A GROUP HOME CLUSTER MODEL FOR PROVIDING COMMUNITY-BASED DEMENTIA CARE

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- **Study**
  - *The Wichita Project*: A naturalistic examination of the evolution of three specialty group homes for dementia-related care of adults with intellectual disabilities
- **Funding**
  - University of Illinois at Chicago (US National Institute of Rehabilitation and Disability Research)
  - University at Albany (Center for Excellence in Aging & Community Wellness Innovation Fund)
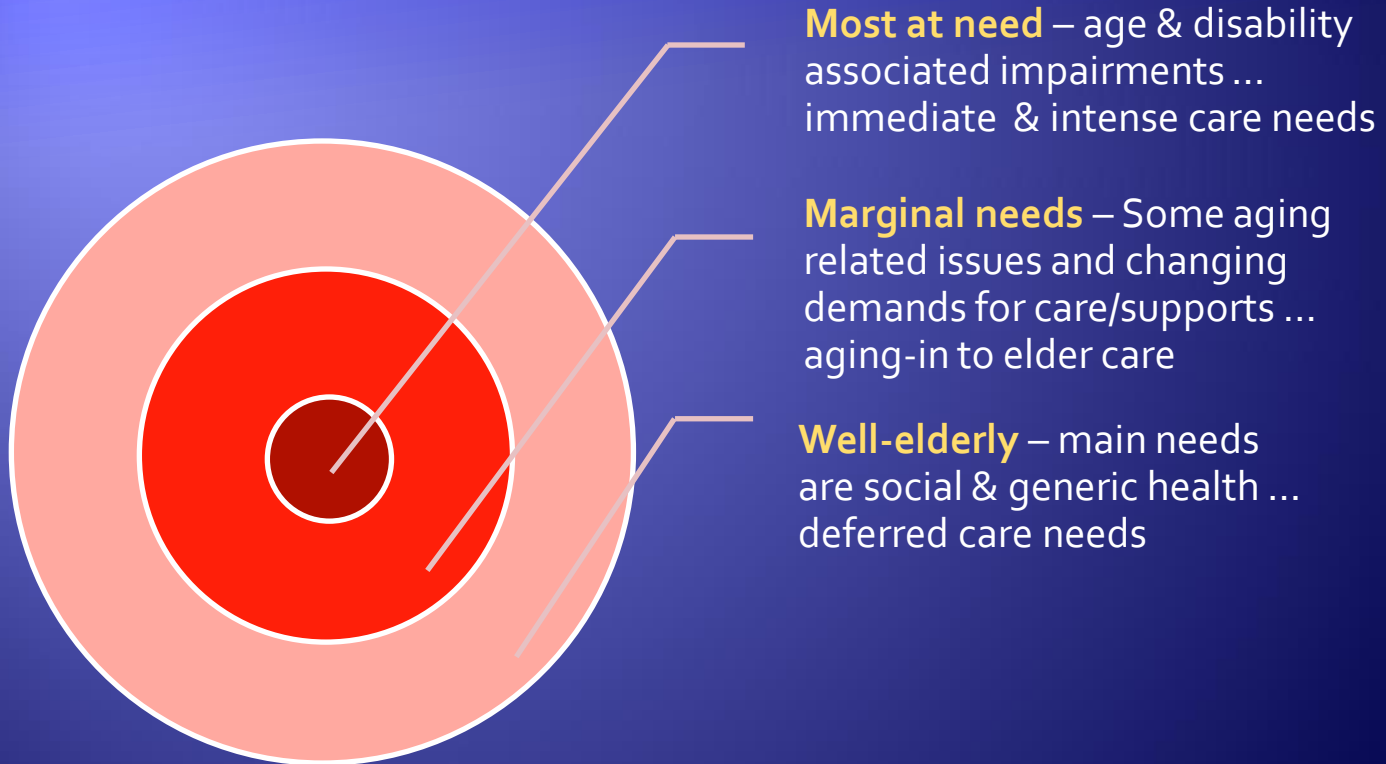
International dementia care options

Traditional options

- *Institutional care* – long term care facilities, nursing homes, old age homes, dementia special care units

- *Family care* – living with family, other relatives, or other family members or carers

Innovative options

- *Neighborhood group care* – generic group homes, specialized ID group homes
  - Group homes for persons with ID who age in the homes
 - Group homes for specialized dementia care

Diverse older population – by urgency of needs

Most at need – age & disability associated impairments ... immediate & intense care needs

Marginal needs – Some aging related issues and changing demands for care/supports ... aging-in to elder care

Well-elderly – main needs are social & generic health ... deferred care needs

Prevalent models of group home care provision

Aging-in-place
- *single care home and stable stay*

Early → Mid 1 → Mid 2 → Late
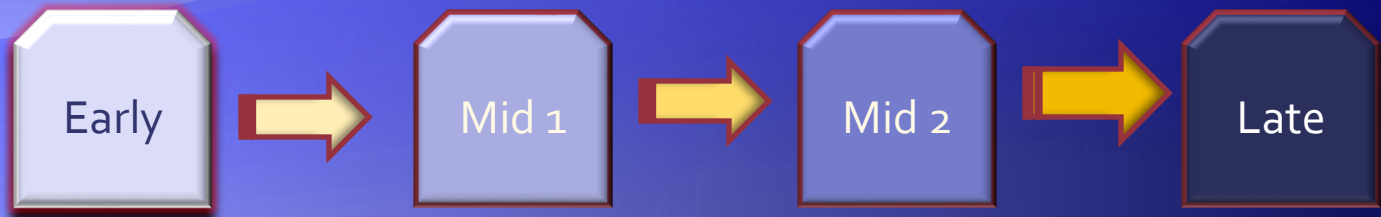
Linear adaptations and care

In-place-progression
- *multiple care homes & movement with progression*

Mid = mid-level stage

Option A

Option B

Early

Mid 1

Mid 2

Mid 1

Mid 2

Late
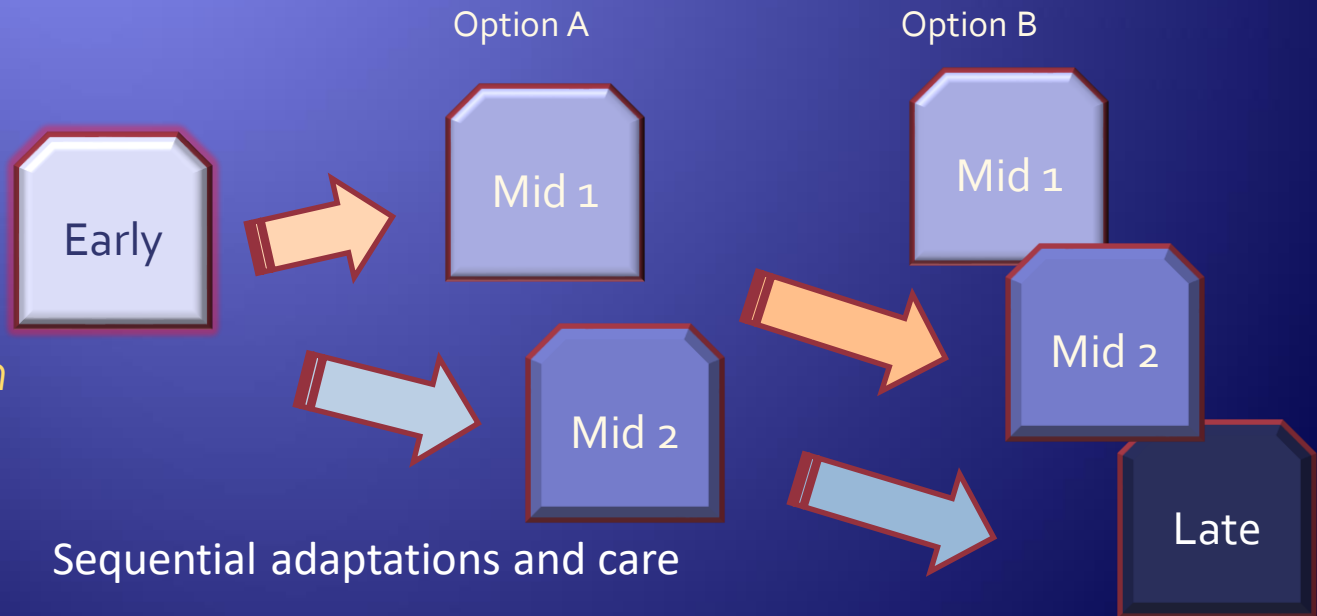
Sequential adaptations and care

Premise

- Given the cluster model employed by an agency of three 'in-place progression' homes ...
- <u>Our hypothesis</u> is that eventually, as changes affect the residents, the agency will begin to specialize the homes based on function and stage
- If this happens, it will show that as homes are established for dementia care, their character will eventually change due to the nature of dementia and that specialization is an organic outcome of multiple group home care programs
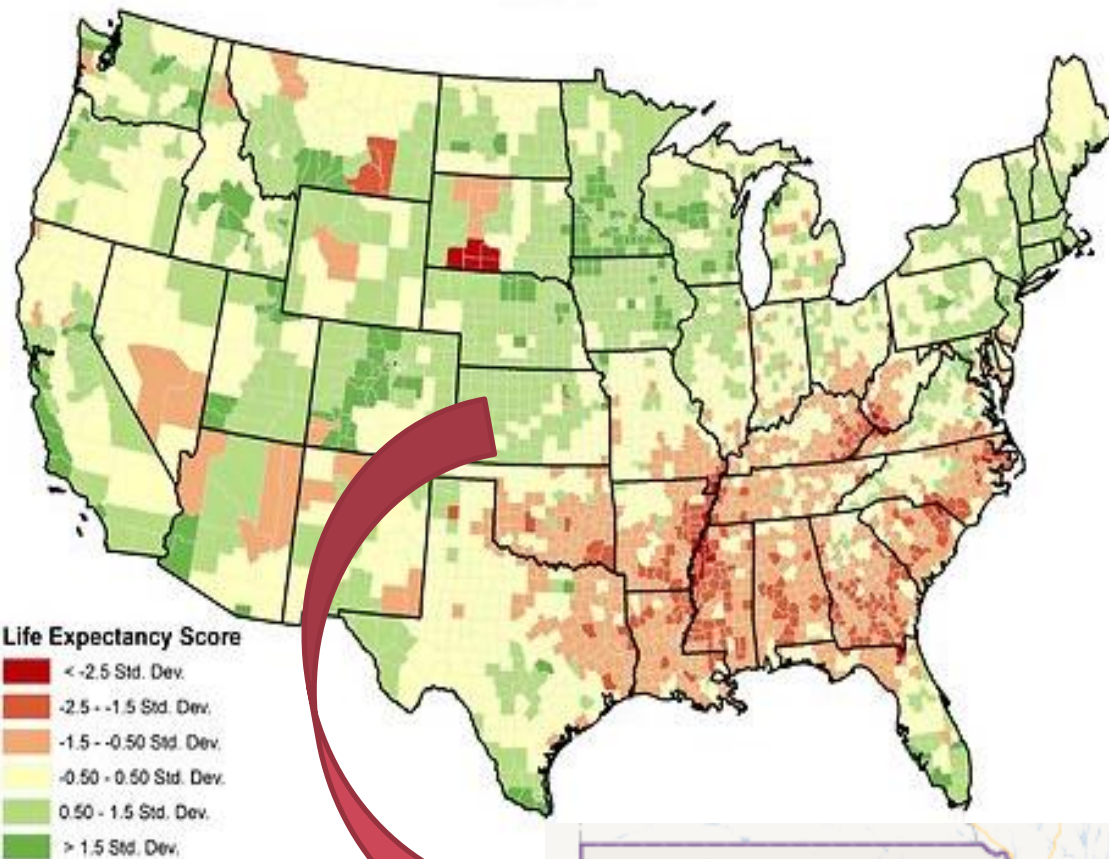
The Goebel LIGHTHouse Project consists of **three specialized homes** for 15 people with intellectual disabilities and dementia.

The Goebel Family-Star Lumber Charitable Foundation was the major benefactor of the project, the first of its kind in Kansas

The three 3,700 square foot (343.7 sq m) homes have five bedrooms each, bathrooms, and shared dining and living spaces

The homes were designed to provide a supportive community living experience for people with disabilities and dementia with specialized staff support until skilled nursing care is required

Study Instruments

- The Longitudinal Health and Intellectual Disability Survey (LHIDS)
- Caregiver Activity Survey-Intellectual Disabilities (CASID)
- Assessment for Adults with Developmental Disabilities Scale (AADS)
- Dementia Status Questionnaire (DSQ)
- Group Home Site Questionnaire (GHSQ)
- Kane Quality of Life Scale (KQoL)
- Caregiving Difficulty Scale (CDS)

Group Home Residents (Yr 1)

	Age (mean)	Sex	Down syndr.	IQ	BMI (mean)	Dem stage	Dem years	Co-morbid
House #1	58.0	2: ♀ 3: ♂	Yes: 2	Mod: 5	30.04 obese	Mod: 5	1-3yr: 3 3-5yr: 2	x̄=8
House #2	61.6	5: ♂	Yes: 2	Mod: 3 Sev:2	26.56 overweight	Mod: 3 Sev: 2	1-3yr: 3 3-5yr: 2	x̄=7.4
House #3	55.8	4: ♀ 1: ♂	Yes: 0	Mild: 1 Mod: 2 Sev: 2	32.86 obese	Mod: 3 Sev: 2	1-3yr: 5	x̄=8.2

Age: mean age; Down Syndr: Down Syndrome; BMI: Body mass index; Dem stage: Stage of dementia; Dem years: Years since onset; Co-morbid: Co-morbidities (Average number/person)

Primary Co-morbidities

Physical Health	%
Urinary incontinence	73.3
Constipation	73.3
High blood cholesterol	53.0
Gastrointestinal	40.0
Thyroid disorder	36.7
Heart burn/acid reflux	35.3
Heart condition	33.3
High blood pressure	33.3
Diabetes	33.3

Mental Health	%
Depression	66.7
Anxiety disorder	33.3
Sleep disorder	33.3

Comparison: Dem GH vs. Control

Dementia Group Homes (n=15)		Control Adults w/ID (n=15)	
Age (mean)	59.1	Age (mean)	59.1
Sex (males)	60%	Sex (males)	60%
Down syndrome present	26.7%	Down syndrome present	6.7%
Mean Weight (lbs/kg)	166.3/74.4	Mean Weight (lbs/kg)	181.7/82.4
Mean BMI	29.82	Mean BMI	34.76
IQ – Moderate/Severe	66.7/27.7 %	IQ – Moderate/Severe	53.3/26.7%
Co-morbidities (Average #)	8.6	Co-morbidities (Average #)	4.8
Mean CAS-ID (min/day)/(hr/day)	275.9m/4.6h	Mean CAS-ID (min/day)/(hr/day)	167.2m/2.8h
Mean Health Now Score	2.3 (F-G)	Mean Health Now Score	3.2 (V-VG)
Health year ago (About same or Better)	53.0%	Health year ago (About same or Better)	86.7%

Care challenges

Dementia Home	
Mean CAS-ID (min/day)	267.47 (4.46h)*
Mean day to day care burden	17.4*
Mean Care Challenges Score	3.6
Mean Quality of Life Score	11.33

Control Settings	
Mean CAS-ID (min/day)	161.47 (2.7h)
Mean day to day care burden	20.67
Mean Care Challenges Score	3.2
Mean Quality of Life Score	11.33

* Statistically Significant Difference

Summary 1

- Dementia affected adults in GH are/have
    - More apt to have Down syndrome
    - Weigh less
    - Lower BMI
    - Greater number of co-morbidities
    - Demand/require 2x more staff time
    - Are healthy
    - Diminishing health over time

Summary 2

- There were no significant differences at this point in quality of life and in care challenges
- Number of minutes providing care was statistically significant (more time spent with dementia)
- Subjective burden experienced by staff in providing day-to-day care was also different at a statistically significant level
  - BUT more subjective burden was experienced in control homes

Group home care model

- At this point agency is satisfied with investment
  - Mean operating cost per person is US$4067 p.a. (€3,014) (cost does not include other program services)
  - No particular changes are being planned after 1 year
- It is too early to validate our hypothesis, but…
- We will continue to
  - study to see if home specialization occurs over time
  - observe residents for change related to dementia or other factors

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