National Core Indicators™ Data Highlight



What Do NCI Data Tell Us About the Characteristics and Outcomes of Older Adults with I/DD?

In the 2017-2018 NCI In-Person Survey (IPS) data collection cycle, the proportion of adults in the sample aged 55+ grew to 25.1% compared to 21.6% in 2007-2008.

Why does it matter? For people with intellectual and developmental disabilities (I/DD), transitions over the lifespan require support to ensure that they are successful. In addition to the transition from school to work, another important transition takes place when people with I/DD enter their later years. That transition has not received as much attention from researchers, providers, and advocates. Over the past 10 years, the general population aged 65 and over increased from 37.2 million in 2006 to 49.2 million in 2016 (a 33% increase) and is projected to almost double to 98 million in 2060 (ACL, 2017). Likewise, the number of people with I/DD aged 65 and over is also growing. This increase is in part the result of growth in their average lifespan, better medical care, and improved living conditions. The number of adults with I/DD aged 60 and older is projected to be 1.2 million by 2030 (Heller, 2017). The 2017-2018 NCI IPS survey results indicate that older individuals with I/DD receiving public services are more likely than their younger peers to have health, mobility, and sensory challenges and to have mood or anxiety disorders; and are less likely to have friends, to be employed, and to be involved in their communities. They are also more likely to have lived in an institutional setting in the past.

Questions to ask: Does the person-centered planning process focus on the changing needs of people as they age? Do case managers and DSPs receive information about community resources available for older participants? Do case managers have access to assessments geared to the needs of older adults with I/DD? Is technology available to older adults through state HCBS waivers (e.g., communication devices, GPS trackers, smart medication dispensers, security systems, and home sensors) and are individuals supported to use and maintain it? Given the numbers of individuals with Down syndrome who will develop Alzheimer's, have there been efforts across aging, disability, and dementia care systems to ensure that supports such as family supports, day respite, residential, or other supports and services are available? Are state I/DD staff building partnerships with state aging agencies to maximize access by I/DD participants to generic aging resources?

Want to know more?

- Administration for Community Living and Administration on Aging. (2018). 2017 Profile of Older Americans.
 https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2018OlderAmericansProfile.pdf
- Alzheimer's Disease International. (2003). Dementia and intellectual disabilities:
 Why the concern about dementia among people with intellectual disabilities?
 London: UK. Retrieved from https://www.alz.co.uk/adi/pdf/intellectualdisabilities.pdf
- American Association on Intellectual and Developmental Disabilities and The Arc. Joint Position Statement on Aging (2008). https://www.aaidd.org/news-policy/position-statements/aging
- Heller, T. (2017). Service and Support Needs of Adults Aging with Intellectual/ Developmental Disabilities: Testimony to the U.S. Senate Committee on Aging. https://www.aging.senate.gov/imo/media/doc/SCA_Heller_10_25_17.pdf
- Jokinen, N., Janicki, M.P., Keller, S.M., McCallion, P., Force, L.T., and the National Task Group on Intellectual Disabilities and Dementia Practices. (2013). Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia. Albany NY: NTGIDDP & Center for Excellence in Aging & Community. http://aadmd.org/ntg

