Using Specialized Group Homes for Long-term Dementia Care of Adults with Intellectual Disability

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Community care

What needs to be considered?

- Where the person is with respect to dementia progression
  - Can he or she stay where they currently live?
  - Should a specialty dementia-care home be considered?
    - If so, what is the most appropriate pairing?
- What are their wishes (or the wishes of the family)?
- What options exist in agencies or in the community?
- Are current services geared up for long term care?
  - Have a dementia-capable residence?
  - Have direct support and clinical staff knowledgeable of dementia and long-term dementia-related care?

Group living with dementia

- Rationale for small group living
  - Recommendations under the WHO report on Dementia: A Public Health Priority
  - Research in ID field supports small settings
  - Small setting can provide dementia-capable care
  - Philosophical commitment to caring in one's home by agencies
  - Degradation of function better handled on individual basis

  - Limited options for dementia specialty care for adults with ID
  - Family preferences

Dynamics of group home dementia care

- Staffing patterns
- Private and public space arrangements
- Peak times for care around dementia
- Flexibility in day care (in or out)
- Specialization of home based on staging

Prevalent dementia care options and their intent

Institutional care

[long term care facilities, nursing homes, old age homes, dementia special care units]

Sheltered dementia care
[assisted living, dementia care homes]

Family care

[living with family, other relatives, or other family members of carers]

Carer supports

Neighborhood group homes

[generic group homes, specialized group homes]

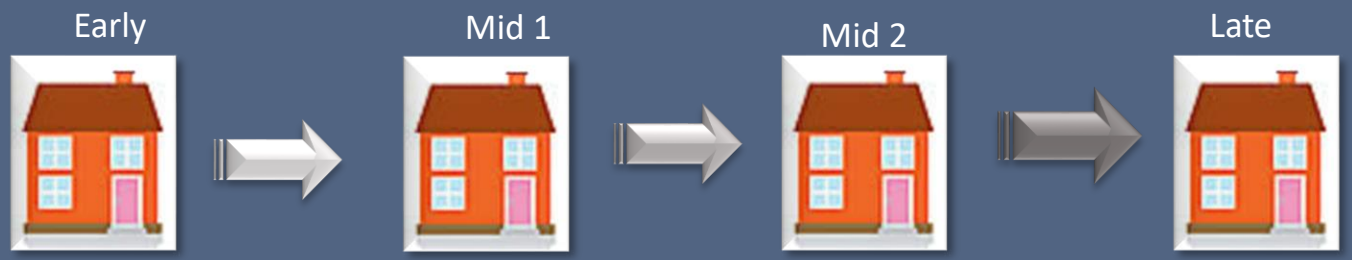
- Group homes for persons with ID who age in the homes
- Group homes for specialized dementia care

Small personalized care settings

Prevalent models of group home-based dementia care

AGING-IN-PLACE

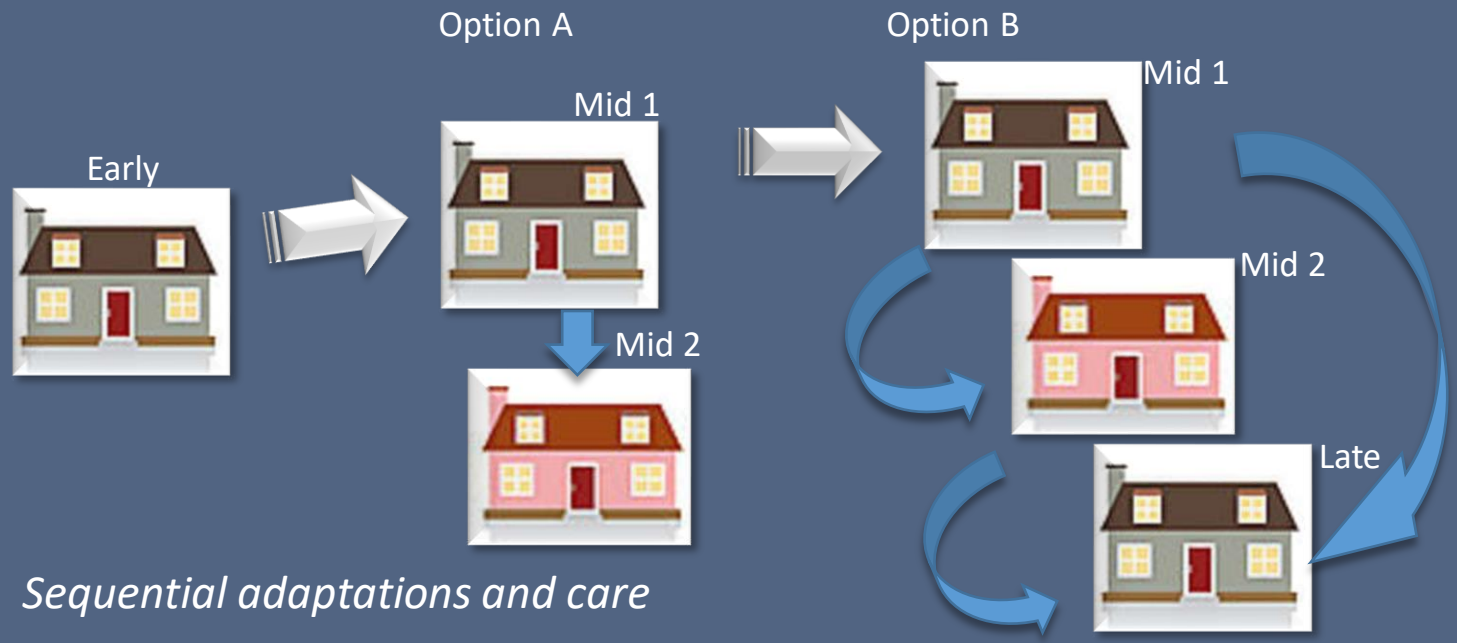
- *single care home and stable stay*



Linear adaptations and care

IN-PLACE-PROGRESSION

- *multiple care homes & movement with progression*



Sequential adaptations and care

Mid = mid-level

Source: JANICKI (2010)

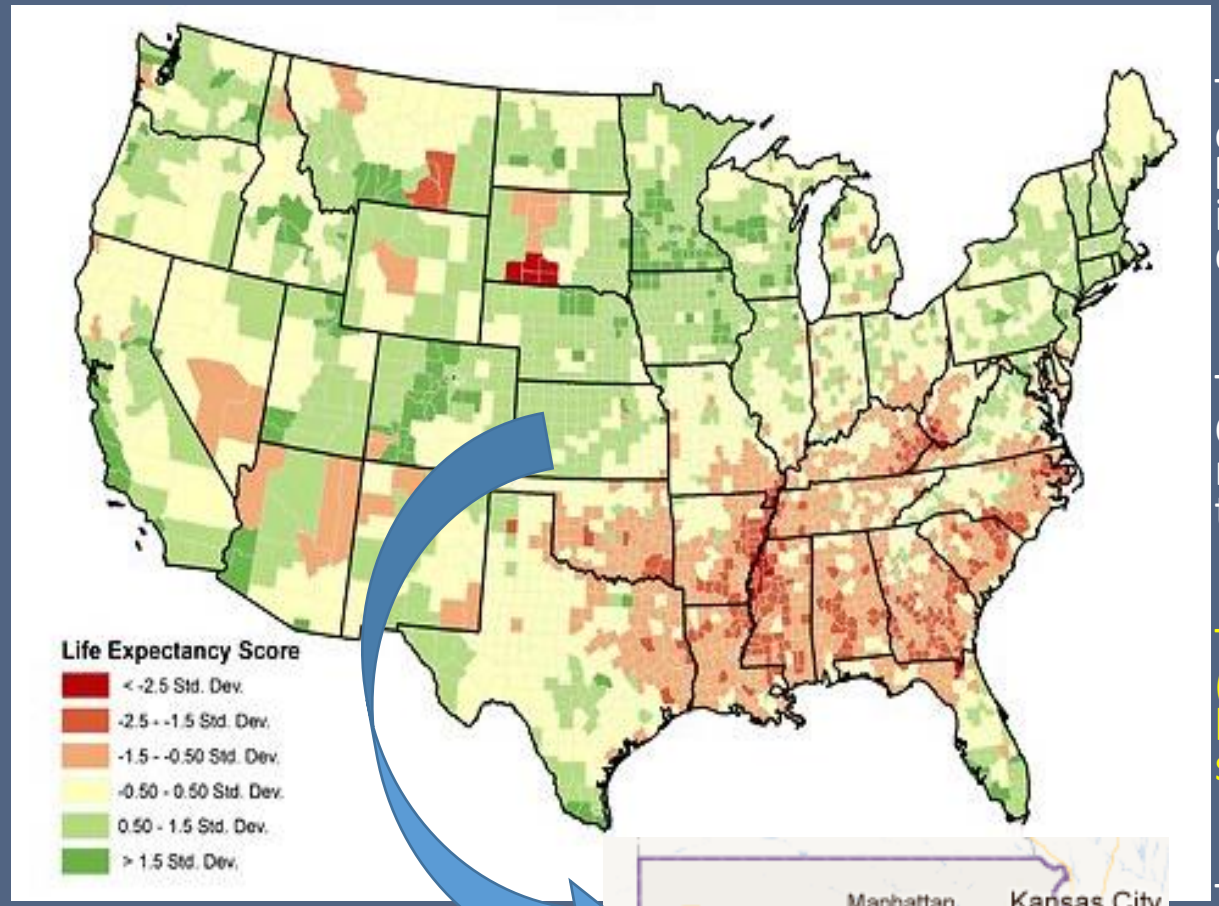
The ‘Wichita Study’

Background

- More local agencies are taking responsibility for the later-life care of aging adults with intellectual disabilities and are developing small dementia-care group homes.
- The homes are designed to be ‘dementia-capable’ and provide extended older age care.
- As dementia affects adults differentially, both with respect to symptoms and decline, it might be that individual dementia care homes will eventually be defined by their residents in terms of residual functional skills and degree of personal care needs.

Aim of Study

- Given that stage-specific changes eventually occur, it was of scientific interest to conduct a longitudinal study of three such dementia-care community-based group homes to observe progression of decline, resident needs, and adaptations to care practices.



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

GH1 = Diana House’ GH2 = WOW House; GH3 = Latimer House

Study method

- Data were collected 4 times – at approximately 6 month intervals
  - T1: February 2011
  - T2: August 2011
  - T3: February 2012
  - T4: August 2012
  - Dementia group home residents (n=15)
  - Controls (same age and general features) (n=15)

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) †

* T1, T2, T3, T 4 ; † T1

First Year – ‘T1’

What were the residents of the three homes like in the first year?

Group Home Residents (Yr 1)

	Age (mean)	Sex	Down syndrome	IQ	BMI (mean)	Dementia stage	Dementia years	Co-morbidities
House #1 	58.0	2: ♀ 3: ♂	Yes: 2	Mod: 5	30.04 obese	Mod: 5	1-3yr: 3 3-5yr: 2	$\bar{x}$=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	$\bar{x}$=7.4
House #3 	55.8	4: ♀ 1: ♂	Yes: 1	Mild: 1 Mod: 2 Sev: 2	32.86 obese	Mod: 3 Sev: 2	1-3yr: 5	$\bar{x}$=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)

Comparison: T1 Dem GH vs. Control

Dementia Group Homes (n=15)	
Age (mean)	59.1
Sex (males)	60%
Down syndrome present	33.4%
Mean Weight (lbs/kg)	166.3/74.4
Mean BMI	29.82
IQ – Moderate/Severe	66.7/27.7 %
Co-morbidities (Average #)	8.6
Mean CAS-ID (min/day)/(hr/day)	275.9m/4.6h
Mean Health Now Score	2.3 (F-G)
Health year ago (About same or Better)	53.0%

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

Group Home Residents (T1/T4)

	T	Age	Sex	Down Synd	IQ	BMI	Dem stage	Dem years	Dem symp	Co-morbid
House 1 	T1	*X*=60.2 51-68	2: ♀ 3: ♂	Yes: 2	Mod: 5	*X*=30.04 obese	Mod: 5	1-3yr: 3 3-5yr: 2	*X*=6.32	*X*=8
	T4	*X*=62.8 53-70	2: ⚧ 3: ⚧	Yes: 2	Mod: 5	*X*=30.28 obese	Mod: 5	1-3yr: 1 3-5yr: 3 5+yr: 1	*X*=4.08	*X*=9.2
House 2 	T1	*X*=61.6 49-76	5: ♂	Yes: 2	Mod: 3 Sev:2	*X*=26.56 overweight	Mod: 3 Sev: 2	1-3yr: 3 3-5yr: 2	*X*=7.88	*X*=7.4
	T4	*X*=63.2 50-78	5: ⚧	Yes: 2	Mod: 3 Sev:2	*X*=26.54 overweight	Mod: 3 Sev: 2	3-5yr: 4 5+yr: 1	*X*=12.96	*X*=8.8
House 3 	T1	*X*=55.8 44-70	4: ♀ 1: ♂	Yes: 1	Mild: 1 Mod: 2 Sev: 2	*X*=32.86 obese	Mod: 3 Sev: 2	1-3yr: 5	*X*=3.72	*X*=8.2
	T4	*X*=57.5 45-72	4: ⚧ 1: ⚧	Yes: 1	Mild: 1 Mod: 2 Sev: 2	*X*=35.5 obese	Mod: 3 Sev: 2	1-3yr: 1 3-5yr: 4	*X*=11.72	*X*=10.2

Age: mean age; Down Synd: Down Syndrome; BMI: Body mass index; Dem stage: Stage of dementia; Dem years: Years since onset; Dem symp: Dementia symptoms (AADS); Co-morbid: Co-morbidities (Average number); T: Time, T1 (Feb 2011), T4 (Aug 2012)

Tables 2,6

Wichita Project

Group Home Residents (T1/T5)

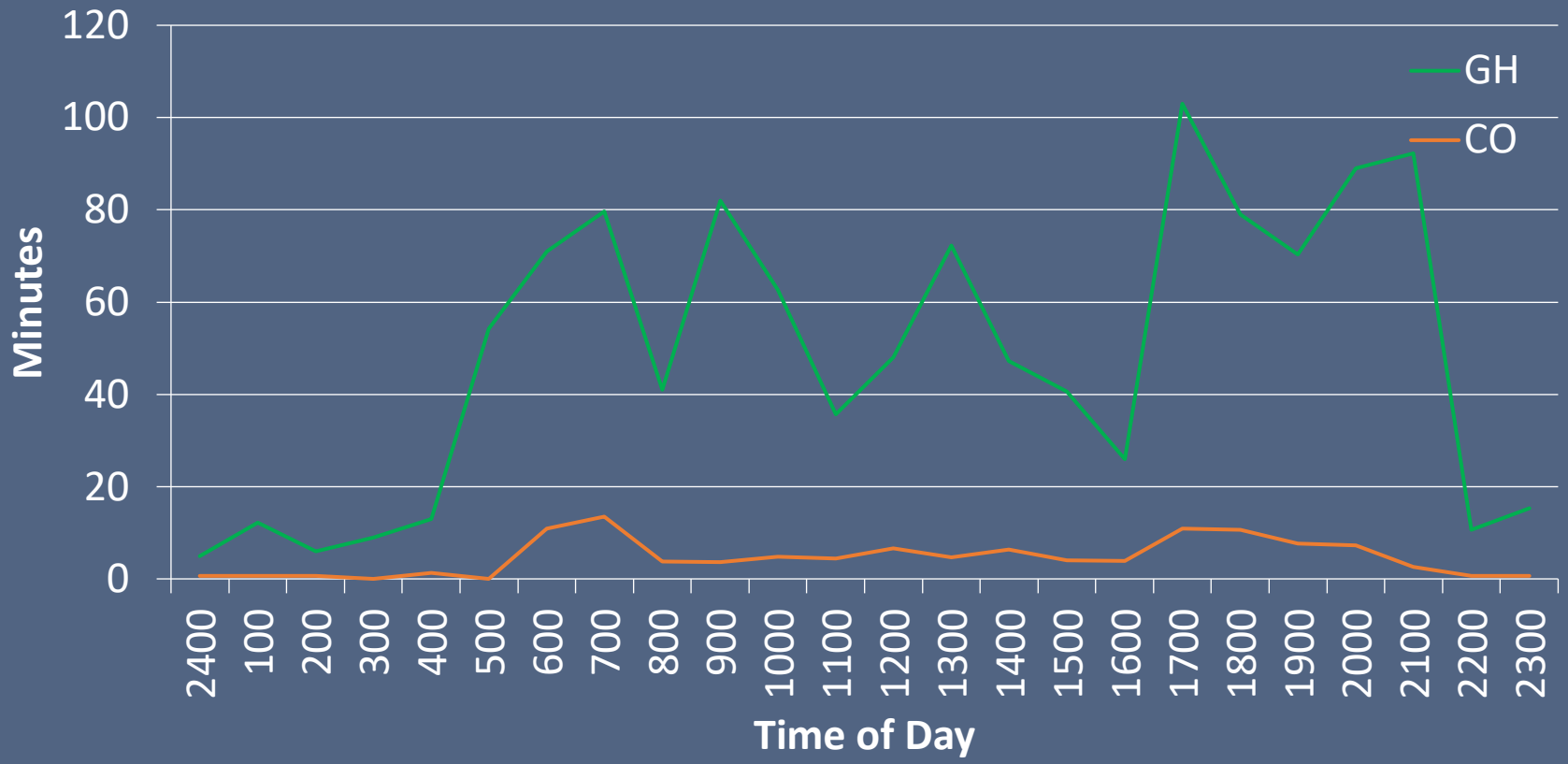
	T	Age	Sex	Down Synd	IQ	BMI	Dem stage	Dem years	Dem symp	Co-morbid
House 1 	T1	*X*=60.2 51-68	2: ♀ 3: ♂	Yes: 2	Mod: 5	*X*=30.04 obese	Mod: 5	1-3yr: 3 3-5yr: 2	*X*=6.32	*X*=8
	T5	*X*=63.8 53-70	2: ⚧ 3: ⚧	NC	NC	*X*=32.2 obese	Mod: 5	1-3yr: 1 3-5yr: 3 5+yr: 1	*X*=4.08	*X*=11.2
House 2 	T1	*X*=61.6 49-76	5: ♂	Yes: 2	Mod: 3 Sev:2	*X*=26.56 overweight	Mod: 3 Sev: 2	1-3yr: 3 3-5yr: 2	*X*=7.88	*X*=7.4
	T5	*X*=57.2 52-69	4: ⚧ 1: ⚧	Yes: 3	NC	*X*=30.6 Obese	Mod: 3 Sev: 2	3-5yr: 4 5+yr: 1	*X*=12.96	*X*=12.4
House 3 	T1	*X*=55.8 44-70	4: ♀ 1: ♂	Yes: 1	Mild: 1 Mod: 2 Sev: 2	*X*=32.86 obese	Mod: 3 Sev: 2	1-3yr: 5	*X*=3.72	*X*=8.2
	T5	*X*=59.2 47-73	4: ⚧ 1: ⚧	NC	NC	*X*=29.9 overweight	Mod: 3 Sev: 2	1-3yr: 1 3-5yr: 4	*X*=11.72	*X*=14.4

Age: mean age; Down Synd: Down Syndrome; BMI: Body mass index; Dem stage: Stage of dementia; Dem years: Years since onset; Dem symp: Dementia symptoms (AADS); Co-morbid: Co-morbidities (Average number); T: Time, T1 (Feb 2011), T5 (Aug 2014); NC = no change

Tables 2,6

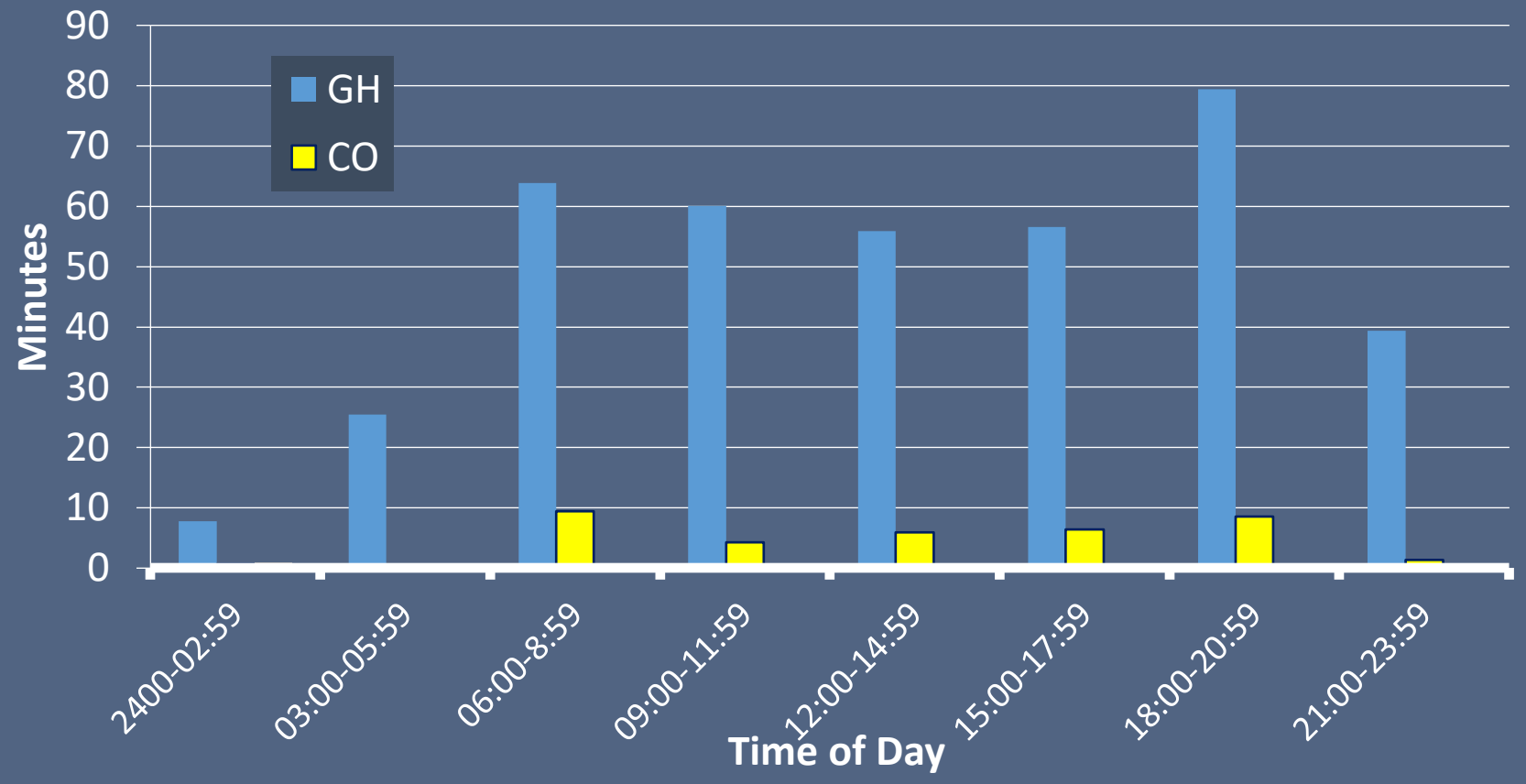
Wichita Project

CAS-ID time of day (min)



GHs vs. CO

CAS-ID time cluster – GH v CO (min)



GHs vs. CO

The 15 residents…two years later

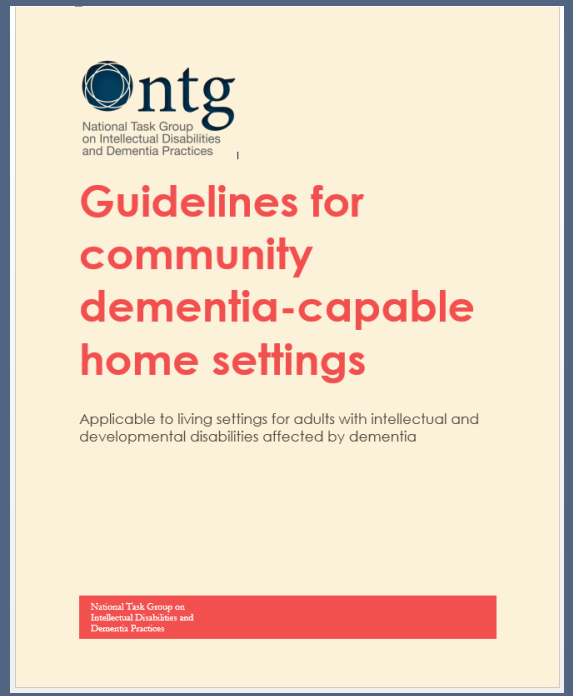
- Are older and there is some evidence of change in function and increasing health problems or less ‘wellness’
- Residents in homes 2 & 3 show the greatest impact of dementia over the two years
- Staff time spent on caregiving varies by home and is are much more than that for ‘the controls’
- Fluctuations of staff times by time of day indicated periods when most staff-resident interactions occur

Resources


Dementia & Down Syndrome
A Handbook for Caregivers
ndss
alzheimer's association
ntg
Caring for a Person with Alzheimer's Disease
Your Easy-to-Use Guide from the National Institute on Aging
NIH
Aging and Down Syndrome
A HEALTH & WELL-BEING GUIDEBOOK
ndss

NTG Guidelines that can help

Coming soon



www.aadmd.org/ntg

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