

From admission to end of life: longitudinal lessons from dementia-specialized group homes for adults with intellectual disability

Matthew P. Janicki, Ph.D.
University of Illinois Chicago, USA

Abstract

Adults with intellectual disability (ID) are increasingly in need of housing models that support dementia care while preserving community living. Dementia-capable group homes offer a promising alternative to institutional settings, yet practical guidance for their long-term design and sustainability is limited. This longitudinal study followed 15 adults with ID and dementia living in three specialized group homes (since 2011), compared with matched controls, examining admission age, length of stay, morbidity, mortality, and functional care patterns. Findings indicate that outcomes are strongly influenced by admission timing and disease progression, with care needs intensifying over time. Overall, the study demonstrated that **planful, stage-informed design and staffing** are critical to sustaining high-quality, community-based dementia care, providing actionable guidance for future housing and service planning.

Background/Issues

Adults with intellectual disability (ID), particularly those with Down syndrome (DS), pose an elevated risk for earlier-onset dementia. Following diagnosis, many adults require community-based housing options that provide dementia-capable supports while maintaining community integration.

Dementia-specialized group homes are frequently proposed as an alternative to institutional care, yet practical guidance for planning and sustaining these models across the course of disease remains limited.

Helpful to designing such settings are data on various factors that affect financial, programmatic, and personnel planning decisions.

Drawing on a decade plus of longitudinal data, this study identified operational and clinical inflection points that influence sustainability, care quality, and resident outcomes in dementia-capable community housing.

Length of stay (LOS) in dementia care homes differs from that of traditional group homes serving adults with special needs. In conventional settings, residency is typically associated with increasing autonomy, stability, and gains in functional capacity over time.

In contrast, length of stay in dementia-capable homes is shaped by progressive neurodegenerative disease and co-occurring medical conditions that contributes to gradual functional decline and increasing care needs.

Methodology

An opportunistic longitudinal study that followed 15 adults with ID and dementia admitted simultaneously and 21 adults admitted subsequently to three purpose build dementia care group homes (2011–present).

Three 5-bed homes co-located in urban neighborhood setting in large Midwest USA city. All residents diagnosed with all-cause dementia; previously resided in other group homes, apartments, or with family;

Data were collected annually and included tracking legacy residents and replacement residents. Study also included 15 matched non-dementia controls.

Data included resident characteristics, age at admission and ‘discharge’, length of stay, morbidity, mortality, functional decline. Administrative data included fiscal, program, and staffing patterns.

All data anonymized and exempt from IRB approval.

LOS & Mortality

Average length of stay: ~4–5 years overall

Admission timing effect:

- Earlier admission → longer stays and slower progression
- Later admission (higher morbidity) → shorter stays and faster decline

Mortality patterns:

- All but one of the 15 legacy residents died over the observation period
- Over one-third of the 21 replacement residents died within ~4 years of admission

Overall trend: Earlier mortality consistent with progressive advanced dementia

Survivability closely tied to age at admission and baseline health status

Characteristic of Residents

Total dementia cohort (n=36): 15 original (“legacy”) residents at opening and 21 subsequent (“replacement”) admissions

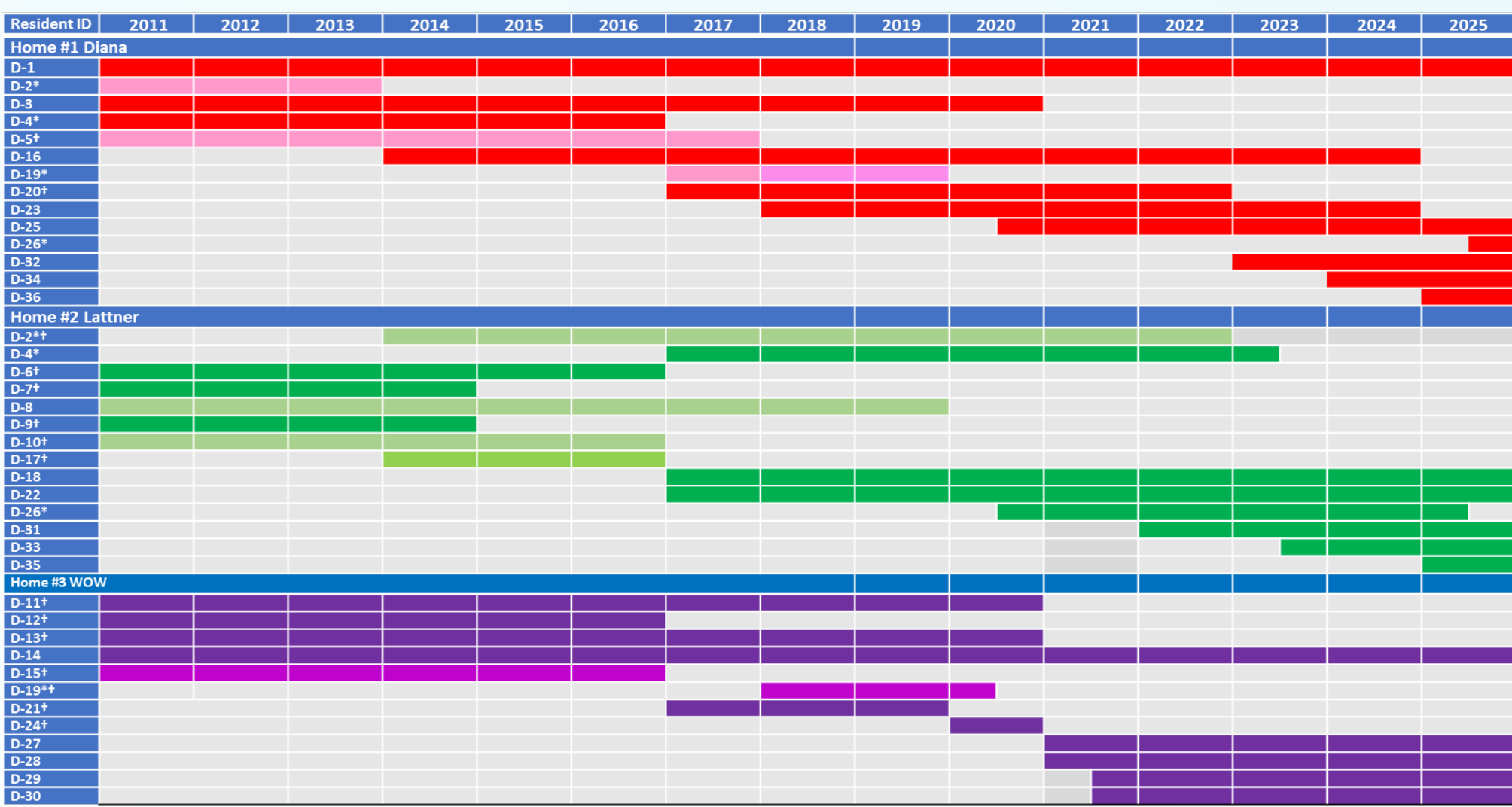
Legacy residents (n=15):

- Admitted at program inception (2011) with established dementia diagnoses
- Mean age at entry ~59 years; ~60% male, 1/3 DS
- Represented the initial service population transitioning from traditional ID supports to dementia-capable care
- Demonstrated gradual functional decline, increasing multimorbidity, and rising care intensity over time

Replacement residents (n=21):

- Admitted as vacancies occurred, beginning in Year 3
- Mean age at admission ~62 years; one-third with DS
- More heterogeneous in clinical presentation and stage at entry
- Average length of stay ~4 years; a subset experienced shorter survival associated with later admission and higher medical complexity

Resident LOS



Key Findings

- Mean admission age: ~59 years; average length of stay: 4 years+
- Dementia progression requires increasing staffing intensity, structured routines, and environmental adaptations – Staffing number contingent on dementia stage
- More nursing-oriented staff with advanced 24/7 in-home dementia care
- Less staffing in mid-stage homes due to outside day programming
- Homes change in character as residents change – some progress to non-ambulatory care, others retain ambulatory status
- Dementia type and trajectories, aging, and comorbidities effects lead to diminishing function and changes in care orientation.

Lessons Learned

Dementia-capable group homes offer a community-based alternative to institutional care, but guidance on how to design and sustain these models is limited.

Dementia-capable group homes can provide sustainable, high-quality community care when planning accounts for admission timing, disease stage, and rising care needs.

Administrative factors findings offer practical guidance for scalable, non-institutional housing models.

Contact Info

Matthew P. Janicki, Ph.D., Institute of Human Development and Disability, University of Illinois Chicago USA and National Task Group on Intellectual Disability and Dementia Practices, USA
mjanicki@uic.edu