

Planning For Older Adults with Developmental Disabilities

Aging and Developmental Disabilities

People with developmental disabilities are living longer. In 1930, the life expectancy of a person with a developmental disability was about 19 years. Today it is more than 66 years. For people with Down syndrome the life expectancy has increased from 9 years to 56 years over the same period. In 2000, there were more than 640,000 adults identified with developmental disabilities over the age of sixty (60) in the United States. This number continues to climb. Approximately two thirds of these persons over 60 are living with family members within the community. In 1993, a study showed that only about half of family caregivers had an actual plan for the future of their family member when they can no longer provide care.

Long Term Planning

Being actively involved in decisions and planning for your future or that of your family members is a right and a responsibility. When no plan for the future is in place, the risk for crisis is elevated. Many times the sudden illness or death of a caregiver results in a family crisis. The individual with developmental disabilities who needs supports not only experiences grief but the prospect of a change in their living environment.

Person-Centered Planning for later life should include the aging adult consumer, family members, and staff from any provider of services to you or your family member. Research on this subject has identified seven goals to be addressed.

1. Increase knowledge of later life options such as programs and services that are specifically designed for older family members.
2. Facilitate greater individual choices and participation in life decisions.
3. Facilitate the setting of realistic goals. Goals will change as you age.
4. Maintain and increase wellness behaviors. Good health habits can help keep down the advancing cost of health care expenses that tend to increase with age.
5. Increase participation in leisure and recreational activities.
6. Increase perceived life satisfaction. The planning process should result in you or your family member feeling good about the choices that you have made.
7. Learn about benefits available to you through Medicaid, Medicare, and other health insurances.

When participating in the Individual Program Planning process, consider adding some or all of these goals, as appropriate, to the Plan. Addressing the future is one of the aims of IPP's and an ideal time to start discussion. Planning to learn about your future options increases the likelihood of making informed choices. Consumers and family members must advocate for services that meet the individual needs of each consumer as they age.