

FACT SHEET



PEDIATRICS

AMERICAN PHYSICAL THERAPY ASSOCIATION

Section on Pediatrics, APTA

1111 North Fairfax Street
Alexandria, VA 22314-1488

Phone 800/999-2782, ext 3254
E-mail: peditrics@apta.org

www.pediatricapta.org



American Physical Therapy Association

Adolescents and Adults With Developmental Disabilities (AADD): Health Issues

Special-Interest Group

Overview

The life expectancy of children with intellectual and/or developmental disabilities (I/DD) such as cerebral palsy, spina bifida, and other neuro-developmental disabilities has improved dramatically over the last 30 years.¹ The majority of children with I/DD survive well into adulthood, and the number of adults with I/DD is growing at a rapid rate. Although many diagnoses are “static” or “nonprogressive,” adults with I/DD experience increased risk for health issues as compared to adults without I/DD.^{2,3}

Health Issues

Adults with I/DD may face health issues as early as their second decade due to the phenomenon described as “pre-mature” or “early-onset of aging.”^{4,5} Areas of potential health and wellness issues include, but are not limited to: (1) musculoskeletal or orthopedic, (2) metabolic or endocrine, (3) nutritional intake and elimination, (4) genitourinary, (5) subjective complaints of fatigue and difficulty with sleep, and (6) psychosocial adaptation.⁶ Possible problems related to each category are described below:

1. The presence of musculoskeletal or orthopedic problems can be a catalyst for other problems. Musculoskeletal problems may include:
 - Musculoskeletal deformities⁷: patella alta, hip dislocation, spondylolysis, cervical stenosis, scoliosis, foot deformities, compounded by osteoporosis
 - Osteoporosis/osteopenia^{3,8}: inactivity results in underdevelopment of appropriate bone mineral density in early childhood, medication interactions and side effects, and hypogonadism
 - Pain^{9,10}: secondary to osteoarthritis in the back, hips, upper and lower extremities related to overuse, and/or prolonged abnormal joint movement
 - Changes in spasticity or spasm¹¹
2. Metabolic or endocrine issues such as early onset (second or third decade) “metabolic syndrome,”⁴ as well as early onset diabetes, coronary artery disease, and high cholesterol. Risk factors may include:
 - Lack of muscle mass and high ratio of adipose tissue to muscle⁴
 - Poor dental health (compounded by seizure medications),^{3,12} which increases risk for cardiac conditions
3. Nutritional intake and elimination problems:
 - Poor hydration and nutrition
 - Compounded by lack of physical activity, gastro-esophageal reflux, and bladder and bowel control^{3,13,14}
 - Lack of accessible scales. Weight changes may be precursors of a health crisis¹⁵
4. Genitourinary problems from childhood may be exacerbated or new ones may arise:
 - Bladder and bowel incontinence may be exacerbated by early onset aging and compounded by changes in muscle tone, deformity, and loss of muscle strength^{2,3,14}
 - Lack of regular preventative and primary care leads to reduced frequency of screening for common cancers related to the genitourinary system (colon, breast, and prostate)¹⁶
5. Perceived chronic fatigue due to the level of exertion necessary to perform daily activities; this may be compounded by:
 - Decreased muscle mass and force production⁴
 - Decline in functional status:¹⁷ secondary to pain, fatigue, deconditioning, and lack of muscular development from early infancy through adolescence
 - Poor ability to sleep (influenced by pain and reflux)

6. Challenges with psychosocial adaptation that are compounded by:
- Lack of social interaction
 - Challenges with successful employment¹⁸
 - Lack of independent living¹ opportunities
 - Risk for depression and substance abuse¹⁹

Social Barriers to Care

In addition to underutilizing ancillary allied health services such as physical and occupational therapy, adults with I/DD as a group underutilize primary care and preventative health services.¹⁶ Several factors contribute to underutilization of services. Adults with I/DD may have difficulty locating providers who provide person-centered care, who are sensitive to the rights and dignity of people with I/DD, and who provide evidence-based care.¹⁶ Many physicians do not have training in caring for people with disabilities and are unwilling or unable to spend the extra time required. Extra time may be needed to deal with issues such as reliable/affordable transportation, finding ways to negotiate physical barriers such as small doorways or adjustable examining tables, and physical assistance or devices needed for lifting and weighing people who are nonambulatory.¹⁶ Additionally, speech or other communication difficulties can make diagnosis and treatment even more challenging and further increase the amount of time health care professionals must take with appointments.²⁰

Exercise as a Treatment

Adults with I/DD are at risk for lack of physical activity.^{21,22} Coinciding with the use of exercise to promote health and wellness and minimize secondary conditions,^{21,22} community-based exercise has been shown to increase motivation and provide opportunities for social interaction.²¹ Physical therapists are uniquely qualified to assist adults with I/DD in meeting goals for health and wellness.

Role of the Physical Therapist

Physical therapists can assist adults with I/DD in meeting health goals while utilizing the following resources and methods:

- Safe physical exercise programs:
 - Physical therapists can design and implement safe exercise programs to enhance health, increase vitality, and assist with pain management by targeting weight management, bone health, increasing muscle mass, or cardiovascular fitness.^{21,23,24}
 - Aquatics,²⁵ resistance training or power training in available active range,^{26,27} whole body vibration,²⁸ upper extremity ergometer,²⁹ active assist cycling,^{30,31} virtual reality games,³² and elliptical training³³ demonstrate promise as exercise options.
- Identifying community resources:
 - Community gyms that have personal trainers or equipment accessible for people with disabilities
 - Consultation with vocational services or employers to optimize health
 - Advocacy for accessible recreational and outdoor opportunities for individuals with I/DD
- Adaptive equipment and positioning:
 - Physical therapists can consult with community organizations and primary care providers concerning equipment to support full participation.
 - Physical therapists can assist with identifying proper positioning and equipment to enhance comfort for sleeping in the home.

Lauren is a 27-year-old woman with spastic quadriplegic cerebral palsy who uses a power chair as her primary means of mobility. She is concerned about increasing her physical fitness (cardiovascular, bone, and muscle mass) and minimizing fatigue and joint pain. She has problems falling asleep and staying asleep. She worked with a physical therapist to implement and monitor an exercise program to meet her goals. The therapist assisted her in identifying a local gym that was accessible, and trained staff to position Lauren on the exercise equipment. The therapist recommended cable weight and ankle weight exercises on a vibrating table to build muscle mass, core strengthening exercises on the incline bench, and upper extremity ergometer training. The therapist also evaluated her current bed, and made suggestions for a bed that provided pressure relief and assist with positioning.

Increased physical activity and a change in mattress improved Lauren's ability to sleep and made positive a positive impact on her cholesterol and blood sugar levels. Perceived energy levels increased. Back and neck pain also were reduced.

Websites

- ENACT (Center for ENhancing ACTivity and Participation Among Persons With Arthritis) enact@bu.edu
- www.ncpad.org/104/795/Developmental~Disability~and~Fitness
- www.ucp.org/resources/health-and-wellness
- www.spinabifidaassociation.org/site/c.evKRI7OXIoJ8H/b.8029553/k.7027/Health_Information_Sheets.htm
- www.ncpad.org/
- <http://cpisra.org/main/>
- www.accessportamerica.org/
- www.aacpdm.org/publications/currentbooks

References

1. 1Roebroek ME, Jahnsen R, Carona C, Kent RM, Chamberlain MA. Adult outcomes and lifespan issues for people with childhood-onset physical disability. *Dev Med Child Neurol*. Aug 2009;51(8):670-678.
2. Turk MA. Health, mortality, and wellness issues in adults with cerebral palsy. *Dev Med Child Neurol*. Oct 2009;51(suppl 4):24-29.
3. Turk MA, Scandale J, Rosenbaum PF, Weber RJ. The health of women with cerebral palsy. *Phys Med Rehabil Clin N Am*. Feb 2001;12(1):153-168.
4. Peterson MD, Gordon PM, Hurvitz EA. Chronic disease risk among adults with cerebral palsy: the role of premature sarcopenia, obesity and sedentary behaviour. *Obes Rev*. Feb 2013;14(2):171-182.
5. Tosi LL, Maher N, Moore DW, Goldstein M, Aisen ML. Adults with cerebral palsy: a workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population. *Dev Med Child Neurol*. Oct 2009;51(suppl 4):2-11.
6. Haak P, Lenski M, Hidecker MJ, Li M, Paneth N. Cerebral palsy and aging. *Dev Med Child Neurol*. Oct 2009;51(suppl 4):16-23.
7. Murphy KP. Cerebral palsy lifetime care—four musculoskeletal conditions. *Dev Med Child Neurol*. Oct 2009;51(suppl 4):30-37.
8. Henderson RC, Lark RK, Gurka MJ, et al. Bone density and metabolism in children and adolescents with moderate to severe cerebral palsy. *Pediatrics*. Jul 2002;110(1 Pt 1):e5.
9. Jahnsen R, Villien L, Aamodt G, Stanghelle JK, Holm I. Musculoskeletal pain in adults with cerebral palsy compared with the general population. *J Rehabil Med*. Mar 2004;36(2):78-84.
10. Jahnsen R, Villien L, Egeland T, Stanghelle JK, Holm I. Locomotion skills in adults with cerebral palsy. *Clin Rehabil*. May 2004;18(3):309-316.
11. Tuzson AE, Granata KP, Abel MF. Spastic velocity threshold constrains functional performance in cerebral palsy. *Arch Phys Med Rehabil*. Sep 2003;84(9):1363-1368.
12. Morgan JP, Minihan PM, Stark PC, et al. The oral health status of 4,732 adults with intellectual and developmental disabilities. *J Am Dent Assoc*. Aug 2012;143(8):838-846.
13. Bohmer CJ, Klinkenberg-Knol EC, Niezen-de Boer MC, Meuwissen SG. Gastroesophageal reflux disease in intellectually disabled individuals: how often, how serious, how manageable? *Am J Gastroenterol*. Aug 2000;95(8):1868-1872.
14. Henderson CM, Rosasco M, Robinson LM, et al. Functional impairment severity is associated with health status among older persons with intellectual disability and cerebral palsy. *J Intellect Disabil Res*. Nov 2009;53(11):887-897.
15. Donnelly JE, Saunders RR, Saunders M, et al. Weight management for individuals with intellectual and developmental disabilities: Rationale and design for an 18month randomized trial. *Contemp Clin Trials*. Sep 2013;36(1):116-124.
16. Heller T, Sorensen A. Promoting healthy aging in adults with developmental disabilities. *Dev Disabil Res Rev*. Aug 2013;18(1):22-30.
17. Jahnsen R, Villien L, Stanghelle JK, Holm I. Fatigue in adults with cerebral palsy in Norway compared with the general population. *Dev Med Child Neurol*. May 2003;45(5):296-303.
18. Vogtle LK. Employment outcomes for adults with cerebral palsy: an issue that needs to be addressed. *Dev Med Child Neurol*. Nov 2013;55(11):973.
19. Owen DM, Hastings RP, Noone SJ, et al. Life events as correlates of problem behavior and mental health in a residential population of adults with developmental disabilities. *Res Dev Disabil*. Jul-Aug 2004;25(4):309-320.
20. Marks B, Sisirak J, Hsieh K. Health services, health promotion, and health literacy: report from the State of the Science in Aging with Developmental Disabilities Conference. *Disabil Health J*. Jul 2008;1(3):136-142.
21. Thorpe D. The role of fitness in health and disease: status of adults with cerebral palsy. *Dev Med Child Neurol*. Oct 2009;51(suppl 4):52-58.
22. Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther*. May 1999;79(5):495-502.
23. Vogtle LK, Malone LA, Azuero A. Outcomes of an exercise program for pain and fatigue management in adults with cerebral palsy. *Disabil Rehabil*. 2014;36(10):818-825.
24. Vogtle LK. Pain in adults with cerebral palsy: impact and solutions. *Dev Med Child Neurol*. Oct 2009;51(suppl 4):113-121.
25. Fragala-Pinkham MA, Smith HJ, Lombard KA, Barlow C, O'Neil ME. Aquatic aerobic exercise for children with cerebral palsy: a pilot intervention study. *Physiother Theory Pract*. Feb 2014;30(2):69-78.
26. Moreau NG, Falvo MJ, Damiano DL. Rapid force generation is impaired in cerebral palsy and is related to decreased muscle size and functional mobility. *Gait Posture*. Jan 2012;35(1):154-158.
27. Moreau NG, Holthaus K, Marlow N. Differential adaptations of muscle architecture to high-velocity versus traditional strength training in cerebral palsy. *Neurorehabil Neural Repair*. May 2013;27(4):325-334.
28. Ahlborg L, Andersson C, Julin P. Whole-body vibration training compared with resistance training: effect on spasticity, muscle strength and motor performance in adults with cerebral palsy. *J Rehabil Med*. Sep 2006;38(5):302-308.
29. Fernandez JE, Pitetti KH. Training of ambulatory individuals with cerebral palsy. *Arch Phys Med Rehabil*. May 1993;74(5):468-472.
30. Chen CL, Chen CY, Liaw MY, Chung CY, Wang CJ, Hong WH. Efficacy of home-based virtual cycling training on bone mineral density in ambulatory children with cerebral palsy. *Osteoporos Int*. Apr 2013;24(4):1399-1406.
31. Chen CL, Hong WH, Cheng HY, Liaw MY, Chung CY, Chen CY. Muscle strength enhancement following home-based virtual cycling training in ambulatory children with cerebral palsy. *Res Dev Disabil*. Jul-Aug 2012;33(4):1087-1094.

32. Chang YJ, Chen SF, Huang JD. A Kinect-based system for physical rehabilitation: a pilot study for young adults with motor disabilities. *Res Dev Disabil.* Nov-Dec 2011;32(6):2566-2570.

33. Peterson MD, Lukasik L, Muth T, et al. Recumbent cross-training is a feasible and safe mode of physical activity for significantly motor-impaired adults with cerebral palsy. *Arch Phys Med Rehabil.* 2013;94(2):401-407.

Copyright 2014, Section on Pediatrics, APTA. Developed by the Adolescents and Adults With Developmental Disabilities Special-Interest Group of the Section on Pediatrics, APTA, with special thanks to expert contributors Mary Gannotti, PT, PhD, Lorrie Sylvester, PT, PhD, and Susan LaCourse, PT, MS.