Long-range planning for group home dementia care for adults with intellectual disability

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Disclosures

No conflicts of interest to report

Support – various federal support grants to the University of Illinois Chicago from the Administration for Community Living

Acknowledgement – Grateful appreciation is extended to Kris Macy, COO, and the dedicated team at the Starkey Organization in Wichita, Kansas, for their generous support and collaboration, which made possible the data and insights presented in this report.

Overview

- As the need for specialized dementia care among adults with intellectual disability (ID) grows, group homes have emerged as a viable community-based care model.
- Effective long-range planning is essential to ensure sustainability, quality of care, and appropriate resource allocation.
- Data from one small-scale 3-group home housing program for adults with ID and dementia provides a look at staff, environment, and support factors that can provides insight into long-term planning for community-based housing.

Issues

- Group homes for adults with ID are a significant option within the array of community-living options operated by local ID agencies
- With aging and neuropathologies, small group homes take on prominence as a community living option (alternatives a long-term care settings, e.g., nursing facilities, etc.)
- Group homes are funded via state appropriations, private funds, and Medicaid
- Local agencies are serving an increasing number of older adults with ID, with potentially 10% affected by dementia

Transitions to older age housing

Older adults with ID may still be living with their families, but their caregivers are aging

Some live on their own or with mates in various housing options

With aging and lessening capacities – possibly due to MCI/dementia – autonomous living is a less viable option

Some age in group homes – and agencies are seeking options for ‘aging-in-place’ specialized housing

Planning for such settings lacks a data framework for considering admission and LOS factors, and viable dementia care models

What are the factors underpinning planning for dementia-capable group homes in the ID space?

Location – need adapted housing – safety, yet freedom	Accessible ancillary services (day programs, medical services, social supports)
Duration of dementia – Length of Stay	Changing needs and changing staff capabilities Resident turnover Shifting focus on level of care
Financing	Cost of care and screens for dementia services
Staffing	Education in dementia care – specialized skills for early/mid vs. advanced dementia care
Impact of changes	Medical surveillance for comorbidities Functional and behavioral changes

Longitudinal Study of Dementia-Capable Group Homes (2011–Present)

- Tracking outcomes of adults with intellectual disability (ID) and dementia
  - Legacy group (n=30; 15 with dementia, 15 controls)
  - Replacement residents (26 new)

- Situation
  - Three co-located 5-person group homes in a large Mid-western city

Study Overview

Duration: 2011–present

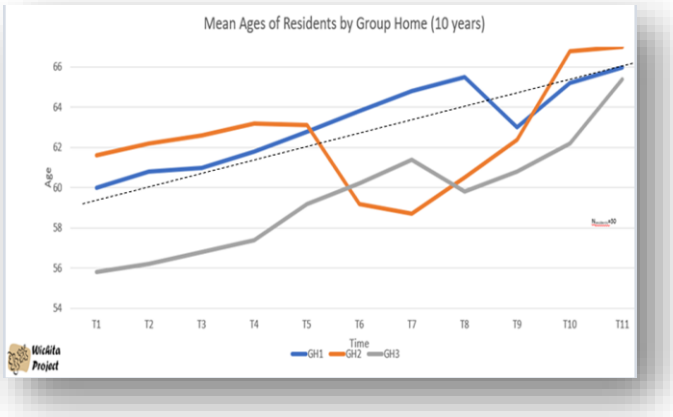
Design: Longitudinal observational study

Settings: Three dementia-capable group homes (5 residents each)

Participants: 15 adults with ID and dementia

15 matched controls (non-dementia; various residential settings)

Participant Characteristics



Mean age at entry: 59.1 years

Mean age at death: 68.1 years

1/3 with Down syndrome (X entry: 53.5 yrs)

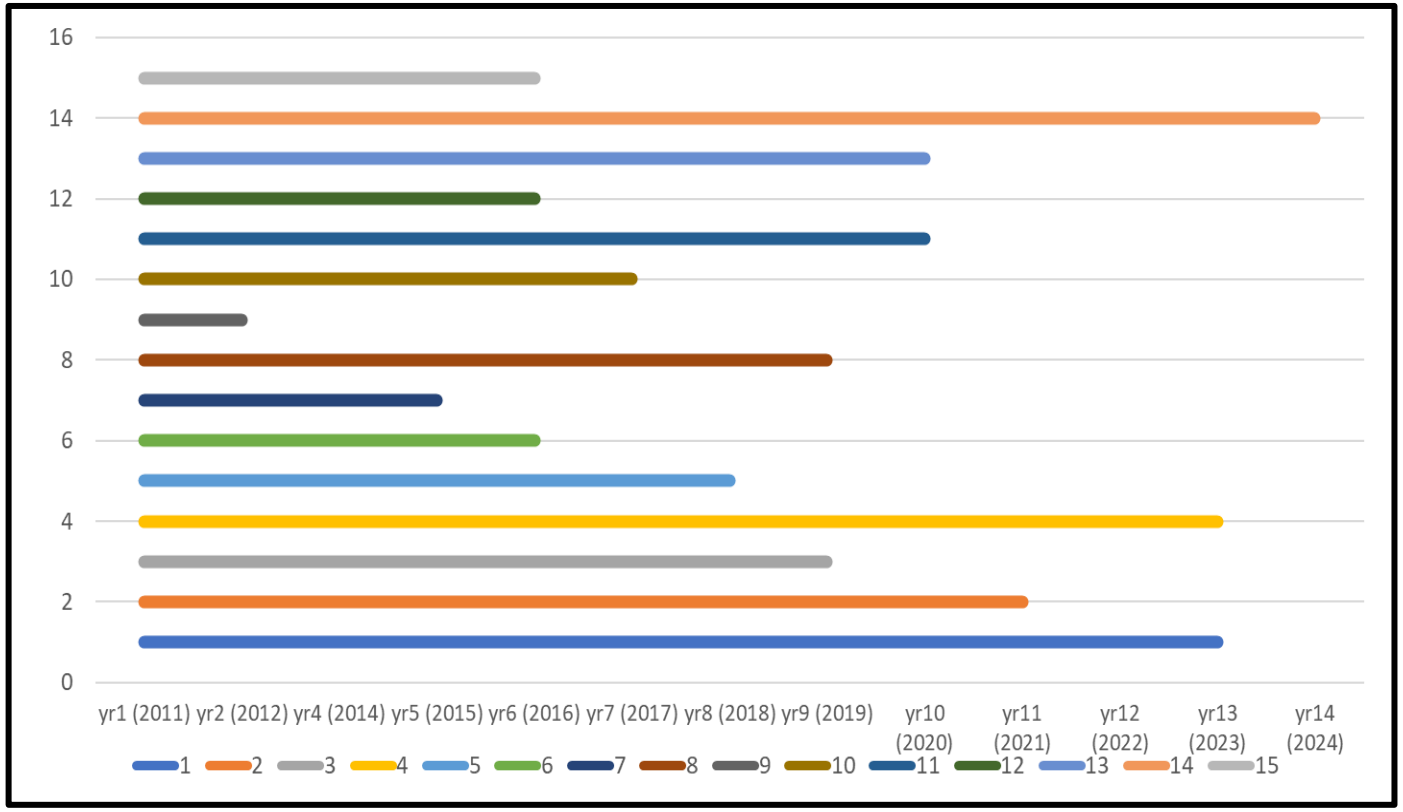
2/3 with ID (X entry: 62.2 yrs)

9 males / 6 females

Death X age: males = 66.3 yrs; females = 69.5

Controls matched on age, ID, sex

- older when died (X= 71.3); 3/15 developed dementia; 60% of 10 deaths in nursing facilities



Mortality and Longevity

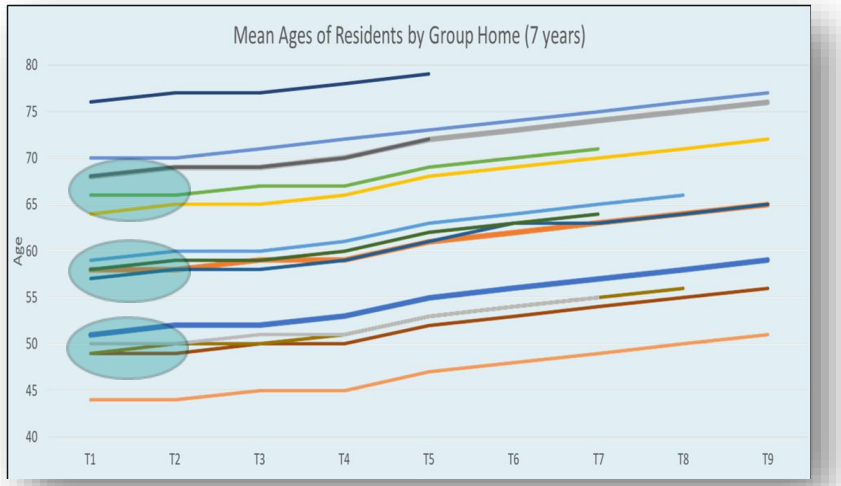
Dementia cohort showed higher mortality

1 survivor (dementia group) vs 5 survivors (controls)

Average length of stay (LOS): 4.75 years before death

LOS was shorter for older adults and those with multiple health conditions

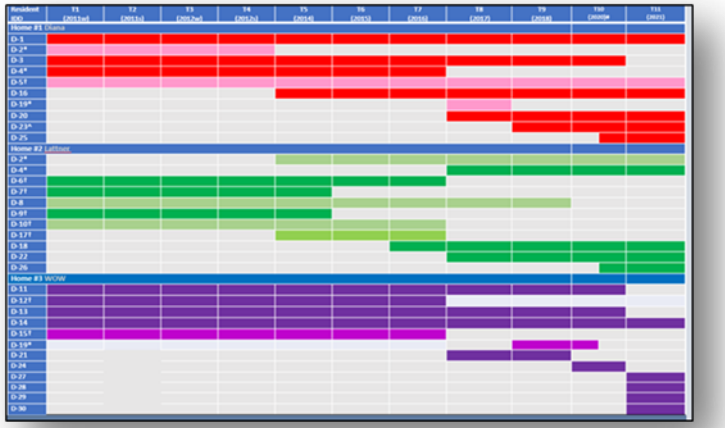
Admissions and Age Patterns



- Tri-modal age distribution at admission:
  - Peaks at 50.5, 57.0, and 66.5 years
  - Younger admits greater LOS; older admits lessor LOS

  These patterns shaped:
  - Care planning intensity
  - Longevity outcomes
  - Resource allocation needs

Population Turnover

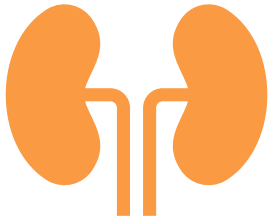


Over 14 years, 35 adults cycled through the three homes

Resident mix continually evolved due to mortality and admissions

Ongoing adjustments required in staffing, training, and care approaches

Comorbidities and Health Complexity



Mean number of comorbidities:
8.6 at entry → 12.1 at death

Reflects:

Progressive health deterioration

Greater medical and behavioral care needs

Variations observed between homes linked to resident turnover and case mix

Key Takeaways

Dementia-capable group homes can sustain long-term operation with evolving populations

Age at admission and health complexity strongly influence LOS and outcomes

Data underscore the importance of:

- Continuous medical support
- Adaptive staffing models
- Proactive end-of-life planning

Implications for Long-Term Planning

1. Anticipate Progressive Health Complexity

- Rising comorbidity counts (8.6 → 12.1) highlight the need for sustained medical, behavioral, and palliative supports.
- Staffing models must evolve to integrate nursing and health coordination expertise.

2. Plan for Shorter Lengths of Stay (LOS)

- Average LOS of 4.75 years suggests frequent turnover and ongoing admissions management.
- Resource planning should assume continuous intake and transitional support.

3. Adjust Housing and Care Models to Admission Age

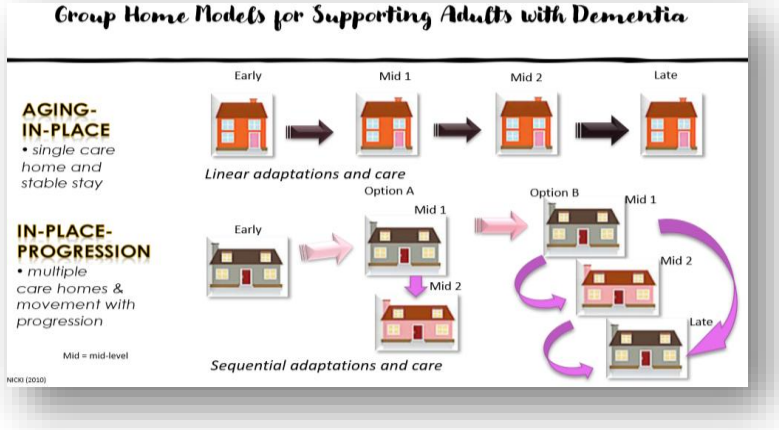
- Tri-modal admission ages (≈50, 57, 66 years) imply distinct care trajectories:
  - *Younger entrants (esp. with Down syndrome):* longer potential duration of support.
  - *Older entrants:* higher acuity and shorter residency.

4. Develop Flexible Funding and Workforce Strategies

- Predictable mortality and turnover necessitate dynamic budgeting for training, recruitment, and backfilling vacancies.
- Incorporate grief and resilience supports for staff teams.

5. Use Data to Inform Policy and Replication

- 14-year operation demonstrates feasibility and sustainability of small dementia-capable homes.
- Data can guide replication standards, capacity forecasting, and regional system design.



Critical Findings

Consider whether to specialize the homes based on staging

Reserve a home for advanced/end stage dementia residents

Use ‘aging in place’ and have a multi-tiered stage setting home

Recognize staff capabilities

Some function better in social situations in homes with early/mid stage dementia residents

Some function in health care situations with late-stage dementia residents

Plan ahead for turnover

Track staging and health of residents for trajectory planning

When planning decide on nature of new admissions (their stage/age/function)

- Admit to match general staging at home
- Admit to create of cycle of functionality to dysfunctionality

Summary & Strategic Implications

Optimizing Dementia-Capable Group Home Models

1. Stage-Based Residential Design

- Homes organized by dementia stage enabled tailored care and smoother transitions.
- Advanced dementia home provided focused palliative and end-of-life care.

2. Critical Determinants of Long-Term Viability

- **Age at admission**, **dementia stage**, and **morbidity progression** associated with length of stay and staffing intensity.
- Mortality-driven turnover shaped continuity of operations and fiscal stability.

3. Workforce and Care Optimization

- Align staffing ratios with resident acuity and turnover patterns.
- Build cross-trained teams skilled in health management, behavioral support, and dementia care.

4. Strategic Planning for Sustainability

- Integrate clinical, operational, and financial data for ongoing system adaptation.
- Leverage evidence from 14-year outcomes to guide replication of dementia-capable homes within ID service networks.

Key Takeaway:

Effective long-term planning depends on considering admission age, dementia progression, morbidity trends, mortality-driven transitions, staffing, and dementia care policies for adults with ID

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