Community-based Housing and NPI-care Practices for Adults with Intellectual Disability and Dementia

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Abstract

Aging persons with intellectual disability (ID) represent a vulnerable population with respect to cumulative neuropathological conditions, including dementia. Adults with Down syndrome (DS) have a recognized high risk for Alzheimer's disease. With dementia present, how to provide post-diagnostic supports is a challenge. Dementia care group homes (GHs) are emerging as a mode for providing out-of-home community supports. Data from a longitudinal study provide insights on what care organizations need to consider when organizing specialty group home care. The study, begun in 2011, follows three co-located homes providing a macro-NPI program to 15 adults with dementia.

NPI-related practices included day program activities (adults in mid- to later stages were engaged in regular off-site day activities that agency provided; adults with advanced dementia remained in homes), staffing patterns differed based on level of care – more staff assigned to homes with residents with advanced dementia – and staff training that included dementia capable communications, engagement, and managing daily routines.

Trends show that adults with Down syndrome are admitted to homes earlier but had more life-years in the GHs than older adults admitted at later age but who succumbed earlier to disease complications. Dementia care GHs should expect varied trajectories of decline; mortality linked to complexity of pre-existing conditions and progression of dementia; and changes in the focus of care needs over time (including advanced dementia and end-of-life care).

Dementia care GHs as an encompassing macro-NPI can enable provision of in-community group housing and quality care in accord with stage-defined functional changes and needs if structured in a planful way (factoring in dementia-stage, type of dementia, mortality expectations, health status, patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents).

Dementia Group Home NPI

A small community-based group home for long-term dementia care for adults with ID and dementia can morph into an intellectual disability focused macro-non-pharmacological intervention program (NPI) when it is composed of dementia-capable services and supports. This macro-NPI model is designed to minimize typical adverse behaviors and BPSDs generally seen in adults with neurodegenerative conditions such as dementia. In care settings for adults with ID and dementia, NPI components include (a) the home's physical layout, (b) the presence of trained dementia-capable care staff, and (c) a dementia focused individualized care plan that considers the person's behaviors, capabilities, and interests, and means to minimize presentation of adverse behaviors by targeted techniques updated periodically to reflect an agreed upon dementia care plan.

NPI / Dementia Care Plan Considerations

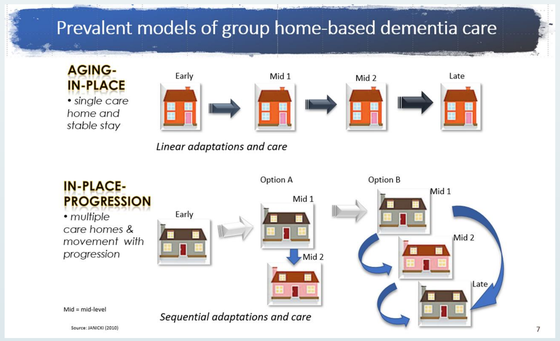
Dementia care plan components

- Assessment of function, BPSDs, and functional limitations
- Parallel implementation of plan in home and at off-site resources
- Determination of responsiveness to micro-interventions
- NPI-related programs include day program activities (adults in mid- to later stages can engage in regular off-site day activities that agencies provide; adults with advanced dementia may remain in homes) and dementia related care and supports at the residence.

Data Drawn from Longitudinal Study

Data from a longitudinal study provided insights on what care/provider organizations need to consider when organizing dementia specialty group home care. An opportunistic longitudinal study of three co-located dementia-care group homes (GHs) for adults with intellectual disability (ID) and dementia provided the basis for examining a GH as a long-term macro-NPI. The study, begun in 2011, annually follows residents in three homes for adults with ID and dementia. The cohort of 15 adults with ID (w/ 8 replacements) lived in 3 purpose-built, 5-resident, dementia-capable GHs, along with 15 community-dwelling (non-dementia) adults with ID as age-matched controls. Annual data included resident demographics, function, health, day services, and other related information as well as staff/home administrative factors.

Over 9 years, of the original 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 – 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. The NPI included supports provided by trained dementia-capable staff, socialization, 24/7 individualized care (of varied intensities), and participation in day services off-site.



General ID/Dementia-related Considerations

- Distribution of dementias among adults with ID as in general population; in Down syndrome (DS) it was mostly AD
- Average onset age in early 50s for DS – late 60s for others
- Notable presentations of BPSDs - apathy, sleep disturbance, agitation, incontinence, uncooperativeness, aggressiveness, irritability, etc.
- Late onset seizures in adults w/ DS; atypical in other ID
- Aggressive AD in DS can lead to death <2 years of onset
- Mean duration 2-7+ years and probable death within 3-5 years of onset among adults with DS; more typical in other ID
- Trajectories of decline variations matched those of other adults
- Prevalent comorbidities/conditions include incontinence (71.4%); depression (57.1%); back pain, constipation, foot pain, & heartburn (42.9%); arthritis and thyroid disorder (37.5%); high cholesterol and high blood pressure (28.6%); impaired vision or impaired vision (28.6%).

Implications of Community Dementia Care

Specialized housing for adults with intellectual disability and dementia has become more prevalent as agencies set up such housing for when families exhaust their physical and financial capital for continued home-based care.

Study findings revealed key features that include trajectories of changes over time, housing need/function level patterning, and varied health status outcomes.

Key findings noted:

- Three age-of-admission clusters (χ=50.5; χ=57.1; χ=66.8)
- Overall mortality (χage-death=65.4; ID=69.3; DS=56.3)
- Half of original entrants died within 7 years
- Average age at entry (χ= 59.1)
- Years from entry to death (χ= 5.4 yrs.)
- LOS (χ=49.4 months/4.12 yrs.)
- Morbidities (number of co-morbidities decreased among survivors)

NPI-related practices included day program activities (adults in mid- to later stages were engaged in regular off-site day activities that agency provided; adults with advanced dementia remained in homes)

Planning Community Dementia Care

Dementia care GHs should expect

- varied trajectories and durations 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
- varied trajectories and needs for care depending upon type of dementia and pre-existing co-conditions

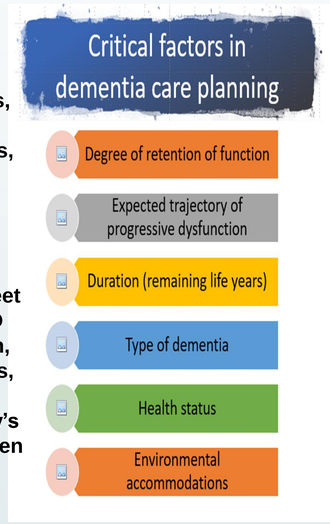
Planning dementia care GHs involves

- Setting up / operating single dementia care home
- If using multiple homes, determine whether stage specialization might be beneficial at each home
- Decide whether to use "aging-in-place" or "in-place-progression model (see figure)
- Consider the length of stay and what the home will look like in several years
- Assign staff with skills commensurate with prevalent functional skills and needs of residents
- Functional design for long-term dementia care (see figure)

Conclusions

Dementia care GHs can enable provision of in-community group housing as a macro-NPI (in lieu of/complementary to specific therapy/intervention micro-NPIs) and enhance quality care by considering stage-defined functional changes and needs.

• Homes need to factor in dementia-stage, type of dementia, mortality expectations, health status, patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents.



• Dementia care GH stage specialization can help meet the needs of adults with ID with dementia progression, and to adapt NPI strategies, contingent on resource availability and the agency's administrative policies when an agency has multiple homes.

• GH planning should factor in varied trajectories of decline, mortality linked to complexity of pre-existing conditions and progression of dementia, changes in the focus of care needs in GH cohorts over time (including end-of-life care), and need for differential staffing patterns and cost demands due to stage of dementia

• Small group home community-based dementia-capable care can be viable if constructed as an effective macro-NPI program and based on incorporating key variables, such as dementia-stage, mortality expectations, health status factors, daily patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents.

• Important to plan long-term as home character will change over time contingent on progression of dementia.

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Additional data reports can be sourced at **https://www.the-ntg.org/wichita-project**

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