

Aging and Developmental Disabilities

What Can Nurses Do?

The likelihood of older persons with developmental disabilities living into their own retirement and outliving their family caregivers has increased substantially in recent years.

- Older Adults and Their Aging Caregivers – AAMR, 2005

Thanks to medical advances, individuals with developmental disabilities are now living longer life spans.

The age for “older” or “elderly” individuals with developmental disabilities is considered to be age 50, or age 45 for individuals with Down syndrome. As many as 500,000 “elderly” in the United States are developmentally disabled.

By 2025 the average age of individuals served by the New York State Office of Mental Retardation and Developmental Disabilities will be age 50.

The health care needs of individuals with developmental disabilities are often complex, and the needs become more challenging as individuals age. Health assessment of an older person with developmental disabilities can be multi-faceted as there is potential for a number of underlying conditions or diseases causing health concerns.

To add to the complexity, many individuals with developmental disabilities cannot verbally communicate about their symptoms. Some symptoms may present as behavioral problems rather than as health problems.

Nurses will be required to manage the multiple health and behavior changes of aging individuals with developmental disabilities. Nurses will not only have to be aware of changes that occur during the natural aging process, but will need to be familiar with the age-specific conditions that can develop with individuals with developmental disabilities.

Compared to persons in the general population, most individuals with intellectual disabilities will have similar rates of older age-related health conditions including coronary heart disease, type 2 diabetes, some forms of cancer, osteoarthritis, disorders of hearing and vision, and dementia.

- American Association of Intellectual Disabilities and DD



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Check Up

Nurses can arrange for the following assessments related to aging. All of these factors can impact physical and behavioral health.

- ✓ eye exam
- ✓ hearing test
- ✓ tracking of menstruation
- ✓ dental exam
- ✓ mammogram
- ✓ gynecological exam
- ✓ prostate exam
- ✓ skin inspection
- ✓ exercise routine
- ✓ toileting
- ✓ diet
- ✓ smoking
- ✓ alcohol consumption
- ✓ living situation
- ✓ status of caregivers
- ✓ social activities
- ✓ access to transportation
- ✓ interests/hobbies
- ✓ sleep routine
- ✓ community activities
- ✓ home safety and security

Conditions of Aging and Developmental Disabilities

For individuals with Down syndrome, the symptoms of aging such as diminished hearing, cataract development, respiratory difficulties, and obesity-related diseases such as hypertension and diabetes can occur earlier, as well as the onset of dementia. Individuals with Down syndrome may already have medical conditions such as thyroid problems, intestinal abnormalities, seizure disorders, or cardiac problems – all of which can continue into adulthood.

Hearing and vision changes are often overlooked in individuals with cognitive disabilities. These changes can result in increased isolation and maladaptive behavior.

The stages of menopause can contribute to changes in behavior, comfort level, and physical well-being. Some women with developmental disabilities may not express their concerns about how they are feeling, especially if symptoms occur gradually over time.

Sedentary lifestyle can contribute to the severity of health problems such as hypertension, obesity, diabetes, osteoporosis, back and joint pain, and decreased flexibility, endurance, and mobility.

There are also psychological and environmental factors that may impact health, such as social isolation due to physical changes that can result from aging; changes in the circle of support as caregivers age; or relocation to a new environment to accommodate health changes.

Although some people with developmental disabilities experience an early onset and more rapid progression of Alzheimer's, many older adults with DD may show functional decline because of other treatable conditions.

- 2008 Task Force Recommendations – Washington State DD Council

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What Can Nurses Do?

What Nurses Can Keep In Mind

- Sensory changes in sight, hearing, taste, and smell can cause changes in behavior.
- Falls related to balance, cataracts or glaucoma, or environmental changes may not be reported by the individual to caregivers.
- Social changes such as death of a caregiver, loss of friends, new residential situations, or limitations in interacting with the community may cause withdrawal, depression, or behavior problems.
- Side-effects of medications, timing of medications, and/or combinations of multiple medications on an aging body may contribute to physical and behavioral problems. Changes in medication dosage may be required, particularly if individuals have been on the same medications for several years.
- Early onset of dementia should be considered as an explanation for changes in behavior.
- Sleep disruptions due to environmental factors, medications, and/or physical challenges such as chronic pain or menopause could explain changes in health and behavior.
- Gait and balance changes due to aging may be misinterpreted as a reaction to medication or alcohol/drug abuse.
- Difficulty in pursuing past interests due to the effects of aging can cause frustration and confusion, resulting in changes in overall behavior.
- Psychiatric disorders should be considered, as they are about five times more common among this population compared to adults the same age.



Aging and Developmental Disabilities What Can Nurses Do?

Women and Aging

Menopause is unique for every woman. For women with developmental disabilities, the symptoms may occur earlier than the average age of 51 as in the general population. Women who present with hot flashes, sweating, insomnia, heart palpitations, itchy skin, backaches, joint pain, headaches, bloating, weight gain, thinning hair and the growth of facial hair may be experiencing peri-menopausal symptoms. In addition, depression and other mental health changes may be associated with menopause. The cessation of periods can be a factor in determining whether changes (behavioral and physical) are related to menopause, but the above changes may also have other causes such as the onset of a health problem, changes in environment or eating habits, or limited exercise.

Major health issues for adults with DD living in the community are lack of proper nutrition and sufficient exercise. Obesity among this population, particularly for females, is higher than the general population.

- Older Adults with DD and Their Aging Caregivers, 2009

Lessons Learned

In their publication *Aging in Community*, the NYS Office of Mental Retardation and Developmental Disabilities presents a series of real-life scenarios about the experiences of individuals with developmental disabilities as they age. "Lessons learned" follows each story. The following are selected suggestions for nurses:

Be a good listener so that you can hear what the individual and family really want. Be ready to offer choices. Restate key points to affirm understanding and to confirm priorities.

Empower the person by directly involving them with treatment considerations and decisions. Encourage family involvement and participation in planning. Identify and involve "circles of support" during transitions to new environments.

Respect people's need to be independent and to live and die as they choose. Help them to pursue their personal dreams.

Watch for signs of loneliness, depression, or isolation, especially if there are changes in living situations. Review all possible medical and environmental factors to determine etiology of changes in behavior.

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