# Community-based dementia care for adults with intellectual disability

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# About us

**Matthew P. Janicki, Ph.D**. is co-president of the US National Task Group on Intellectual Disabilities and Dementia Practices, as well as an associate professor in the Department of Disability and Human Development at the University of Illinois at Chicago and a member of the federal Advisory Council on Alzheimer's Research, Care, and Services. Formerly, he was director for aging and special populations for the New York State Office for People with Developmental Disabilities.

**Kathryn Service, RN, MS, FNP-BC, CDDN** had worked as an RN/NP for close to 40 years with the Massachusetts Department of Developmental Services. In addition to 'hands-on' clinical support, she has worked together with and presented to people with ID and their families and direct support professionals and now still consults independently on matters on dementia, aging and end-of-life care. She is an officer of the National Task Group on Dementia and Intellectual Disabilities.

# Some Background on Dementia and Using a Group Home Model

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# Why something to think about?

- Dementia is the result of a brain disease or injury, such as Alzheimer's disease, Lewy body disease, or a brain injury or trauma
- With progression an adult with dementia is increasingly less able to take care of him or herself … and requires supervision and someone to help him or her with basic necessities
- Main dementia care options for most agencies are to support the person in place (whether at home or in their residential accommodation), refer to a long-term care facility, or admit to a specialty dementia-capable group home
- Dealing with dementia calls upon agencies to make some critical decisions about dementia care and developing support resources

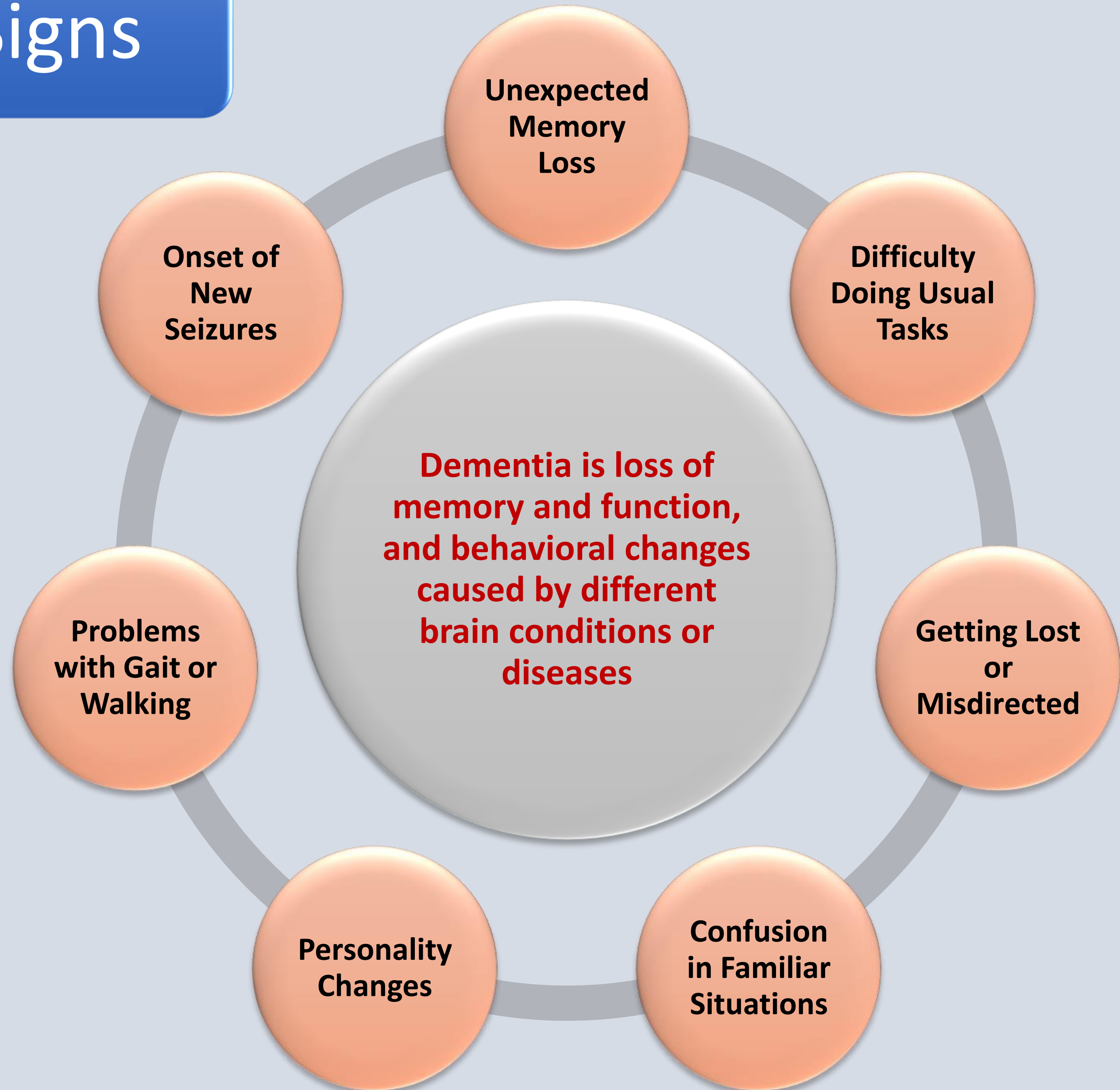
# Things to know about dementia

- **Dementia an umbrella term** for a range of changes in behavior and function affecting aging adults and usually linked to brain disease (e.g., Alzheimer's) or injury (e.g., stroke)
  - Alzheimer's is **a disease of the brain** – dementia describes the resulting behavior
  - Most adults with Down syndrome (DS) are at **risk of Alzheimer's disease** and consequently dementia; same risk as general population for adults with other ID
  - **Average age of 'onset**' in Down syndrome is about **52** and +60s/-70s for ID; Alzheimer's begins some 20 years before 'onset'
  - **Changes in memory** often signal dementia in ID; changes in personality often signal dementia in DS
  - After diagnosis **progressive decline in DS** can last for from 1 to 7+ years; up to 20 years in other ID
  - Care after the early stage can become more challenging as memory, self-care, communication, and walking become more difficult… eventually leads to advanced dementia

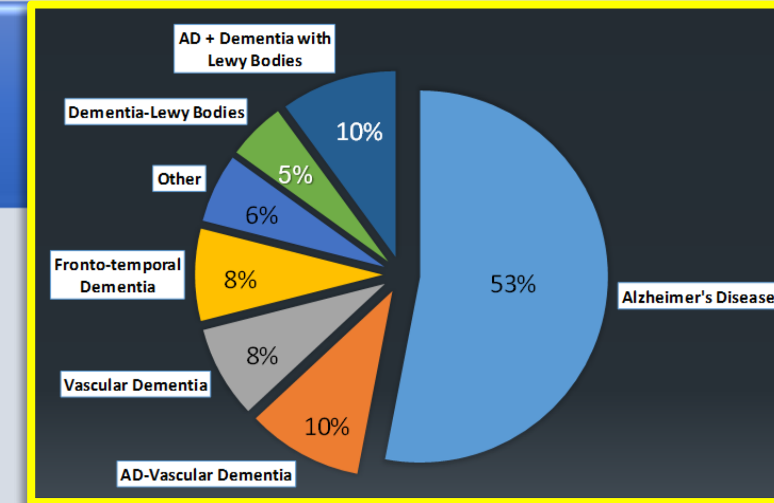
# Dementia Warning Signs

These problems must be notable and usually occur in a cluster

*In ID similar signs but of varying presentation depending on level of ID*



# Type of dementia can influence tx




- **Persons with intellectual disability (varying etiologies) may have a variety of dementias due to various causes**
- **Most adults with Down syndrome will have dementia caused by Alzheimer's disease**

Generally,

- ***Alzheimer's type dementia*** is linear and leads to a slow, progressive decline of function and loss of cognitive abilities
- ***vascular dementia*** is sporadic, will affect specific parts of the brain damaged by a vascular accident, and will cause a 'stepped' diminution of function
- ***fronto-temporal dementia*** will first affect behavior and personality and then eventually all function

***Why is it useful to know type?***

- *To determine 'course of treatment' and expectations of staging and rate of decline*
- *To help with determining best ways to handle 'challenging behaviors'*
- *To help with organizing care staffing patterns and clinical supports*

Janicki

# Impact and changes… ID and dementia

| | |
|---|---|
| **Rate of occurrence**[1,3,5,8,14] | ➢ Age-cohort % for adults with intellectual disability (ID) is like general population (~5-6% over 60)<br>➢ Much higher prevalence (60% >age 60) and neuropathology indicative of AD in most adults with Down syndrome (DS) |
| **Dementia type**[2,9] | ➢ Generally, dementia of the Alzheimer's type is prevalent *in DS*<br>➢ Similar range of dementias found in other ID as in other people |
| **Risk**[15] | ➢ DS & head trauma are significant risk factors in ID; social deprivation also a factor |
| **Onset**[1,2,3,10] | ➢ Average onset age in early 50s *for DS* – late 60s for others<br>➢ Most DAT diagnosed within 3 years of "onset" in adults *with DS* |
| **Behavioral changes**[2,3,6,11,12,13] | ➢ *In DS* - early change in personality more evident<br>➢ In other ID - initial memory loss more evident<br>➢ Notable changes in behavior: aggressiveness, agitation, apathy, incontinence, irritability, sleep disturbance, uncooperativeness |
| **Neurological signs**[1,2,4,7,16,17,18,19] | ➢ Late onset seizures in 24%-53% of adults w/DS<br>➢ Late onset seizures in DS - indicator of life expectancy of less than 2 years<br>➢ Seizures more common at end-stage (84%) versus at mid-stage (39%) AD |
| **Duration**[2, 17] | ➢ Aggressive AD *in DS* can lead to death <2 years of onset<br>➢ 2-7+ years mean duration *in DS*; probable death within 3-5 years of onset<br>➢ Same duration expected among other ID as in other people with dementia |

Sources: [1]Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. Mental Retardation,38, 277-289. [2]Janicki, M.P., & Dalton, A.J. (1999). Dementia, Aging, and Intellectual Disabilities: A Handbook. Philadelphia: Brunner-Mazel; [3]Bush, A., & Beail, N. (2004). Risk factors for dementia and Down syndrome. AJMR, 109, 83-97. [4] Menendez M. (2005). Down syndrome, Alzheimer's disease and seizures. Brain Development, 27(4), 246-252. [5]Zigman, W.B., Schupf, N., Devenny, D., et al. (2004). Incidence and prevalence of dementia in elderly adults with MR without DS, AJMR, 109, 126-141. [6]Ball, S.L., Holland, A.J., Hon, J., Huppert, F.A., Treppner, P., & Watson, P.C. Personality and behavior changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study. International Journal of Geriatric Psychiatry, 2006, [Jun 26]. [7]Crespel, A., Gonzalez, V., Coubes, P., & Gelisse, P. (2007). Senile myoclonic epilepsy of Genton: Two cases in Down syndrome with dementia and late onset epilepsy. Epilepsy Research, 77,165-168. [8]Evenhuis, H. (1997). The natural history of dementia in ageing people with intellectual disabilities. JIDR. 41(1), 92-96. [9]Strydom, A., Livingston, G., King, M., & Hassiotis, A. (2007).Prevalence of dementia in ID using different diagnostic criteria. Br. J. Psychiatry, 191, 150-157. [10] Margallo-Lana et al., (2007). Fifteen year follow-up of 92 hospitalized adults with DS. JIDR, 51, 463-477. [11]Gianpietro, N. (2013). Research in dementia in Down syndrome. Presentation at the SR Congresso Internazionale sulla Sindrome di Down, Roma, Italy, November 9, 2013. [12]Deb S. , Hare M., & Prior L. (2007). Symptoms of dementia among adults with Down's syndrome: a qualitative study. Journal of intellectual disability Research , 51(9), 726-739. [13]Cooper, S-A. (1997). A population-based health survey of maladaptive behaviours associated with dementia in elderly people with learning disabilities. Journal of Intellectual Disability Research, 41(6), 481-487. [14] Torr, J.,& Davis, R. (2007). Ageing and mental health problems in people with intellectual disability. Current Opinion in Psychiatry, 20(5), 467-471. [15]Moran J.A., Rafii, M.S., Keller, S.M., Singh, B.K., & Janicki, M.P., (2013). The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. Mayo Clinic Proceedings, 88(8), 831-840. [16] Esbenson, A.J., (2010). Health conditions associated with aging and end of life of adults with Down syndrome. Int Rev Res Ment Retard. 2010 ; 39(C): 107–126. [17] Prasher, V.P. & Corbett, J.A> (1993). Onset ofseizures as a poor indicator of longevity in people with down syndrome and dementia. International Journal of Geriatric Psychiatry, 8(11), 923–927. [18] Robertson, Hatton, Emerson, & Baines. (2015). Prevalence of epilepsy among people with intellectual disabilities: A systematic review. Seizure, 29, 46–62. [19] McCarron M, Gill M, McCallion P, Begley C. (2005). Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia. J Intellect Disabil Res., 49, 560–566.
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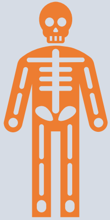
# Signs & Symptoms - Staging in AD

| Early Stage | Middle Stage | Late Stage |
|---|---|---|
| Confusion and memory loss | Difficulties with ADLs [“activities of daily living”] | Loss of speech |
| Disorientation in space | Anxiety, paranoia, agitation and other compromising behaviors | Loss of appetite, weight loss |
| Problems with routine tasks | Sleep difficulties | Loss of bladder and bowel control |
| Changes in personality and judgment | Sleep difficulties | Loss of mobility |
| | Difficulty recognizing familiar people | Total dependence on others |
| | | ~Death |

# Key Aspects of Dementia Presence to Consider When Planning Housing



## Onset

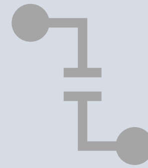
***When change is first noticed***

**For DS**: $\bar{X}$ = 52

**For ID**: $\bar{X}$ = late 60s - early 70s

Prevalence (DS ↗ 66%+

ID ⇄ 5 - 6%)



## Progression

***Patterns of change and decline***

For DS: Some quick losses, other more normative (changes in personality before memory)

For ID: Varied trajectories; leading to progressive decline

## Duration

***Length of time persons are affected***

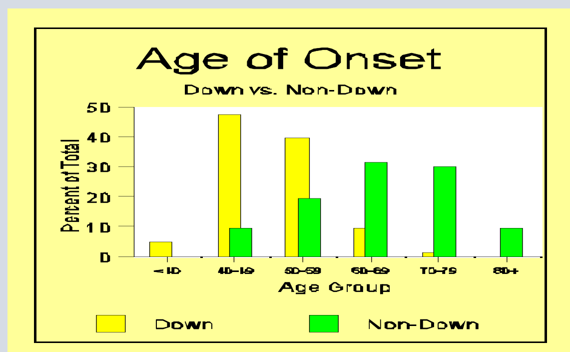
For DS: Compressed duration

For ID: Similar to general pop

# Factors to consider in dementia housing and care planning

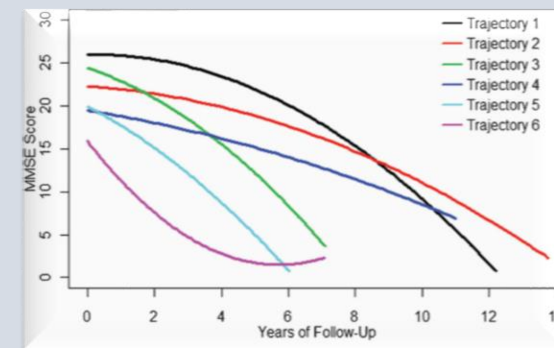
**Onset**

- *Onset is speculative . . .*
  - the best we can do is identify that point when significant change or impairment has become noticeable
  - early 50s for Down syndrome & late 60s for other ID




**Trajectory**

- Be aware of the expected trajectory of progressive dysfunction
- Influenced by
  - Duration (remaining life years)
  - Type of dementia
  - Health status/co-incidence conditions



# Why is 'onset' of importance?

- Knowing expected onset gives a head's-up for surveillance
  - Look for changes
  - Introduce periodic screening
  - Alert staff/caregivers to be watchful
  - Provides for an 'index of suspicion'
- Helps us to reformulate services and care practices
  - Creating safer environments
  - Signaling changes in demands for daily efforts
  - Planning ahead for eventualities
  - Setting goals for terms of service – adapting personal program plans

# EXPECTATION OF CHANGE AND FACTORS IN ID AND DEMENTIA UNDERLYING HOUSING AND CARE PRACTICES

**Expectations of change**

- Cognitive skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections, nutritional deficiencies, seizures

**Care factors**

- Watch for signs of abuse and neglect (including self-neglect)
- Watch for signs of caregiver burn-out and stress at home … affected on adult's behavior
- Watch for advanced dementia and needs for end-of-life care (palliative care and hospice)

**ID associated issues that extenuate these factors:**

- Co-incident conditions that may affect gait, sensory faculties, and cognition
- Co-morbidities or diseases that may affect physiological functions
- Previously identified 'mental health' issue
- Late-onset seizures
- Precocious (early) aging effects
- Expressive language difficulties
- Nutritional deficiencies & diet inadequacies
- Presence of polypharmacy

# Options for dementia care

## Staying

### Staying at home

- Continued care by family members until eventual advanced dementia and end-of-life
- *Considerations*: home adaptation, close supervision for safety and avoiding self-harm or neglect 24/7, possible *wheelchair* use, palliative and/or hospice aid

**Agency focus**
Outreach and community supports (HCBS)
Helping support family caregivers

## Leaving

### Leaving home

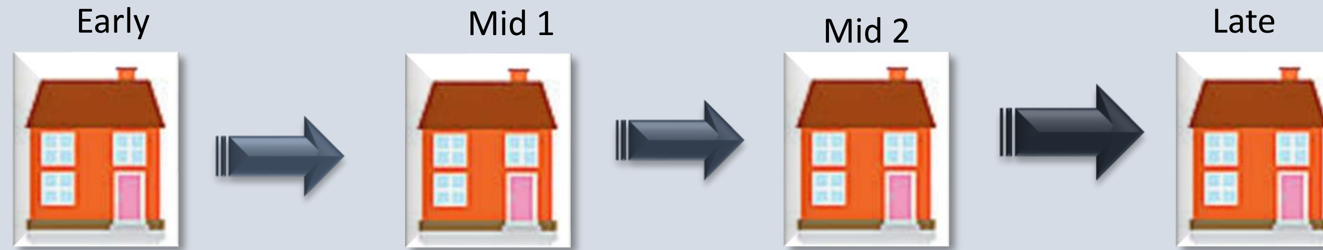
- Admission to a nursing facility after non-ambulatory care is necessary
  - *Consideration*: SNF capability & understanding of DS?
- Looking for an agency run specialty dementia care group home
- Other options – perhaps memory care centers, assisted living programs?

**Agency Focus**
Securing housing with dementia specialty care
Clinical team supports
Training for staff

# Prevalent models of group home-based dementia care

**AGING-IN-PLACE**

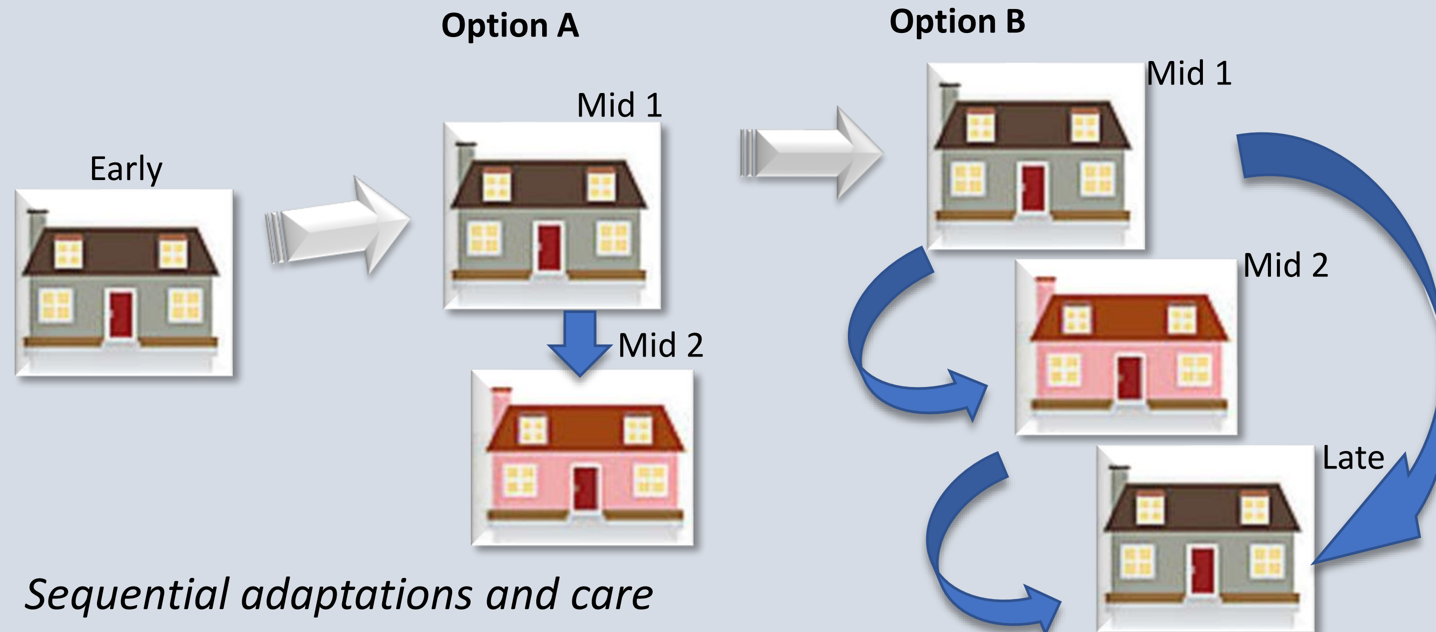
- *single care home and stable stay*




*Linear adaptations and care*

**IN-PLACE-PROGRESSION**

- *multiple care homes & movement with progression*




Mid = mid-level

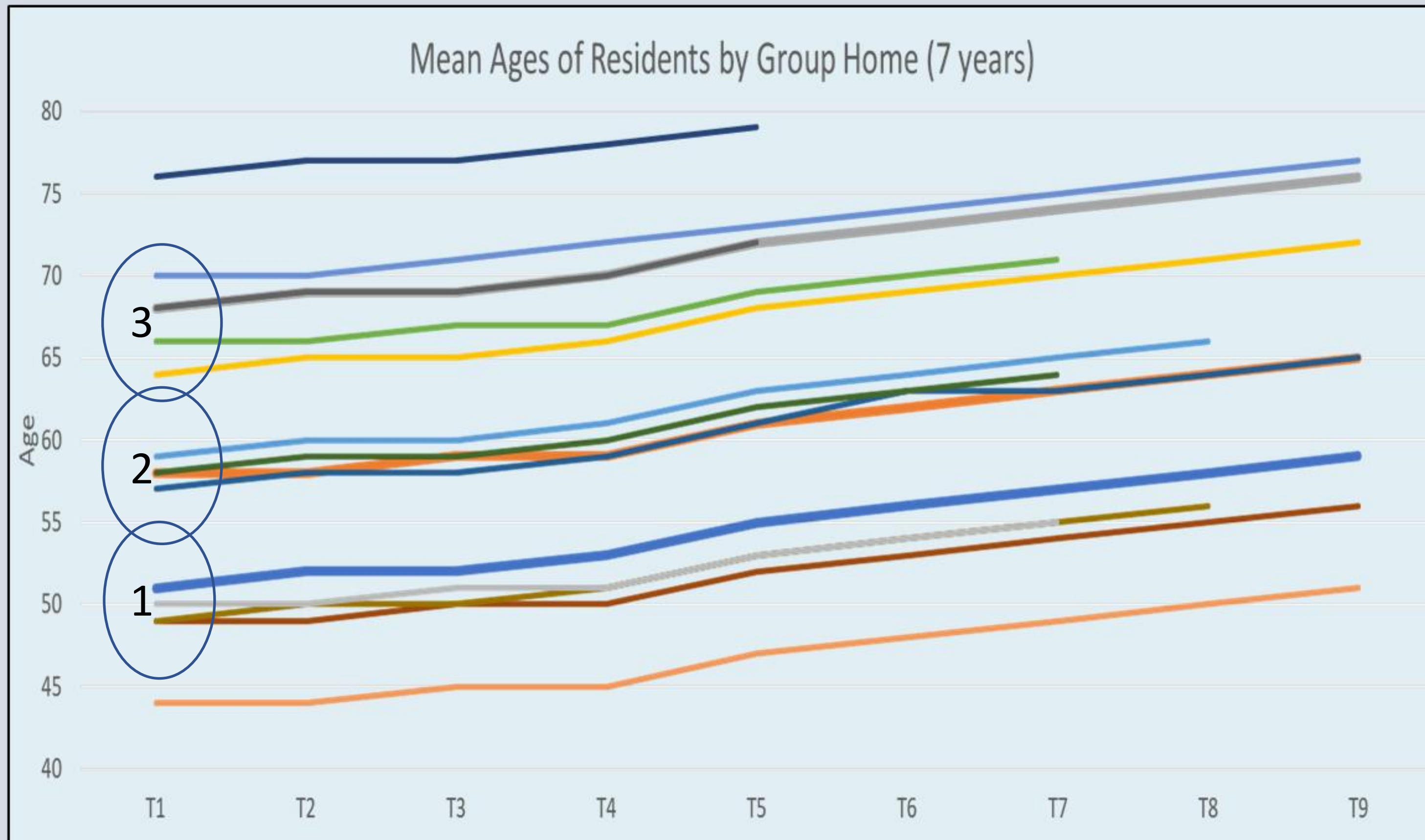
*Sequential adaptations and care*

Source: JANICKI (2010)

# Study

- Since 2011, we have been following a cohort of 15 legacy adults with ID (w/15 replacements) who lived in **3 purpose-built, 5-resident, dementia-capable GHs**
  - along with 15 community-dwelling (non-dementia) adults with ID as age-matched controls
- Data collected include resident function, demographics, health, and other related information as well as staff/home administrative factors

- √ Admission trends
- √ LOS
- √ Mortality
- √ Care patterns
- √ Staffing




# Admission age clusters

Admissions based on dementia and age showed a tri-modal pattern

- Admit Age Group #1 entry: ± age 50 [X=50.5] [range: 49-53] – *generally DS*
- Admit Age Group #2 entry: ± age 57 [X=57.1] [range: 56-59] – *some DS and ID*
- Admit Age Group #3 entry: ± age 67 [X=66.8] [range: 64-70] – *generally ID*

Outliers were either

- much older [76, 79] or
- much younger [40, 44]

| Resident IDD | T1 (2011w) | T2 (2011s) | T3 (2012w) | T4 (2012s) | T5 (2014) | T6 (2015) | T7 (2016) | T8 (2017) | T9 (2018) | T10 (2020)# | T11 (2021) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Home #1 Diana | | | | | | | | | | | |
| D-1 | | | | | | | | | | | |
| D-2* | | | | | | | | | | | |
| D-3 | | | | | | | | | | | |
| D-4* | | | | | | | | | | | |
| D-5† | | | | | | | | | | | |
| D-16 | | | | | | | | | | | |
| D-19* | | | | | | | | | | | |
| D-20 | | | | | | | | | | | |
| D-23^ | | | | | | | | | | | |
| D-25 | | | | | | | | | | | |
| Home #2 Lattner | | | | | | | | | | | |
| D-2* | | | | | | | | | | | |
| D-4* | | | | | | | | | | | |
| D-6† | | | | | | | | | | | |
| D-7† | | | | | | | | | | | |
| D-8 | | | | | | | | | | | |
| D-9† | | | | | | | | | | | |
| D-10† | | | | | | | | | | | |
| D-17† | | | | | | | | | | | |
| D-18 | | | | | | | | | | | |
| D-22 | | | | | | | | | | | |
| D-26 | | | | | | | | | | | |
| Home #3 WOW | | | | | | | | | | | |
| D-11 | | | | | | | | | | | |
| D-12† | | | | | | | | | | | |
| D-13 | | | | | | | | | | | |
| D-14 | | | | | | | | | | | |
| D-15† | | | | | | | | | | | |
| D-19* | | | | | | | | | | | |
| D-21 | | | | | | | | | | | |
| D-24 | | | | | | | | | | | |
| D-27 | | | | | | | | | | | |
| D-28 | | | | | | | | | | | |
| D-29 | | | | | | | | | | | |
| D-30 | | | | | | | | | | | |

# Length of stay patterns by home

Average LOS over 10 years for 3 group homes was 4.9 years (58.5 months)

*includes transfers, deaths, and new admissions*

Average LOS for 15 ‘legacy’ residents over 10 years was 8.3 years (99.6 months)

Implication

*home compositions may change over time*

Lighter color = DS

# Mortality

Original residents n=15
Survivor residents n=4 (27%)
11/15 (73.3%) died over 10 years

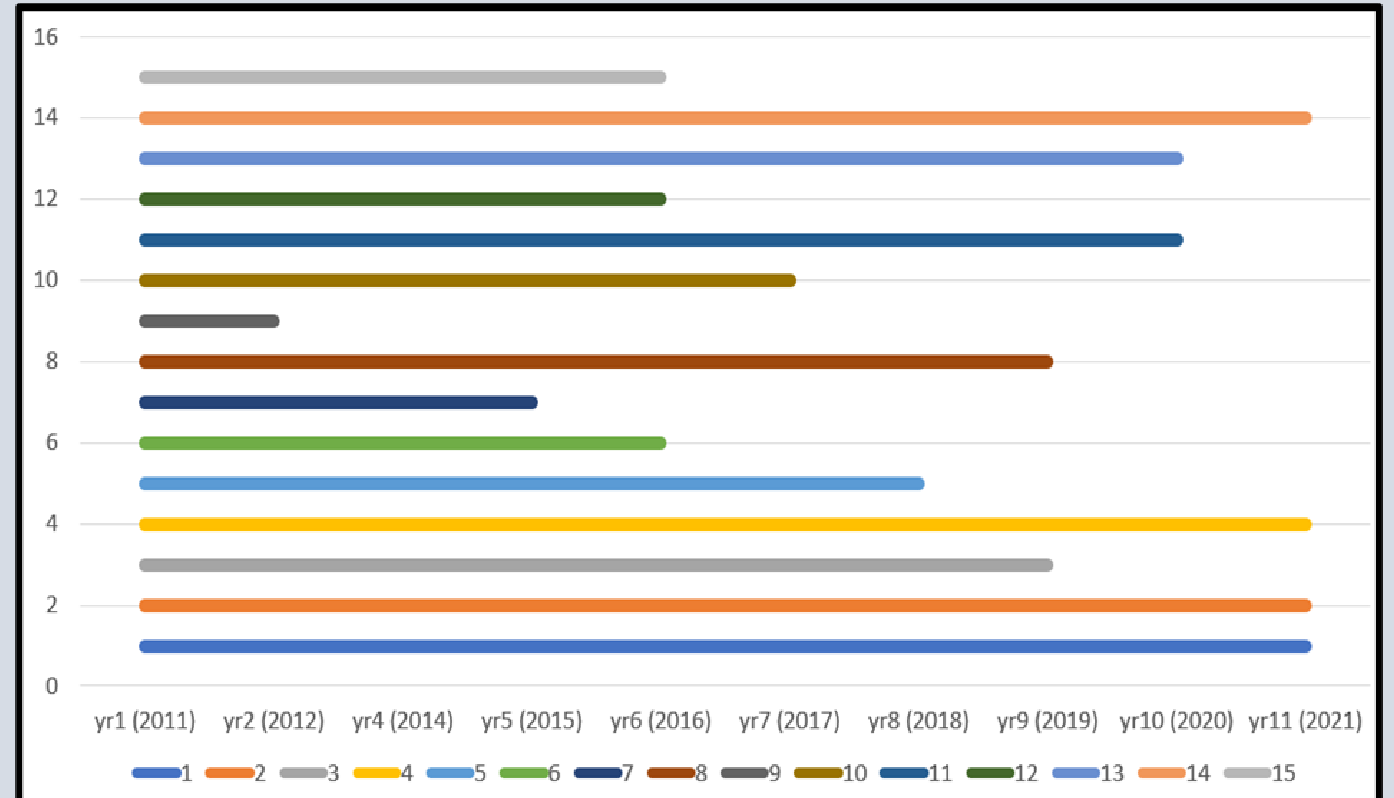
- *Mean age at entry: 59.1*
  - *[ID: 66.2; DS: 53.5]*
- *Mean* age at death = 67.5
  - *[DS: 58.8; ID: 72.4]*
  - *Males = 66.3 yrs; Females = 69.5 yrs*
- Mean years from entry to death: 5.4 yrs

Mean age at entry of original residents who

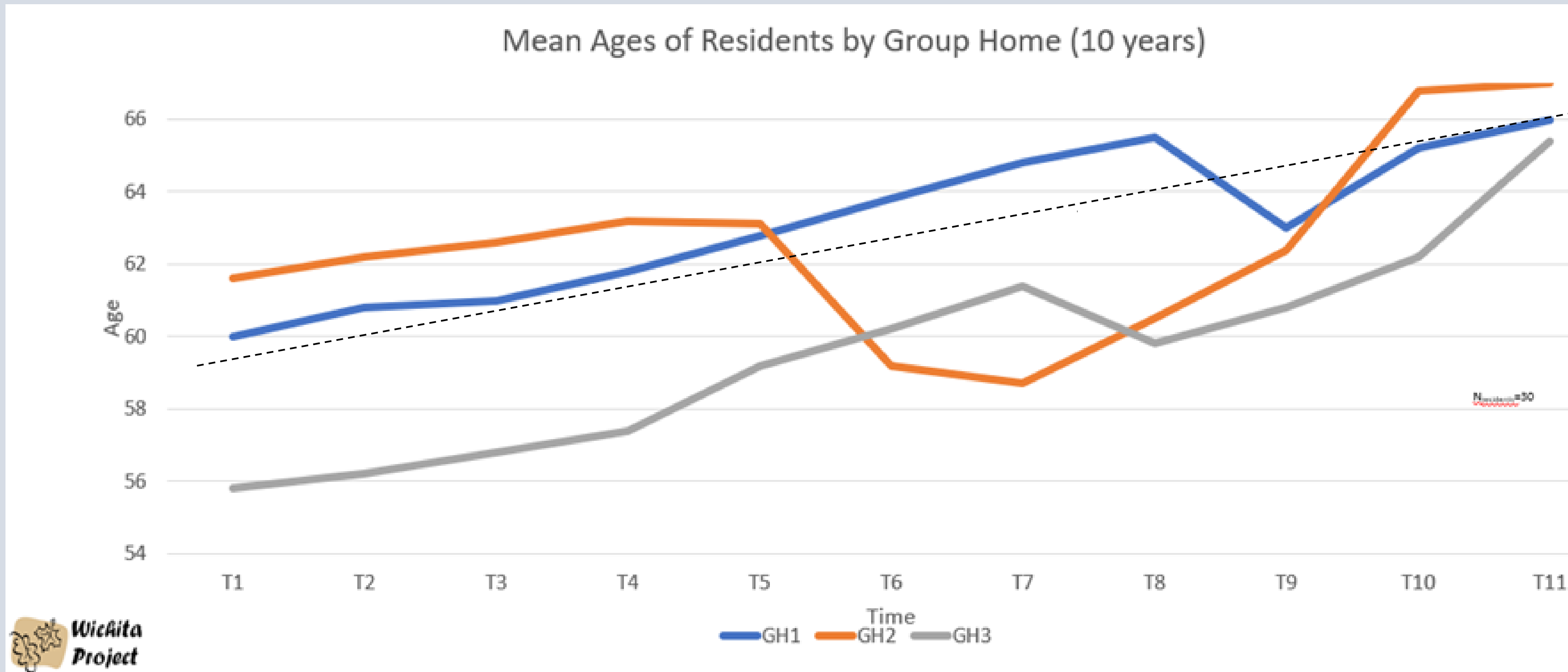
> died = 60.9

> are survivors = 54.4

- Deaths began 2 years following admission
- Average age of death for controls: 71.4 yrs
  - 5/15 (33%) deaths among controls



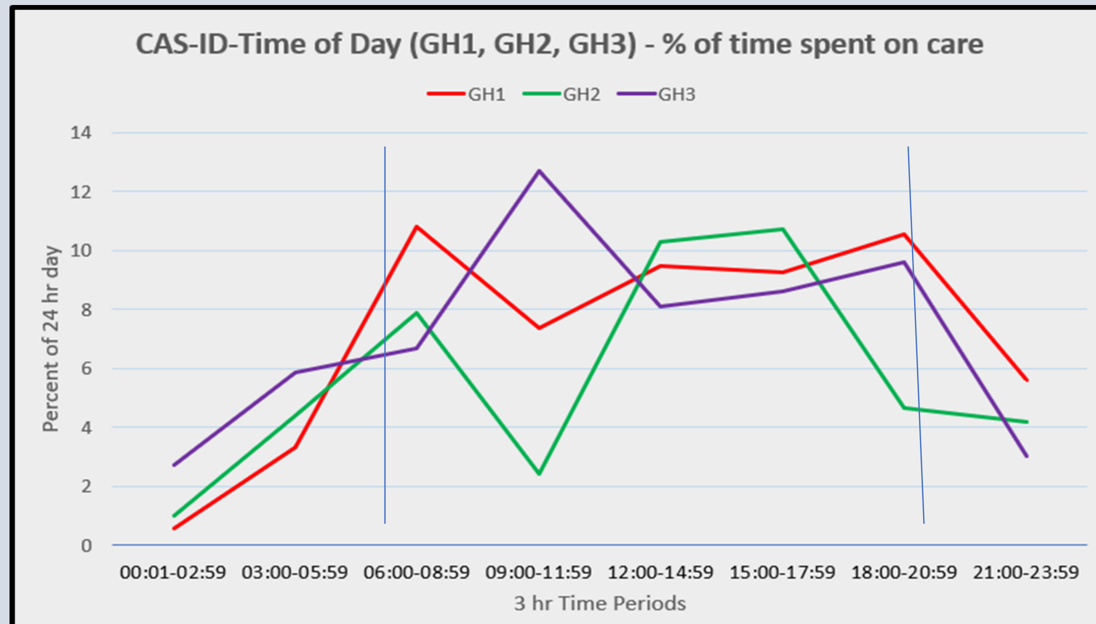

Legacy residents



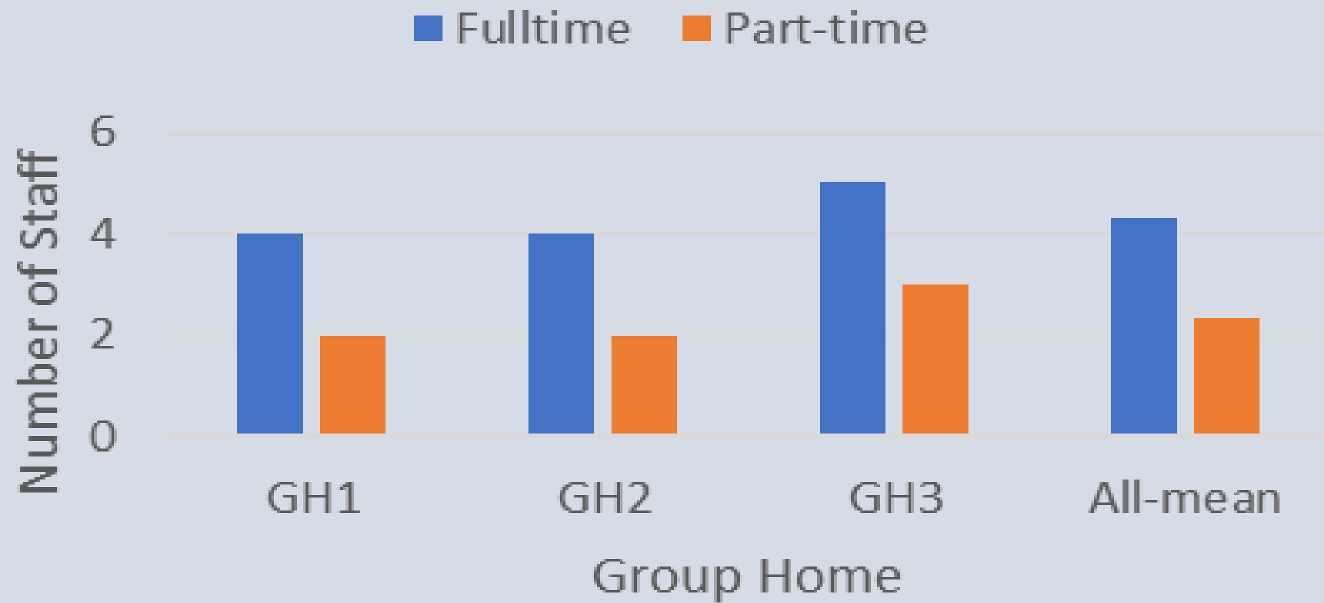

## Aging in place

- Long-term residents age in place and mean age of residents progressively rises
- New entry residents, if younger, lead to lower mean age, but eventually also show aging in place
- Implications – with aging, comorbidities increase need for health and medical care

# Staff time care patterns by home




- Staff care time patterns varied by homes as well as the caregiving focus
- Most time was spent on
  - **toileting aid** (GH1/GH3)
  - **eating/drinking assistance** (GH1/GH2)
  - **behavior management** (GH2)
- *Chart shows 3hr block pattern variations by home (averaged over 3 times – T1, T5 & T8)*




# Staff assignments by home

- More staff were assigned to GH3 – the advanced dementia home
- Mean staffing: 4.3 full-time and 2.3 part-time
- Implication – consider staffing patterns at home
  - Need more staff during times of peak activities and care
  - Need specialized staff
  - Plan for turn-overs

# Findings

- Of the 15 legacy residents 11 died and were replaced by 15 others (*greater mortality was noted among legacy residents with ID compared to DS*)
- All 30 residents (legacy and replacements) – exhibited features related to decline (*increasing problems, more comorbidities with age, and lessened function with dementia progression*)
- With multiple homes, over time there were inter-home transfers and new admissions, and the GHs trended toward stage/level specialty care
- There was an ebb and flow of movement related to stage of dementia and changes in character among the 3 dementia GHs, as well as variations in staffing patterns and periods of focused staff care and intensity during the day
- Costs and staffing patterns varied among the homes

# Implications for dementia care housing

| Location | Safety | Utility | Design |
| --- | --- | --- | --- |
| * Normative appearance and siting<br>* Ease of access to off-housing resources and amenities | * Control egress and facilitate outdoor use<br>* Evacuation factors<br>* Wandering paths<br>* Minimizing risk | * Single story<br>* Ambulation ease<br>* Wheelchair use<br>* Privacy vs public spaces | * Planful transitions with decline<br>* Functionality (bathing, common areas, colors, lighting, etc.) |

# What to think about…

- Is the **building** set up for dementia care? (single level, lighting, barrier free, yard)
- Have **staff** received specialized training?
- At what point does the agency **'admit'** to the home? Criteria? Matching to level of other residents?
- At what point does the agency **'terminate'** care? What are the policies? End-of-life options?
- How is the daily **support program** individualized? Involvement in community? How adapted to change in functions? How long do people **stay** at the home? Adaptable for advanced dementia?
- What are the attitudes and **capabilities** of staff? Is there comfort with dementia-capable care? Comfort with skills?
- What are the training and **clinical supports**?

- Dementia care expectations
  - **varied trajectories of decline**
  - **mortality linked to** complexity of **pre-existing conditions** and **progression of dementia**
  - **changes in the focus of care needs over time** (including advanced dementia and end-of-life care)

- Effective in-community dementia care is contingent on understanding
  - **what dementia does** to behavior and function
  - how well **staff are trained**
  - how agencies **provide supports** – *such as*
    - clinicians who can consult on care issues
    - help with planning when changes occur
    - staffing levels based on needs for care

# NTG Guidelines

**Guidelines** for **Dementia-related Health Advocacy** for Adults with Intellectual Disabilities and **Dementia** of the National Task Group on Intellectual Disabilities and Dementia Practices

**GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AFFECTED BY DEMENTIA**

## The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moran, DO; Michael S. Rafii, MD, PhD; Seth M. Keller, MD; Baldev K. Singh, MD; and Matthew P. Janicki, PhD

**Abstract**

Adults with intellectual and developmental disabilities (I/DD) are increasingly presenting to their health care professionals with concerns related to growing older. One particularly challenging clinical question is related to the evaluation of suspected cognitive decline or dementia in older adults with I/DD, a question that most physicians feel ill-prepared to answer. The National Task Group on Intellectual Disabilities and Dementia Practices was convened to help formally address this topic, which remains largely underrepresented in the medical literature. The task group, comprising specialists who work extensively with adults with I/DD, has promulgated the following Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities as a framework for the practicing physician who seeks to approach this clinical question practically, thoughtfully, and comprehensively.

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The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed as a response to the National Alzheimer's Project Act, legislation signed into law by President Barack Obama. One objective of the NTG is to highlight the additional needs of individuals with intellectual and developmental disabilities (I/DD) who are affected or will be affected by Alzheimer's disease and related disorders. The American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging With Developmental Disabilities—Lifespan Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities combined their efforts to form the NTG to ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are and continue to be considered as part of the National Plan to Address Alzheimer's Disease[1] issued to address the requirements of the National Alzheimer's Project Act.

Among the NTG's charges were (1) the creation of an early detection screen to help document suspicions of dementia-related decline in adults with intellectual disabilities, (2) the development of practice guidelines for health care and supports related to dementia in adults with intellectual disabilities, and (3) the identification of models of community-based support and long-term care of persons with intellectual disabilities affected by dementia. In 2012, the NTG issued "'My Thinker's Not Working': A National Strategy for Enabling Adults With Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports."[2]

A subgroup of the NTG was formed to focus specifically on health practices. The guidelines and recommendations outlined in this document represent the consensus reached among said specialists at 2 plenary meetings and ongoing discussions that followed, informed by a review of the current literature and drawn

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