

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

A Case Study and a Story

Trajectory of **LIFELONG CARING/CAREGIVING**

“Can we keep her?”



Variety of Settings



Human Ecology

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National Task Group on
Intellectual Disabilities and
Dementia Practices

*With gratitude to and
respect of the families*



National Task Group
on Intellectual Disabilities
and Dementia Practices

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

PAST

Under the auspices of the National Task Group on Intellectual Disabilities and Dementia Practices:

- May 2016 Mother & Sister of men with Down Syndrome (DS) 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)
- Peer Support Model
- Down Syndrome almost all family members (d/t increased incidence of Alzheimer's Disease – young onset)
- Meets 1X month- some educational offerings.
- Original organizers/facilitators left
- Current facilitator- Nurse Practitioner – (Trained thru Alzheimer's Association as Support Group Facilitator, but also family member)

“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 Syndrome) is so wearing, plus, now, 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 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, thinking we didn't value his life but it reflects who we are all as family -our values-**his values** probably including our parents where he lived til 7 years ago. He loved and trusted 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.”

PRESENT

• 10 participants average/80 email list

• Increase in # Family Support Groups throughout US

• Organization: Some trained Facilitator; Most: Peer Support Model

• Some meet in person and are location specific.

• Most Specific for DS

• NTG welcomes families w/member without DS.