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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 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

UNDERSTANDING DEMENTIA

Knowns…

- People with ID have same rate of dementia as general population
- Some people with ID have higher rates (e.g., Down syndrome, head injury)
- Some % of any adult client pool will be affected
- Early interventions can aid in adapting to changes and prolonging lucid periods
- Effects of dementia will be progressive and eventually lead to death

Unknowns…

- Who will be affected?
- How pronounced will be early changes?
- How dramatic will be the changes in function?
- How long will person live after diagnosis?
- What other diseases or medical conditions may be co-incident?
- Which particular dementia-related behaviors will be more evident?

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

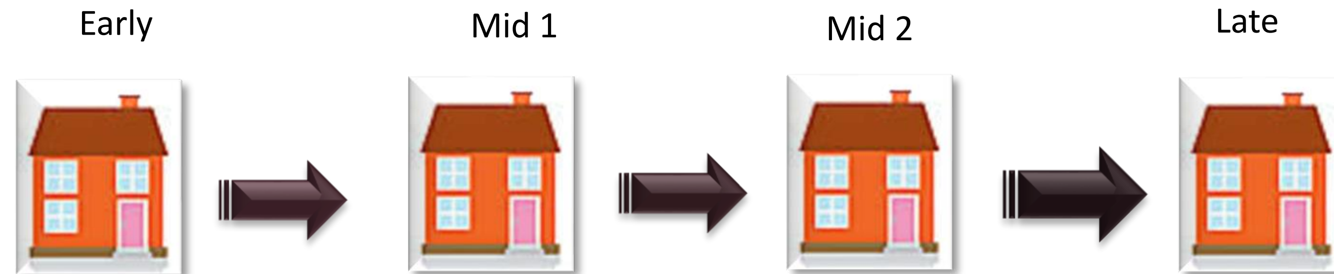
- Admission to a nursing facility after non-ambulatory care is necessary
  - *Consideration*: SNF capability & understanding of DS?
- Looking for an agency run specialty dementia care group home
- Other options – perhaps memory care centers, assisted living programs?

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

Group Home Models for Supporting Adults with Dementia

AGING-IN-PLACE

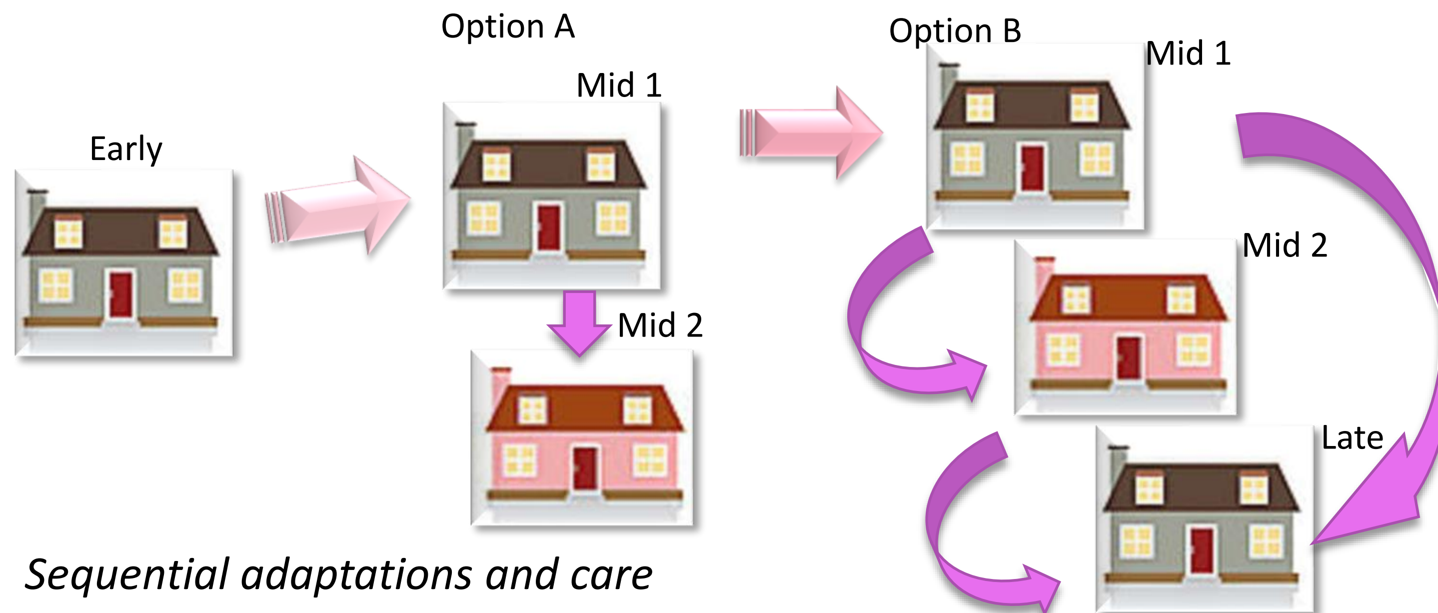
• *single care home and stable stay*



Linear adaptations and care

IN-PLACE-PROGRESSION

• *multiple care homes & movement with progression*



Sequential adaptations and care

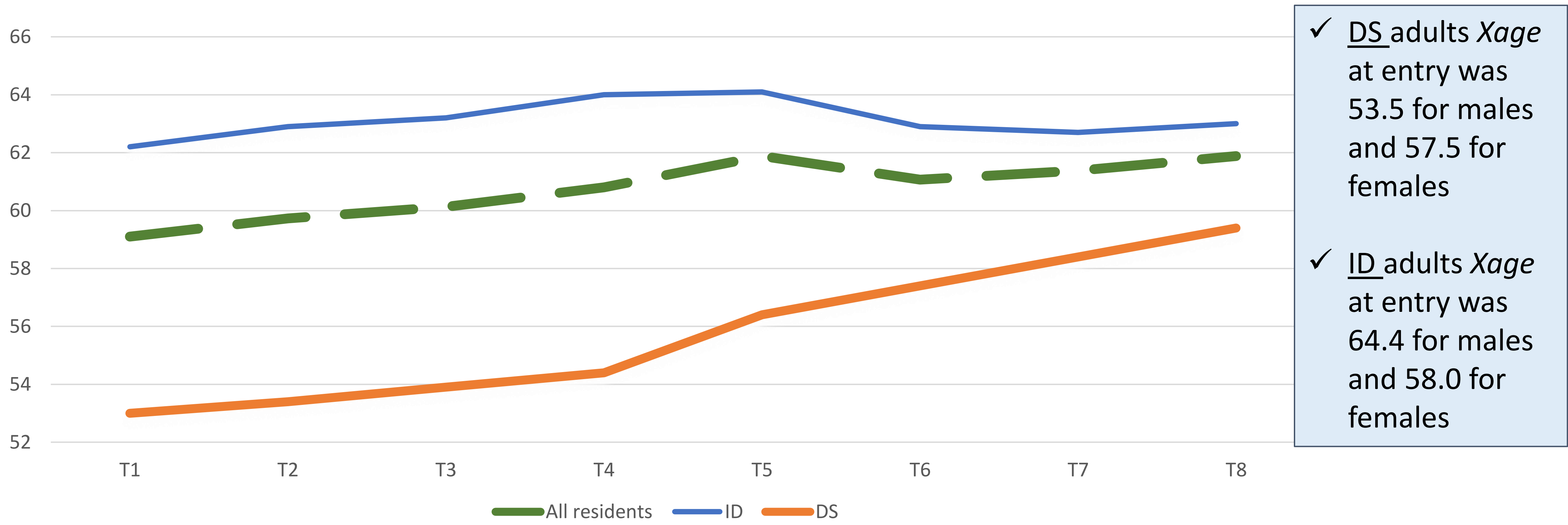
Mid = mid-level

Source: JANICKI (2010)

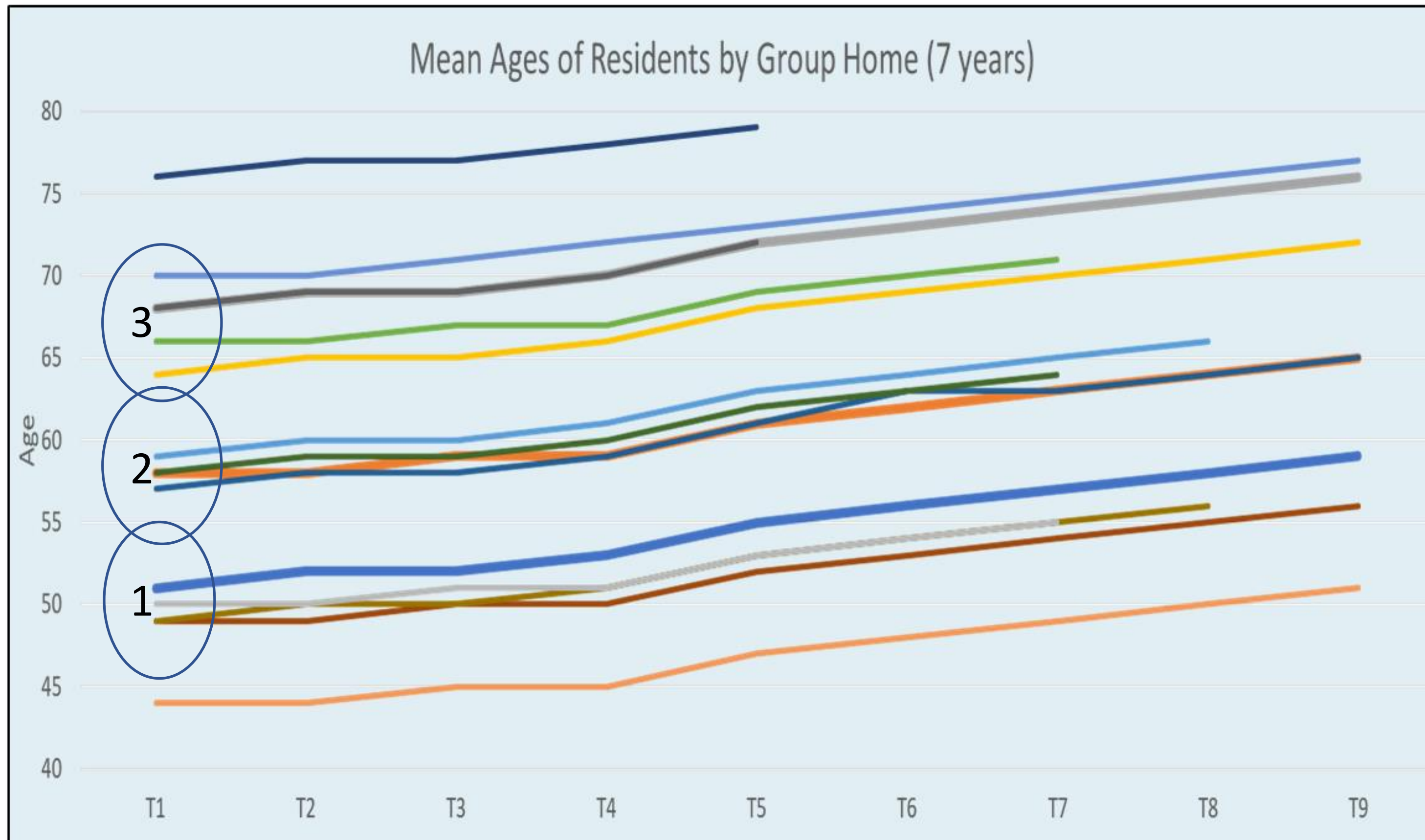
Planning Dementia Capable Housing

- Considerations RE: adults living with dementia
  - When to ‘admit’?
    - Ages, conditions, home capabilities, expectations for length of stay eventual needs
    - How to determine appropriateness (diagnostics)
    - Staff make-up and capabilities
  - Housing stock?
    - Nature of physical housing: Adaptable for long term care? Barrier free design? Suitable for dementia care? Size (N residents)?
    - Locational issues – In-community? Safety factors? Wandering?
  - Preparation?
    - Staffing (training – dementia care); Adaptability for ambulatory to non-ambulatory care; Consultation availability?
    - Licensing demands – State regulatory standards? Which ‘system’ accountable? Financing?

Mean ages of GH residents – ID vs DS



Wichita Project



Ages at admission

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]

Wichita Project

Deaths and length of stay

Original residents n=15
Survivor residents n=3 (27%)
12/15 (80.0%) died over 11 years

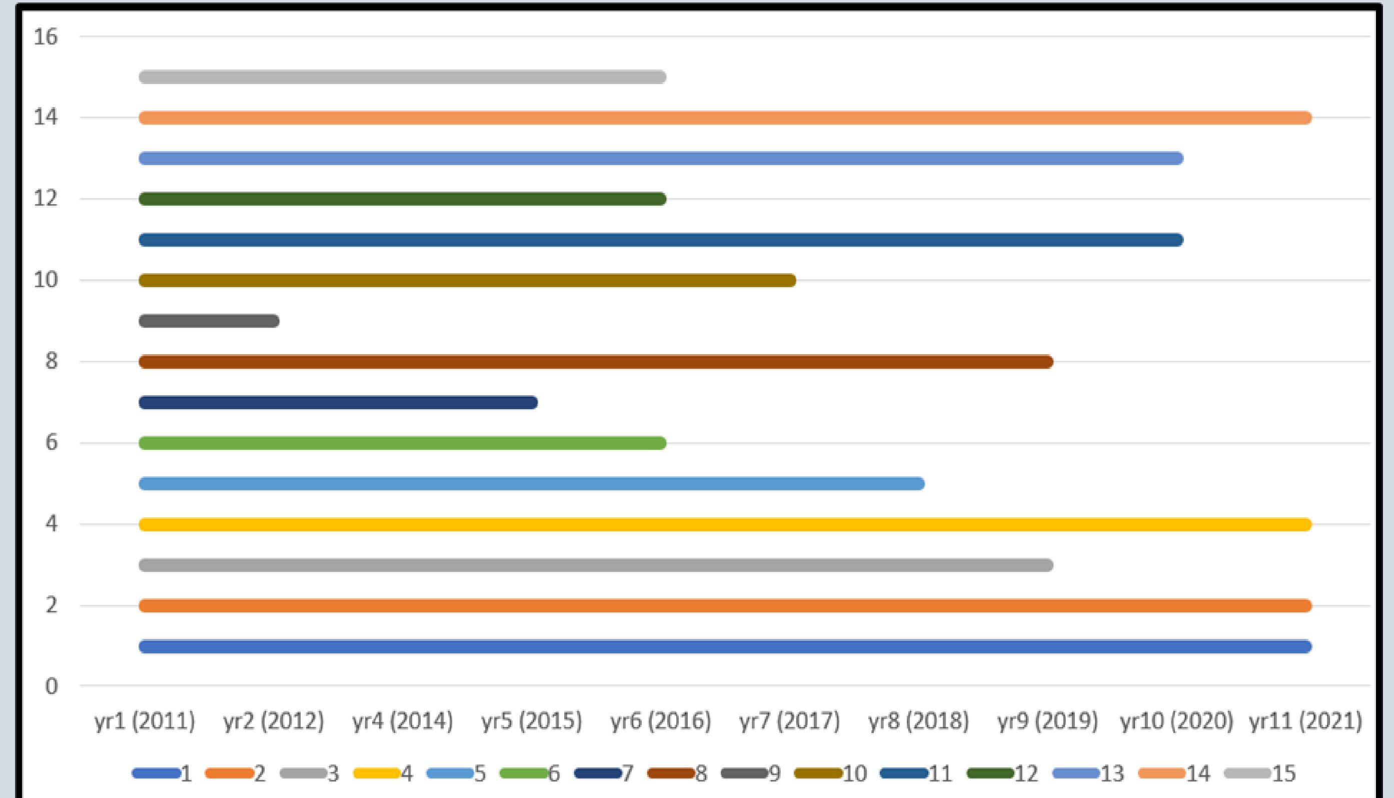
- *Mean age at entry: 59.1*
  - *[ID: 66.2; DS: 53.5]*
- *Mean* age at death = 67.5
  - *[DS: 58.8; ID: 72.4]*
  - *Males = 66.3 yrs; Females = 69.5 yrs*
- Mean years from entry to death: 5.4 yrs

Mean age at entry of original residents who

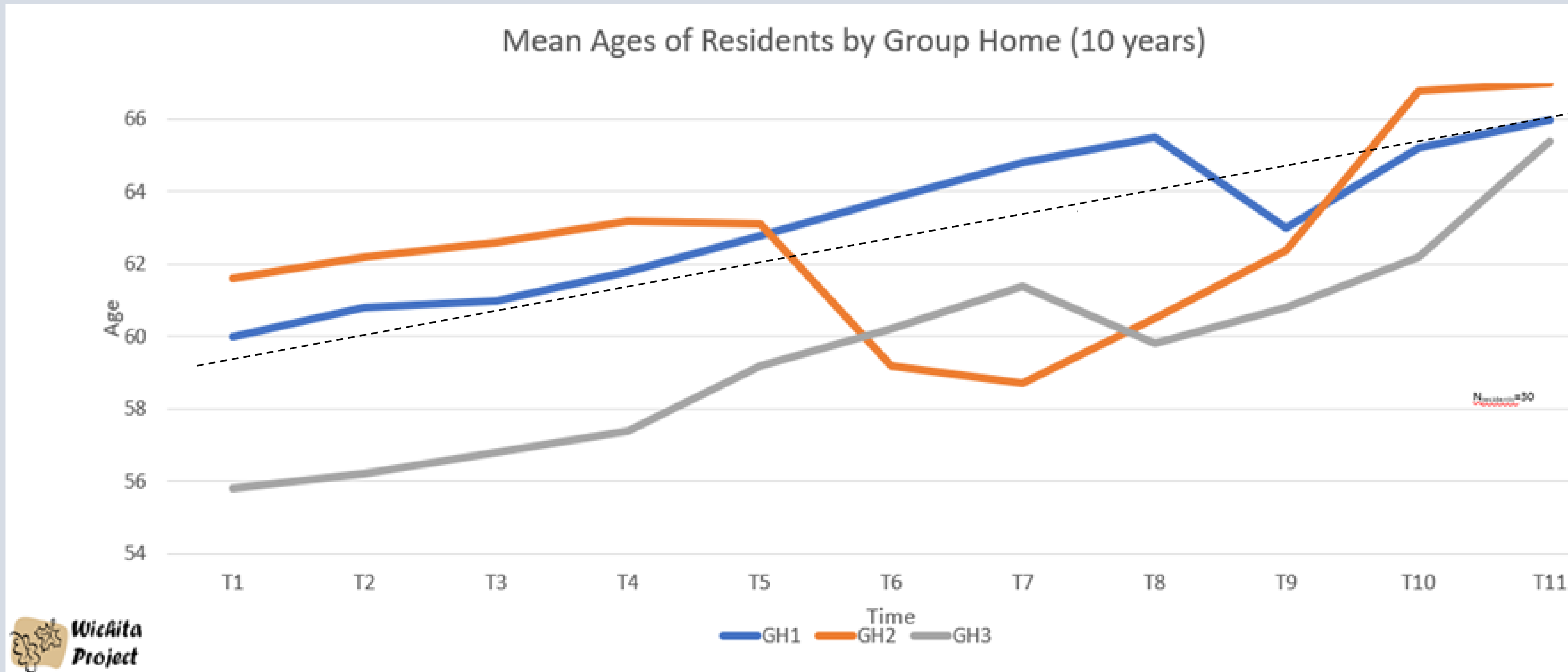
> died = 60.9

> are survivors = 54.4

- Deaths began 2 years following admission
- Average age of death for controls: 65.5 yrs
  - 7/15 (47%) 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

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

Key Points

- 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

- 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?

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.)

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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