

FACT SHEET



SECTION ON
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

Adolescent and Adults With Intellectual and Developmental Disabilities Special-Interest Group FACT SHEET: Independent Living

Overview

The purposes of this document are to provide an overview of the current trends towards independent living for persons with Intellectual and Developmental Disabilities (I/DD) and to describe the role of physical therapists in supporting those trends.

What are intellectual and developmental disabilities (I/DD) and how prevalent are they?

- *Developmental disabilities* are mental and/or physical impairments manifested before the age of 22 years that last throughout the person's lifetime.¹⁻²
- *Intellectual disability*, formerly known as mental retardation, is a limitation in general mental capacity (such as problem-solving) or in adaptive behavior (such as conceptual, social, and practical skills).¹
- Intellectual and developmental disabilities result in functional limitations in 3 or more of the following major life activities: self-care, language, learning, mobility, self-direction, potential for independent living, and potential for economic self-sufficiency.¹⁻²
- According to the Centers for Disease Control and Prevention, 13.9% of children aged 3-17 have a developmental disability. It affects roughly 1.5% to 2.5% of the total general population. The severity of these disabilities varies widely.³

Levels of Care/Services

Where do adolescents and adults with I/DD live and where do they receive most of their services?

- Most persons with I/DD live in home settings; the trend is away from large institutions. To live as independently as possible is a right for all persons, including those with disabilities.⁴
- Long-term care and supported services can include: group homes, foster care, supervised apartments, supported living, and personal assistance.
- Community-based service systems, which are accessible to families in their natural environments, are now considered best practice and promote the best outcomes. The community-based systems are more economical and provide persons with disabilities more freedom to choose living arrangements and service providers.⁴
- Successful community integration of persons with I/DD requires planning and teamwork of families, caregivers, and health professionals.⁵

Role of Physical Therapy

How do physical therapists (PTs) help individuals with I/DD to live in and integrate into their communities?

Physical therapists evaluate persons with I/DD to determine the supports needed by the individual, family, and caretakers to maximize independent living. This includes evaluating:

- Independent self-care
- Independent mobility
- Access to leisure and fitness activity
- Participation in education (secondary and postsecondary)
- Participation in vocational opportunities

For example, Sally is an 18-year-old woman with myelodysplasia and a mild cognitive disability. She wants to move into an apartment with her friend following her upcoming graduation from high school. During the transition planning meetings, the school-based PT is asked to determine what type of environmental and physical supports Sally will need to live in an apartment and access her part-time job as a receptionist in a law firm. In collaboration with Sally, the team, and Sally's family, the PT investigates the local transportation options, including the system requirements for wheelchair tie-downs for Sally's chair. The PT investigates the potential architectural barriers and furniture requirements for Sally's apartment so that she can continue to care for herself and independently transfer to all surfaces.

Physical therapists determine what types of assistive technology⁶ and environmental modifications are needed for each individual in order to:

- Support mobility needs
- Support community living
- Support recreational choices
- Support educational and vocational choices

For example, Paul, a 20-year-old man diagnosed with spastic diplegia, comes to an outpatient physical therapy clinic where he previously received services. He graduated from high school more than a year ago, but was unsuccessful in finding a job. He decided to enhance his skills by attending college and he wants to live in the dorms. He is worried about whether he will be able to propel his wheelchair the distances between the scheduled classes and get to class on time. He is also concerned about whether the small dorm rooms will accommodate his wheelchair. In collaboration with Paul and representatives of the college, the PT determines whether Paul's current assistive technology is consistent with the environment and physical demands of his schedule and the campus and/or whether he needs new technology, such as a power chair.

Physical therapists promote the health and wellness of persons with I/DD by:

- Designing and individualizing community-based physical activity and fitness activities⁸⁻⁹
- Preventing secondary conditions that often affect persons with disability such as: osteoporosis; obesity; and decreased balance, strength, endurance, fitness, and flexibility⁷
- Promoting healthy behaviors

For example, a PT is a consultant for an agency that provides group residences and coordinates services for persons with intellectual and developmental disabilities. One of the caretakers in a group residence requests input on weekend recreational fitness activities appropriate for the 3 young women who reside in the apartment. The PT, in collaboration with the residents and caregivers, determines the fitness and leisure activity preferences of each person, as well as the community resources available to support those preferences.

Where do persons with I/DD, caretakers, and families access physical therapist services?

- Persons with I/DD, caretakers, and families may access physical therapist services in their own community. Local listings may include hospital and free-standing outpatient clinics as well as independent practitioners.
- PTs working in all settings should be prepared to provide high-quality services that accommodate the specialized needs of persons with I/DD. This may include adapting treatment approaches and accommodating the communication strategies of the person with I/DD.
- Persons with I/DD experience functional limitations in major life activities including the potential for independent living. Best practice considers the promotion of community-based service systems and community integration for this population. Physical therapists serve a unique role in supporting this integration through assessment of resources and skills, promotion of health and wellness, and provision of individualized, community-based services.^{8,9}

References

1. American Association on Intellectual & Developmental Disabilities. *Intellectual Disability: Definition, Classification, and Systems of Supports*. 11th edition. Washington, DC: American Association on Intellectual & Developmental Disabilities; 2011.
2. Introduction to intellectual disabilities. The Arc website. <http://www.thearc.org/page.aspx?pid=2448>. Accessed August 29, 2013.
3. Centers for Disease Control and Prevention. Developmental disabilities increasing in US. http://www.cdc.gov/features/dsdev_disabilities/. Accessed November 16, 2013.
4. Latkin KC, Stancliffe RJ. Residential supports for persons with intellectual and developmental disabilities. *Ment Retard Dev Disabil Res Rev*. 2007;13:151–159.
5. Cicirello NA, Doty AK, Palisano RJ. Transition to adulthood for youth with disabilities. In: Campbell SK, Palisano RJ, Orlin MN, eds. *Physical Therapy for Children*. 4th ed. St Louis, MO: Elsevier-Saunders; 2012:1030–1058.
6. Hammel J, Lai JS, Heller T. The impact of assistive technology and environmental interventions on function and living status with people who are ageing with developmental disabilities. *Disabil Rehabil*. 2002;24:93–105.
7. Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther*. 1999;79:495–502.
8. Badia M, Orgaz MB, Verdugo MA, Ullan AM. Patterns and determinants of leisure participation of youth and adults with developmental disabilities. *J Intellect Disabil Res*. 2013;57(4):319–332.
9. Hilgenkamp TIM, van Wijck R, Evenhuis HM. Feasibility of eight physical fitness tests in 1,050 older adults with intellectual disability: results of the Healthy Ageing with Intellectual Disabilities Study. *Intellect Dev Disabil*. 2013;51(1):33–47.

Useful Websites

National Council on Independent Living

www.ncil.org

ADAPT

www.adapt.org

Money-Follows-the-Person

www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html

National Council on Disability. Living, Learning & Earning.

www.ncd.gov

American Association on Intellectual and Developmental Disabilities

<http://aaidd.org>

Rehabilitation Engineering and Assistive Technology Society of North America

www.resna.org/resources/

Health Matters CAP: Real People, Practical Solutions, Real Changes

www.healthmattersprogram.org

Research and Training Center on Community Living

www.rtcil.org/~rtcil/cl/

Working With People With Intellectual Disabilities in a Health Care Setting

www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf

APTA Section on Pediatrics

www.pediatricapta.org

For information on the Adolescents and Adults with Developmental disabilities SIG, click on “Special Interest Groups.”

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 Joyce Maring, PT, DPT, EdD, and Jeanne O’Neil McCoy, PT, DPT, MS, NCS.