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
Dementia is 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.

Source: Figure 2 from Wilkosz et al., (2009). Trajectories of cognitive decline in Alzheimer’s disease. International Psychogeriatrics, 28,1-10
Options for dementia care

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<tr>
<th>Staying</th>
<th>Leaving</th>
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| **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 |
| **Leaving**       | • 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**  
Outreach and community supports (HCBS)  
Helping support family caregivers

**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

**IN-PLACE-PROGRESSION**
- multiple care homes & movement with progression

Mid = mid-level

Source: JANICKI (2010)
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: ± 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]
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.
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)
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?
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

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<th>Safety</th>
<th>Utility</th>
<th>Design</th>
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| * 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.) |
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?
• 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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