

Planning Dementia-
Capable Community-
based Housing for
Adults with
Intellectual Disability

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Alzheimer Europe Conference - 2020

Abstract

- Specialized housing for adults with intellectual disability (ID) and dementia (ID/AD) is becoming more prevalent. Many jurisdictions are setting up such housing for when families exhaust their physical and financial capital for continued home-based care. Having advance information on the mechanics of such alternative care settings can help agencies to be proactive in planning for such homes, providing post-diagnostic supports, training staff, and anticipating effects of progression and length of stay.
- An opportunistic longitudinal study (2011-2018) of three such group homes (GHs) provided information on the mechanics. Beginning in 2011 a cohort of 15 adults with ID/AD (w/ 7 replacements) were followed annually, along with 15 non-demented community-dwelling adults as matched controls. The 15 residents lived in 3 purpose-built, 5-resident, dementia GHs. Data on their behavior, function, and health were collected annually as were specific data related to dementia-related impairment and administrative factors.
- Prevalence and trends in health/function factors as well as morbidity data obtained can be useful for administrative planning. Deaths, occurred at age-norms in accord to trajectory and duration expectations. Co-morbidities showed presence of cognitive and physical health issues typically associated with dementia and physical debilitation. An ebb and flow of movement related to stage of dementia was observed when an agency has multiple dementia GHs, as well as variations in staffing patterns and periods of staff care intensity during the day. Over time, the 3 dementia GHs, due to administrative decisions for inter-home transfers and selective new admissions, have trended toward stage/level specific care settings.
- These data provide useful administrative guidance on the feasibility of home development and maintenance, as well as markers for tracking of health and function, planning for morbidity and home transitions, and enabling agencies to provide in-community group housing and quality care in accord with stage-defined functional changes and needs.

Rationale for planning

- Small group homes are a growing option for community-based dementia care of adults with intellectual disability
- Information on the dynamics of dementia care group homes can help agencies to be proactive with planning for such homes, for
 - providing post-diagnostic supports
 - training staff, and
 - anticipating effects of progression and length of stay
- Planning involves administrative guidance for home development and maintenance, as well as
 - defining markers for tracking of health and function,
 - planning for turn-over and out-of-home transitions,
 - assessing quality of care associated with stage-defined functional changes, and
 - enabling to finance the home program at when care demands change

What's useful to know ahead of time?

- What the home will be purposed to provide? Temporary care vs. long-term care?
- Planning for the changes that the home's residents will experience and when those changes will occur?
- Staffing needs that may change as the character of the home changes?
- What factors may impact the nature of the home and what to expect from the residents?
- How to factor in shifting changes of the clientele into program processes, financing, and supporting staff?

Study



- Since 2011, we have been annually following a cohort of 15 legacy adults with ID (w/ 9 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

<https://www.the-ntg.org/wichita-project>



Administrative factors

√ Admission trends

√ LOS [length of stay]

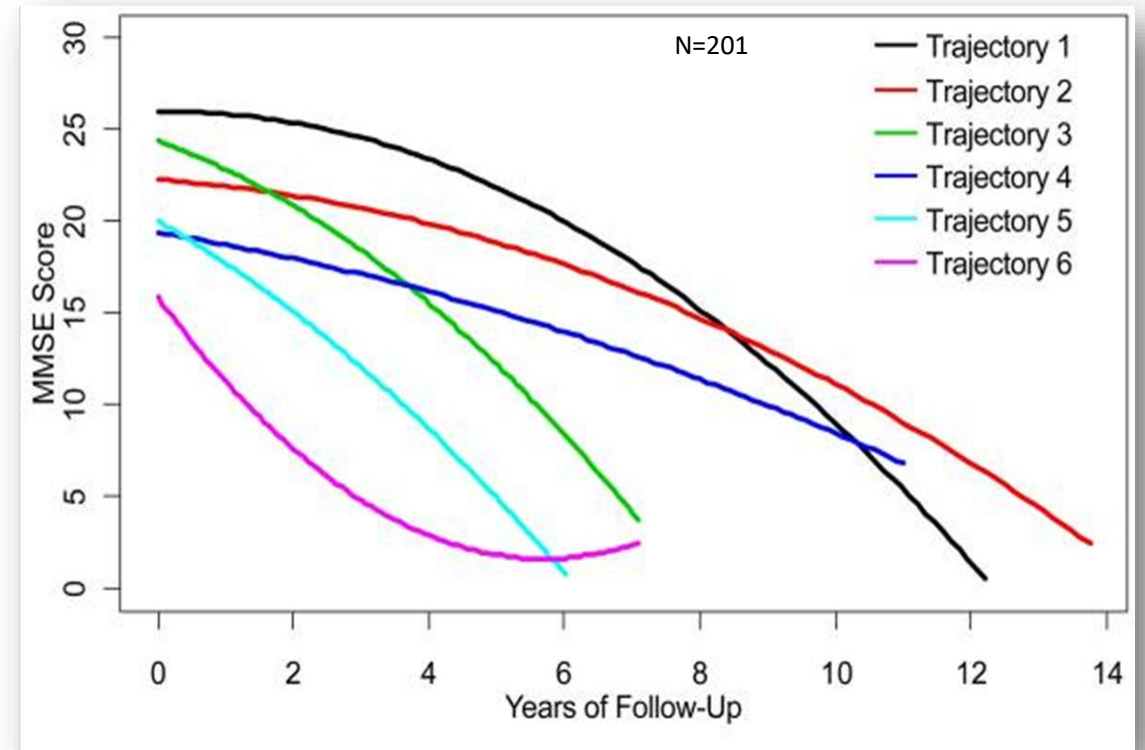
√ Mortality

√ Care patterns

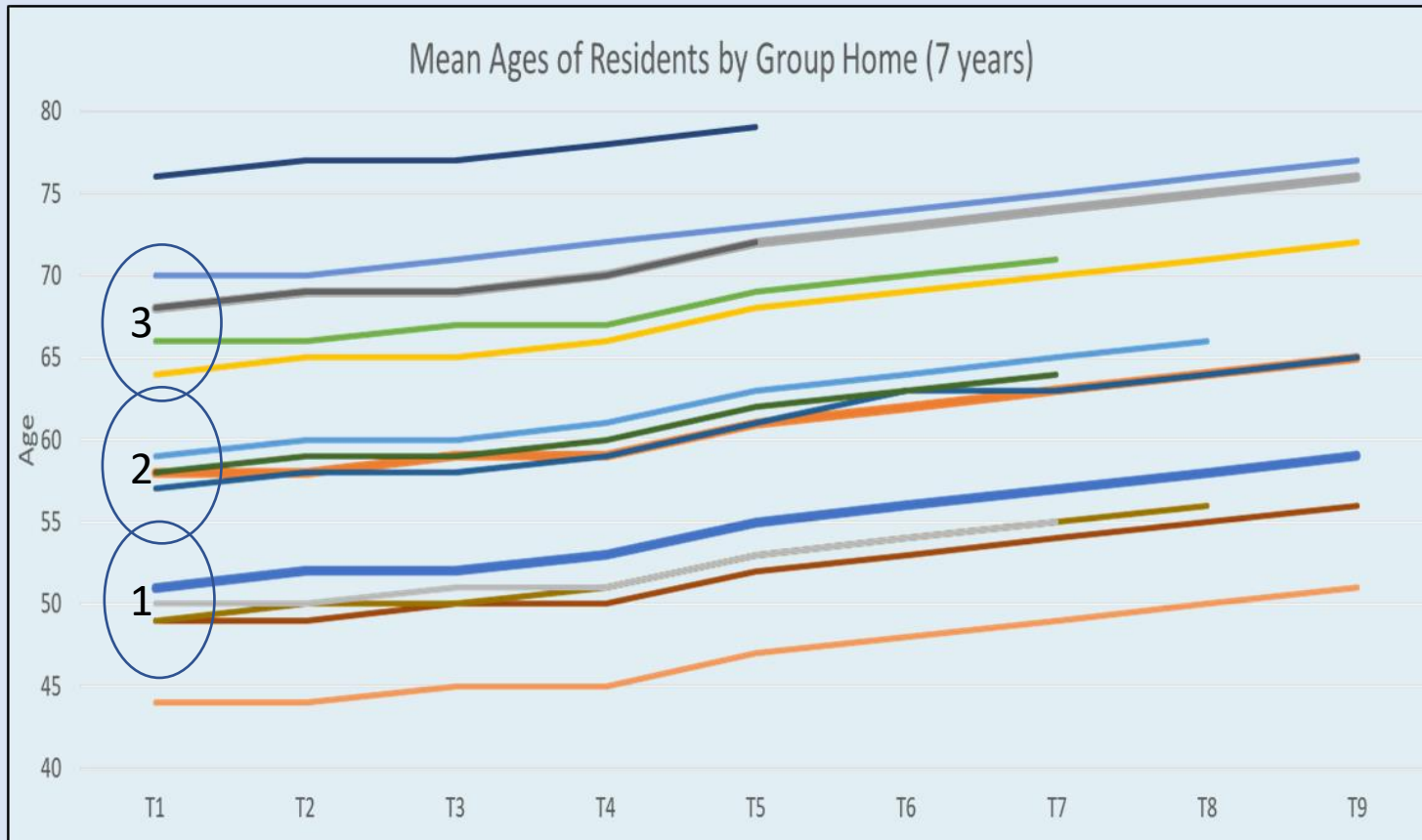
√ Staffing

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



When & what to expect with demands for admissions?

Admission request 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 |

How long may residents remain in the home?

Length of stay patterns by home

Average LOS **over 9 years** for each home was

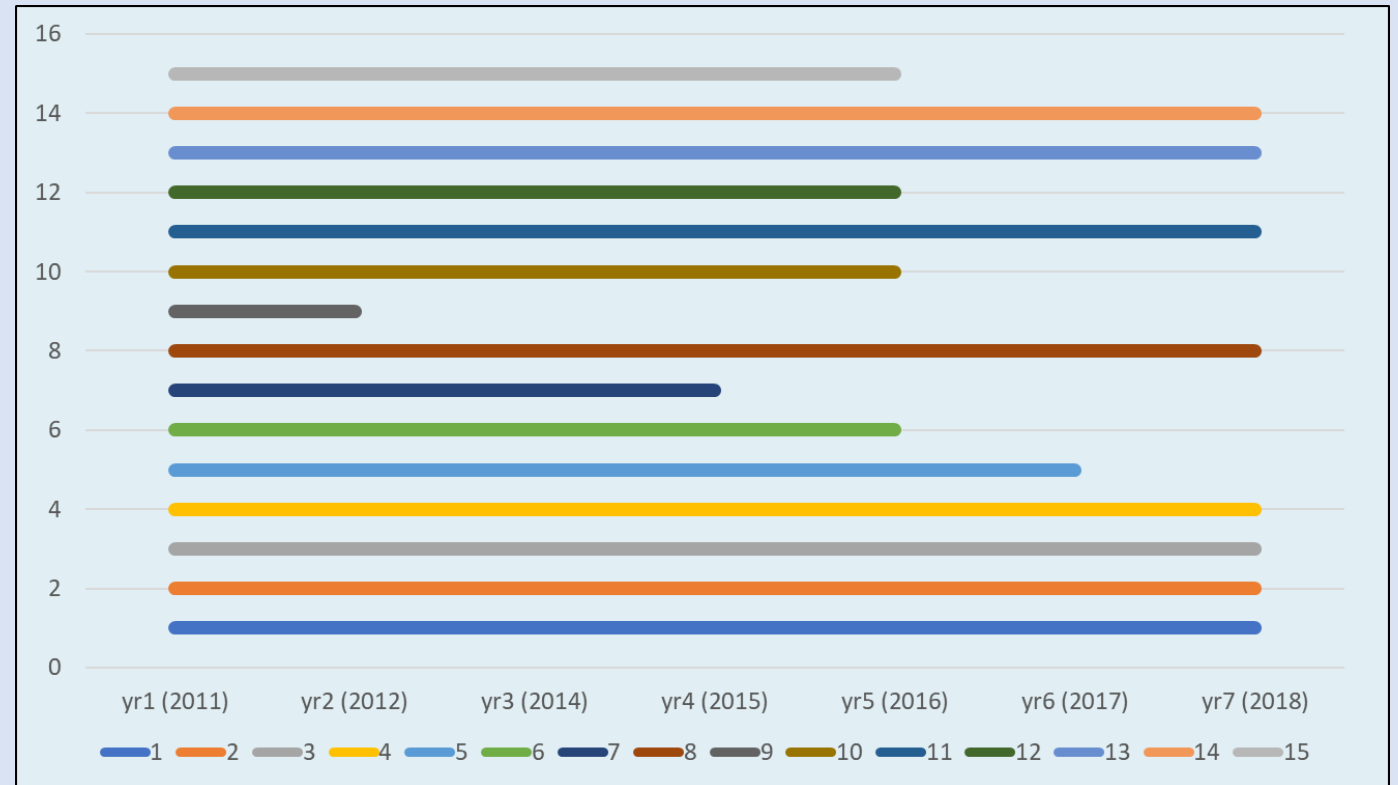
- GH1: 49.0 months (4.0 yrs.)
- GH2: 45.6 months (3.8 yrs.)
- GH3: 56.7 months (4.7 yrs.) (most stable)
- Overall mean LOS for all was 49.4 months (4.12 yrs) post admission
- Implication – home compositions may change over time (due to mortality or transitions)

Lighter color = DS

How will deaths affect length of stay?

Of legacy adults, 9/15 (60%) died over 9 years

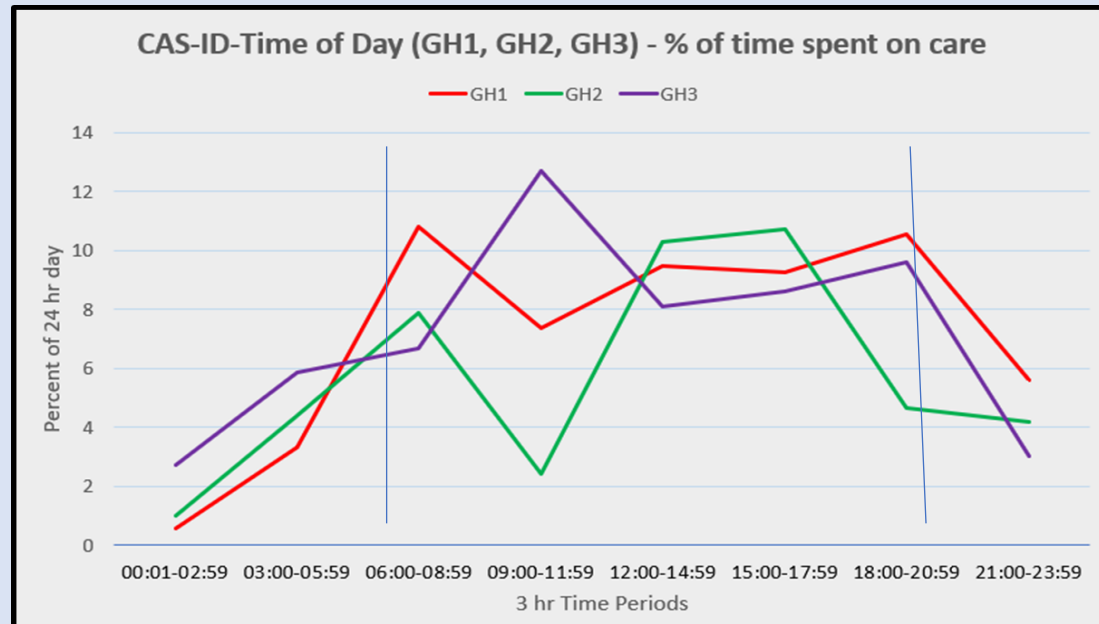
- Average age at entry: 59.1
 - [ID: 66.2; DS: 53.5]
- Mean age at death = 65.2
 - [DS: 58.8; ID: 71.5; M: 66.6; F: 65.0]
- Mean years from entry to death: 5.4 yrs
- Deaths began 2 years following admission
- Average age of death for Controls: 78.5 yrs.



Legacy residents

How do resident needs affect staffing?

What happens in the homes and when?



- 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)
- Staff numbers vary by home, based on resident factors and level of care needs 24/7

Staff time care patterns by home

Planning implications for homes

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.)



Planning considerations

- 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 to individualize the daily support program? Degree of involvement in community? How to adapt program to change in functions? Will residents stay in place or leave during the day? Is program 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?



Take-aways

- 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***

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