

A Support Group for Families with a Member with Intellectual Disability Who is Living with Dementia

#776

Kathryn Service
RN, MS, FNP-BC, CDDN

Under the auspices of the National Task Group on Intellectual Disabilities and Dementia Practices (<https://www.the-ntg.org>):

- May 2016 Mother & Sister – (men with Down Syndrome) started a virtual Support Group for Family members - child/sibling/other with Intellectual Disability (ID) also living with dementia, who may live with family or elsewhere in paid care settings (e.g., group residence)
- Based upon Peer Support Model (ID)
- Almost all families' members have Down syndrome (DS) d/t increased incidence of Alzheimer's Disease – young onset
- Meets 1X month- some educational offerings, either by request or facilitator's suggestion.
- Original organizers/facilitators left
- Current facilitator- Nurse Practitioner – (trained thru Alzheimer's Association as Support Group Facilitator, but also family member)

THE STORY

Trajectory of LIFELONG CARING/CAREGIVING



Photos with Kind Permission from Jane Boyle, sister of Ellen.

Variety of Settings

Human Ecology

"I went to a family support group run by the Lewy Body association. The others were nice, but they just didn't get it. . . what life is or has been like with someone with my sister's rare syndrome."

"I'm 75- my son's seizure disorder (Lennox-Gastaut) 'wears me down' plus, the dementia. . . there's no one out there who gets it. . . It's so hard to hear all your sad stories, but I feel a part of this. . .there's a place for me."

"Although my brother with Down syndrome lives in a group home- I've always been involved. Staff don't think I care- challenged me when his brother and I wanted to ask for a DNR as he in mid-late stage of Alzheimer's, thought we didn't value his life but it reflects who we are all as family -our values- his probably. . including our parents where he lived til 7 years ago. He loves and trusts us"

"You know what's special; that families whose loved one has passed away still come and share their wisdom and advice. They show us that there is life after all of this. . ."

- ~10 participants at most attending /~80 email list
- Increase in # Family Support Groups throughout US
- Organization: Some Trained Facilitator (e.g., Alz Assn); Most: Peer Support Model
- Some meet in person and some are location specific.
- Most groups specific for DS
- NTG group welcomes families with a member who doesn't have Down syndrome.



Background: Research findings- Qualitative= positive, Quantitative= mixed
Methodological challenges=Fluctuating membership – unpredictable participation, inconsistent connections
Outside support hours: where do families get help? (Mentoring)
Chakrabarti et al, 2021; Leung et al, 2021; McLoughlin, 2023