

A Lifecourse Approach in Cerebral Palsy: The ICF Perspective

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International Alliance
of Academies of
Childhood Disability

Lifecourse Health Development Concept

- Health development occurs through person–environment interactions that enable well-being and participation in desired social roles throughout life.
 - The environment includes physical, family, social, educational and cultural environments
- Neurodevelopmental disabilities often disrupt these interactions due to biomedical, environmental or personal barriers

Lifecourse Health Development

- Emphasizes the importance of early relationships and the unique aspects of different life stages
- Pathways of social and cultural factors that provide a “social scaffolding” tend to direct health development towards predictable [positive] outcomes
- Aims to foster experiences that promote resilience and plasticity within changing environmental contexts
- Various known environment factors can alter the life course trajectory

Halfon N, et al. Lifecourse Health Development: Past, Present and Future. *Matern Child Health J.* 2014 Feb;18(2):344–65.



“So, how do you want to play this?
Nature, nurture, or a bit of both?”

The Challenge in Cerebral Palsy

- Cerebral palsy is viewed as a pediatric specialty
- Coordinated care systems typically end at age 18 or 21, if they are present at all
- Children, parents and sometimes medical teams are not prepared for the changes with growth and age
- Few practitioners are trained to provide care to adults with CP



“The child with cerebral palsy will become the adolescent and then adult with cerebral palsy”



Promoting Lifecourse Health Development

Address healthy living across the lifecourse

- Provide the child and adolescent with the tools to optimize their health outcome – whatever and whenever possible
- Use strength-based and ability-focused language
- Address physical activity and prevention of secondary impairments

Focus on contexts of healthy living

- Be flexible and open to different ways to think about services and supports
- Consider child and family context during goal setting and treatment planning

Palisano RJ, et al. Promoting capacities for future adult roles and healthy living using a lifecourse health development approach. *Disabil Rehabil.* 2019 Jan 8;1–10.

Promoting Lifecourse Health Development

Focus on everyday experiences and experiential learning

- Don't assume what a child or youth can or cannot do
- Encourage social participation and experiences in multiple contexts throughout the day
- Collaborate with the child or adolescent and family to identify desired home and community participation

Pay attention to the timing of opportunities and experiences

- Consider timing of interventions, assistive technology and environmental modifications to correspond with readiness

Palisano RJ, et al. Promoting capacities for future adult roles and healthy living using a lifecourse health development approach. *Disabil Rehabil.* 2019 Jan 8;1–10.

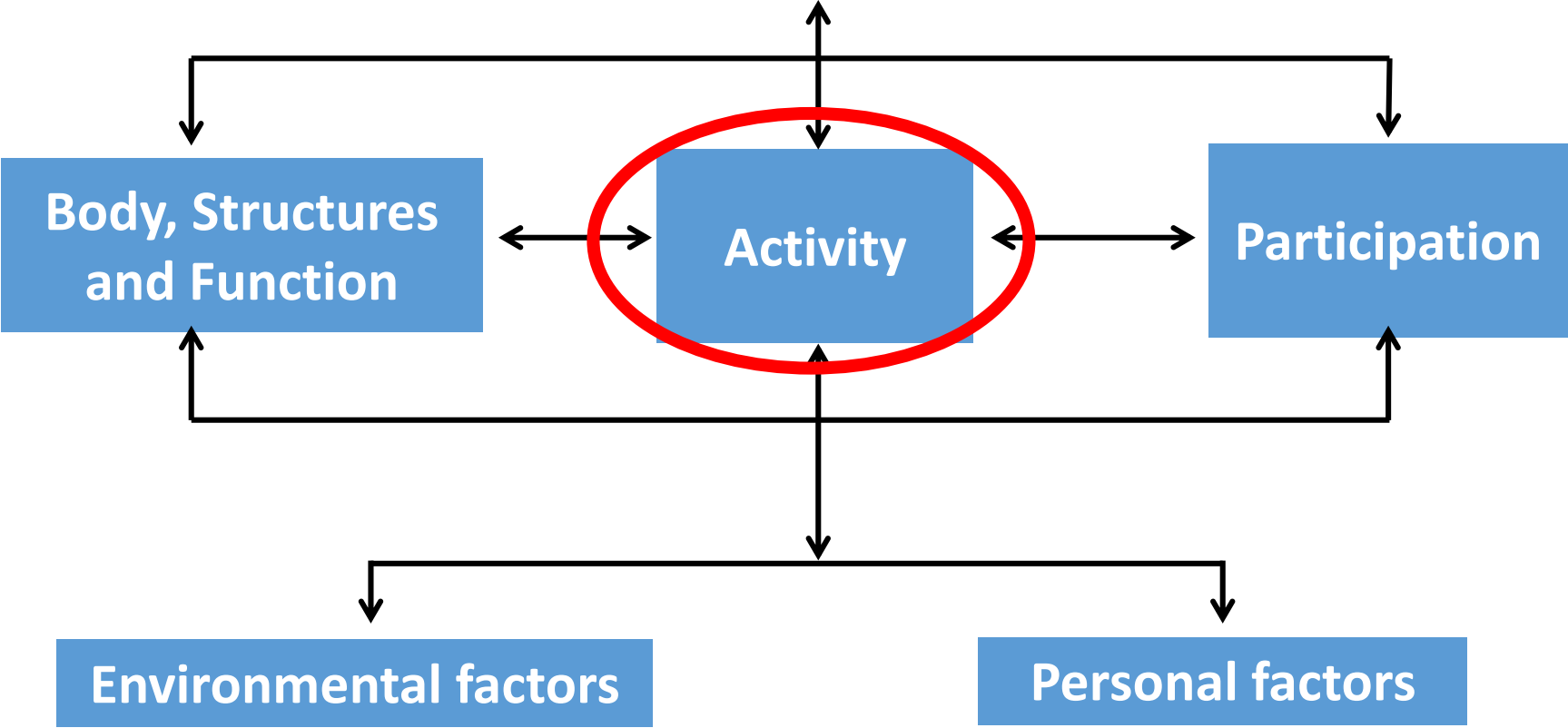
Facilitating Lifecourse Development

- “How do you see yourself in the future?”
- “What’s going well?”
- “What’s challenging?”
- “Is there something you would like to do or are expected to do but have not had an opportunity to try or it is difficult?”

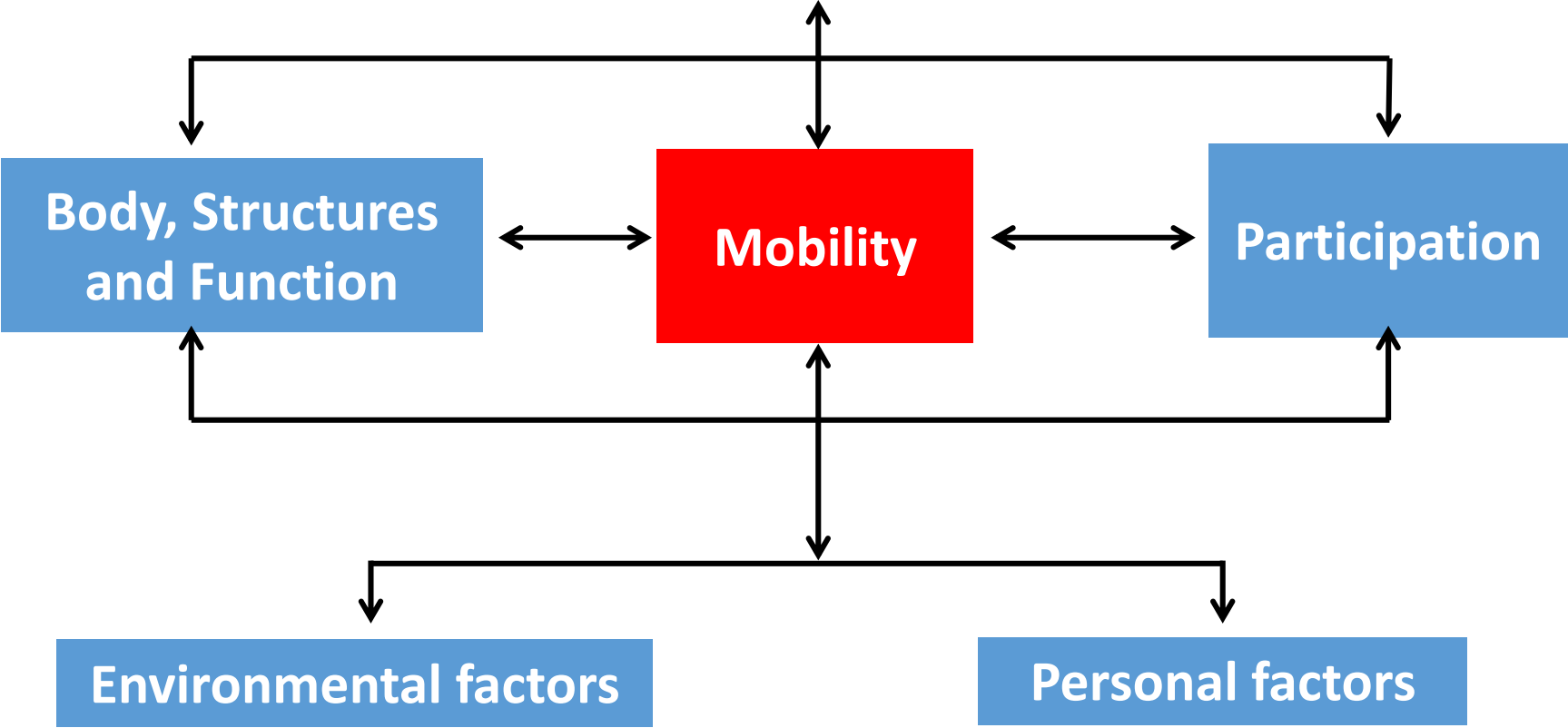


Palisano RJ, et al. Promoting capacities for future adult roles and healthy living using a lifecourse health development approach. *Disabil Rehabil.* 2019 Jan 8;1–10.

Cerebral Palsy



Cerebral Palsy



Mobility in Children with Cerebral Palsy

- Children interact with their environment for social, emotional and physical development
- Independent mobility can foster curiosity and promote overall development, including cognitive development in young children
- Children as young as 2 years old are capable of operating a power wheelchair
- In older children and adolescents, independent mobility can enhance participation at home, school and in the community



Mobility in Adolescents with Cerebral Palsy

- Mobility is important for self-sufficiency
- Adolescents make choices – walking with or without assistive device, manual or power wheelchair – depending on the environment
- Adolescents need to constantly adapt and make choices to new situations
- Safety and efficiency are important aspects in their choices
 - Carrying objects
 - Crowds
 - Terrain
 - Weather
 - Time and distance

Palisano RJ, et al. Experiences of Adolescents with Cerebral Palsy. *Phys Occup Ther Pediatr*. 2009 Jan;29(2):133–53

Mobility and Adults with Cerebral Palsy

- Declines in physical function may begin in 20s and 30s ([Day 2007](#), [Hilberink 2007](#))
- Higher incidence of pain and fatigue than general population ([Jahnsen 2003, 2004](#))
- Bilateral CP have more loss of mobility than unilateral CP ([Opheim 2009](#))
- Lower level of mobility associated with osteopenia and osteoporosis ([Fowler 2015](#))
- Adults with CP who lost walking ability commented that earlier access to a wheelchair may have prolonged their limited walking ability and reduced their stress ([Bottos 2001](#))

Mobility

- *Mobility* is moving within one's environment to get from one place to another
- **Why?**
- **Where?**
- **Why?**





Lifecourse Approach to Mobility in CP

Four different ages

- Infant and toddler
- School age
- Adolescent
- Adult

Consider

The participation and personal factors (WHY) and the environmental factors (WHERE) that may affect the type of mobility (HOW) that is best for the person

- Questions you will ask the parent, child or adult
- When to ask
- How the responses will guide you
- Be flexible

Clinical Example – TJ Age 1

Born premature with PVL and delayed in all milestones. Appears alert and engaged. Needs support to sit. Just starting to roll over; attempts belly crawling

- GMFCS?
- Participation?
- Environment?
- Questions for parents?
- How will the responses will guide you?



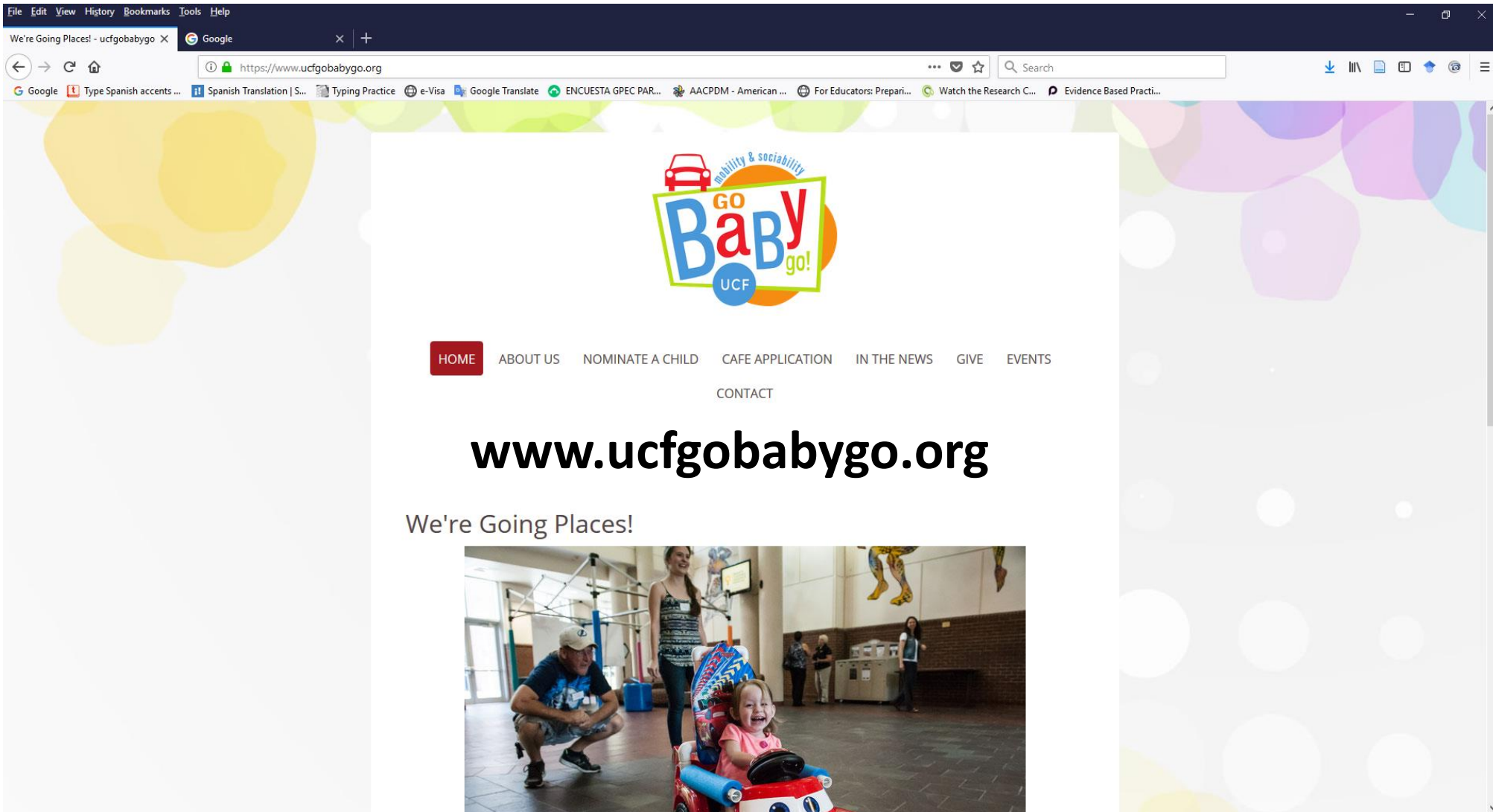
Clinical Example – TJ Age 3

Now combat crawling. Starting to “bunny hop” crawl. Can pull himself to stand but cannot stand alone. Taken one or two steps with support and encouragement.

Body, structure and function: developing some spasticity (MAS 1+/2 in legs); some trunk weakness, full passive ROM

- GMFCS?
- Participation?
- Environment?
- Questions for parents?
- How will the responses will guide you?





Walking Through the Lifespan with CP

- Energy cost of walking increases with GMFCS level and age ([Johnson, 2004](#))
- GMFM and PEDI scores improve from young child to teen years, but energy cost of walking increases over the same time ([Kerr, 2010](#))
- In adolescence, increased hip and knee flexion during stance is associated with decreased efficiency of walking ([Noorkoiv, 2019](#))
- Adults with CP have lower aerobic capacity (VO_2 Max) and higher energy cost walking than unaffected adults ([Slaman, 2013](#))

Clinical Example – TJ Age 9

Had tendon lengthening (hamstrings), gastrocnemius recessions and femoral varus osteotomies to prevent subluxation 10 months ago. Walking with walker in home and is pushed in wheelchair at school.

- Participation?
- Environment?
- Questions for parents?
- Questions for TJ?
- How will the responses will guide you?



TJ Age 14



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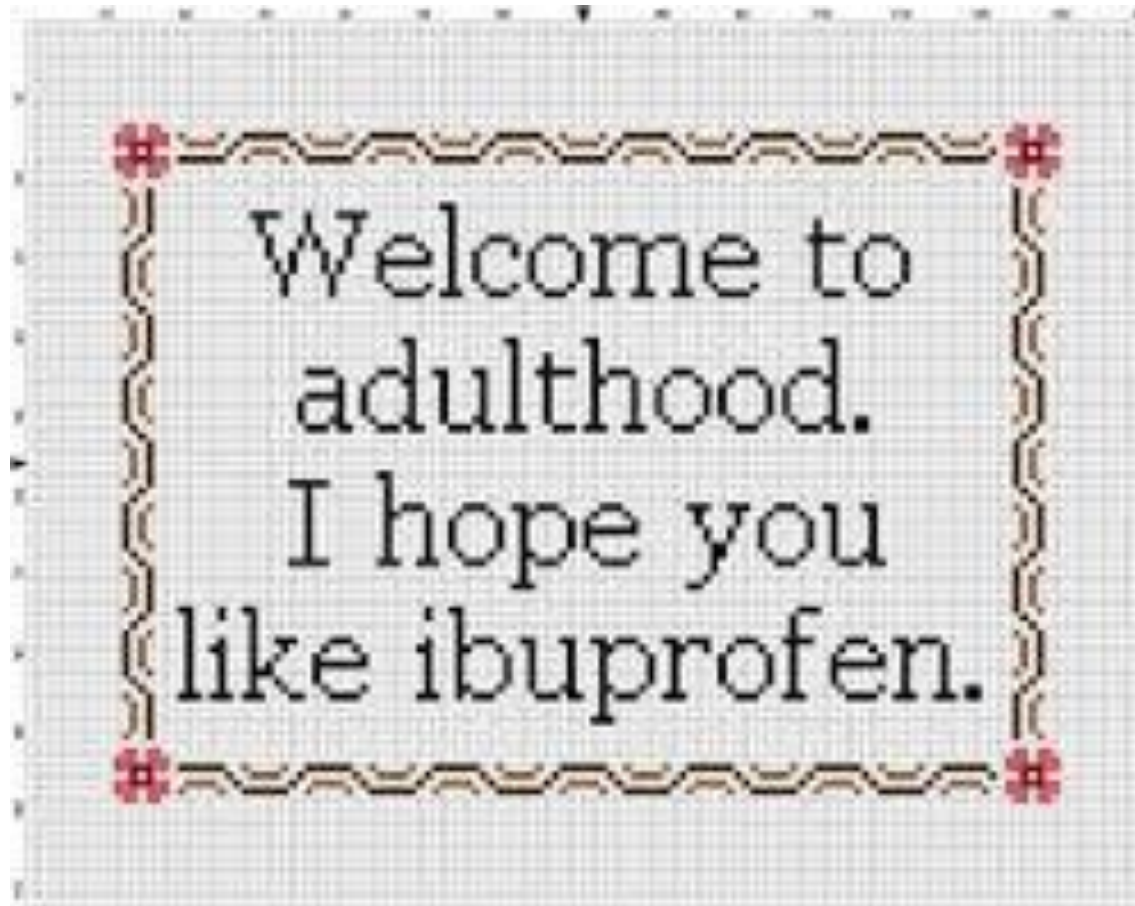
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Mobility for TJ – Age 14

- “How do you see yourself in the future?”
- “What’s going well?”
- “What’s challenging?”
- “Is there something you would like to do or are expected to do but have not had an opportunity to try or it is difficult?”
- “What’s your school environment like?”
- “What’s your social environment like?”
- “Do you participate in physical activity, fitness or exercise?”

Mobility for TJ as an Adolescent



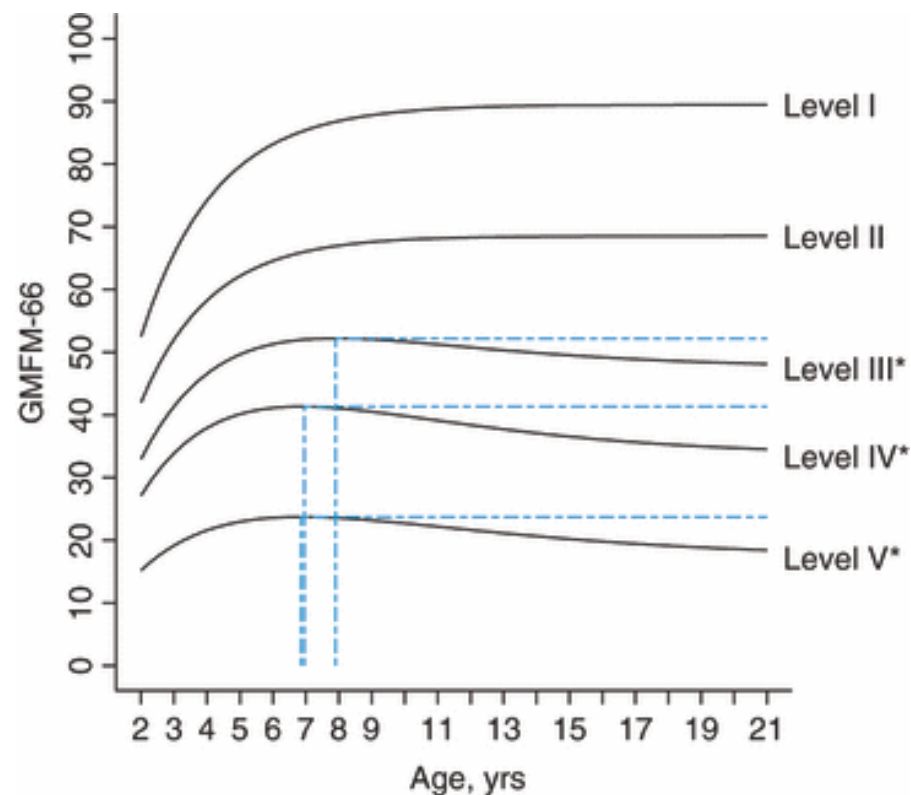


Health Issues in Adults with Cerebral Palsy

- Lower levels of fitness and physical activity ([Rimmer 2001](#))
- High rates of diabetes mellitus, high cholesterol, hypertension and atherosclerosis, obesity ([Peterson 2018](#))
- Higher risk of stroke, COPD, ischemic heart disease ([Ryan 2018](#))
- Higher rates of depression in diplegic cerebral palsy ([Van de Slot 2012](#))
- Lower health-related QoL ([Usuba 2014](#)) which may be associated with falls ([Morgan 2014](#))
- Lower global QoL – physical health, psychological, social relationship ([Roebroeck 2009](#))

GMFCS and Adults with Cerebral Palsy

- Validated up to age 18
- No other tool to characterize mobility in adults with CP
- Influence of environment and personal factors
- Documented decline with aging



Hanna SE et al. Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 years. *Dev Med Child Neurol*. 2009 Apr;51(4):295–302.

Musculoskeletal Problems in Adults with CP

Patella alta

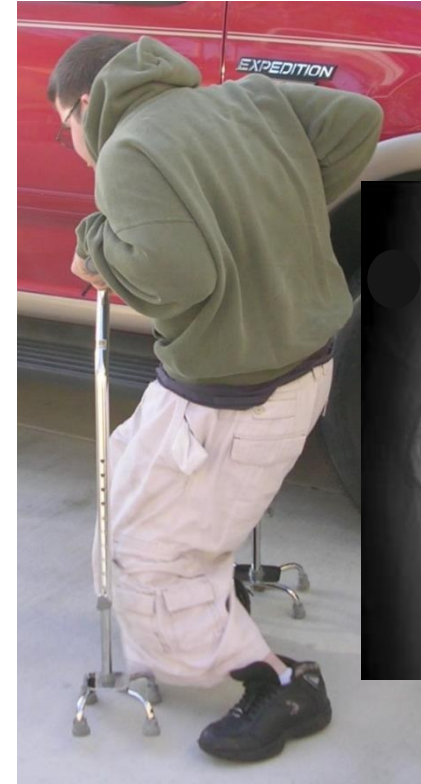
- Ambulatory, diplegia

Hip dysplasia

- Higher rate of dislocation in quadriplegia
- Severity of radiograph not predictor of pain

Hip osteoarthritis

- Higher rate in diplegia, ambulatory



Musculoskeletal Problems in Adults with CP

Spondylolysis/spondylolisthesis

- Diplegia, ambulatory and dystonia



Cervical stenosis

- Quadriplegia, dystonia, choreo-athetosis



FACT SHEET

Walking Changes and Associated Implications across the Lifespan for Individuals with Cerebral Palsy

American Academy
for Cerebral Palsy and
Developmental Medicine



www.aacpdm.org/publications/fact-sheets

FACT SHEET

Care of Adults with Cerebral Palsy

FACT SHEET

Adults with Cerebral Palsy: Do you have spinal cord complications?

American Academy
for Cerebral Palsy and
Developmental Medicine



Mobility for TJ as an Adult

- Address physical activity and prevention of secondary impairments
- “What are you doing for regular physical fitness or exercise?”
- “What’s going well?”
- “What’s challenging?”
- “Has anything changed lately?”
- “What’s your work environment like?”
- “What’s your home environment like?”

Mobility for TJ as an Adult



Summary

- Lifecourse health development is about recognizing the person-environment interactions that enable well-being and participation in desired social roles throughout life
- It is best achieved through an knowledgeable and committed multi-disciplinary team



What Can We Do About It?

Anticipate likely biological, environmental and societal changes

- Address physical activity and prevent secondary impairments
- Prepare and empower families and caregivers

Plan careful transition from childhood to adulthood

- Introduce adolescent and family to new service providers

Educate and advocate

- Teachers, institutions and policy makers
- Support an advocacy framework

www.yourcpf.org

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