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. 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.

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." 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. 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 deformities: patella alta, hip dislocation, spondyloysis, cervical stenosis, scoliosis, foot deformities, compounded by osteoporosis
   - Osteoporosis/osteopenia: inactivity results in underdevelopment of appropriate bone mineral density in early childhood, medication interactions and side effects, and hypogonadism
   - Pain: secondary to osteoarthritis in the back, hips, upper and lower extremities related to overuse, and/or prolonged abnormal joint movement
   - Changes in spasticity or spasm
2. Metabolic or endocrine issues such as early onset (second or third decade) “metabolic syndrome,” 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 muscle
   - Poor dental health (compounded by seizure medications), 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
   - Lack of accessible scales. Weight changes may be precursors of a health crisis
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
   - 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)
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 production
   - Decline in functional status 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 employment
   - Lack of independent living opportunities
   - Risk for depression and substance abuse

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. 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. 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. 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.

Exercise as a Treatment
Adults with I/DD are at risk for lack of physical activity. Coinciding with the use of exercise to promote health and wellness and minimize secondary conditions, community-based exercise has been shown to increase motivation and provide opportunities for social interaction. 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 training\(^{33}\) 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
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References


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