

Meeting the Needs of People with IDD and Dementia: Strategies for Professionals

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Level Setting

Intellectual and Developmental Disability (IDD) is defined as a disability that originates before the age of 18 and is characterized by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills.

Autism spectrum disorder (ASD) is defined as an assortment of neurological differences that may contribute to sensory processing difficulties, repetitive behaviors, and challenges with social interaction, executive function, transitioning between activities, and communication.

Key Takeaways

Advances in medicine, screening, and living conditions have **increased life expectancy for people with IDD**. From 2000 to 2030, the number of adults with IDD aged 60 and older is expected to nearly double, to 1.2 million.

Among people with Down syndrome, dementia is more prevalent than among the general population, and it appears earlier in life. The average age of onset of Alzheimer's disease for people with Down syndrome is 55 years and the average duration of disease is 4.6 years.

The relationship between ASD and dementia is not well understood. Some studies report that people with ASD are more likely to be living with dementia than the general population, while other research suggests that rates of dementia are similar between people with ASD and the general population.

Supporting Caregivers

Caregivers of people with IDD have been in their caregiving role for the entire life of the person with IDD. While they often do not recognize themselves as caregivers, they are typically strong advocates for the person with IDD and often know the most about the person's abilities.

Caregivers are generally not familiar with dementia service providers. **Reaching people with IDD and their caregivers through IDD service organizations and networks** can be an effective way to identify people at risk and begin to build trust.

Caregivers, especially parents, of people with IDD may have challenges with their own memory or cognition. They may have particular concerns about how the person with IDD will be supported if the caregiver develops dementia.



Scan the QR Code to download the
*Intellectual and Developmental
Disabilities and Dementia: Practical
Strategies for Professionals* document

Supporting People with IDD

Dementia symptoms may show up differently for people with IDD and can include cognitive and memory changes, behavioral and emotional changes, changes in communication and social skills, difficulties with daily functioning and routine, motor and physical decline, and sensory and neurological changes. Symptoms typically associated with dementia can be masked by preexisting differences in cognitive functioning.

Resources for Aging Network Professionals

[Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers](#): This booklet was created to empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging, and guidance about how to adapt and thrive within an ever-changing caregiving role when a diagnosis is made.

[Aging and Down Syndrome: A Health and Well-Being Guidebook](#): This document provides a comprehensive overview of how individuals with Down syndrome can stay healthy as they age. It provides information on common medical conditions, including dementia, and medication management.

[Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia](#): This article includes guidelines that delineate what actions should be undertaken and are presented in a manner that reflects the progressive nature of prevalent dementias beginning with the prediagnosis stage when early symptoms associated with cognitive decline are recognized and continuing through to the early, mid, and late stages of dementia.

[KAER Toolkit: Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities](#): This toolkit adapts GSA's KAER framework for people with IDD, which includes: Kickstarting the brain health conversation, Assessing for cognitive impairment, Evaluating for dementia, and Referring to community resources.

[Screening for Dementia in Persons with Intellectual Disability](#): This training, developed by the Wisconsin Alzheimer's Institute, includes five sessions for professionals who work with people with IDD to improve their understanding and utilization of the NTG-EDSD tool.

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