ▶ Aging with Cerebral Palsy: Adult Musculoskeletal Issues
- ▶ Community Engagement for Adults with Cerebral Palsy
- ▶ Community Resources: Sports and Active Recreation for Individuals with Cerebral Palsy
- ▶ Life Care Planning for the Child with Cerebral Palsy

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