Fact Sheet
Older Adults With Down Syndrome

Q. How many older people with mental retardation are there?

A. There are an estimated 526,000 adults age 60 and older with mental retardation and other developmental disabilities (e.g., cerebral palsy, autism, epilepsy). Their numbers will double to 1,065,000 by 2030 when all of the post World War II "baby boom" generation, born between 1946 and 1964, will be in their sixties.

Q. How do people with mental retardation age compared to the general population?

A. They age the same. They age the same in that the general life expectancy and age-related medical conditions of adults with mental retardation are similar to those of the general population.

They age differently. They age differently if they have severe levels of cognitive impairment, Down Syndrome, cerebral palsy, or have multiple disabilities. Research indicates that sensory, cognitive, and adaptive skill loses associated with aging may occur earlier with these individuals.

Individuals with Down Syndrome appear to have a higher incidence of Alzheimer's Disease occurring at an earlier age. For these adults symptoms of dementia may often be caused by other conditions that are treatable, such as hypo/hyperthyroidism, depression, and visual and hearing impairments.

People with a life-long history of taking certain medications (e.g., psychotropic, anti-seizure) are at a higher risk of developing secondary conditions (e.g., osteoporosis, tardive dyskinesia).

Q. What are the age-related concerns of adults with mental retardation and their families?

A. They are the concerns of all aging adults -- securing housing, living independently, getting help when its needed, leading productive and meaningful lives, and staying healthy.

Q. Is there enough housing for aging adults with mental retardation?
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A. No. A recent national survey estimated that 60,876 people with mental retardation and other developmental disabilities are on waiting lists for residential services in 37 states. As adults age, there is a growing need for housing options outside of the family home. In the last twenty years, there has been a 70% decrease in the number of residents of all ages in large institutions and widespread institutional closures. Concurrently, there has been a large increase in the use of community-based smaller homes and supported living arrangements. Also, over 10,000 adults with mental retardation/developmental disabilities have moved out of nursing homes since 1987.

Q. Can aging adults with mental retardation remain in their homes? Can they "age in place?"

A. They can with the proper support. There will be an increased need for services and supports for older adults with mental retardation, whether they are living 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 could include mobility and communication devices, home modifications, and techniques for maintaining and improving functioning.

Q. How can we provide support to families who are primary caregivers and are experiencing diminished capacity?

A. Families continue to be the primary providers of care. At least 80% of adults of all ages with mental retardation live at home, and many may not be known to the developmental disabilities services system. Because adults with mental retardation 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 future, when they can no longer provide care to their relative. Future planning involves providing for future 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: 1) information regarding residential programs; 2) financial plans; 3) guardianship; and 4) 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 mental retardation services, and often target families of children. More needs to be done to support families of adults.

Q. What is Alzheimer's disease?
A. Alzheimer's disease is a slowly progressive, degenerative disorder of the brain that eventually results in abnormal brain function and death. The disease was first described in 1907 by a German physician, Dr. Alois Alzheimer. Alzheimer's disease is a disorder marked by a gradual decline in brain function that gets worse with time. It used to be assumed that this change was a normal part of aging that we called "senility." Some persons develop this condition when they are as young as 40 years of age. However, the disease is most common in persons over the age of 65. It is estimated that approximately 10 percent of persons over 65 years of age may have Alzheimer's disease and that in persons over the age of 85, up to 50 percent may be affected.

Alzheimer's disease is not a normal part of the aging process. It is not known how it can be prevented. While the physical changes in the brain are very similar among different people, the behavioral and psychological symptoms that result are complex and may differ from person to person. These symptoms lead to a form of "dementia" which is the loss of mental skills and abilities, including self-care capabilities. As Alzheimer's disease progresses, these losses will result in total dependency for even the simplest activities.

Q. What are the symptoms of Alzheimer's disease?

A. The early symptoms of Alzheimer's disease in the general population often include:

- Language problems. The person cannot find the right word or name for a familiar person, place or object. This is not the same as taking longer to recall a word. It is far more than the "occasional" slip of a name that everyone experiences.
- Loss of recent memory. The person may forget that he or she just had breakfast or has left something cooking on the stove, or may check and recheck that the bed has been made. However, recall of events from the distant past is often unaffected.
- Loss of a sense of time and place. The person may become more and more confused about what day it is, or forget the route to well-known places.
- Decline in activities of daily living. The person may exhibit an unexplained loss of activities of daily living (ADL) skills. What once was an easy task for the person may now be difficult.
- Personality changes. These may be so slight that, at first, they are difficult to notice. Some people become more quiet and withdrawn. In other cases, they may become more and more restless. Some persons may start to get angry over little things or have sudden changes of mood for no apparent reason.

Q. Is there a test for Alzheimer's disease?

A. There is no single diagnostic test for Alzheimer's disease. If the presence of
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Alzheimer's disease is suspected, a complete physical examination and more frequent medical, neurological, and psychological evaluations are strongly recommended to establish the progressive nature of the symptoms, particularly for adults with a developmental disability. A "definitive" diagnosis can only be made at the time of autopsy. The numerous tests and evaluation procedures will result in a "possible" or "probable" diagnosis of Alzheimer's disease. To make a probable diagnosis of Alzheimer's disease, it is necessary to observe a well-documented progression of symptoms and rule out any other possible conditions or disorders. To help secure such a probable diagnosis, complete evaluations must be performed periodically. Such evaluations or tests are necessary to rule out conditions that are not Alzheimer's disease, or are reversible forms of dementia. A complete evaluation should include:

A detailed medical history, provided by a family member, caregiver or someone else well acquainted with the individual. This is the best way to determine accurately whether or not there has been progressive deterioration and personality changes, problems with memory, and difficulty with daily activities. As much as possible, the person should be involved in this process and asked what he or she feels is changing

A thorough physical and neurologic examination, including the testing of sensory-motor systems, to rule out other disorders.

A "mental status test" to evaluate orientation, attention, recent recall and the ability to calculate, read, write, name, copy drawing, repeat, understand and make judgments. Mental status evaluations may not be useful with individuals with preexisting cognitive limitations, such as severe mental retardation. Because of this, mental status examinations need to take into account the individual's past history and abilities and should never be the sole clinical assessment.

A psychiatric assessment to rule out the presence of a psychiatric disorder, particularly depression.

Neuropsychological testing to measure a variety of functions that include memory, orientation, language skills, intellectual abilities, and perception.

Routine laboratory tests, including blood work, health exams, such as urinalysis, chest x-ray, electroencephalography (EEG), and electrocardiography (EKG), as well as certain specialized tests as deemed appropriate. Imaging techniques, such as CT (computerized axial tomography) and MRI (magnetic resonance imaging), can be useful in showing progressive brain atrophy and helping to rule out other selected dementias. However, these techniques are costly and are mostly used in research.

Q. What is the connection between Down syndrome, aging and Alzheimer's disease?

A. People with Down syndrome may experience health problems as they age
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that are different from those experienced by older persons in the general population. The presence of extra genetic material found among persons with Down syndrome may lead to abnormalities in the immune system and a higher susceptibility to leukemia, seizures, cataracts, respiratory illness, and heart conditions. Persons with Down syndrome also experience premature aging—that is, they show physical changes related to aging some 20 to 30 years ahead of persons of the same age in the general population. With increased age, persons with Down syndrome may experience "typical" hearing loss and vision changes that are "expected to accompany being older," but will do so 20 to 30 years before other persons in the general population. Vision problems may be mostly due to cataracts. There may also be problems with motor abilities and changes in the skin, nerve, muscle, digestive, and urinary systems.

Compared to age peers, people with Down syndrome have higher rates of Alzheimer's disease. This may be another example of age-related changes occurring earlier in persons with Down syndrome than would be expected in persons in the general population. Adults with Down syndrome are often in their mid to late 40s or early 50s when symptoms may first appear, while symptoms first appear in persons in the general population beginning in the late 60s. Although about 20 to 40 percent of adults with Down syndrome show the behavioral symptoms of dementia, upon autopsy nearly all older adults with Down syndrome show the brain changes associated with Alzheimer's dementia.

Q. What is the progression of the disease?

A. The progression of the disease takes, on the average, about eight years—somewhat less time than among persons in the general population. Men and women seem to be equally susceptible. The symptoms of the disease may be expressed differently among adults with Down syndrome. For example, at the early stage of the disease, memory loss is not always noted, and not all symptoms ordinarily associated with Alzheimer's disease will occur. Generally, changes in activities of daily living skills are noted, and there may be the onset of seizures when there had been no seizures in the past. Cognitive changes may also be present, but they are often not readily apparent or they may be ignored because of limitations in the individual's general functional level.

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- A thorough physical and neurologic examination, including the testing of sensory-motor systems, to rule out other disorders.
- A "mental status test" to evaluate orientation, attention, recent recall and the ability to calculate, read, write, name, copy drawing, repeat, understand and make judgments. Mental status evaluations may not be useful with individuals with preexisting cognitive limitations, such as severe mental retardation. Because of this, mental status examinations need to take into account the individual's past history and abilities and should never be the sole clinical assessment.
- A psychiatric assessment to rule out the presence of a psychiatric disorder, particularly depression. Neuropsychological testing to measure a variety of functions that include memory, orientation, language skills, intellectual abilities, and perception.
- Routine laboratory tests, including blood work, health exams, such as urinalysis, chest x-ray, electroencephalography (EEG), and electrocardiography (EKG), as well as certain specialized tests as deemed appropriate. Imaging techniques, such as CT (computerized axial tomography) and MRI (magnetic resonance imaging), can be useful in showing progressive brain atrophy and helping to rule out other selected dementias. However, these techniques are costly and are mostly used in research.

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