

Navigating the complex care landscape: Addressing challenges and advancing adult care frameworks for individuals with cerebral palsy

Jensine' Clark^{a,*}, Cristina Sarmiento^b, Jessica Sanders^b, Lauren Wang^c, Lauren Fetsko^d, Unoma Akamagwuna^e

^a University of Cincinnati, College of Medicine, Department of Neurology and Rehabilitation Medicine, 260 Stetson St Suite 5200, Cincinnati, OH 45214, USA

^b University of Colorado Anschutz Medical Campus, Department of Pediatric Rehabilitation Medicine, Children's Hospital Colorado, 13123 East 16th Ave, Box 285, Aurora, CO 80045, USA

^c University of Cincinnati, College of Medicine, Department of Family and Community Medicine, 231 Albert Sabin Way, Medical Sciences Building, Suite 4012, Cincinnati, OH 45267-0582, USA

^d University of Wisconsin School of Medicine and Public Health, Department of Pediatrics, 600 Highland Ave, H6/568 CSC, Madison, WI 53792, USA

^e Baylor College of Medicine, Texas Childrens Hospital, H. Ben Taub Department of Pediatric Rehabilitation, 7200 Cambridge St, Houston, TX 77030, USA

ARTICLE INFO

Keywords:

Adult providers
Adult-focused care
Cerebral palsy
Emerging adults
Interdisciplinary care

ABSTRACT

Despite cerebral palsy (CP) being the most common motor disability in childhood, there are more adults living with CP than children. The necessitates a systematic approach to the care of adults with CP. This perspective piece presents the complex nature of a lifespan approach to the care of a childhood-onset disability. We share the multidisciplinary considerations from a primary care model to address chronic health conditions and preventive care. We also present a care model with an emphasis on Neurology and Neurodevelopmental Disability with its implications for adults with CP. Finally, we advocate for a care model that encompasses a biopsychosocial approach to treatments and interventions with essential elements that include the adult perspective.

Introduction

Cerebral palsy (CP) is the most common cause of physical disability in childhood and one of the most common causes of developmental disability with an incidence of approximately 3 per 1000 births.¹ As medical advances and care continue, life expectancy is increasing. Up to 90% of children with CP reach adulthood, and the greatest gains have occurred in those with severe CP.²⁻⁵ More than 500,000 adults with CP in the United States (US) can currently expect near-normal lifespans, and the number of adults with CP over the age of 65 years in Canada is expected to triple by 2031.^{6,7} As such, CP is increasingly viewed as a *lifespan* condition. However, even though about 80% of individuals with CP are adults, the vast majority of clinical services, interventions, funding, and research studies focus on children.⁸⁻¹⁰

This perspective piece focuses on the unique challenges that adults with CP face as they attempt to receive and access appropriate health care. There is an inadequate number of health professionals who are knowledgeable in the care of adults with CP, and the pediatric system does not translate well to the adult population.¹¹ We will first define the diverse population of adults with CP. We will then discuss the

differences between the pediatric and adult health care systems and how the transition process can have negative implications as patients enter adulthood. We will highlight how creative care models can address the chronic medical comorbidities that are common in adults with CP along with the potential pitfalls of preventive screenings. Special considerations for the neurologic, musculoskeletal, and developmental sequelae of CP will be reviewed. An adult care framework is introduced that utilizes a biopsychosocial approach to developing a patient-centered model of care.

Defining the heterogeneous phenotype of adults with CP

Population-based programs have been used since the 1950s and shed valuable insights into the aging population of adults with CP. Jonsson et al.¹² found that data on prevalence, subtype distribution, and impairments in children with CP are not applicable to adults with CP, necessitating population-based studies focused on adults. These studies often rely on data from patient registries. In addition to disease surveillance, the aims of registries include providing resources for CP research, understanding etiology/targets for prevention, service

* Correspondence to: 260 Stetson Street, Suite 5200, Cincinnati, OH 45214, USA.

E-mail address: Clark4jj@ucmail.uc.edu (J. Clark).

<https://doi.org/10.1016/j.hctj.2024.100051>

Received 1 October 2023; Received in revised form 8 February 2024; Accepted 15 February 2024

Available online 19 February 2024

2949-9232/© 2024 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

planning, and providing information.¹³ Longitudinal registries and follow up surveillance can offer an opportunity to describe multiple aspects of adult life with CP and how these change over time. Along with the medical data, data are also being collected on variables that may be more applicable to adulthood – such as activities of daily living, occupation/education status, living arrangements, and relationship status.¹⁴

In a Swedish cohort of adults with CP, 36.9% of younger adults went to mainstream/higher education and 20.5% went to special schools (schools for individuals with an intelligence quotient (IQ) < 70).¹⁴ In older adulthood, however, 17.5% had competitive employment and 45.2% attended activity centers for people with intellectual disabilities. It was also found that 55.6% of 25- to 29-year-olds lived independently, increasing to 72.4% in 40- to 49-year-olds. Independent living was almost equal in adults with the most mobility (40.2%) and least mobility (38.6%). This was explained by access to personal assistance (>160 h/week), which was readily available in this managed health care system. Unfortunately, this may not be reflected in the US health care system, which is currently understaffed and under-resourced. This Swedish example demonstrates how a large study population can be differentiated and compared to understand the needs of this unique population with the goal of delivering interventions and services that promote the best possible outcomes throughout the lifespan. It is only possible when there is longitudinal surveillance and adequate resource support. Of the 27 CP registry and surveillance programs reviewed, only four had longitudinal follow-up components,¹³ leading to the continued dearth of information regarding aging with CP.

Differences in pediatric vs. adult care

Given its heterogeneous phenotype, CP can co-exist with various neurologic and non-neurologic comorbidities.¹⁵ Within the pediatric setting, it is common for individuals with CP to be supported by a variety of medical specialists, therapists, and school professionals throughout their childhood. The goals of pediatric care are to nurture the development and attainment of milestones and to strive towards independence. This is accomplished through therapies, the procurement of equipment and orthotics, and medical interventions.¹⁵ Another focus in the pediatric world is on the prevention of secondary impairments such as hip dysplasia/subluxation, and to provide support for other medical comorbidities that could affect overall development (e.g., nutritional needs, educational needs, management of changes in vision or hearing).¹⁵ Many pediatric centers often host a multidisciplinary team that specifically treats children with CP. Research on the management of pediatric CP care is well-established and continues to evolve. Systematic reviews exist that describe the treatment options for children with CP to help guide providers in determining the most efficacious management.^{16,17}

However, as patients with CP transition into the adult care model, they experience abrupt shifts in health care approach and attitudes. Appointments with specialists often span multiple separate visits, instead of a one-stop multidisciplinary clinic, leading to feelings of fragmented, uncoordinated care. Rather than focusing on prevention, the focus is divided in favor of acute management of medical concerns.¹¹ Many physicians serving adult patients report that people with significant disability have worse quality of life than those without disabilities, and a minority feel very confident in their ability to provide equitable quality care to patients with disabilities.¹⁸ The high rate of multimorbidity and complexity found in adults with CP is not easily addressed in a single office visit. Adult clinic schedules are also very busy and don't lend to the length of multidisciplinary clinics, further leading to perceptions of fragmented care.^{11,19} Providing accessible clinic spaces and appropriate accommodations have also been identified by physicians as barriers to providing care for adults with disabilities.¹⁸

Education in professional schools on the care of those with disabilities is limited.¹¹ In one study, only 40% of adult specialists noted that they felt very confident that they can provide the same quality of care for

those with disabilities.¹⁸ Adult specialists likely have limited exposure in treating individuals with developmental disabilities during training. Consequently, young adults with disabilities have noted difficulty in finding adult providers who were knowledgeable about CP.²⁰ Another challenge noted by youth is difficulty in navigating educational and health care services in the adult world.²⁰ Pediatric providers must help prepare families for these changes through utilization of transition planning. This planning process should be a longitudinal process, beginning in early adolescence and guided by the pediatric provider before transitioning to adult-based care.²¹

Health care transitions (HCT) from pediatric to adult health care are recommended to begin early in adolescence, as recommended by “Got Transition”.²² At the age of 12, pediatric providers should share clinic policies on HCT with patients and families.²² Readiness of the family should continue to be explored from age 12–18. Among other topics, transition planning should include discussions on medical transitions, potential changes to insurance coverage or waiver programs starting at age 18, vocational plans, and the patient’s decision-making capacity. Vocational options can include enrollment in post-secondary education, extending special education to the age of 21, or entering the workforce. For individuals with cognitive impairments, families should discuss if the patient requires assistance with decision making once they become a legal adult at 18.¹⁵ Options such as supported decision-making and guardianship should be explored well before the age of 18 to ensure a plan is in place by this time. To facilitate transition, a medical summary should be created by the pediatric team to provide to the adult clinician.²² The transfer of care to an adult provider can be considered between the ages of 18–21.²² Future research into HCT should consider developing a CP-specific HCT toolkit to help guide providers, patients, and families.

Care delivery frameworks

A clinical report by The American Academy of Pediatrics and American Academy of Cerebral Palsy and Developmental Medicine¹⁵ was released with guidance for providing a primary care medical home for children and youth with CP. It outlines the goals of pediatric CP care to include guidance for early detection, collaboration with specialists, and management of associated medical, developmental, and behavioral problems. This coordinated, interprofessional care is often lacking in the adult health care setting. Relatedly, the transition period has been characterized by gaps in primary care services and an increase in utilization of emergency services.²³ A systematic review¹⁹ found that the general practitioner was the most commonly and frequently visited health professional among adults with CP. As such, the primary care physician can serve as an important provider for adults with special health care needs.

One type of care delivery model that may comprehensively address the health-related needs of adults with CP is the medical home model.²⁴ A medical home model to care for adults with intellectual and developmental Disabilities (IDD) was formed at an academic health center as a collaboration between Primary Care, Psychiatry, and Physical Medicine and Rehabilitation (PM&R; [Table 1](#)) This specific example, The Freeman Center²⁵, was founded with the mission to provide specialized, coordinated, patient-centered health care for adults with IDD and to train and empower future physicians to care for this population in their communities. This type of clinical model addresses the need for trained medical providers to provide care for adults with IDD and special health care needs. There are affiliates in neurology, urology, dermatology, anesthesiology, dentistry, and speech/occupational/physical therapy who are important members of the interdisciplinary team and are necessary to meet the unique and often complex medical needs of this patient population. The medical home model can serve as the “home base” for adults with CP, providing comprehensive primary care while also coordinating and connecting patients with subspecialty care.

This intradisciplinary care model was developed in an urban area in

Table 1

Care Delivery Frameworks: Clinical examples of different care delivery frameworks that help to address health care disparities for individuals with cerebral palsy.

Care Delivery Frameworks				
Clinic Example	Care Structure	Providers	Ancillary Staff	Health Care Disparities Addressed
Primary Care University of Cincinnati- Freeman Center	Medical Home Model- Interdisciplinary	Primary Care Provider (Family Medicine), Psychiatrist, Physiatrist, Dietician, Pharmacist	RN care manager, social worker, behavior support specialist, community navigator, medical assistants	Comprehensive, coordinated care, trained medical providers, access to specialty services
University of New Mexico- Transdisciplinary Evaluation and Support Clinic (TASC) Neurodevelopmental Disability	Consultative Model- Interdisciplinary	Family Medicine Physician, Psychiatrists, Pharmacists, Neuropsychologists	Nurses, Social Workers	Physical access barriers, trained medical providers, coordinated care
University of Colorado- Adult Neurodevelopmental Disability Clinic	Consultative Clinic- Interdisciplinary	Neurodevelopmental Disabilities Physician, Genetic Counselor	Nurses, Medical Assistants, Vocational Counselor	Access to specialty services, trained medical providers, connection to community vocational support, genetic testing

a mid-size metropolitan city in the US. Coordination of care for those with disabilities may be more difficult for rural residents with more limited transportation and access to clinics and hospitals.²⁶ A consultative model may offer increased health care access to patients living in rural areas who would otherwise have limited access to services. The University of New Mexico is an example of an institution that has addressed this barrier to care by utilizing a consultative care model (Table 1). An interdisciplinary team provides consultative services for adults with IDD who present to their established medical provider with complex medical or behavioral needs. The consultative service does not replace the patient’s local medical or therapy providers but rather provides recommendations and resources to their local care teams. A comprehensive assessment and evaluation are completed and recommendations for additional community resources are given to the patient’s primary provider. These two examples of unique care delivery models provide opportunities to address the health care disparities that many adults with CP face.

Primary care pitfalls

The primary care provider²⁴ often utilizes prevention and screening services to address specific medical concerns for adults with CP. Adults with CP experience higher rates of many chronic diseases, and at earlier ages, compared to the general population. This includes higher prevalence of many cardiovascular, metabolic, respiratory, musculoskeletal, and psychological chronic conditions as well as high rates of multimorbidity (i.e., multiple chronic conditions).^{27–33} Some specific examples include: diabetes in 9.2% of adults with CP (compared to 6.3% of adults without CP, $p < 0.001$); hypertension in 30% of adults with CP (compared to 22.1%, $p < 0.001$); and arthritis in 31.4% of adults with CP (compared to 17.4%, $p < 0.001$).³⁰ In a nationwide sample³⁴ of adults with CP, higher prevalence of cardiorespiratory, metabolic-related, osteoarthritis, and mental health conditions were found at an earlier age (18–30 years) compared to the general population with an abrupt further increase in prevalence by ages 50–60 years. The overall increase in morbidity at earlier ages falls under the typical cut off (age 65) used in several US Preventive Services Task Force screenings, leaving adults with CP subject to being missed with routine clinical monitoring.

Adults with CP also have an increased risk of premature mortality with a median age of death at 40 years, though there is great variability given the heterogeneity of CP severity and associated comorbidities. This early mortality rate has been attributed to underlying preventable morbidities, mainly cardiorespiratory diseases.^{34,35} Primary prevention, which aims to prevent disease, can focus on reductions in tobacco smoking, alcohol consumption, promoting healthy diets, and participation in physical activity to decrease risk factors for cardiovascular disease. Secondary prevention, which aims to reduce the impact of a disease that has already occurred, can combine screening tests with

multi-factorial lifestyle interventions to promote improved health outcomes.³⁶ While further research is needed^{36,34,35} to explore effective primary and secondary prevention interventions specific to the CP population, current evidence from Whitney et al. supports preventive and monitoring measures in early adulthood (i.e., 18–30 years) when morbidity starts to increase. This may support the widespread adoption of earlier preventive efforts for adults with CP; however, further evidence and consensus are needed to develop detailed recommendations.³⁴ Specifically, given their increased risk of chronic disease and at younger ages, further research is needed to identify key ages to begin screening for many of these chronic diseases, which may differ from recommendations for the general population.

Many preventive screenings are based on clinical measures to assess for health constructs that rely on underlying assumptions about the general population,³³ and these may not hold true for many adults with CP, particularly given the variability in severity of CP. These measures are generally accurate and repeatable, but interpreting their value within the context of CP can lead to inaccurate assumptions. Screening for cardiovascular disease, bone health, and kidney disease are strongly impacted by the proposed pathogenesis of unhealthful aging for adults with CP.³³ These common health conditions can be prevented, delayed, or managed with early intervention strategies, but these efforts rely on sufficient detection in the clinical setting.

Obesity,³⁷ assessed using body mass index (BMI), leads to the development of cardiovascular disease and is often used to screen for heart disease risk. BMI is calculated by body mass (kg)/height (m²) and can indicate high body fatness.³⁸ It also reflects the composition of fat mass and fat-free mass. In non-obese individuals, the BMI is primarily composed of fat-free mass. Utilizing BMI to assess an adult with CP is problematic for several reasons. They have lower muscle mass, a major component of fat-free mass, with differences in muscle composition across the body.³³ They often have a lag in height and body mass growth during childhood with continued lags in height gains over time. Accurate assessment of height for adults with CP who have significant spasticity and/or contractures may also be limited. This discrepancy between proportions of body mass, fat mass, and fat-free mass as well as the technical difficulties in accurate height assessment can alter values of measurement meant to capture obesity risk in adults with CP. As a result, BMI frequently underestimates the total body fat in individuals with CP especially those with more severe forms of CP.³³ Furthermore, studies have shown that individuals with CP have higher visceral fat in the abdomen, a cardiovascular disease risk marker that is independent of BMI.³⁷

Neurologic and musculoskeletal complications

CP by definition is nonprogressive. While the initial neuropathology does not get worse,²⁷ there are complications of aging changes seen in

the neurologic and musculoskeletal systems that warrant surveillance.

Adults with CP have a two-times greater risk of stroke and eight-times greater risk of myelopathy compared to others of the same age, and therefore changes in baseline function, strength, tone, or other neurologic symptoms require prompt evaluation and management.²⁷ Fatigue and pain are significant issues as well, with more than 65% of adults with CP experiencing chronic fatigue and up to 70% with chronic pain.²⁸ In fact, prior studies have demonstrated that pain is the most consistently reported health condition for adults with CP and has significant impacts on function and quality of life.^{39–42} Musculoskeletal issues can contribute significantly to pain and are very common in adults with CP – with up to 76% reporting musculoskeletal issues.^{43,44} These issues often localize to weightbearing joints of the hip (osteoarthritis, subluxation, dislocation), knees (osteoarthritis, patella alta), feet, neck and/or back (scoliosis, spondylosis) and often begin earlier in adults with CP compared to the general population. Additional musculoskeletal issues include contractures, overuse injuries, and fragility fractures in the setting of osteoporosis. Such musculoskeletal issues may be present in childhood without causing pain, though often progress and can become painful in adolescence or adulthood.^{45,46}

With age, adults with CP also experience early onset sarcopenia, which, in combination with the aforementioned chronic disease risks and decreased access to health care and opportunities for physical activity in adulthood, place adults with CP at high risk for functional decline.^{47–51} More than one-third of adults with CP will worsen by one Gross Motor Function Classification System (GMFCS) level in adulthood.²⁷ As such, screening for and management of chronic diseases, including pain and fatigue, monitoring for neurologic changes, and supporting access to appropriate services and resources are all critical to preserve and optimize the function and well-being of adults with CP.

Given the lack of evidence base to guide the care and healthy aging of adults with CP, the National Institutes of Health and stakeholders, including adults with CP and caregivers, have identified increasing our understanding of aging and related issues as a priority area for the CP research agenda.^{52,53}

Addressing cognitive impairments

As a consequence of early disturbance to the developing brain, individuals with CP are at a higher risk of having an intellectual disability with a prevalence as high as 42%.⁵⁴ This impairment can affect activities of daily living and exacerbate existing health care disparities. Adults with neurodevelopmental disabilities (NDD) overall, which include adults with CP, face many challenges. Decreased access to medical therapies and services, disparities in housing and living arrangements, and a lack of providers who are knowledgeable about adults with NDD are all potential barriers adults face in the current health care system. Comprehensive adult-based care for adults with CP should include providers who can counsel patients and families about access to available resources and supports.

First, there is a lack of therapy, medical, and support services as individuals face the often-difficult transition from pediatric to adult care. During childhood, the Individuals with Disabilities Education Act is a federal law that mandates a free appropriate public education for individuals with disabilities until age 21 years.⁵⁵ A free appropriate public education often includes therapy services such as physical therapy, occupational therapy, speech therapy, and behavioral therapy for individuals with disabilities who require therapies and supports to access school curricula. In turn, these therapies also help the individuals and their families thrive both in and out of school. However, no similar law exists that mandates activities, or support for therapy services, for individuals with disabilities after age 21 years. This severe “drop off” of services makes transitioning to adulthood for individuals with NDD even more challenging.⁵⁶

It is also important to note that living situations vary significantly across the country among people with IDD. Medicaid Home and

Community Based Services (HCBS) waiver programs provide the majority of long-term services and supports for people with IDD.⁵⁷ Nationally, in 2019, 60% of individuals with IDD lived with family, 5% lived in a host or foster family home, 16% lived in a group home shared by six or fewer people with IDD, and 8% lived in larger IDD facilities, nursing homes, or psychiatric facilities.⁵⁸ In Colorado, data from 2019 estimated that 16,405 adults with IDD had Medicaid waivers, and of those, 3314 (20%) lived in host/foster homes, 3115 (19%) in a group home, 1596 (10%) in their own home, and 8380 (51%) in a family home receiving waiver services.⁵⁹ The diversity and disparity of service provisions including therapy services, housing resources, waiver wait lists (with some states having wait times of 10 + years), and others, makes national expectations, as well as comparisons, challenging.

As patients with NDD transition from pediatric to adult health care systems, they often have difficulty finding providers who comprehensively address their physical health, mental health, and community support needs. Additionally, as most adults with NDD have Medicaid,⁶⁰ they face barriers in adult health care systems that limit the amount of publicly insured patients that are accepted for care. Overall, individuals with NDD are more likely to have sedentary lifestyles and unmet chronic health conditions that contribute to the challenges faced in adulthood.⁶¹ Hence there is currently no consistent health care model for improving access and coordinated care for these individuals.⁶² Many adults with NDD do not receive high quality care that attends to these unique and complex needs. A novel adult-based clinic for adults with NDD, which fills a gap in care, creates a unique training opportunity for medical providers and addresses health care disparities for adults with NDD. This care delivery model serves as an example for addressing the physical health, mental health, and community support needs of adults with CP (Table 1).

The NDD training pathway that combines board certification in Pediatrics, Neurology with Special Qualifications in Child Neurology, and Neurodevelopmental Disabilities uniquely positions physicians to care for individuals with NDD throughout the lifespan and to collaborate with neurologists, developmental pediatricians, and other specialists to provide holistic care to this population.⁶³ The innovative cross training between adult and pediatric neurology providers with expertise in behavioral health is successfully improving access to age-appropriate specialty care for this vulnerable population of patients. Future studies should investigate how experiential training and practice improves comfort levels of trainees and practicing physicians, and how that can translate to better care for adults with NDD in the future.

Developing an adult care framework to optimize function

Health and function are inextricably linked, including for adults with CP. Health care interventions for adults with CP should focus on optimizing function and often include rehabilitation-related needs. However, study of health care service use among adults with CP revealed that only 22% of adults visited a rehabilitation specialist over the preceding 12 months with up to only 50% reporting they received similar services over unspecified time periods.¹⁹ While some primary care providers or other subspecialists may manage some rehabilitation-related needs, other providers may not feel confident providing this level of specialty care. This results in many adults having to self-manage their condition without specialist guidance.

A recent systematic review of clinical practice guidelines related to care of individuals with CP⁶⁴ failed to develop a set of evidence-based rehabilitation interventions, thus further complicating coordination and systemization of care. Specific guidelines were identified and evaluated, and data were extracted across functional domains in accordance with the International Classification of Functioning, Disability, and Health (ICF). The ICF fosters a comprehensive approach to research and clinical practice by describing function using a biopsychosocial model that includes the components of body functions, body structure, and activities and participation.⁶⁵ The additional

contextual factors address the components of environment and personal factors. Most of the evaluated guidelines addressed mobility and body function with comorbid conditions and lifespan considerations being included.⁶⁴ No guidelines focused on physical or occupational therapies to improve activity and participation. This represents a considerable mismatch between evidence-based interventions that focus on body function and structures and the contextual domains that are important to adults with CP and their caregivers. Despite this limitation, an ICF Core Set⁶⁶ was developed as a shortlist of the most relevant categories according to key stakeholders: adults with CP and their families, researchers, and health professionals. Almost half (42%) of the categories included activity and participation domains with another 24% representing environmental factors as essential elements to assessing function in adults with CP.⁶⁵ The most frequently mentioned categories of those with lived experiences were emotional function, pain, muscle tone function, support of family, products and technology, and health services.⁶⁶

While the current interventions focused on body function and structure could not contribute to the development of clinical guidelines,⁶⁴ there is considerable evidence to support the utilization of information from the ICF Core Set as a foundation for the assessment and creation of goal setting and treatment planning for adults with CP.⁶⁵ The ICF Core Set can be used as a framework to develop and guide function-focused, patient-centered care for adults with CP. For example, a functioning profile (Table 2) can be developed using the ICF qualifiers to indicate which body functions and activities and participation categories are impaired and can provide an overview of functioning and identify areas of needed support. Standardized clinical assessments or patient-reported outcome measures that are aligned with the content of ICF Core Sets can help determine how to measure relevant aspects of functioning.⁶⁷ System-level changes¹⁹ with clear care pathways and resources to improve accessibility for adults with CP must be combined with coordinated care and adequate training⁶⁸ to help adult providers meet the needs for effective service delivery of high-quality patient-centered care.

Essential elements of adult care

The musculoskeletal, neurologic, and medical complications along with preventive care measures address the body structures and function domains for adults with CP. The biopsychosocial model also includes contextual domains of environmental and personal factors. Adults with CP and their caregivers voiced a large number of environmental factors such as health system challenges and accessibility issues as priority areas for health service use.¹⁹ Personal factors that facilitated care included caregivers' involvement and barriers included health workers' overall lack of experience with the needs associated with ageing in adults with CP.¹⁹ It is vital to include the perspective of adults with CP to get a complete picture of relevant aspects of their functioning.

Adults with CP experience challenges with health care access due to affordability, transportation issues, or environmental barriers especially for those who use assistive devices.¹⁹ Insurance payments and eligibility for therapy or equipment are also barriers for adults trying to access services. In the private insurance system, therapy interventions require medical justification and can still be limited in total number of visits. In universal health care systems, where therapy services are publicly and charity funded, interventions are based on variable referral streams that can impact eligibility. Regardless of payor source, adults with CP have challenges in finding a therapist with knowledge or expertise in CP or an interest treating adults with CP. A recent study found that only 21% of adults were satisfied with the availability and the quality of therapy services once they were received.¹⁹ To adequately address the therapy needs of adults with CP, an annual physical therapy assessment and person-centered goals for short episodes of therapy should be prescribed.⁶⁷ These treatment plans should address mobility decline, stiffness, pain, and spasticity management which were identified as the most

Table 2

Example of a co-produced care plan for an adult with CP who presents to their Physical Medicine & Rehabilitation clinic for a follow-up visit. Neuro-QOL: Neuro Quality of Life, PROMIS: Patient Reported Outcomes Measurement Information System.

Jamie's Personal Care Plan			
Body Functions/ Structures	Screening/ Evaluation	Frequency	Intervention
Preventive health	Screening with PCP	Annually	
Emotional functions	PROMIS Anxiety-Short Form	Every 3 months	If elevated anxiety, psychology referral
Structure of upper extremity	Neuro-QOL: Upper Extremity Function-Short Form	Annually	Occupational Therapy
Structure of lower extremity	Neuro-QOL: Lower Extremity Function Short Form	Annually	Physical Therapy
Muscle power functions	5 Repetitions Sit to Stand	Every 6 months	Physical Therapy for strengthening program
Muscle tone functions	Modified Ashworth Scale	Every 3 months	Re-adjust tone medications, consider neurotoxin
Activities and Participation	Screening/ Evaluation	Frequency	Intervention
Making decisions	PROMIS Self-Efficacy	Every 6 months	Review medications, how to call pharmacy and make appointments
Carrying out daily routine	PROMIS Self-Efficacy for Managing Daily Activities	Every 6 months	Occupational therapy to help problem solve
Walking	1 Minute Walk Test	Annually	Physical Therapy for strengthening program if needed
Acquiring a job	Vocational Rehab Referral and Follow up	Annually	Vocational Rehab referral Job coaching, Job fairs
Environmental Factors	Screening/ Evaluation	Frequency	Intervention
Products and technology for personal indoor and outdoor mobility	Functional Mobility Assessment	Every 5 years	Wheelchair Clinic referral if needed
Health professionals	Review Medical Team and Providers	Annually	Review personal care plan at next visit
Social security services, systems and policies	Case Manager or Social Work Review	Every 2 years	Case Manager or Social Work referral

common reasons for seeking therapy. Specific therapies may additionally target prevention, plasticity, or participation.⁶⁷ A comprehensive therapy plan of care should combine rehabilitation strategies that address acute needs within ICF domains with effective techniques driven by evidence-based interventions specific to CP when available.^{67,69}

Another identified barrier for adults with CP is related to the lack of appropriately accessible equipment in the health care setting. This includes height-adjustable examination tables or diagnostic equipment, wheelchair-accessible weighing scales, and manual handling equipment for transfers.¹⁹ In addition, several studies highlighted that hospital and physician services lacked accessible examination rooms, accessible toilets, wheelchair-accessible entrances, accessible car parking locations, or had only stair access that further limited accessibility.^{11,19,49} These barriers in the physical environment of the health care system must be addressed when caring for adults with CP. Clinical spaces should allow for ease of access of mobility devices, accommodate appropriate

physical exams with proper tables and equipment, and allow caregivers and staff to assist with transfers and mobility (Fig. 1).

Personal factors, which are defined as the background information about the life and lifestyle of an individual, have not been classified in the ICF but they influence how disability is experienced by individuals.^{70,71} Personal factors are integral in understanding an individual's motivation to participate and their commitment to rehabilitation which are a key tenets in person-centered care.⁷¹ In person-centered care, a coproduced care plan is developed to consider which factors are important and relevant, and this knowledge is used to help adults move forward in the rehabilitation process.⁷¹ This patient-centered approach is relatively unique to adult health care and is not usually found in the pediatric, parent-supervised health care system. Pediatric care is family oriented and relies on significant parental involvement in decision making; however, adult care is patient-specific and requires autonomous, independent skills of patients.⁷² Caring for adults with CP can often combine both of these strategies as caregivers often continue to be involved in the adult's care. The personal factors of self-efficacy, attitudes, expectations, motivation, personality traits, and life goals should be addressed for the person and/or their caregiver.⁷³ This is often done with patient-reported outcomes in the form of Health-Related Quality of Life (HRQOL).

HRQOL focuses on health-related aspects of well-being and includes elements of physical functioning, as well as the person's appraisal of their function's effect on daily life and social functioning. This multidimensional construct is of particular relevance to adults with CP as it takes into account aspects of physical health, emotional status, and cognitive ability.⁴¹

The Short Form-36 Health Survey measures the self-perceived burden of illness and has been shown to be a reliable and valid standardized instrument to assess HRQOL in adult community and chronic disease populations.^{41,74} The questionnaire covers 8 domains: bodily pain, vitality, physical functioning, physical role functioning, emotional role functioning, mental health, social functioning, and general health.

Individuals with CP experienced a lower HRQOL, especially in the domains of motor and social functioning, compared to typically developing individuals.⁷⁴ This deterioration was most evident in the late 20 s-30 s and remained fairly stable over time in a longitudinal cohort of individuals with CP.⁷⁵ This stable pattern of subjective functioning with age suggests that individuals with CP are resilient and may adapt continuously to new life situations as social roles change. Adults with CP are reported to have difficulty engaging socially,⁷⁶ and this should be added as an essential element of adult CP care.

Summary

Adults with CP represent a heterogenous and diverse patient population that deserves unique considerations. A lifespan approach is critical to address evolving concerns during adolescence in an effort to ensure successful transition to the adult health care system, and throughout adulthood. Adults with CP have an increased risk of medical comorbidities, and a creative primary care model may be able to provide needed treatment interventions. Preventive screenings should consider how the physiologic development of individuals with CP affects measurement values and their interpretation. Secondary musculoskeletal complications should be addressed with therapy interventions that promote a holistic approach to care focused on function. Essential elements of care should include contextual factors of the physical environment and personal factors that are unique to adults with CP.

A comprehensive case example

Jamie is a 22-year-old African-American female with CP. She previously had hamstring lengthening surgery as a child and wore ankle braces but has not done so in several years. She uses forearm crutches for short distances and in familiar locations. She uses her power wheelchair for community distances. She has completed high school and has started taking college classes on campus. She lives at home with her parents and

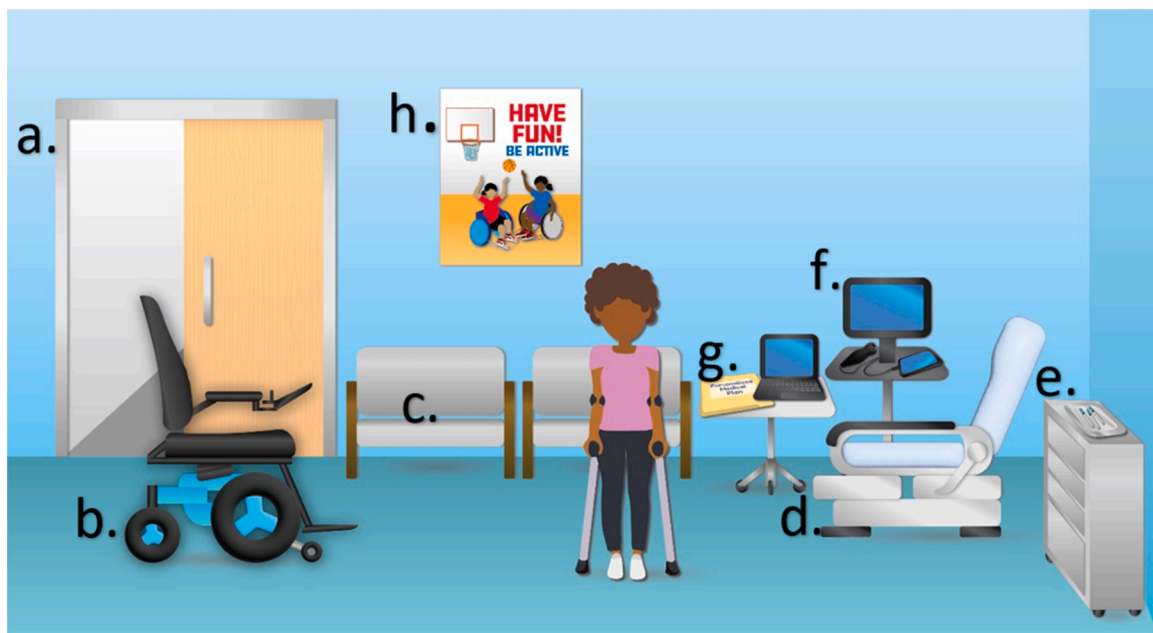


Fig. 1. Essential elements of Adult Cerebral Palsy (CP) Care. A program to meet the needs of adults with CP requires a thoughtfully planned clinical space. The space is easily accessible, with wide doors^a and hallways to accommodate stretchers and large wheelchairs^b. This clinical space accommodates a range of patient mobility and medical equipment. The exam rooms are large enough to easily accommodate a patient's wheelchair to facilitate an inclusive visit, while flexible seating options^c create a welcoming environment that supports additional members, like parents and caregivers. Examination tables^d feature adjustable height and the ability to recline. These features facilitate safe transfers and appropriate physical exams for adults with motor deficits. These examination tables also allow for proper patient positioning during interventional procedures for spasticity management^e to address functional decline. These procedures often require the use of ultrasound, electromyography, and/or electrical stimulation^f. Co-producing an individualized medical plan^g with adults and their caregivers can promote self-advocacy and increase engagement in medical management. Community engagement^h is also crucial to successful programming.

is looking for a part time job. She is anxious about whether her job will be able to accommodate her needs. She does not have any pain and has not had any recent trips or falls. She is presenting for her 3 month follow up visit in the PM&R rehabilitation clinic. Her care plan (Table 2), was co-produced with Jamie and her care team during the visit using a framework based on the ICF Core Set.

Submission declaration and verification

The work described has not been published previously, that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder.

Funding

No funding source was utilized for that submission.

Ethical statement

Studies in humans and animals.

This work did not involve human or animal subjects.

CRedit authorship contribution statement

Sarmiento Cristina: Writing – review & editing, Writing – original draft. **Sanders Jessica:** Writing – review & editing, Writing – original draft. **Wang Lauren:** Writing – review & editing, Writing – original draft. **Fetsko Lauren:** Writing – review & editing, Writing – original draft. **Akamagwuna Unoma:** Writing – review & editing, Writing – original draft. **Clark Jensine:** Writing – review & editing, Writing – original draft, Visualization, Conceptualization.

Declaration of Generative AI and AI-assisted technologies in the writing process

No AI was used in the writing process for this work.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

No data was used for the research described in the article.

References

- Michael-Asalu A, Taylor G, Campbell H, Lelea LL, Kirby RS. Cerebral palsy: diagnosis, epidemiology, genetics, and clinical update. *Adv Pediatr*. 2019;66:189–208. <https://doi.org/10.1016/j.yapd.2019.04.002>.
- Strauss D, Brooks J, Rosenbloom L, Shavelle R. Life expectancy in cerebral palsy: an update. *Dev Med Child Neurol*. 2008;50(7):487–493.
- Strauss D, Shavelle R, Reynolds R, Rosenbloom L, Day S. Survival in cerebral palsy in the last 20 years: signs of improvement? *Dev Med Child Neurol*. 2007;49(2):86–92.
- Brooks JC, Strauss DJ, Shavelle RM, Tran LM, Rosenbloom L, Wu YW. Recent trends in cerebral palsy survival. Part II: individual survival prognosis. *Dev Med Child Neurol*. 2014;56(11):1065–1071. <https://doi.org/10.1111/dmcn.12519>.
- Rapp JrCE, Torres MM. The adult with cerebral palsy. *Arch Fam Med*. 2000;9(5):466.
- Peterson MD, Hurvitz EA. Cerebral palsy grows up. *Elsevier*. 2021;1404–1406.
- Amankwah N, Oskoui M, Garner R, et al. Cerebral palsy in Canada, 2011–2031: results of a microsimulation modelling study of epidemiological and cost impacts. *Health Promot Chronic Dis Prev Can*. 2020;40(2):25–37.
- Lungu C, Hirtz D, Damiano D, Gross P, Mink JW. Report of a workshop on research gaps in the treatment of cerebral palsy. *Neurology*. 2016;87(12):1293–1298.
- Wu YW, Mehravari AS, Numis AL, Gross P. Cerebral palsy research funding from the National Institutes of Health, 2001 to 2013. *Dev Med Child Neurol*. 2015;57(10):936–941. <https://doi.org/10.1111/dmcn.12789>.
- Australia C.P. The economic impact of cerebral palsy in Australia in 2007. *Access Economics Pty Ltd*. 2008:74.
- Hurvitz EA, Whitney DG, Waldron-Perrine B, et al. Navigating the pathway to care in adults with cerebral palsy. *Front Neurol*. 2021;12, 734139. <https://doi.org/10.3389/fneur.2021.734139>.
- Jonsson U, Eek MN, Sunnerhagen KS, et al. Cerebral palsy prevalence, subtypes, and associated impairments: a population-based comparison study of adults and children. *Dev Med Child Neurol*. 2019;61:1162–1167.
- Goldsmith S, McIntyre S, Smithers-Sheedy H, et al. An international survey of cerebral palsy registers and surveillance systems (and) *Dev Med Child Neurol*. 2016; 58:11–17. <https://doi.org/10.1111/dmcn.12999>.
- Alriksson-Schmidt A, Hägglund G, Rodby-Bousquet E, Westbom L. Follow-up of individuals with cerebral palsy through the transition years and description of adult life: The Swedish experience. *J Rehabil Rehabil Med*. 2014;7:53–61.
- Noritz G, Davidson L, Steingass K, et al. Providing a primary care medical home for children and youth with cerebral palsy. *Pediatrics*. 2022;150(6). <https://doi.org/10.1542/peds.2022-060055>.
- Novak I, McIntyre S, Morgan C, et al. A systematic review of interventions for children with cerebral palsy: State of the evidence. *Dev Med Child Neurol*. 2013;55(10):885–910. <https://doi.org/10.1111/dmcn.12246>.
- Novak I, Morgan C, Fahey M, et al. State of the evidence traffic lights 2019: systematic review of interventions for preventing and treating children with cerebral palsy. *Curr Neurol Neurosci Rep*. 2020;20(2). <https://doi.org/10.1007/s11910-020-1022-z>.
- Iezzoni LI, Rao SR, Ressleram J, et al. Physicians' perceptions of people with disability and their health care. *Health Aff*. 2021;40(2):297–306. <https://doi.org/10.1377/hlthaff.2020.01452>.
- Manikandan M, Kerr C, Lavelle G, Walsh M, Walsh A, Ryan JM. Health service use among adults with cerebral palsy: a mixed-methods systematic review. *Dev Med Child Neurol*. 2022;64:429–446.
- Bagatell N, Chan D, Rauch KK, Thorpe D. Thrust into adulthood": transition experiences of young adults with cerebral palsy. *Disabil Health J*. 2017;10(1):80–86. <https://doi.org/10.1016/j.dhjo.2016.09.008>.
- White PH, Cooley WC, Boudreau ADA, Cyr M, Davis BE, Dreyfus DE, AMERICAN ACADEMY OF FAMILY PHYSICIANS. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5). <https://www.gottransition.org/six-core-elements/>.
- Brandon Erin, Ballantyne Marilyn, Penner Melanie, Lauzon Andrea, McCarvill Erin. Accessing primary health care services for transition-aged young adults with cerebral palsy; perspectives of young adults, parents, and physicians. *J Transit Med*. 2019;vol. 1(1):20190004. <https://doi.org/10.1515/jtm-2019-0004>.
- <https://www.aahrq.gov/ncepcpr/research/care-coordination/pcmh/define.html>.
- Smith, J., Hand B., Johnson E., Keeton C., Wang L., Freeman Center for intellectual and developmental disabilities: Patient-centered interdisciplinary care. *Health Care Transitions*, Volume 1, 2023, 100003, ISSN 2949–9232, <https://doi.org/10.1016/j.hctj.2023.100003>.
- <https://www.census.gov/library/stories/2023/06/disability-rates-higher-in-rural-areas-than-urban-areas>.
- Smith SE, Gannotti M, Hurvitz EA, et al. Adults with cerebral palsy require ongoing neurologic care: a systematic review. *Ann Neurol*. 2021;89(5):860–871. <https://doi.org/10.1002/ana.26040>.
- van der Slot WMA, Benner JL, Brunton L, et al. Pain in adults with cerebral palsy: a systematic review and meta-analysis of individual participant data. /05/01/ 2021 *Ann Phys Rehabil Med*. 2021;64(3), 101359. <https://doi.org/10.1016/j.rehab.2019.12.011>.
- Cremer N, Hurvitz EA, Peterson MD. Multimorbidity in middle-aged adults with cerebral palsy. *Am J Med*. 2017;130(6), 744. e9-744. e15.
- Peterson MD, Ryan JM, Hurvitz EA, Mahmoudi E. Chronic conditions in adults with cerebral palsy. *JAMA*. 2015;314(21):2303–2305.
- Peterson MD, Lin P, Kamdar N, Hurvitz EA, Mahmoudi E. Psychological, cardiometabolic, and musculoskeletal morbidity and multimorbidity among adults with cerebral palsy and spina bifida: a retrospective cross-sectional study. *Am J Phys Med Rehabil*. 2021;100(10):940–945.
- Smith KJ, Peterson MD, O'Connell NE, et al. Risk of depression and anxiety in adults with cerebral palsy. *JAMA Neurol*. 2019;76(3):294–300.
- Whitney DG, Rabideau ML, Mckee M, Hurvitz EA. Preventive care for adults with cerebral palsy and other neurodevelopmental disabilities: are we missing the point? *Front Integ Neurosci*. 2022;16, 866765.
- Whitney DG, Schmidt M, Haapala H, Ryan D, Hurvitz EA, Peterson MD. Timecourse of morbidity onset among adults living with cerebral palsy. *Am J Prev Med*. 2021;61:37–43.
- Ryan JM, Peterson MD, Ryan N, et al. Mortality due to cardiovascular disease, respiratory disease, and cancer in adults with cerebral palsy. *Dev Med Child Neurol*. 2019;61(8):924–928. <https://doi.org/10.1111/dmcn.14176>.
- Ryan JM, Allen E, Gormley J, Hurvitz EA, Peterson MD. The risk, burden, and management of non-communicable diseases in cerebral palsy: a scoping review. *Dev Med Child Neurol*. 2018;60:753–764.
- Powell-Wiley TM, Poirier P, Burke LE, et al. Obesity and cardiovascular disease a scientific statement from the American Heart Association. *Circ (N Y, N Y)*. 2021; 143:E984–E1010.
- <https://www.cdc.gov/healthyweight/assessing/bmi/index.html>.
- Turk MA. Health, mortality, and wellness issues in adults with cerebral palsy. *Dev Med Child Neurol*. 2009;51:24–29.

40. Benner JL, Hilberink SR, Veenis T, Stam HJ, van der Slot WM, Roebroek ME. Long-term deterioration of perceived health and functioning in adults with cerebral palsy. *Arch Phys Med Rehabil.* 2017;98(11):2196–2205. e1.
41. Morgan PE, Soh S-E, McGinley JL. Health-related quality of life of ambulant adults with cerebral palsy and its association with falls and mobility decline: a preliminary cross sectional study. *Health Qual Life Outcomes.* 2014;12(1):1–10.
42. Opheim A, Jahnsen R, Olsson E, Stanghelle JK. Walking function, pain, and fatigue in adults with cerebral palsy: a 7-year follow-up study. *Dev Med Child Neurol.* 2009;51(5):381–388.
43. Turk MA. Health, mortality, and wellness issues in adults with cerebral palsy. *Dev Med Child Neurol.* 2009;51:24–29. <https://doi.org/10.1111/j.1469-8749.2009.03429.x>.
44. Gajdosik CG, Cicirello N. Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. *Phys Occup Ther Pediatr.* 2002;21(4):49–68. DOI:10.1080/J006v21n04_04.
45. Cassidy C, Campbell N, Madady M, Payne P. Bridging the gap: the role of physiatrists in caring for adults with cerebral palsy. *Disabil Rehabil.* 2016;38(5):493–498. DOI: 10.3109/09638288.2015.1044031.
46. Haak P, Lenski M, Hidecker MJ, Li M, Paneth N. Cerebral palsy and aging. *Dev Med Child Neurol.* 2009;51(Suppl 4(0 4)):16–23. <https://doi.org/10.1111/j.1469-8749.2009.03428.x>.
47. Peterson M, Gordon P, Hurvitz E. Chronic disease risk among adults with cerebral palsy: the role of premature sarcopenia, obesity and sedentary behaviour. *Obes Rev.* 2013;14(2):171–182.
48. Peterson MD, Hurvitz EA, Burant CF. Secondary muscle pathology and metabolic dysregulation in adults with cerebral palsy. *Am J Physiol-Endocrinol Metab.* 2012;303(9):E1085–E1093.
49. Peterson MD, Hurvitz EA. Cerebral palsy grows up. *Elsevier.* 2021;1404–1406.
50. Peterson MD, Lin P, Kamdar N, et al. Cardiometabolic morbidity in adults with cerebral palsy and spina bifida. *Am J Med.* 2020;133(12):e695–e705.
51. Murphy KP. Cerebral palsy lifetime care—four musculoskeletal conditions. *Dev Med Child Neurol.* 2009;51:30–37.
52. Lungu C, Hirtz D, Damiano D, Gross P, Mink JW. Report of a workshop on research gaps in the treatment of cerebral palsy. *Neurology.* 2016;87(12):1293–1298.
53. Gross PH, Bailes AF, Horn SD, et al. Setting a patient-centered research agenda for cerebral palsy: a participatory action research initiative. *Dev Med Child Neurol.* 2018;60(12):1278–1284.
54. Reid SM, Meehan EM, Arnup SJ, Reddihough DS. Intellectual disability in cerebral palsy: a population-based retrospective study. *Dev Med Child Neurol.* 2018;60(7):687–694.
55. Individuals with Disabilities Education Act; 20 USC; United States Code Annotated, Title 20. Education, Chapter 33
56. McGovern E, Pringsheim T, Medina A, et al. Transitional care for young people with neurological disorders: a scoping review with a focus on patients with movement disorders (and) *Mov Disord.* 2021;36:1316–1324. <https://doi.org/10.1002/mds.28381>.
57. Friedman C. Stakeholders' home and community based services settings rule knowledge. *Res Pract Pers Sev Disabil.* 2018;43(1):54–61. <https://doi.org/10.1177/1540796917743210>.
58. Residential Information Systems Project (2022). Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: (<https://risp.umn.edu>).
59. Residential Information Systems Project. (2022). *Living Arrangements of LTSS Recipients by Fiscal Year Over Time.* University of Minnesota. (<https://risp.umn.edu/viz/living-arrangements/living-arrangements-of-ltss-recipients-by-fiscal-year-over-time>).
60. (<https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-%E2%80%93-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf>).
61. Videlefsky A.S., Reznik J.M., Nodvin J.T., Heiman H.J. Addressing Health Disparities in Adults with Developmental Disabilities. *Ethn Dis.* 2019 Jun 13;29 (Suppl 2):355–358. doi: 10.18865/ed.29.S2.355. PMID: 31308605; PMCID: PMC6604783.
62. Bobbette N, Ouellette-Kuntz H, Tranmer J, Lysaght R, Uffholz LA, Donnelly C. Adults with intellectual and developmental disabilities and interprofessional, team-based primary health care: a scoping review (Jul) *JBI Evid Synth.* 2020;18(7):1470–1514. <https://doi.org/10.11124/JBISRIR-D-19-00200>. PMID: 32813389..
63. Sanders JS, Mabry M, Scarbro S, Filley CM. New frontier: the first year of an adult neurodevelopmental disabilities clinic. *Cogn Behav Neurol.* 2023. <https://doi.org/10.1097/WNN.0000000000000362>. Epub ahead of print. PMID: 38063505.
64. Damiano DL, Longo E, Carolina de Campos A, Forsberg H, Rauch A. Systematic review of clinical guidelines related to care of individuals with cerebral palsy as part of the World Health Organization efforts to develop a global package of interventions for rehabilitation. *Arch Phys Med Rehabil.* 2021;102:1764–1774.
65. Noten S, Selb M, Troenosemito LAA, et al. ICF core sets for the assessment of functioning of adults with cerebral palsy (and) *Dev Med Child Neurol.* 2022;64: 569–577. (<https://doi-org.uc.idm.oclc.org/10.1111/dmcn.15104>).
66. Noten S, Troenosemito LAA, Limsakul C, et al. Development of an ICF core set for adults with cerebral palsy: capturing their perspective on functioning. *Dev Med Child Neurol.* 2021;63:846–852.
67. Gannotti M, Frumberg D. *Clinical therapy services for adults with cerebral palsy: Optimizing health and well being across the lifespan.* Cerebral Palsy. Cham: Springer International Publishing.; 2020:2519–2541.
68. Brandenburg JE. Health care for adults with cerebral palsy and spina bifida—must it be so difficult? *Mayo Clin Proc.* 2022;97:2186–2188.
69. Lawrence H, Hills S, Kline N, Weems K, Doty A. Effectiveness of exercise on functional mobility in adults with cerebral palsy: a systematic review. *Physiother Can.* 2016;68(4):398–407.
70. (https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf).
71. Karhula M, Saukkonen S, Xiong E, Kinnunen A, Heiskanen T, Anttila H. ICF personal factors strengthen commitment to person-centered rehabilitation – a scoping review. *Front Rehabil Sci.* 2021;2, 709682-709682.
72. Castillo C, Kitsos E. Transitions from pediatric to adult care. *Glob Pediatr Health.* 2017;4, 2333794X17744946-2333794X17744946.
73. Geyh S, Schwegler U, Peter C, Müller R. Representing and organizing information to describe the lived experience of health from a personal factors perspective in the light of the international classification of functioning, disability and health (ICF): a discussion paper. *Disabil Rehabil.* 2019;41:1727–1738. <https://doi.org/10.1080/09638288.2018.1445302>.
74. Tan PhD SS, van Meeteren PhD J, Ketelaar PhD M, et al. Long-term trajectories of health-related quality of life in individuals with cerebral palsy: a multicenter longitudinal study. *Arch Phys Med Rehabil.* 2014;95:2029–2039.
75. Yi YG, Jung SH, Bang MS. Emerging issues in cerebral palsy associated with aging: a physiatrist perspective. *Ann Rehabil Med.* 2019;43(3):241–249. <https://doi.org/10.5535/arm.2019.43.3.241>. Epub 2019 Jun 28. PMID: 31311245; PMCID: PMC6637058.
76. van der Slot WM, Nieuwenhuijsen C, van den BergEmons RJ, et al. Participation and health-related quality of life in adults with spastic bilateral cerebral palsy and the role of self-efficacy. *J Rehabil Med.* 2010;42:528–535.