

The Adult Down Syndrome Center

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The Adult Down Syndrome Center of Advocate Health Care is an innovative multidisciplinary clinic in Glenview, Ill., (suburban Chicago) that provides comprehensive medical and psychosocial care for adults with Down syndrome, with an emphasis on prevention. The clinic is a unique collaboration among three parties, the National Association for Down Syndrome (NADS), a parent advocate group; Advocate Health Care Systems, a large healthcare provider; and the Institute on Disability and Human Development of the University of Illinois at Chicago, an institute serving the needs of people with disabilities.

The center was developed in response to the urging of parents for the National Association for Down Syndrome. Although these parents have been able to help children with Down syndrome, they were frustrated with the lack of resources for adults with Down syndrome. A needs assessment of association family members showed that health and psychosocial services were sorely needed for adults with Down syndrome.

The Adult Down Syndrome Center was established in January 1992 in response to this expressed need. Each person attending the center receives a thorough medical evaluation, a psychosocial assessment, an audiological and nutritional assessment, and a meeting with a family advocate from NADS. Over 500 adults with Down syndrome and their care providers have been served since the center opened. Referrals to the center have come from parent advocate groups, community service agencies, residential facilities and healthcare professionals. Response to the center has been overwhelming. In 1995, to meet the growing demand for service, a second physician from Advocate Health Care staff and a psychiatric consultant from the University of Illinois at Chicago were added to the staff. Additionally, staff of the center have provided technical assistance to numerous groups around the country that were interested in establishing their own centers to serve adults with Down syndrome.

Findings of the Center

The center is providing a sizable clinical database for assessing age-related changes adults with Down syndrome experience. This is important because people with Down syndrome age prematurely and there is little data on their health status. The database will allow us to assess the aging process and to better inform people with Down syndrome and caregivers how to deal with these changes. We have found adults with Down syndrome age approximately 10 to 20 years earlier than the general population. Thus a 40-plus or 50 year old with Down syndrome may be more like a 60 or 70 year old in the general population. Adults with Down syndrome may experience this process as a

shortened middle age or as a rapid onset of aging. Many caregivers are struck by the seemingly rapid change from a youthful and active lifestyle to the more sedentary lifestyle of an older person.

Despite this early aging, it appears that individuals who live in community settings and stay active are more likely to maintain their skills and moderate the aging process. Even when the premature aging process results in a lack of interest in or retirement from formal work pursuits, a high level social or recreational activities should be maintained whenever possible. Similar to the retired general population, we have found that older adults with Down syndrome who have retired from work but still remain active are more likely to live longer and healthier lives. Caregivers' knowledge of the premature aging process may help to prevent a cut-off of programs or services from agencies unfamiliar with this occurrence. Uninformed staff who misinterpret slowdowns in work or other activities as symptoms of Alzheimer's dementia or oppositional behavior may move to discharge the individual from these programs and services. These staff need to be encouraged to design new programs and services that meet the needs of "prematurely" older adults with Down syndrome. Older adult programs could be developed or existing workshops could be adapted for more retirement activities such as arts and crafts, travel and recreational activities.

Association of Alzheimer's Dementia and Down Syndrome

Because of a tendency to associate Alzheimer's disease with Down syndrome in previous research, a loss of skills may be misdiagnosed as Alzheimer's dementia, which is untreatable and irreversible. More recent research has found that Alzheimer's dementia occurs earlier in adults with Down syndrome, possibly due to premature aging in this population, but it is not clear whether this disorder occurs at a greater rate than in general population.

In a recent survey of the individuals attending the center, we found that two-thirds were seen for routine health exams and had no significant problems while the remaining third were referred to the center for some loss of skills or functioning. We found that skill loss most often occurs as a result of reversible conditions other than Alzheimer's dementia, such as depression, hypothyroid medical condition or visual or hearing losses. From the data we have gathered to date on 447 people at the center, 123 individuals (30%) showed a loss of skills or function. Of the 123 with skill loss, 11 individuals, all over the age of 40, were diagnosed with Alzheimer's dementia representing 9 percent of this group. Even among individuals with the greatest risk of Alzheimer's, those over the age of 40 with skill loss (53 individuals), the 11 diagnosed with Alzheimer's dementia represented only 21 percent of those in this age group. All others in this age group (79%) showed a positive response to medical and mental health treatments or to remedial treatments for sensory impairments. For caregivers, the implication of these more recent findings is obvious. You need not either assume or accept a diagnosis of Alzheimer's dementia particularly if a rigorous attempt to find or rule out other causes or sources of the skill loss have not been made.