

## Fact Sheet: AGING

### Older Adults and Their Aging Caregivers

**Q 1. How many older people with intellectual disabilities/mental retardation are there?**

Current estimates for adults age 60 and over with intellectual disabilities/mental retardation and other developmental disabilities (e.g., cerebral palsy, autism, epilepsy) range between 600,000 and 1.6 million. This population is growing rapidly, and although many persons are unidentified and the true number is not known, we can expect that by 2030, there will be several million.-

**Q 2. How do people with intellectual disabilities/mental retardation age compared to the general population?**

- A. In many ways they age the same as do people in the general population. The life-expectancy of the majority of persons with intellectual disabilities/mental retardation approaches or equals that of the general population. Factors that impact on a person's aging are genetics, lifestyle choices, environmental factors, and attitude. How pre-existing conditions interact with these factors will result in the unique manifestation of a person's aging. Compared to persons in the general population, most individuals with intellectual disabilities/mental retardation 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. Risk factors for older age-related health conditions (e.g., obesity, high blood pressure, high cholesterol, lack of exercise, smoking, and alcohol-related concerns) are the same as in the general population.
- B. Specific groups of persons with intellectual disabilities/mental retardation or other developmental disabilities, such as those with Down syndrome or significant lifelong physical disabilities, may exhibit particular patterns of older age-related health disorders. These are *superimposed* on disorders acquired during early development.

Older persons with Down syndrome are at higher risk for developing Alzheimer disease at earlier ages compared with older persons in the general population. However, many older persons with Down syndrome may show functional decline because of other treatable health problems, such as hypothyroidism, depression, and visual and hearing loss. The symptoms of these health problems may sometimes be mistaken for signs of dementia or exist along with Alzheimer disease, and worsen the functional consequences in older persons with Down syndrome. Notably, many older adults with Down syndrome do not show

symptoms of dementia in spite of the fact that studies show that almost all older adults with Down syndrome have the brain neuropathology that, is indicative of Alzheimer disease.

Older persons with cerebral palsy may develop *secondary conditions* related to or caused by the lifelong consequences of the physical disability, including chronic pain, osteoarthritis, and osteoporosis.

Older persons with long histories of using specific medications (e.g., psychotropic, antiseizure) are also at a higher risk of developing secondary conditions (e.g. tardive dyskinesia, conditions related to being overweight, or osteoporosis).

**Q 3. What are the age-related concerns of adults with intellectual disabilities/mental retardation and other developmental disabilities and their families?**

They are the concerns of all aging adults—securing housing, living independently, getting help when it is needed, leading productive and meaningful lives, and staying healthy. The situation is more complicated for some older adults with intellectual disabilities/mental retardation and other developmental disabilities, because, on the whole, they are more dependent on caregivers (family members as well as agency staff).

**Q 4. Is there enough housing for aging adults with intellectual disabilities/mental retardation?**

Research has shown that both younger and older adults with intellectual disabilities/mental retardation and other developmental disabilities are able to benefit from living in community settings. Because many of these individuals live on limited incomes and there is a dearth of affordable housing, especially in the large urban areas of the U.S., finding adequate housing is a problem. It is important to find housing that is practical, safe, or easy to live in for older persons. For instance, problems in ambulation may make it difficult to manage stairs, which is an important consideration in finding a place to live.

**Q 5. Can aging adults with intellectual disabilities/mental retardation and other developmental disabilities remain in their homes? Can they “age in place?”**

They can do this with the proper support. There will be an increased need for services and supports for older adults with intellectual disabilities/mental retardation and other developmental disabilities, whether they are living independently, with their families, or in other residential settings. These services and supports, which can enable them to maintain functioning and live as independently as possible, include personal care services, assistive technologies, home health care, and other in-home supports. Assistive technologies often include mobility and communication devices, home modifications, and techniques for maintaining and improving functioning.

**Q 6. How do aging adults with intellectual disabilities/mental retardation and other developmental disabilities continue to lead productive and meaningful lives as they age?**

Older adults with intellectual disabilities/mental retardation and other developmental disabilities have many of the same age-related concerns as older adults. However, they typically have less income, fewer opportunities to make choices, and less knowledge of potential options than do older adults in the general population.

As is true for any older person, older adults with intellectual disabilities/mental retardation and other developmental disabilities differ widely in their desire to retire, with many preferring to continue in work or vocational activities. This is often related to the need for ongoing socialization and support, not always because of a desire to keep on working. Because many of these adults are unemployed, underemployed, or participating in day or sheltered programs with little or no pay and no pension plans, the prospect of retirement may take on a different meaning. They typically have not been employed most of their adult lives, few have retirement plans and little or no retirement income.

They can, however, remain active by using available community services. Community inclusion models include (a) links with aging services, such as senior centers, companion programs, and adult day care; (b) church-run or other recreational programs in the general community; and (c) later-life planning educational programs. Many community services agencies are developing individualized options, including preferences for working part-time. The success of these options depends on the follow-up formal and informal supports available in the community. To be more responsive to individuals' needs and preferences, agencies rely on volunteers, variable reimbursement rates, external funds, and flexible schedules.

**Q 7. How can we promote optimal health in older age?**

Promoting healthy living requires a lifespan focus, starting in childhood and continuing through adulthood into old age. We need to understand the connection of the impact of lifestyle choices in people's younger years on their health as they age.

Many health conditions in old age are related to long-term *lifestyle* factors. Obesity among this population, particularly for females, is higher than for the general population. Exercise, proper diet, and weight control need to be promoted to prevent older age-related health disorders, such as type 2 diabetes and coronary heart disease.

Older persons with intellectual disabilities/mental retardation and other developmental disabilities may have problems with *access* to specific types of health services. Advocacy is needed so that access issues (transportation, environmental modification, special equipment) are addressed to enable the provisions of primary health care, cancer screening, dental care, etc.

Older adults with mental retardation need *adequate health insurance*.

*Specific screening, diagnosis, treatment, and rehabilitation technologies* need to be developed or implemented. Many older adults with intellectual disabilities/mental retardation often have difficulty communicating their symptoms or concerns. These communication difficulties are often aggravated by severe cognitive disability, autism, mental health disorders, early dementia, or cognitive decline. They also may have difficulty cooperating during diagnostic or screening procedures or participating in rehabilitation efforts. Health care providers (including physicians, nurses, and dentists) need training to deliver high quality health care to persons with severe cognitive or behavioral problems. They also need to be familiar with the correct medications to prescribe based on the age and the physical capacity of the person.

*Research* is needed to determine the types and prevalence of health disorders in older persons with intellectual disabilities/mental retardation and other developmental disabilities. A *lifespan approach* is required because many older age health disorders have their origin in lifestyle choices made at earlier ages and may result in secondary conditions that can be prevented, or effectively diagnosed and treated, at early stages.

**Q 8. How can we provide support to families who are primary caregivers and who are declining themselves?**

Families continue to be the primary providers of care. Because adults with intellectual disabilities/mental retardation and other developmental disabilities are living longer, families have a longer period of caregiving responsibility. Older families become less able to provide care as parents and siblings deal with their own aging, careers, and other caregiving responsibilities.

Older family caregivers have concerns about planning for the time when they can no longer provide care to their relative. Future planning involves providing for residential, legal, and financial arrangements in addition to health care, vocational/leisure activities, and community supports.

Key service needs reported by older family caregivers are (a) information regarding alternative places to live, (b) financial plans, (c) guardianship, and (d) respite services. Although in the last 10 years there has been an increase in funding for family support programs, these programs represent a small portion of spending for developmental disabilities services, and often target families of children. More needs to be done to support families of adults.

**Q 9. What are the key aging service programs?**

The Older Americans Act funds comprehensive support services for adults age 60 years and older and can also benefit older adults with intellectual disabilities/mental retardation and other developmental disabilities as well as their older family caregivers. The services include senior centers, nutrition sites, home-delivered meals, homemaker services, and case coordination. Area Agencies on Aging are a starting point for getting information

about local services. The Older Americans Act and other federal agencies fund employment opportunities and volunteer programs for older adults.

**Q 10. What is AAMR's policy?**

The AAMR believes that citizens with disabilities should have access to services that promote quality of life through full participation and community integration. Their empowerment should be strengthened through systems integration and research and training programs.

**RESOURCES**

A good resource for books, journals, and fact sheets on older adults with mental retardation and other developmental disabilities is the Clearing House on Aging and Developmental Disabilities. Contact information is as follows:

Clearinghouse on Aging and Developmental Disabilities  
Department of Disability and Human Development  
University of Illinois at Chicago, 1640 W. Roosevelt Road  
Chicago, IL 60608-6904  
(800) 966-8845 (V) or (800) 526-0844 (Illinois Relay Access).  
[www.uic.edu/orgs/rrtcamr/](http://www.uic.edu/orgs/rrtcamr/)

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