



Dear Families,

Here is an IMPORTANT opportunity to share your thoughts about what you feel you need to know or resources you wish to have regarding the **aging of your loved one with I/DD and cognitive decline/dementia**. Below is information about the survey as well as the SURVEY LINK.

<https://www.surveymonkey.com/r/TJ8T5DV>

INFORMATION ABOUT THE SURVEY...

The NTG is undertaking an initiative to expand the available information on dementia for families, agencies, and others and is reaching out to family and other caregivers to help us better understand where they get their information and what information might be of most use to them.

We have developed a brief 15-item survey with questions tapping some key areas related to information and its access. We’d appreciate it if you might send around to your network of caregivers this notice about the survey and ask them to complete it.

Completing the survey shouldn’t take more than 10 minutes. We do not ask for any identifiers and the information will be used only in aggregate form to help us plan our information initiative.

We are looking to get all responses **ON OR BEFORE OCTOBER 21, 2022,** and anyone who is a friend, advocate, mate, family member, or other care partner can participate.

If you have any questions about the survey, please contact NTG's Family Support at [familysupport@the-ntg.org](mailto:familysupport@the-ntg.org) or [Dr. Adel Herge](mailto:adel.herge@jefferson.edu) via email.

If you would like a copy of the IRB approved survey letter please email Kathryn Pears at [kathrynpears@the-ntg.org.](mailto:kathrynpears@the-ntg.org)

**HERE IS A LINK TO THE NTG WEBSITE IF YOU WISH TO LEARN MORE ABOUT THIS ORGANIZATION.**

[**http://www.the-ntg.org/**](http://www.the-ntg.org/)

Additional information...

The Family Caregiver Alliance [1] estimated that some 65 million people in the United States serve as caregivers to older family members or family members with a disability. Among these is an important and often overlooked group: caregivers of older adults with intellectual and developmental disabilities (IDDs) who are diagnosed with dementia. Of some estimated 46.2 million adults aged 65 years and older in the United States [2], it is estimated that there are least 180,000 older adults with IDDs of which an estimated 11,000 will be affected by dementia [3]. As the population of older adults in the United States continues to rapidly increase, this group will likely need additional services and supports. Caregivers of adults with IDDs and dementia face many of the same challenges as do caregivers of other older adults with dementia; however, they often experience unique patterns of caregiving, face additional challenges and stressors, and benefit from different sources of support and education.

Excerpted from Caregiving, intellectual disability, and dementia: Report of the Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities. 2018.