

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 live with aging caregivers. Demand for state-funded supports and services is expected to swell as caregivers experience age-related support needs. In the 2017 FINDS survey conducted by The Arc, 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. The 2016 Residential Information Systems Project (RISP) data show that the number of people receiving services would have to grow by 23% nationally to serve all the people on waiting lists.¹ Many families with aging parent-caregivers cannot afford to wait. When a crisis occurs, the response is often temporary respite or uncoordinated services if support outside the home is not available.

Questions to ask: How does your state use data to forecast support needs as caregivers age? What is your data source for projecting the number of people waiting for services whose primary caregiver is over 70, 75 or 80 years old? Does your state use age of caregiver, race, and ethnic background to inform your estimates of future demand for out of home placement? How does your state system track unmet needs, and the demographics of people waiting? 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 inform and connect families to local community resources?

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://aaidd.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://nasddds.org/resource-library/supporting-families/wingspread-document/>

¹ University of Minnesota, Institute on Community Integration, 2016 Residential Information System Project, Chart Gallery. <https://risp.umn.edu/viz> Waiting for Medicaid Services