

International Association for the Scientific Study of Intellectual Disabilities

Fact Sheet

Aging and Intellectual Disabilities

People with intellectual disabilities, estimated at approximately 60 million worldwide, represent one of the largest groups of people with lifelong disabilities. As they age, most – those with minimal life difficulties – continue to live independent lives, yet others – those with more severe life difficulties – remain dependent on lifelong support from their families or from charitable organizations. As a result, because of compelling needs associated with their aging, special attention needs to be given to this segment of the world's growing elderly population.

Older people with intellectual disabilities have the same needs as other older people.

People with intellectual disabilities are subject to the same age-related impairments and illnesses as people who do not have life-long disabilities. The vast majority have health care requirements which replicate those of the ageing population in general, and should have access to appropriate social and health care. They have the same needs and rights with regard to medical care, adequate nutrition and housing, social interaction, employment and older age leisure activities, and access to sufficient resources, as other older adults.

The increasing life expectancy of people with intellectual disability is now an established fact.

Although adults with intellectual disabilities have been seen as having inherently shortened life-spans (largely due to lack of medical care, rehabilitation services, and poor living conditions), it is now common in most developed countries for them to live to old age. Even adults with Down syndrome, who previously had notably shortened lifespans, are experiencing a prolonged longevity. As developing nations and countries in transition evolve and their citizens experience prolonged life expectancy, there, too, we will see the life-span of people with lifelong disabilities extended.

Older people with intellectual disabilities are subject to compounded stigmatization.

Achievement oriented societies tend to devalue people with intellectual disabilities as unproductive, dependent, even deviant. As they grow older, they encounter other negative perceptions which reinforce marginalization. For example: ageism compounded with handicapism often is prevalent in many societies and encourages even more discriminatory attitudes against aging adults with intellectual disabilities. To their credit, enlightened societies have attempted to overcome negative stereotypes associated with age and disability and have enabled their older members to live productive lives. Those that haven't have even further marginalized aging people with intellectual disabilities often by relegating them to inferior old age services.

Millions of adults with intellectual disabilities are still living with their families.

Estimates of people with intellectual disabilities who are living within families run as high as 50%, even in nations with highly-developed service networks. Studies in a number of countries have observed significant numbers of adults with intellectual disabilities living with aging parents or other relatives. Public officials are now realizing that support of these families must be given priority, because in their absence the number of adults with special needs requiring services is far greater than service providers' capacity to accommodate them.

Adults with intellectual disabilities are too often excluded from planning for aging services.

As governments and local groups plan to accommodate a growing number of older and aging adults, it is important to include adults with intellectual disabilities in these arrangements. Adults with intellectual disabilities should be included in census counts of older people and their needs factored into planning for, and developing, "age-friendly" communities. Many adults living on their own or with their families require and can benefit from the same specially designed services and supports being provided to the well-elderly. When special needs are present, planning should also consider community-based housing and support services throughout all phases of old age.

Older age services or supports help minimize age-associated conditions and encourage healthy aging.

- ! <u>Social needs.</u> Eliminating stigmatization and discrimination in general community services and promoting equal access to and use of these services can meet the social needs of many adults. People with intellectual disabilities should be able to attend, use and benefit from the social, recreational and leisure resources and amenities that communities develop and operate for their other citizens.
- ! <u>Housing needs.</u> Supporting families when they are the primary carer or providing financial resources for rentals or ownership of property can meet older-age housing needs. Brokering co-living arrangements with other people or providing for small group homes or self-catered apartments can also promote continued independence in older age.
- ! <u>Health needs.</u> Enrolling adults in universal health schemes or health care programs should be the avenue to periodic health assessments and routine health care. Regular preventive health assessment and health care can help reduce the risk for diseases that can compromise quality of life and longevity.
- ! <u>Activity or work.</u> Aging adults with intellectual disabilities need activity or work as a normal part of their life just as do other adults. Research indicates that continued activity prevents old-age associated depression and other emotional problems. Involvement in social and community activities should be the norm. Personal circumstances and abilities should dictate level of need and desire for involvement.
- ! <u>Special care needs.</u> Age-associated conditions, such as Alzheimer's disease and related dementias, increasing fragility, or conditions or diseases compromising independent functioning, should be addressed with the focus on care in community or family settings. As there is a strong association between Down syndrome and Alzheimer's disease, periodic early screening and assessment for decline and dementia should be carried out. Institutionalization of persons with intellectual disabilities can never be justified or rationalized simply on the basis of old age.

Informational resources are available via the Internet

Universities and other organizations have produced many useful materials and resources that can be of help about adults with intellectual disabilities, and to their friends, advocates, and families. The World Health Organization has issued a series of documents expertly detailing a number of health-related issues and circumstances that can affect longevity and has made these reports available on the Internet. They can be assessed at www.iassid.org. The University of Illinois at Chicago in the United States maintains an informational website with many useful publications on aging and intellectual disabilities. The site address is www.uic.edu/orgs/rrtcamr/index.

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