

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

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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 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

Alzheimer's disease is the most common name of a neuropathic or brain disease – that leads to general dysfunction

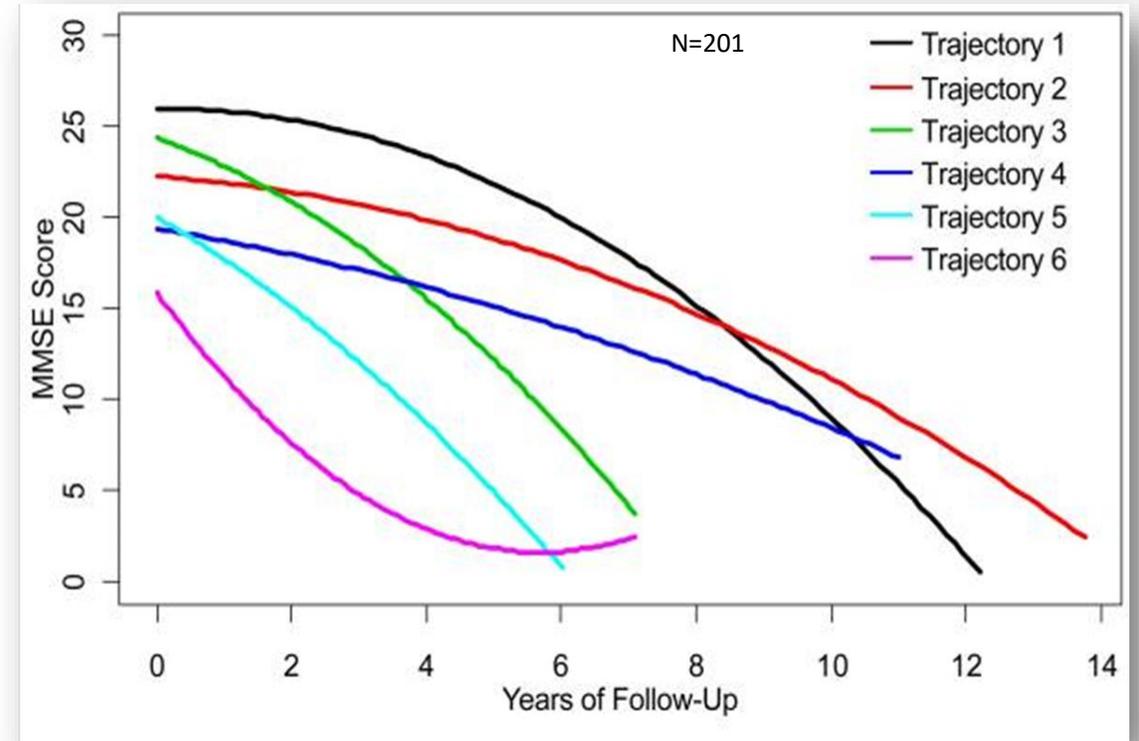
Dementia is the behavioral expression of the brain disease – usually via memory loss and behavioral dysfunction

... losses occur in memory, language, orientation, ADLs [activities of daily living] and changes in personality and functioning

- **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

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

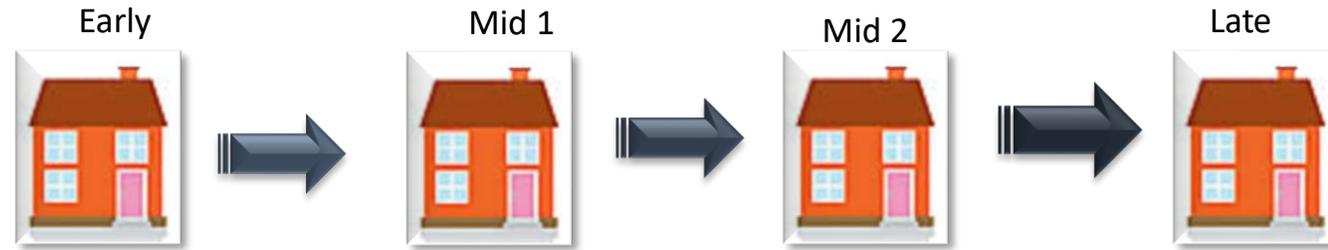
- Admission to a nursing facility after non-ambulatory care is necessary
 - *Consideration:* SNF capability & understanding of DS?
- Looking for an agency run specialty dementia care group home
- Other options – perhaps memory care centers, assisted living programs?

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

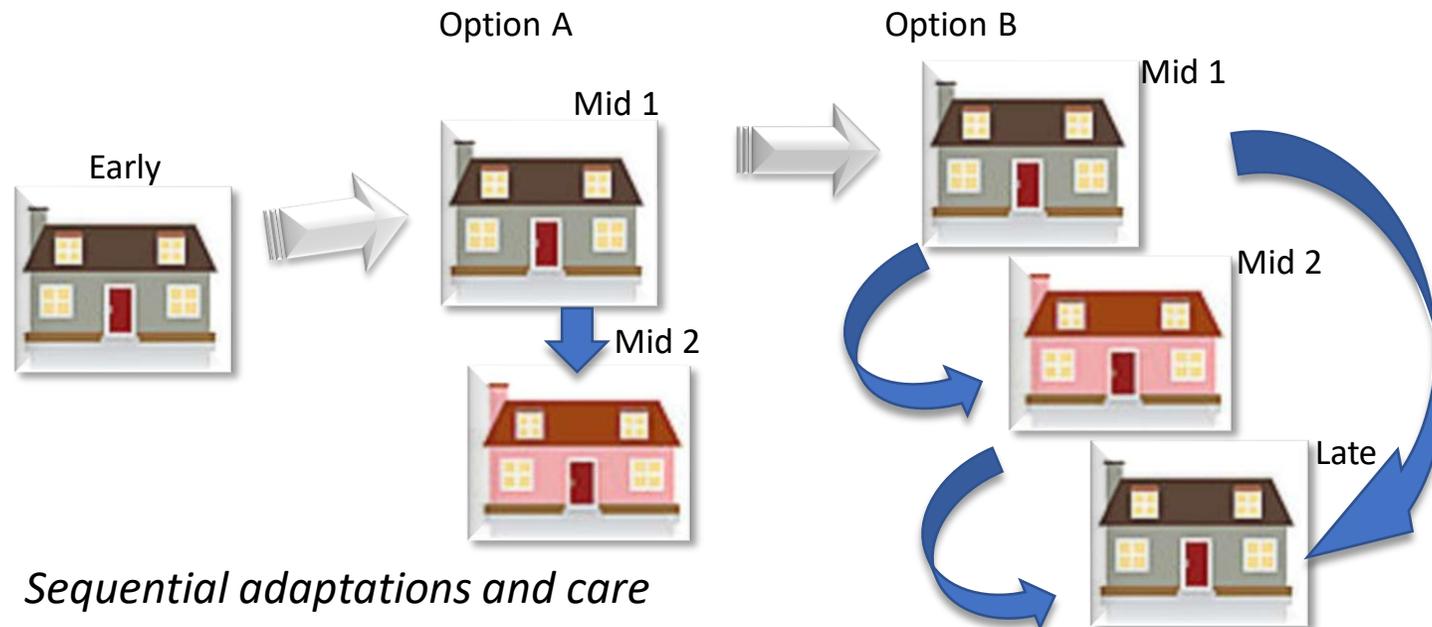
- single care home and stable stay



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?

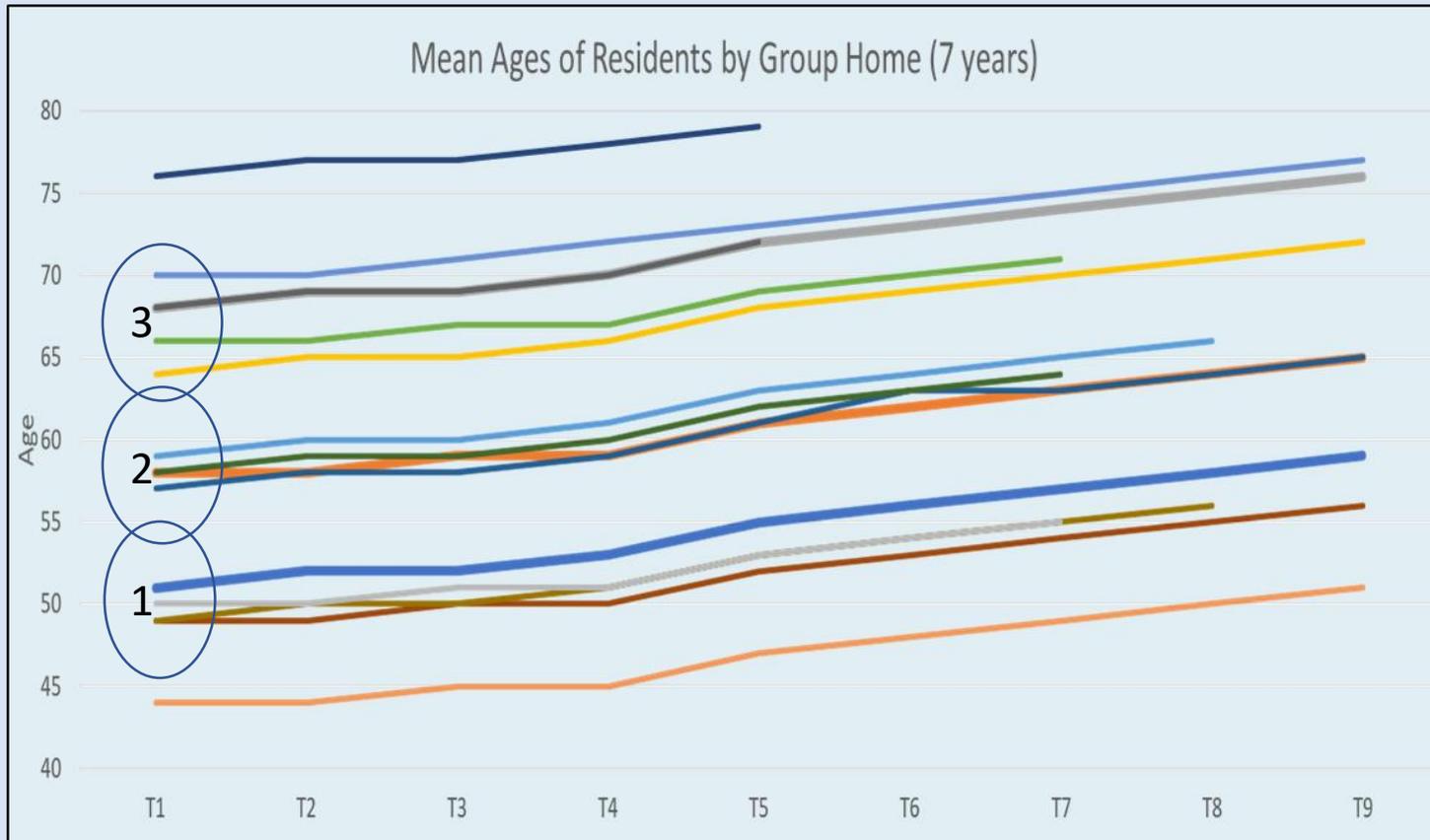
√ Admission trends

√ LOS

√ Mortality

√ Care patterns

√ Staffing



Admission age clusters

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

- Admit Age Group #1 entry:
 \pm age 50 [$X=50.5$] [range: 49-53]
 – *generally DS*
- Admit Age Group #2 entry:
 \pm age 57 [$X=57.1$] [range: 56-59]
 – *some DS and ID*
- Admit Age Group #3 entry:
 \pm age 67 [$X=66.8$] [range: 64-70]
 – *generally ID*
- Outliers were either much older [76, 79] or much younger [40, 44]

Resident ID	T1 (2011w)	T2 (2011s)	T3 (2012w)	T4 (2012s)	T5 (2014)	T6 (2015)	T7 (2016)	T8 (2017)	T9 (2018)
Home #1 Diana									
D-1	Red	Red	Red	Red	Red	Red	Red	Red	Red
D-2*	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink
D-3	Red	Red	Red	Red	Red	Red	Red	Red	Red
D-4*	Red	Red	Red	Red	Red	Red	Red	Red	Red
D-5†	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink
D-16	Light Pink	Light Pink	Light Pink	Light Pink	Red	Red	Red	Red	Red
D-19*	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink
D-20	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Red	Red
D-23^	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Light Pink	Red
Home #2 Lattner									
D-2*	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
D-4*	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
D-6†	Green	Green	Green	Green	Green	Green	Green	Green	Green
D-7†	Green	Green	Green	Green	Green	Green	Green	Green	Green
D-8	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
D-9†	Green	Green	Green	Green	Green	Green	Green	Green	Green
D-10†	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
D-17†	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
D-18	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
D-22	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green	Light Green
Home #3 WOW									
D-11	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple
D-12†	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple
D-13	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple
D-14	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple
D-15†	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple
D-19*	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple
D-21	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple	Purple

Length of stay patterns by home

Average LOS **over 7 years** for each home was

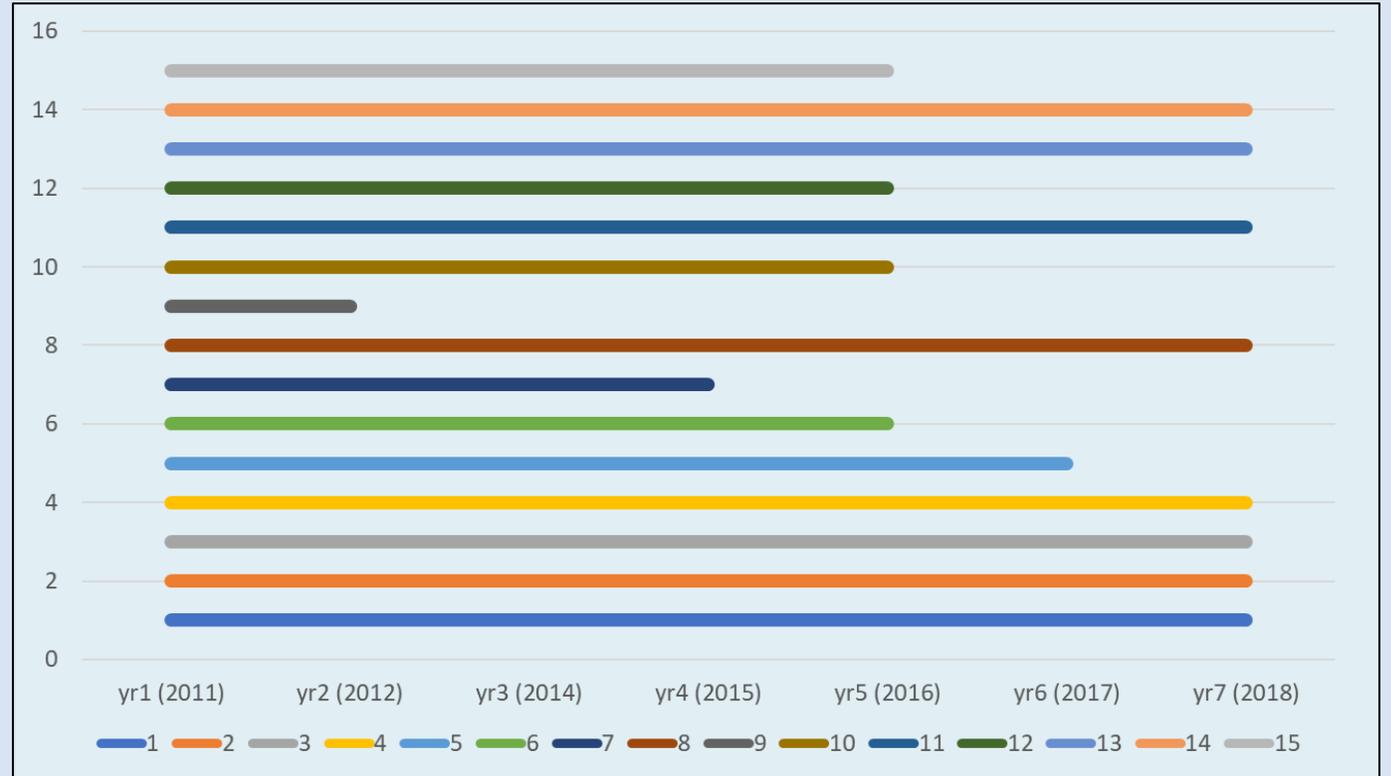
- GH1: 49.0 months (4.0 yrs.)
- GH2: 45.6 months (3.8 yrs.)
- GH3: 56.7 months (4.7 yrs.) (most stable)
- Overall mean LOS for all was 49.4 months (4.12 yrs) post admission
- Implication – home compositions may change over time

Lighter color = DS

Mortality

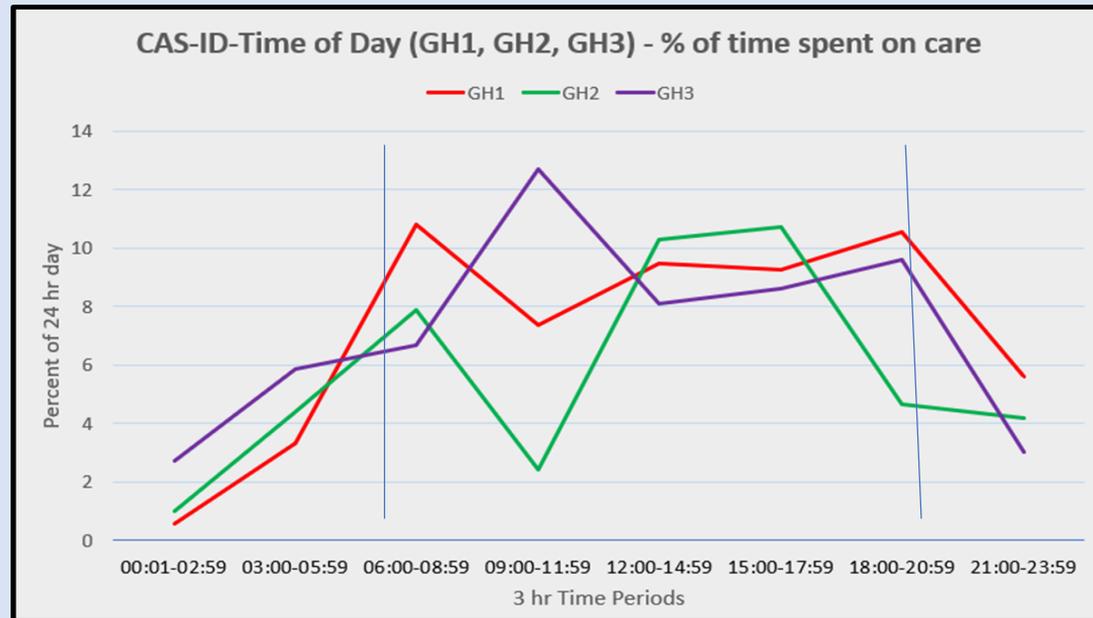
Of legacy adults, 8/15 (53%) died over 7 years

- 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.



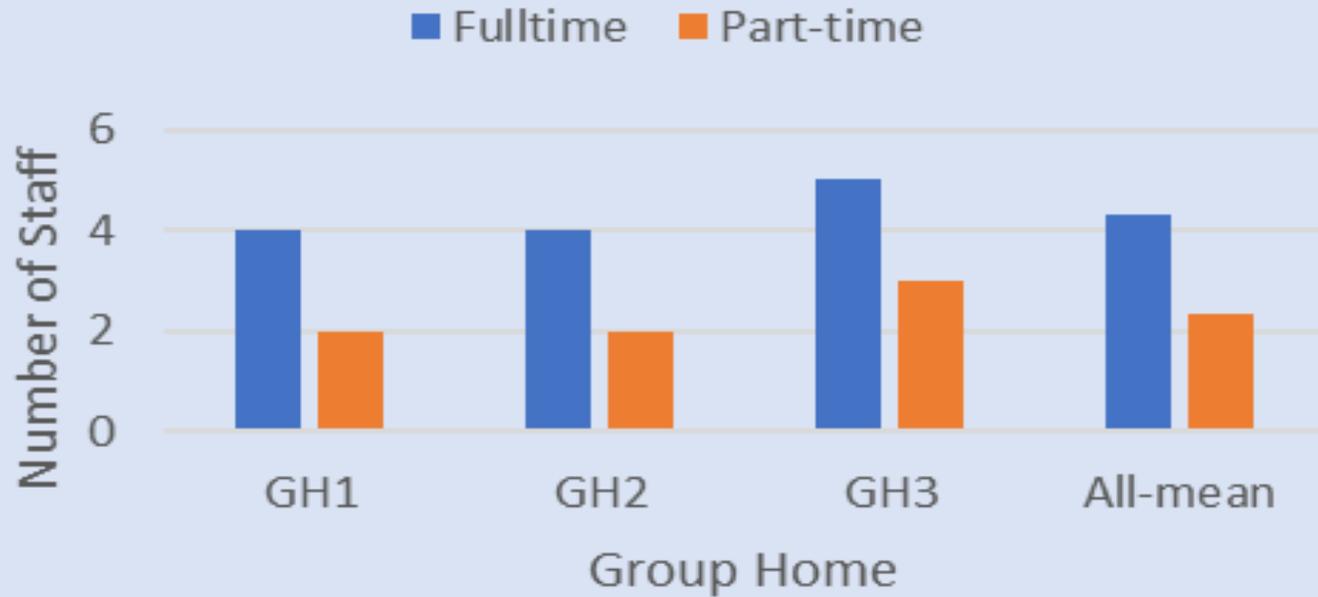
Legacy residents

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 Assigned to Each Home



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

- * Normative appearance and siting
- * Ease of access to off-housing resources and amenities

Safety

- * Control egress and facilitate outdoor use
- * Evacuation factors
- * Wandering paths
- * Minimizing risk

Utility

- * Single story
- * Ambulation ease
- * Wheelchair use
- * Privacy vs public spaces

Design

- * 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

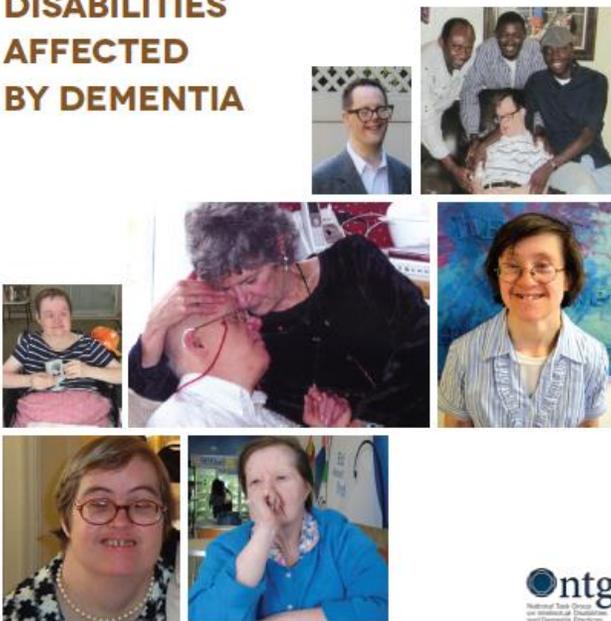


Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices



National Task Group on Intellectual Disabilities and Dementia Practices

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




National Task Group on Intellectual Disabilities and Dementia Practices

MAYO CLINIC

DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

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 (IDD) 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 IDD, 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 IDD, 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 (IDD) 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—Lifetime 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 Disease¹ 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."^{2,3}

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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www.aadmd.org/ntg/guidelines

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