

Retirement For People With Intellectual Disabilities

Definition

Retirement is the period of one's life after leaving one's job and ceasing to work.

Statistics¹

- There are an estimated 641,000 adults age 60 and older with intellectual and other developmental disabilities (e.g., cerebral palsy, autism, epilepsy).
- Their numbers will double to 1,242,794 by 2030 when all of the post World War II "baby boom" generation born between 1946-1964 will be in their sixties.

Additional Considerations

Older adults with intellectual disabilities typically have had less experience and opportunities in making choices, and have limited knowledge of potential options.

Additionally, as people experience age-related declines in physical health, they are likely to require increasing levels of health care.

Have you thought about your retirement?

What would you be doing?

What if today was your last day of work and tomorrow was the start of your retirement?

How would you feel?

Feelings

- Happy? (finally time for things you've always wanted to do?)
 - Apprehension?
 - Lost your routine?
 - Nothing to do?
 - Friends?

Domains of Quality of Life

For an individual with a disability, the most important domains of quality of life, as identified in the literature, are physical health, psychological well-being, family and social support, physical environment, and care environment.

Physical Health

- Physical health is important to the quality of life of older people with a disability, irrespective of the disability.

Psychological Well-Being

- Psychological well-being is also important as it impacts how people deal with the facts of a disability.

Family and Social Support

- Families provide not only practical support but emotional support also, which may be essential in helping the individual cope with their disability.
- Opportunities to connect socially with families and friends remain central to the lives of older people with disability.

Physical Environment

- The physical environment is also important for quality of life for people with a disability. A poor environment can reduce mobility and independence and create dependency where none should exist.

Care Environment

- The care environment also matters. Older people with a disability must be empowered, provided with choice, and given autonomy over their lives in both community and residential care settings.

What do the regulations² say?

W136

Individuals are involved in various types of activities in the community (e.g., going to parks, movies, restaurants, church, community meetings and events) based on their interests and choices.

W147

Promote frequent and informal leaves from the facility for visits, trips, or vacations.

W196

Each individual must receive a continuous active treatment program that is directed toward:

- (1) The acquisition of the behaviors necessary to function with as much self determination and independence as possible; and
- (2) The prevention or deceleration of regression or loss of current optimal functional status. Interventions that are necessary to prevent or decelerate regression are considered to be part of the overall active treatment program.

Regulations require active treatment to include:

- A comprehensive functional assessment that includes an individual's developmental strengths and preferences, specific functional and adaptive social skills which need to be acquired, presenting disabilities and their causes when possible, and service needs without regard to availability;
- An Individual Program Plan (IPP) that describes opportunities for individual choice and self-management, measurable outcomes to be achieved, and specific specialized and generic strategies, supports, and techniques to be implemented;

Regulations require active treatment to include:

- Individualized services or interventions “in sufficient intensity and frequency to support achievement of IPP objectives”;
- Documentation of accurate, systematic, behaviorally stated data about individual performance toward meeting IPP goals as the basis for program changes; and
- Review and update of the functional assessment and IPP by the interdisciplinary team at least annually or as indicated by the individual’s circumstances.

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Active treatment for elderly individuals may need to focus on interventions and activities that promote physical wellness and fitness, socialization, and tasks that stress maintaining skills.

W206

The individual's interdisciplinary team is composed of those individuals who possess the knowledge, skills and expertise necessary to accurately identify the comprehensive array of the individual's needs and design a program which is responsive to those needs.

W211

Assessments must address areas and active treatment needs which are relevant to the person's chronological age.

The assessment process should be sensitive to the behaviors of individuals throughout their life span. For example, elderly citizens are expected to choose whichever form of productive activity meets their needs and interests (employment, handiwork, pursuit of leisure, etc.) for as long as they are able.

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Assessments provide specific information about the person's ability to function in different environments, specific skills or lack of skills, and how function can be improved, either through training, environmental adaptations, or provision of adaptive, assistive, supportive, orthotic, or prosthetic equipment.

W223

Social development includes recreation and leisure, and interpersonal skills that enable an individual to establish and maintain appropriate roles and fulfilling relationships with others.

W233

The IDT identifies which objectives are the most important to work on now.

Skills and behaviors which significantly impact the individual's day-to-day functioning are worked on first.

W247

Individuals are provided opportunities for choice, encouraged and taught to make choices, and to exercise control over themselves and their environment.

W322

Medical services are provided as necessary to maintain an optimum level of health for each individual and to prevent disability. Medical services include evaluation, diagnosis and treatment, as needed, by individuals.

Remember...

As a person gets older, changes occur in all parts of the body.

Therefore, it may be necessary to consult with a medical specialist who explores the diagnosis and treatment of diseases and problems of older individuals.

W435

Staff and individuals have the space, materials and equipment needed for the formal and informal active treatment program to be carried out.

Recreational supplies and materials are available and reflect the interests, abilities and chronological age of the individuals.

Research

In 2000, a comprehensive report was prepared by the Aging Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities, titled *Healthy Ageing - Adults with Intellectual Disabilities*.³

The report addressed four major issues related to aging and retirement: physical health, bio-behavioral issues, women's health, and aging & social policy.

Research

In 2011, a study was conducted by Wilson, N.J., Stancliffe, R.J., Bigby, C., Balandin, S., and Craig, D., titled *Retirement and Older Adults With Intellectual Disability; Toward a Transitional Person-centered Support Model*.⁴

Based on the results, a conceptual framework was developed that described how to implement a transitional person-centered support model.

Additional Resources

The School of Social Welfare is a resource for staff who work with individuals with intellectual disabilities including individuals who are aging and have dementia.⁵

Community Involvement Programs

Community Involvement Programs is a non-profit organization that supports individuals with disabilities.⁶

The focus of their retirement program is to provide a quality community experience for older adults with intellectual disabilities for whom employment is no longer a priority.

Midwest Special Services, Inc.

Midwest Special Services has Continuing Achievement for Seniors and Retirees (CARES) programs which support the changing needs of seniors and retirees with developmental disabilities.⁷ The programs include a variety of activities, community involvement and volunteer options.

Black Hills Training Center

Black Hills Workshop and Training Center provides services to older adults with disabilities.⁸

Activities focus on maintaining fitness, creating or strengthening a personal social network, and expanding and exploring personal interests as well as maintaining daily living activities.

References

¹ Statistics retrieved from <http://www.strengthforcaring.com/daily-care/caring-for-someone-with-developmental-disabilities/older-adults-with-developmental-disabilities-and-their-aging-family-caregivers/>

² *State Operations Manual Appendix J - Guidance to Surveyors: Intermediate Care Facilities for Persons With Mental Retardation.* Retrieved from http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_j_intermcare.pdf

³ Aging Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. (2000). Healthy Ageing - Adults with Intellectual Disabilities. Retrieved from http://www.who.int/mental_health/media/en/22.pdf

References

⁴ Wilson, N.J., Stancliffe, R.J., Bigby, C., Balandin, S., and Craig, D. (2011). Retirement and Older Adults With Intellectual Disability; Toward a Transitional Person-centered Support Model. Retrieved from <http://www.pandda.net/files/2011-Wilson-RetirementTransition.pdf>

⁵ School of Social Welfare retrieved from <http://www.albany.edu>

⁶ Community Involvement Programs retrieved from <http://www.cipmn.org>

⁷ Midwest Special Services retrieved from <http://www.mwsservices.org>

⁸ Black Hills Workshop and Training Center <http://www.bhws.com>

*Send your comments or questions to
fsb@dhw.idaho.gov*