

# FACTS ABOUT ...



## OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES AND THEIR AGING FAMILY CAREGIVERS

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### How many older people are there with developmental disabilities?

There is an estimated 641,000 adults age 60 and older with intellectual (mental retardation) 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.

### How do people with developmental disabilities age compared to the general population?

The life expectancy and age-related medical conditions of adults with developmental disabilities are similar to that of the general population unless they have severe levels of cognitive impairment, Down syndrome, cerebral palsy, or have multiple disabilities.

The onset of age-related changes for people with intellectual disabilities may occur earlier for certain disabling conditions such as Down syndrome. Some research has indicated that sensory, cognitive, and adaptive skill losses occur earlier for adults with Down syndrome

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compared to the general population and other adults with intellectual disabilities. There appears to be a higher prevalence of Alzheimer Disease in adults with Down syndrome and it is likely to occur at an earlier age compared to the general population. For adults with Down syndrome, symptoms of dementia may often be caused by other conditions that are treatable such as hypo/hyperthyroidism, depression, and sensory impairments.

Persons with a lifelong history of certain medications (e.g., psychotropics, anti-seizure) are at a higher risk of developing secondary conditions (e.g., osteoporosis, tardive dyskinesia).

### What are the age-related concerns of adults with developmental disabilities and their families?

**Developing sufficient housing options for older adults:** Recent national estimates of waiting lists for residential services range from 59,000 to 87,000 people. As adults age there is a growing need for housing options out of the family home.

Concurrently, there has been a large increase in

the use of community based smaller homes and supported living arrangements. In addition, over 10,000 adults with intellectual/ developmental disabilities have moved out of nursing homes since 1987. These trends are expected to continue. Many of the residents who have experienced these residential transitions have included older adults. Research has shown that both younger and older adults are able to benefit from these transitions.

**Enabling adults to "age in place":** The growing numbers of older adults with developmental disabilities will increase the need for services and supports that enable them to maintain functioning and continue living as independently as possible, whether they are living with family or in other residential settings. Examples of such services and supports include personal care services, assistive technologies, home health care, and other in-home supports. Assistive technologies could include mobility and communication devices, environmental accommodations, and techniques for maintaining and improving functioning.

**Supporting productive and meaningful lives:** Older adults with developmental disabilities have many of the same age related concerns as other older adults. However, they typically have had less experience and opportunities in making choices, and have limited knowledge of potential options. Older adults with developmental disabilities differ widely in their desire to retire, with many preferring to continue participation in work or vocational activities. Given that many of these adults are un-employed, under- employed, or participating in day or sheltered programs with little or no pay, the prospect of retirement may take on a different meaning than it does for persons who have been employed most of their adult life and who may have retirement income. Community inclusion models include: 1) links with aging

services, such as senior center/companion programs, and adult day care; 2) church-run or other recreational programs in the general community; and 3) later-life planning educational programs. Many community service agencies are developing individualized options, including preferences for working part-time. The success of these options depends on the follow-up support from community service agencies, families and friends 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.

**Promoting healthy living:** As persons experience age-related declines in physical health they are likely to require increasing levels of health care. Major health issues for adults with developmental disabilities living in the community are proper nutrition and sufficient exercise. Obesity among this population, particularly for females is higher than for the general population.

**Providing support to families who are primary caregivers and are experiencing diminished capacity:** Families continue to be the primary providers of care. An estimated 76% of individuals with developmental disabilities live at home. In 25% of these households, the family caregiver was age 60 or older and the average age of the member with a disability was 38 years. Because adults with 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. Important unmet service needs reported by older family caregivers are for information regarding residential programs, financial plans and guardianship, and respite services. While there has been an increase in

funding for family support programs in the last ten years, these programs represent a small portion of spending for developmental disabilities services, and often target families of young children.

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

## **What are the key aging service programs?**

The Older Americans Act funds comprehensive support services for adults age 60 years and older that can benefit older adults with developmental disabilities and their older family caregivers. The services include senior centers, nutrition sites, home-delivered meals, homemaker services, transportation, 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.

**For more information on Aging with Developmental Disabilities contact the:**

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