Community-Based Dementia-Capable Housing for Adults with Intellectual Disabilities

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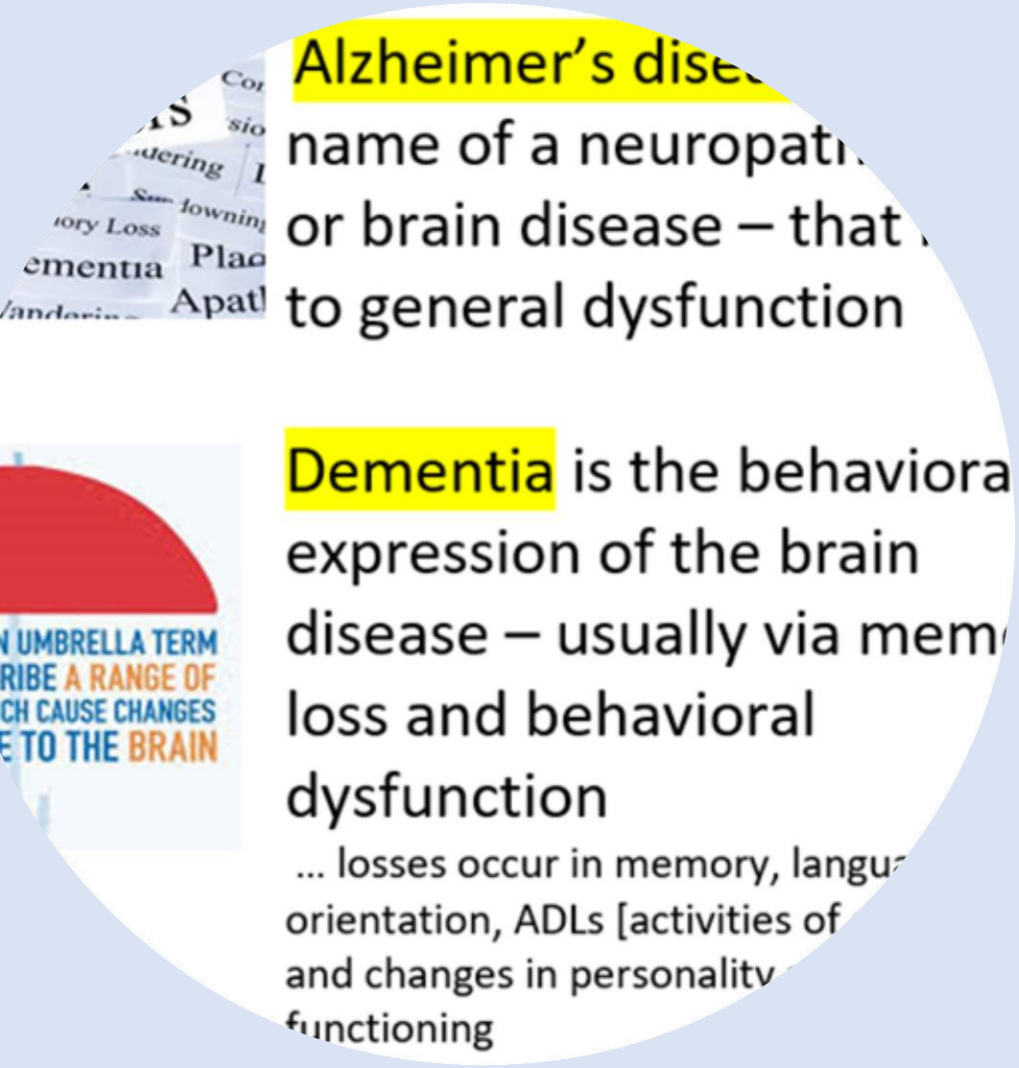
National Task Group on Intellectual Disabilities and Dementia Practices

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 dementia-capable group home
- Dealing with dementia calls upon agencies to make some critical decisions about dementia care and developing support resources

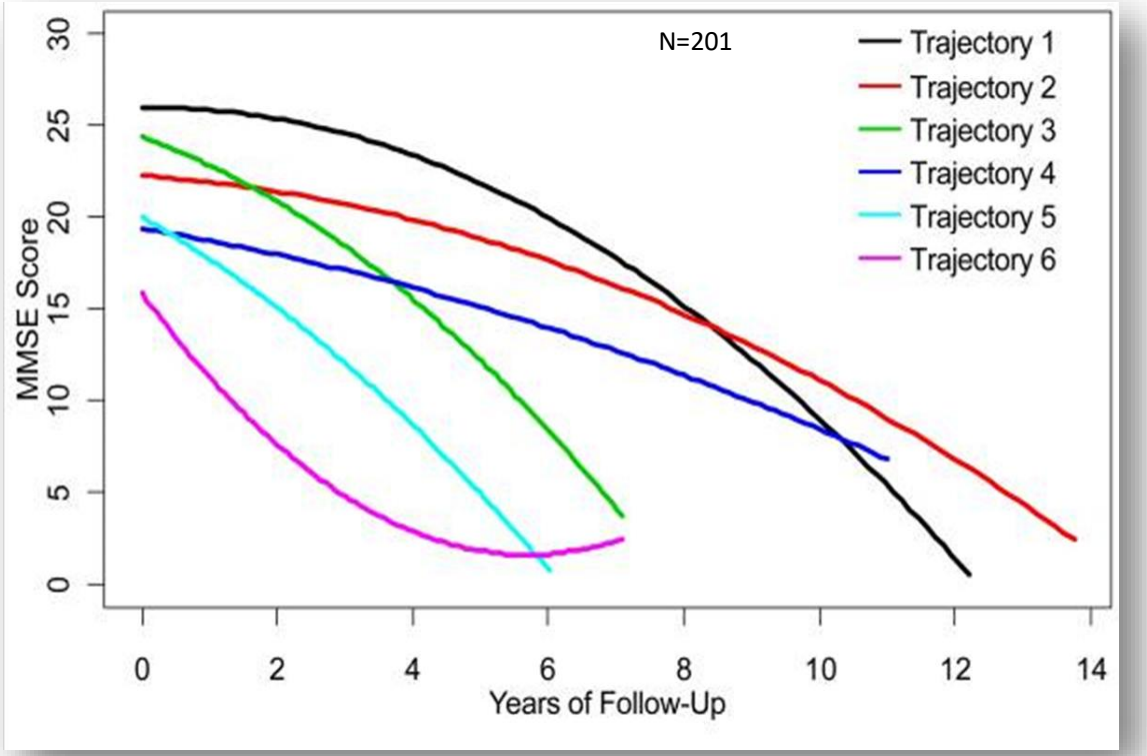


Things to know about dementia

- **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

Critical factors in dementia care planning

- Degree of retention of function
- Expected trajectory of progressive dysfunction
- Duration (remaining life years)
- Type of dementia
- Health status
- Environmental accommodations



Varying trajectories have implications for continual assessment and adaptations to care management

Source: Figure 2 from Wilkosz et al., (2009). Trajectories of cognitive decline in Alzheimer's disease. *International Psychogeriatrics*, 28,1-10

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

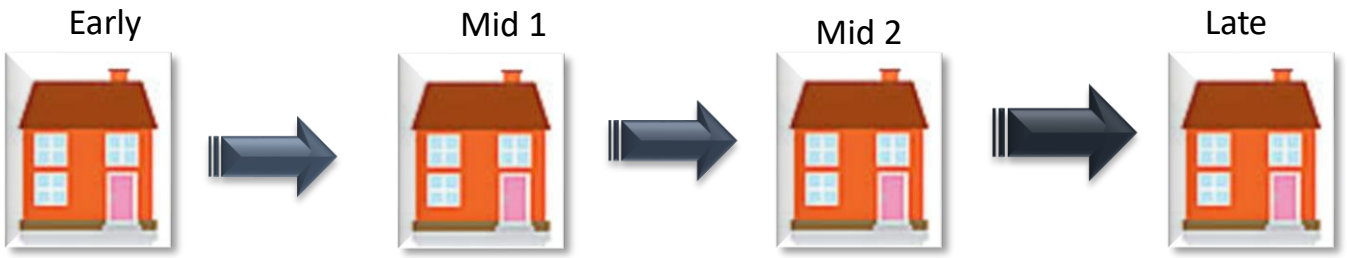
- Admission to a nursing facility after non-ambulatory care is necessary
  - *Consideration*: SNF capability & understanding of DS?
- Looking for an agency run specialty dementia care group home
- Other options – perhaps memory care centers, assisted living programs?

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

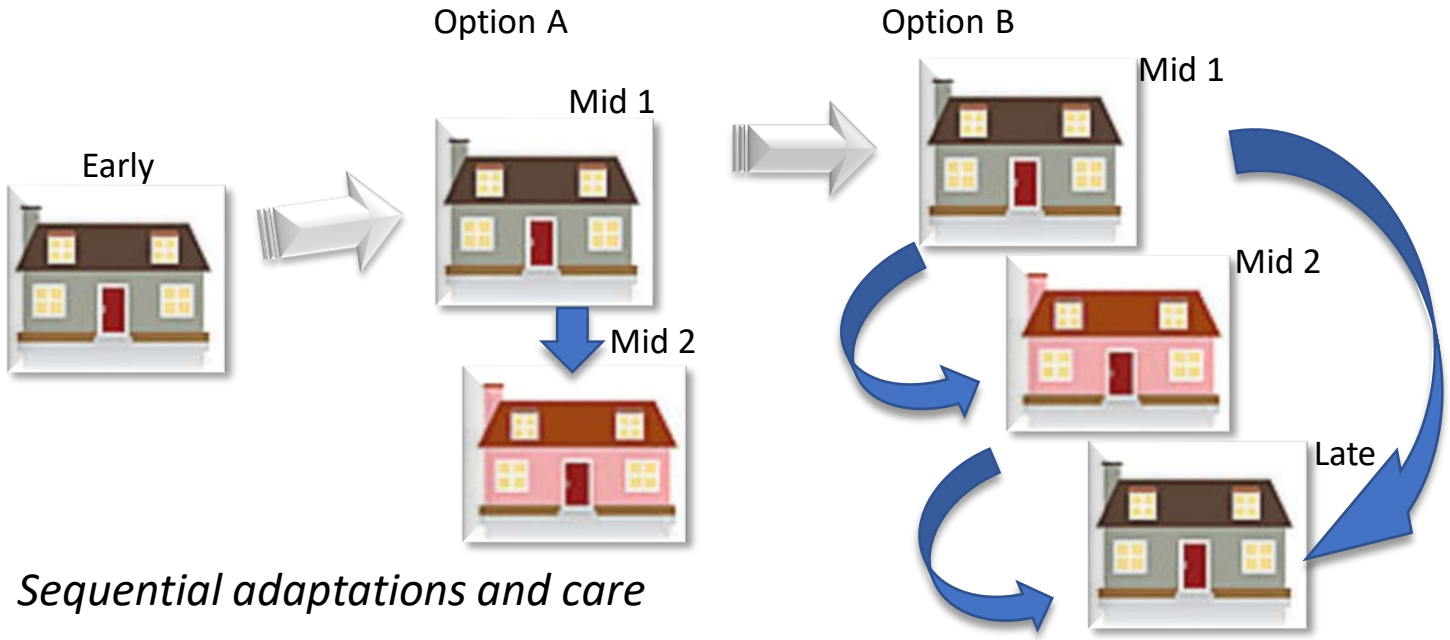
- *single care home and stable stay*



Linear adaptations and care

IN-PLACE-PROGRESSION

- *multiple care homes & movement with progression*



Sequential adaptations and care

Mid = mid-level

Source: JANICKI (2010)

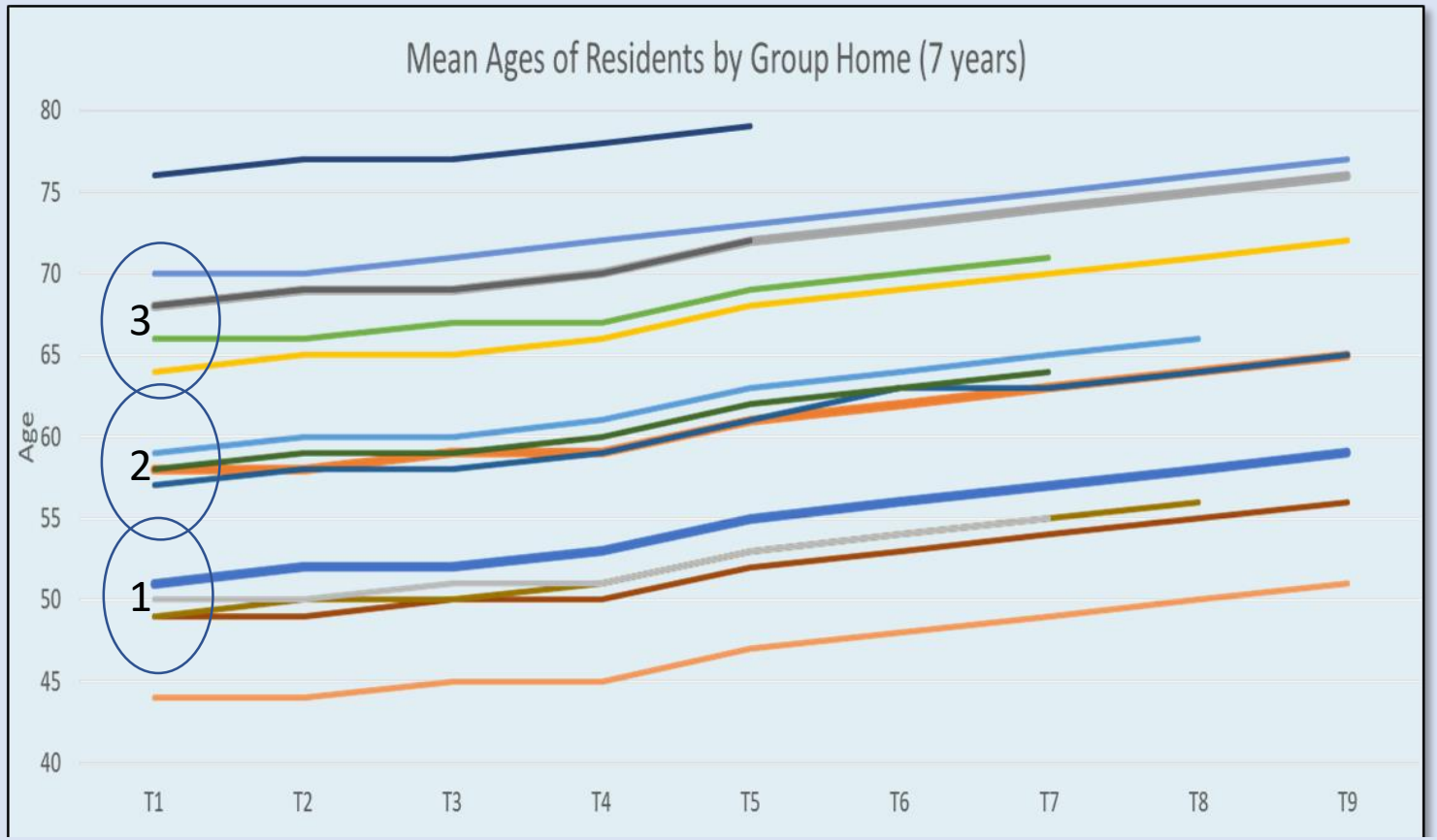
Study

- Since 2011, we have been annually following a cohort of 15 legacy adults with ID (w/ 8 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

What are we finding?

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

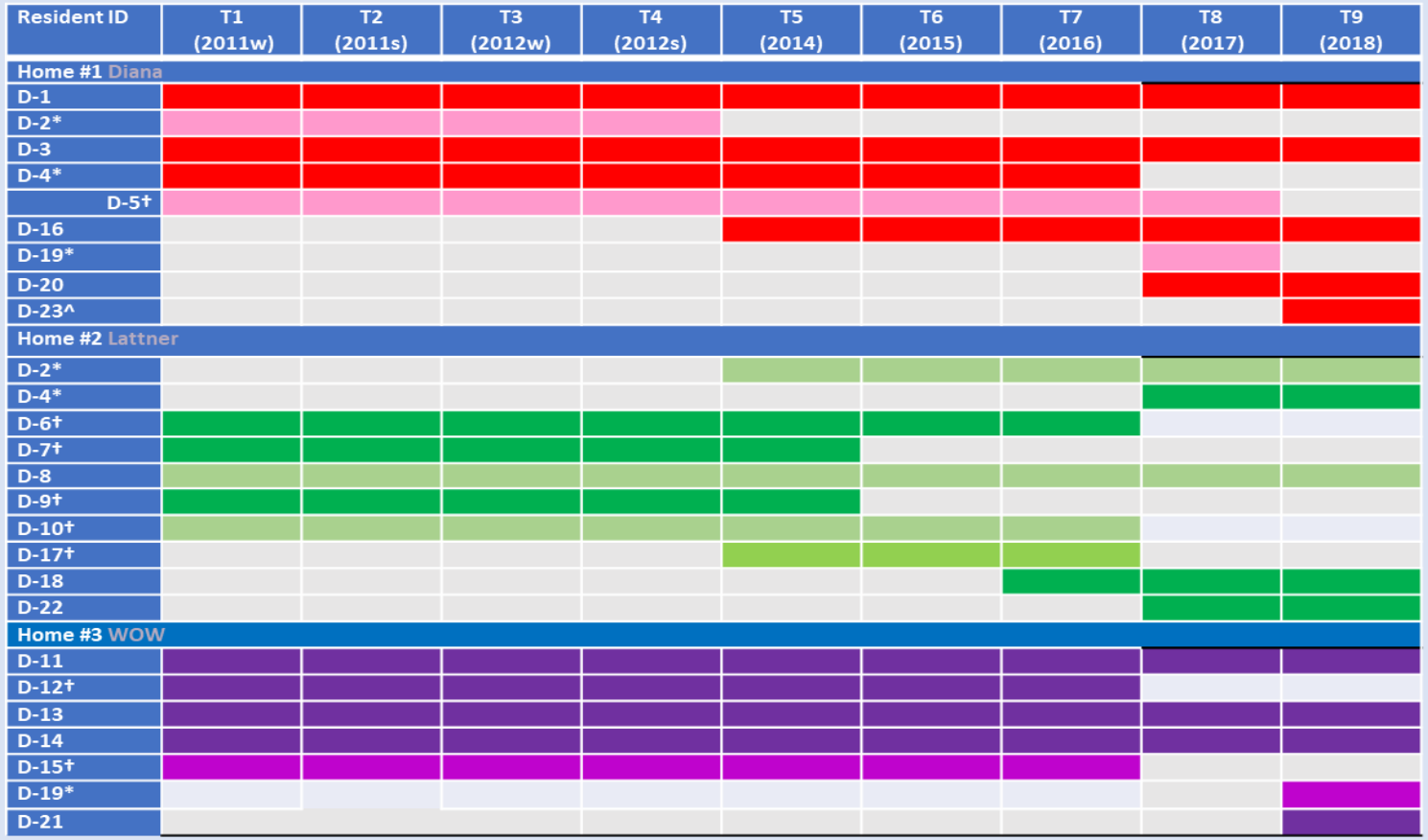


Admission age clusters

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]



Length of stay patterns by home

Average LOS over 7 years for each home was

- GH1: 49.0 months (4.0 yrs.)
- GH2: 45.6 months (3.8 yrs.)
- GH3: 56.7 months (4.7 yrs.) (most stable)
- Overall mean LOS for all was 49.4 months (4.12 yrs) post admission

- Implication – home compositions may change over time

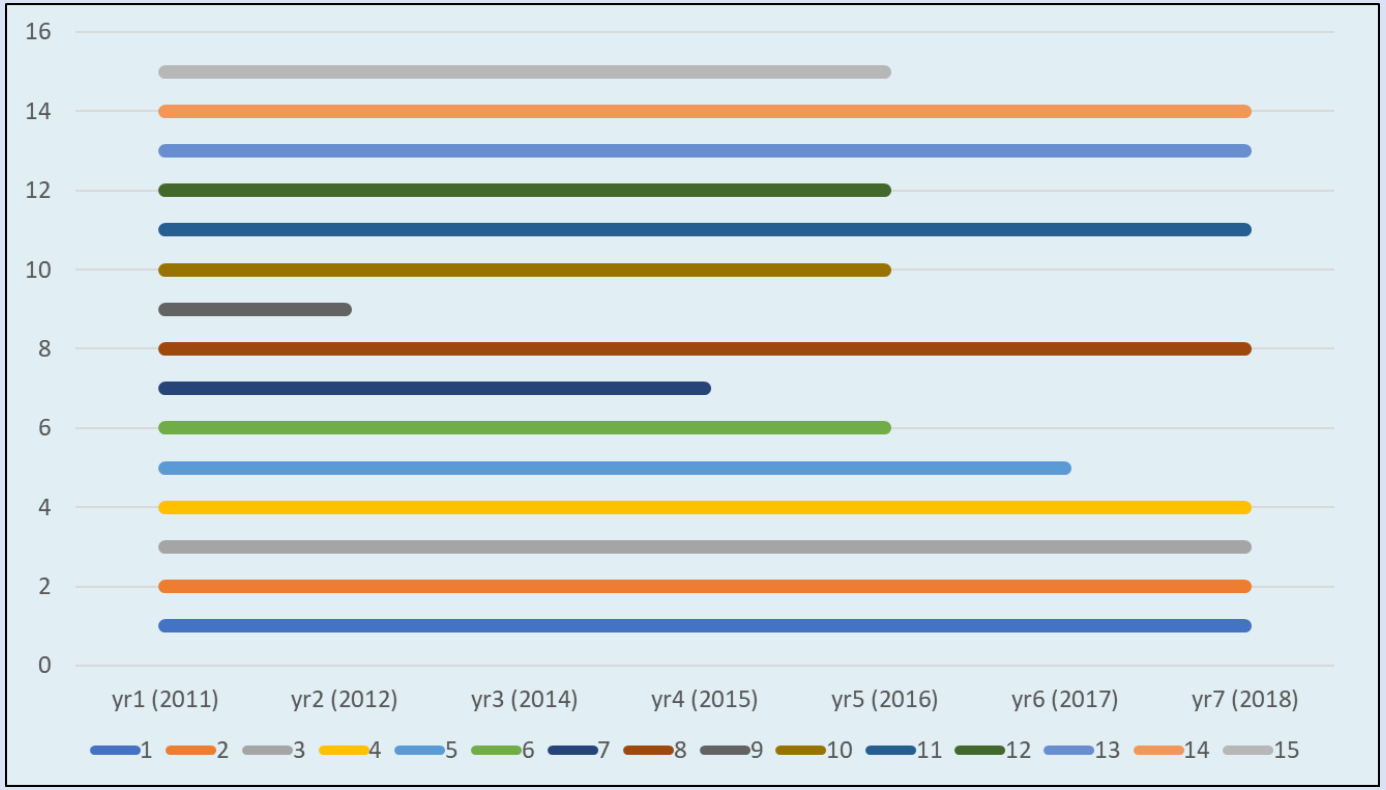
Lighter color = DS

Mortality

Of **legacy adults**, 8/15 (53%) died over 7 years

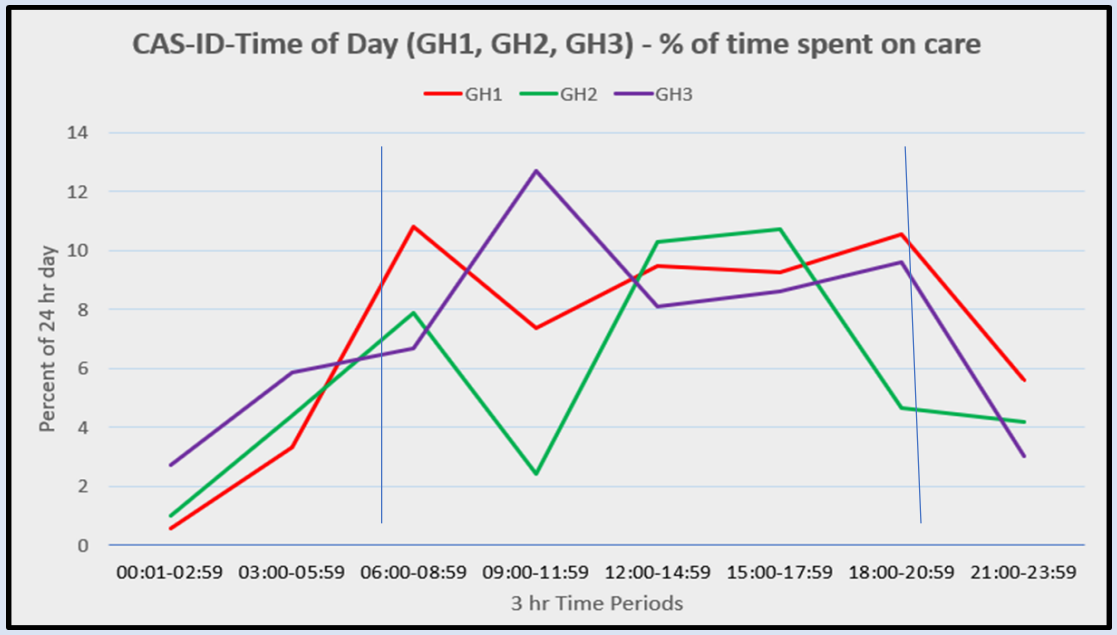
- *Average age at entry: 59.1*
  - *[ID: 66.2; DS: 53.5]*
- *Mean* age at death = 65.2
  - *[DS: 58.8; ID: 71.5; M: 66.6; F: 65.0]*
- Mean years from entry to death: 5.4 yrs
- Deaths began 2 years following admission

- Average age of death for Controls: 78.5 yrs.



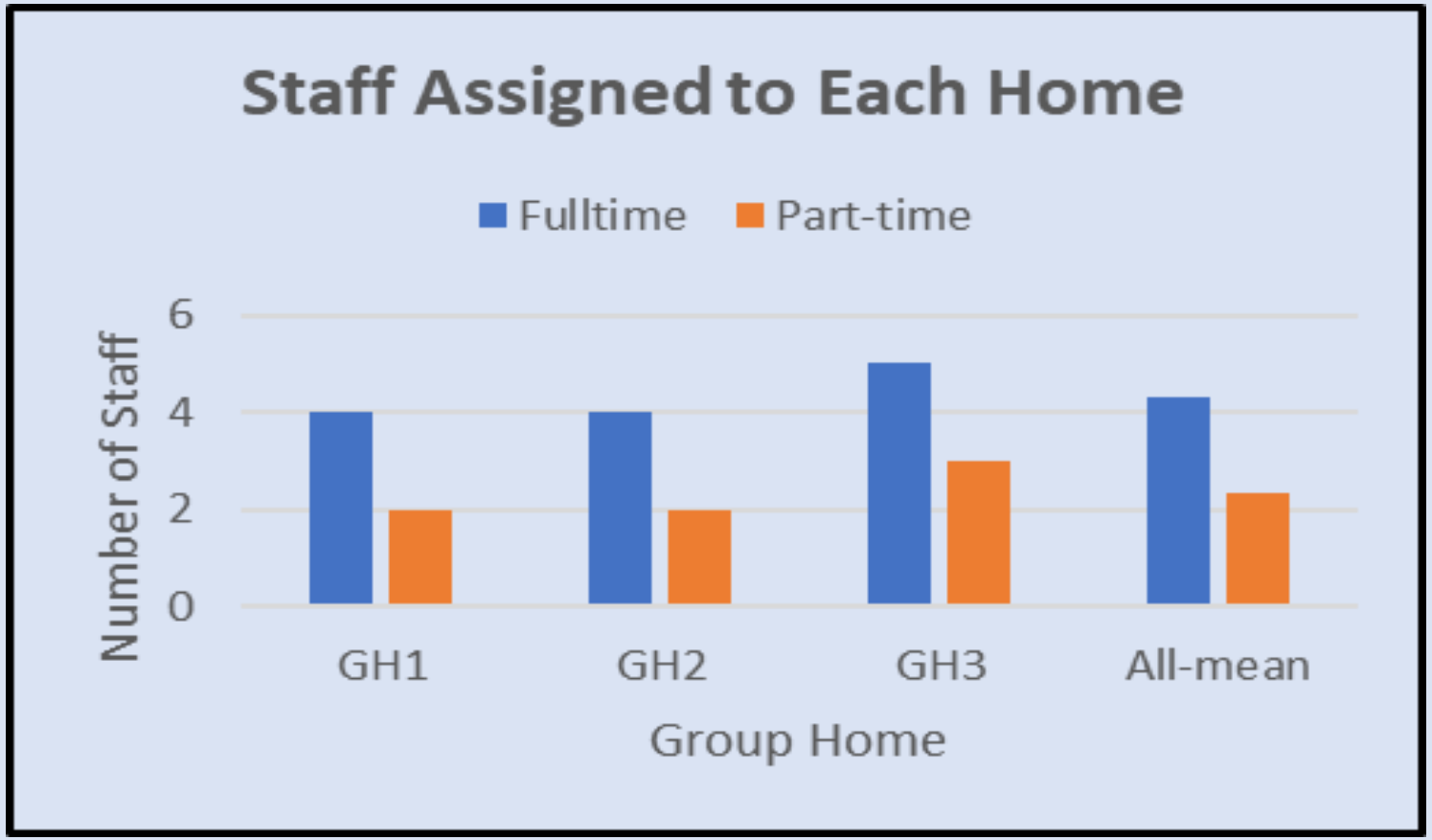
Legacy residents

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 – look at staffing patterns at home
  - Are there more staff during peak activities times?
  - Are there specialized staff?
  - What is the turn-over rate?

Findings

- **Of the 15 legacy residents 8 died and were replaced by 8 others (*greater mortality was noted among legacy residents with ID compared to DS*)**
- **All 23 residents (legacy and replacements – [All-ID/D]) exhibited features related to decline (*increasing problems, more comorbidities with age, and lessened function with dementia progression*)**
- **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 housing

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

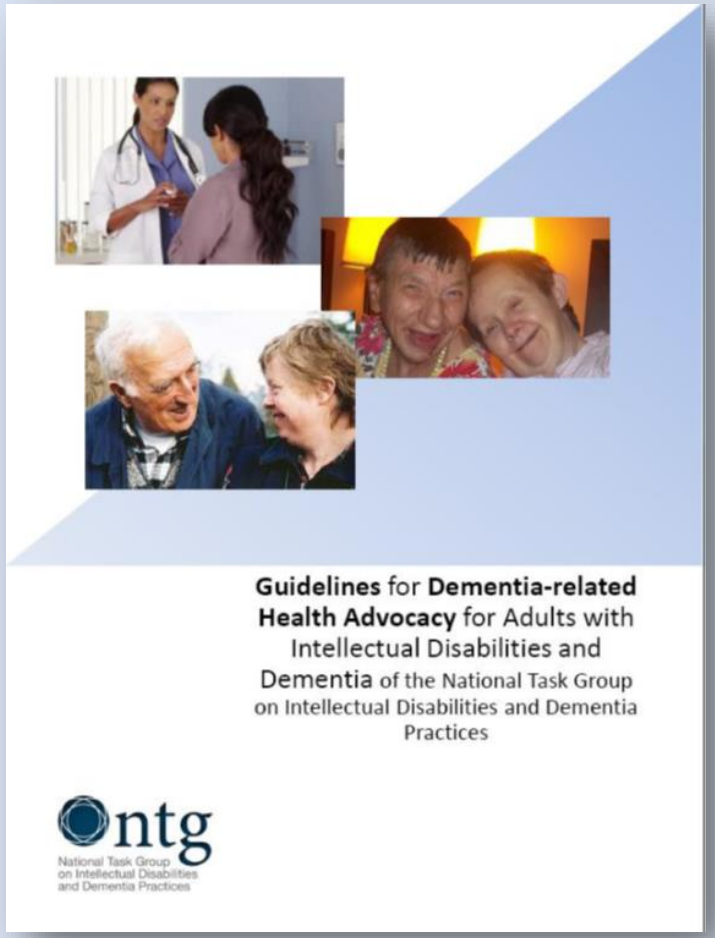
What to think about…

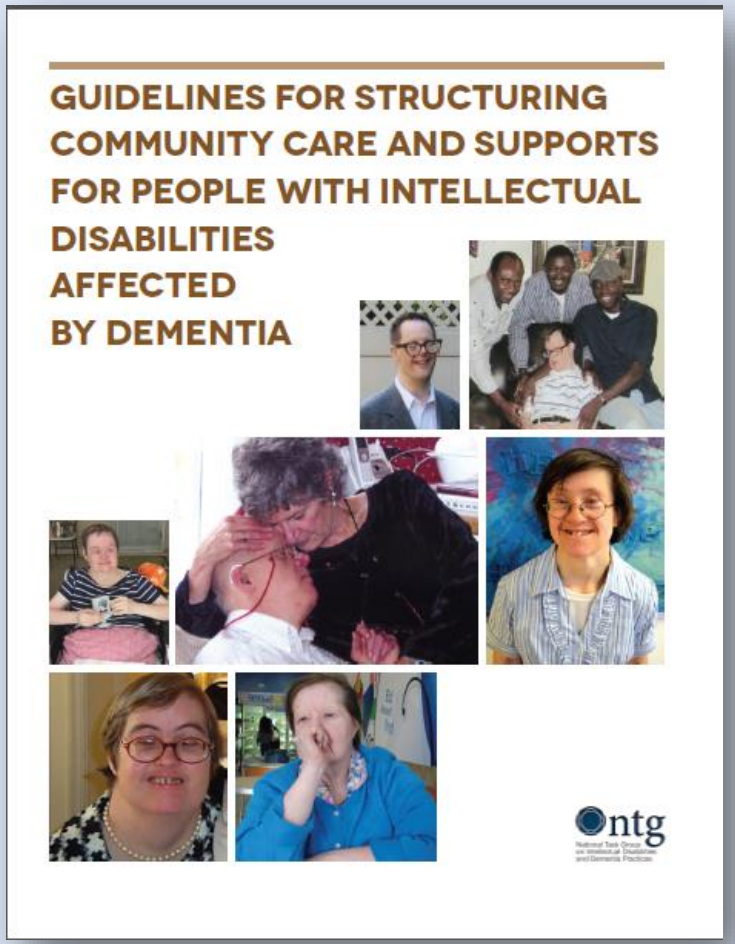
- Is the building set up for dementia care? (single level, lighting, barrier free, yard)
- Have staff received specialized training?
- At what point does the agency ‘admit’ to the home? Criteria? Matching to level of other residents?
- At what point does the agency ‘terminate’ care? What are the policies? 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?

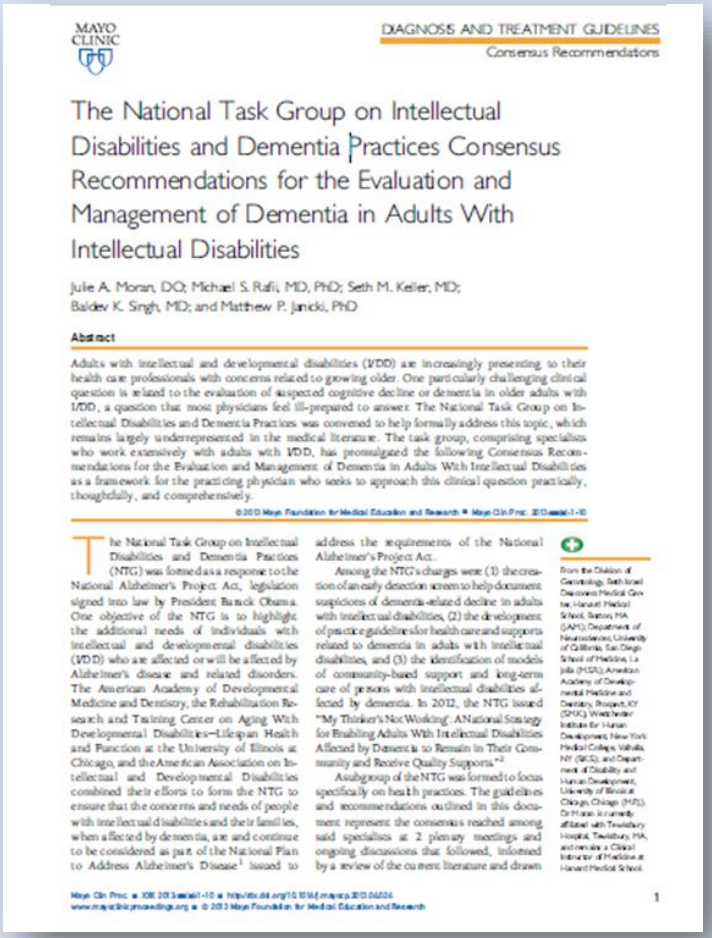
Last thoughts

- Dementia care GHs should expect
  - **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) if residents stay in place
- Dementia care GHs can enable agencies to provide in-community group housing and quality care in accord with stage-defined functional changes and needs ***if structured in a planful way***

NTG Guidelines







www.aadmd.org/ntg/guidelines

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