Report from Wichita Project (2020)

Janicki, M..P. **Community-based housing and NPI-care practices for adults with intellectual disability and dementia**. AAIC 2020 Conference, Poster presentation, July 30, 2020. *Alzheimer's & Dementia*, 16(S8), First published: 07 December 2020. https://doi.org/10.1002/alz.047061

Abstract: Aging persons with intellectual disability (ID) represent a vulnerable population with respect to cumulative neuropathological conditions, including dementia. Adults with Down syndrome (DS), a subset, have a recognized high risk for Alzheimer's disease. With dementia present, how to provide post-diagnostic supports is challenging. Dementia care group homes (GHs) along with NPIs 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, followed three co-located homes providing NPIs to 15 adults with dementia. Findings revealed trajectories of changes over time, housing need/function level patterning, and health status outcomes. Key findings noted 3 age-of-admission clusters (X=50.5; X=57.1; X=66.8); overall mortality (Xage-death=65.4; ID=69.3; DS=56.3) – half of original entrants died within 7 years; age at entry (X= 59.1); years from entry to death (X= 5.4 yrs); LOS (X=49.4 months/4.12 yrs); morbidities (number of co-morbidities decreased among survivors).

In same period, 8/15 deaths in GHs vs 3/15 deaths in Controls. 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 included dementia capable communications, engagement, and managing daily routines. Trends showed adults with Down syndrome were 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; changes in the focus of care needs over time (including advanced dementia and end-of-life care).

Dementia care GHs 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, dementia type, mortality expectations, health status, patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents).