



What can states learn from state and national NCI results about the ages of family caregivers and the implications for future service demands?

The 2016-2017 National Core Indicators™ Adult Family Survey Data indicate that **60% of caregivers responding were between the ages of 55 and 74, and 11% were 75 years and over. In one state, 22% of the respondents were caregivers over 75.**

Why does it matter? Many people with disabilities are living with aging caregivers. Demand for state-funded supports and services is expected to swell as caregivers experience age-related support needs. In 2015, the Family Information Systems Project (FISP) reported that 199,641 people with intellectual and developmental disabilities (I/DD) were waiting for one or more Medicaid home and community-based waiver service. The total number of people with I/DD getting services and supports would have to have grown by 23% nationally to serve all the people on waiting lists. More than half of states reported over 1,000 people on waiting lists and, of those, **15 states reported that 76,682 people were waiting for services to move out of the family home.** In the 2017 The Arc FINDS survey, 1 in 4 caregivers reported that their family member was waiting for a least one service and 20% said that their family member had been waiting for more than 10 years. Families with aging parent-caregivers are not in a position to wait.

Questions to ask: What other data do you have in the state for forecasting support needs as caregivers age? estimate future demand for out of home placement? Do you survey your waiting list to determine ages of caregivers and the sustainability of their ability to care for their family member? Are there significant unmet needs among those waiting for services? Are there racial and ethnic disparities? Does your state provide any outreach to people on the waiting list? Do you assist families on the waiting list to network with other families and plan for the future? Do you assist families to gain access to natural supports?

If you want to know more:

- *How many people with IDD are waiting for long-term supports and services?* <https://fisp.umn.edu/chart-gallery/waiting>
- *State of Caregiving in the I/DD Community*, Arc (2017). www.thearc.org/FINDS
- Burke, M.M. & Heller, T. (2016). Disparities in unmet service needs among adults with intellectual and other developmental disabilities. *Journal of Applied Research in Intellectual Disability*, Volume 30 (5), pp. 898-910.
- *Joint Position Statement of AAIDD and The Arc on Long Term Services and Supports (and Waiting Lists)*. <https://aaid.org/news-policy/policy/position-statements/long-term-supports-and-services>
- Hecht, E., Reynolds, M., Agosta, J., McGinley, K., & Moseley, C. (2011). *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*. National Association of State Directors of Developmental Disabilities Services. <http://nasdds.org/resource-library/supporting-families/wingsrpead-document/>