Designing and Building Dementia Care Homes
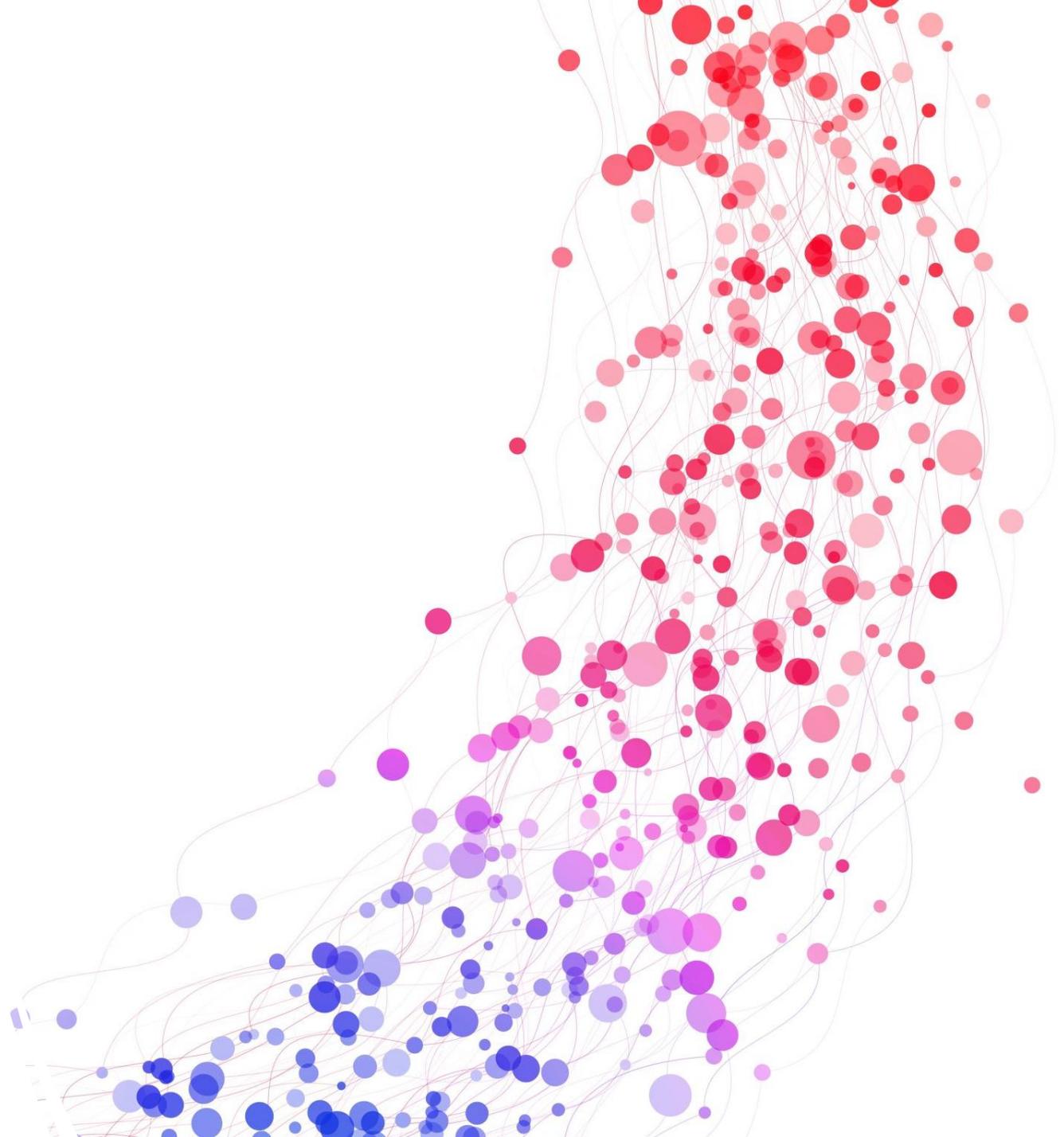
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Options for dementia care

Staying

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

Agency focus
Outreach and community supports (HCBS)
Helping support family caregivers

Leaving

Leaving home

- 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
Securing housing with dementia specialty care
Clinical team supports
Training for staff
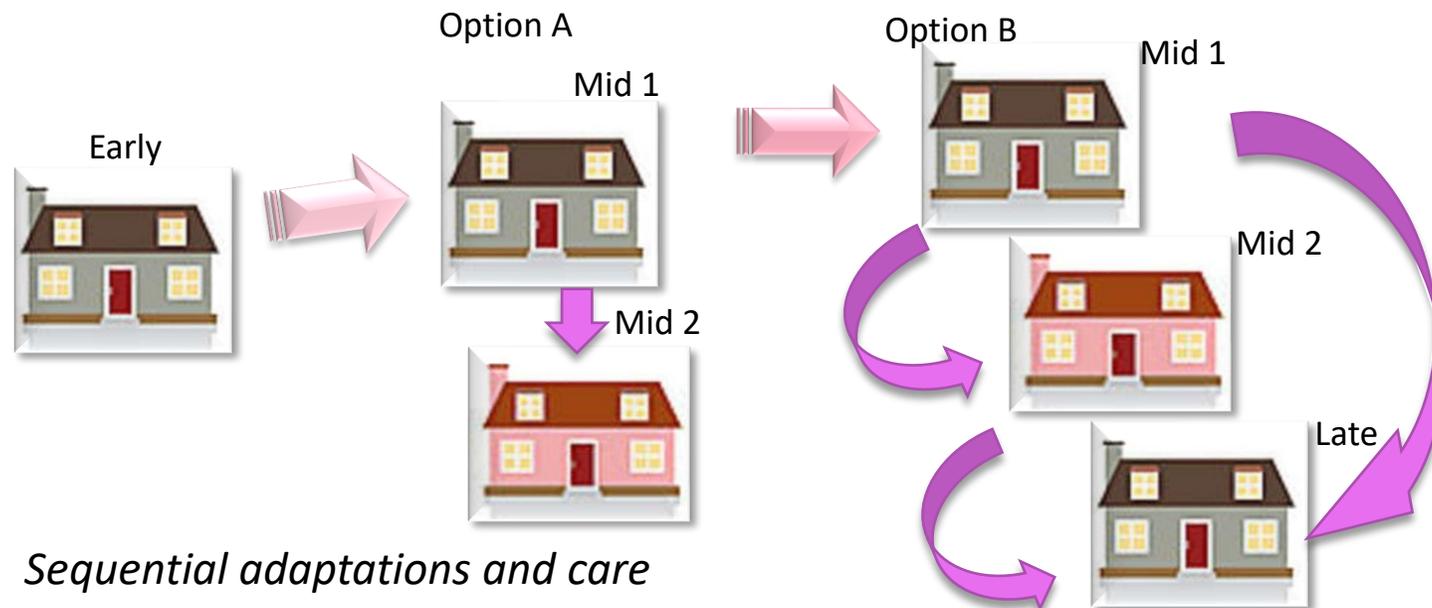
Group Home Models for Supporting Adults with Dementia

Early   Mid 1   Mid 2   Late

AGING-IN-PLACE

• *single care home and stable stay*
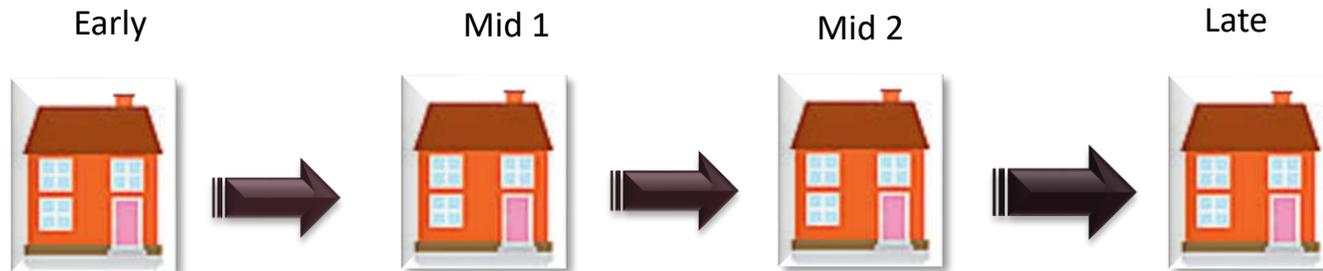
Linear adaptations and care

IN-PLACE-PROGRESSION

• *multiple care homes & movement with progression*

Mid = mid-level

Option A

Mid 1

Early

Mid 2

Option B   Mid 1

Mid 2

Late

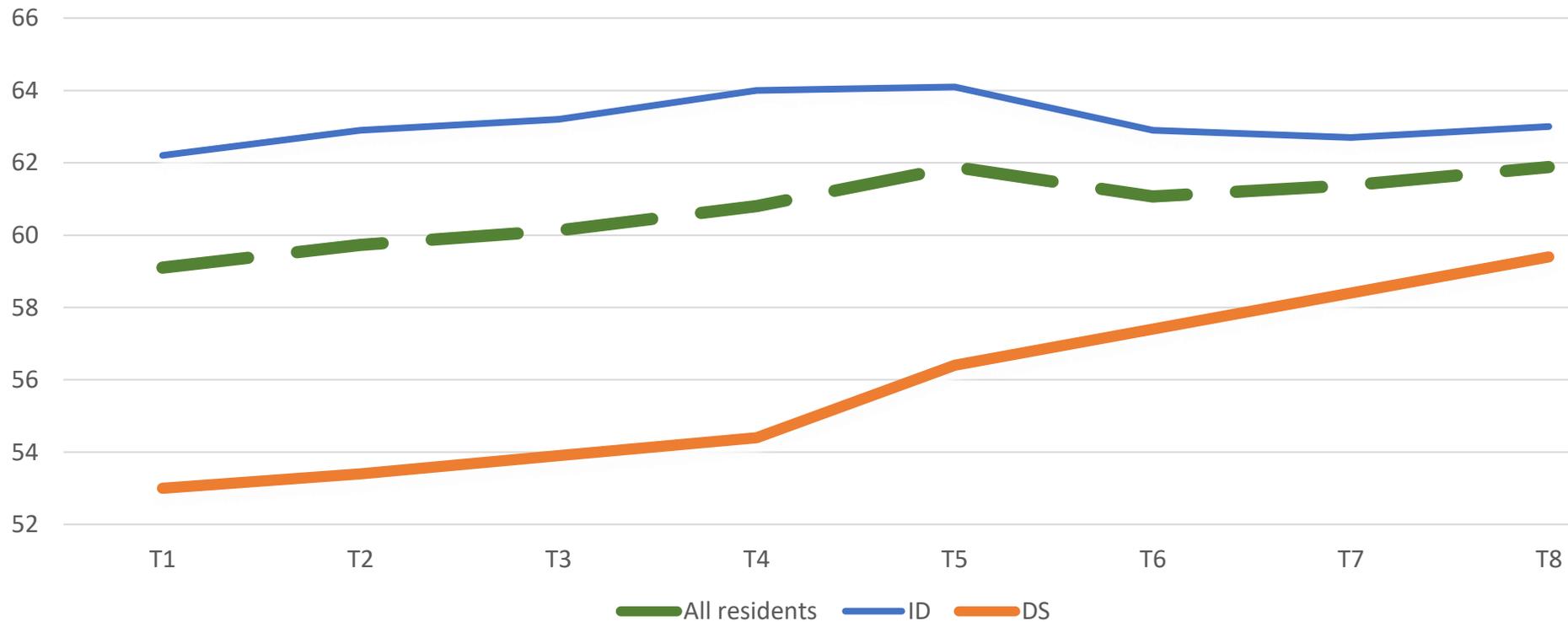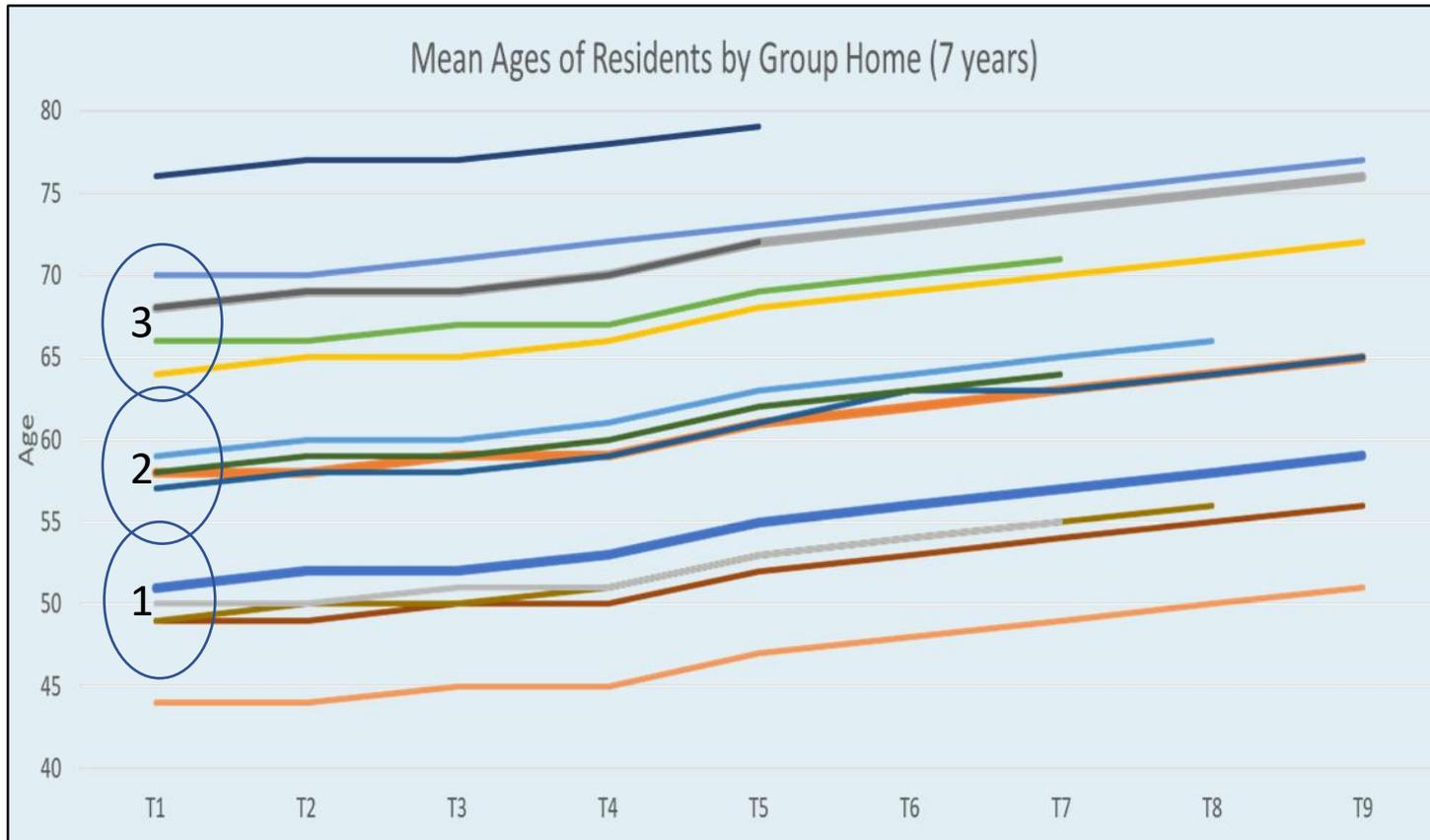*Sequential adaptations and care*

3

Mean ages of GH residents – ID vs DS

Mean ages of GH residents over time (T1-T8)

✓ <u>DS</u> adults *Xage* at entry was 53.5 for males and 57.5 for females

✓ <u>ID</u> adults *Xage* at entry was 64.4 for males and 58.0 for females

Legend: All residents, ID, DS

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Mean Ages of Residents by Group Home (7 years)

Ages at admission

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]

Wichita Project

Deaths and length of stay

Of **legacy adults**, 9/15 (60%) died over 9 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

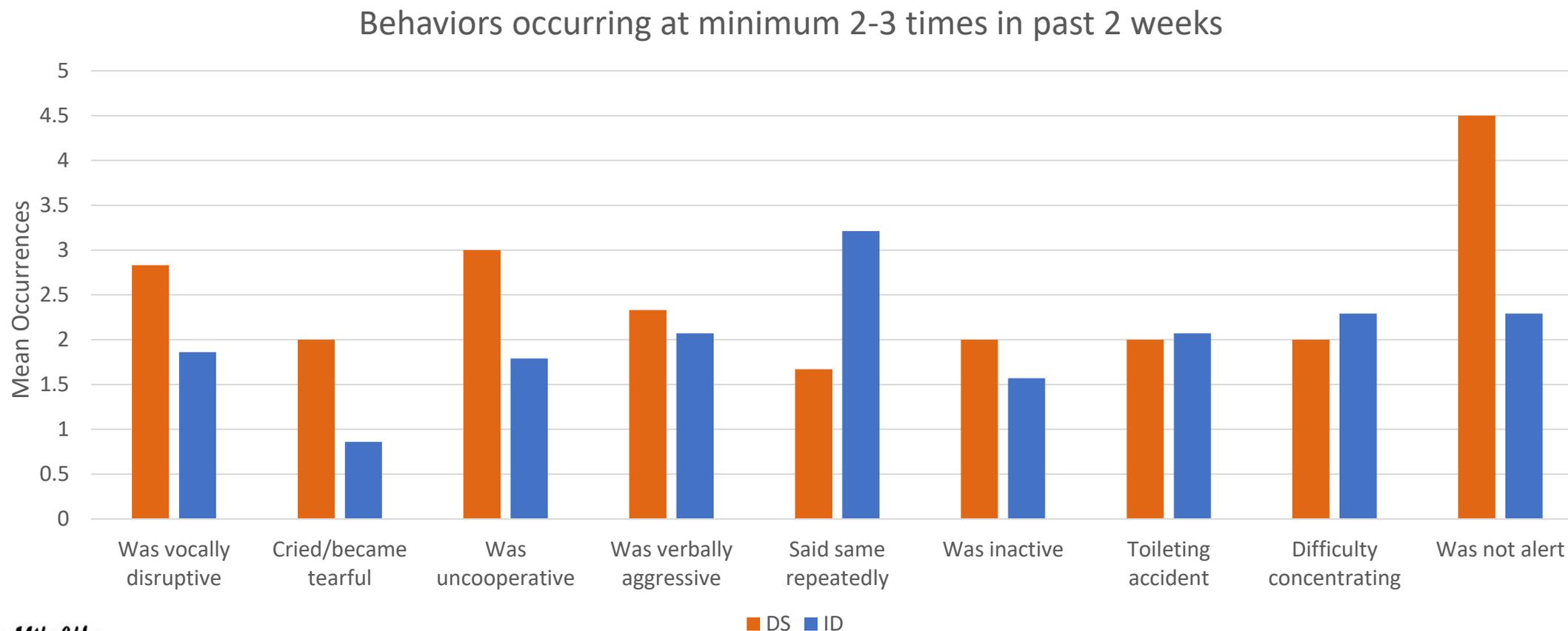- Average age of death for Controls: 78.5 yrs.

Legacy residents

Wichita Project
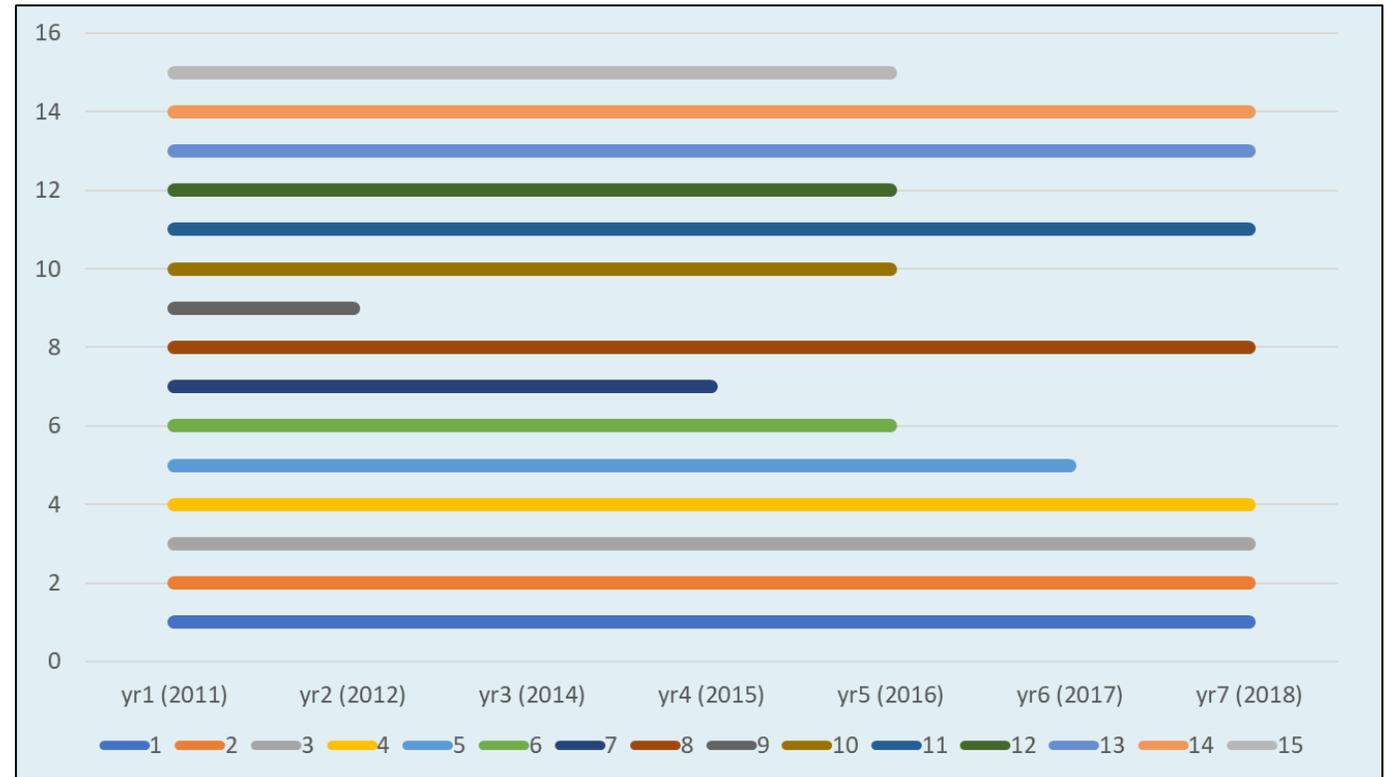
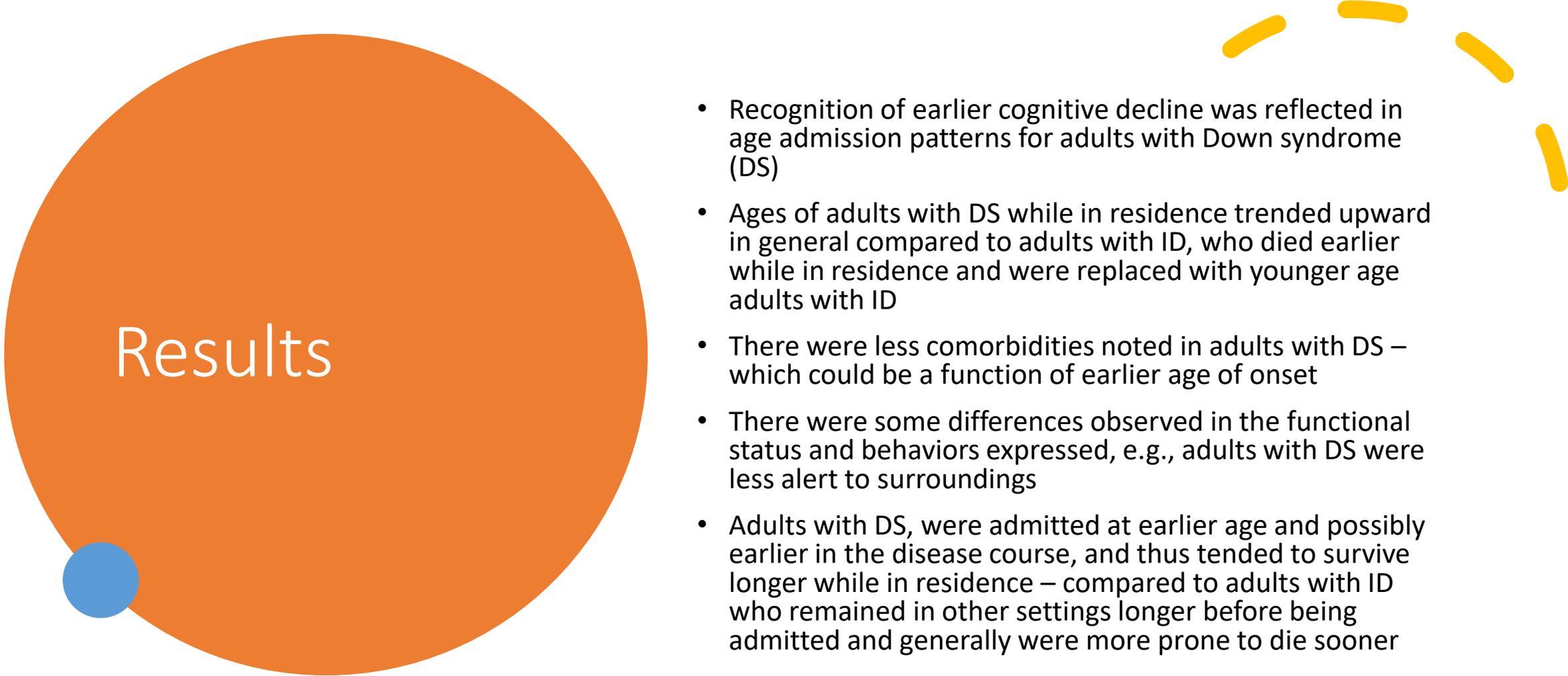# Comparative frequencies of comorbidities of GH residents – ID vs DS (base: 3 or more)

Comorbidity Frequencies
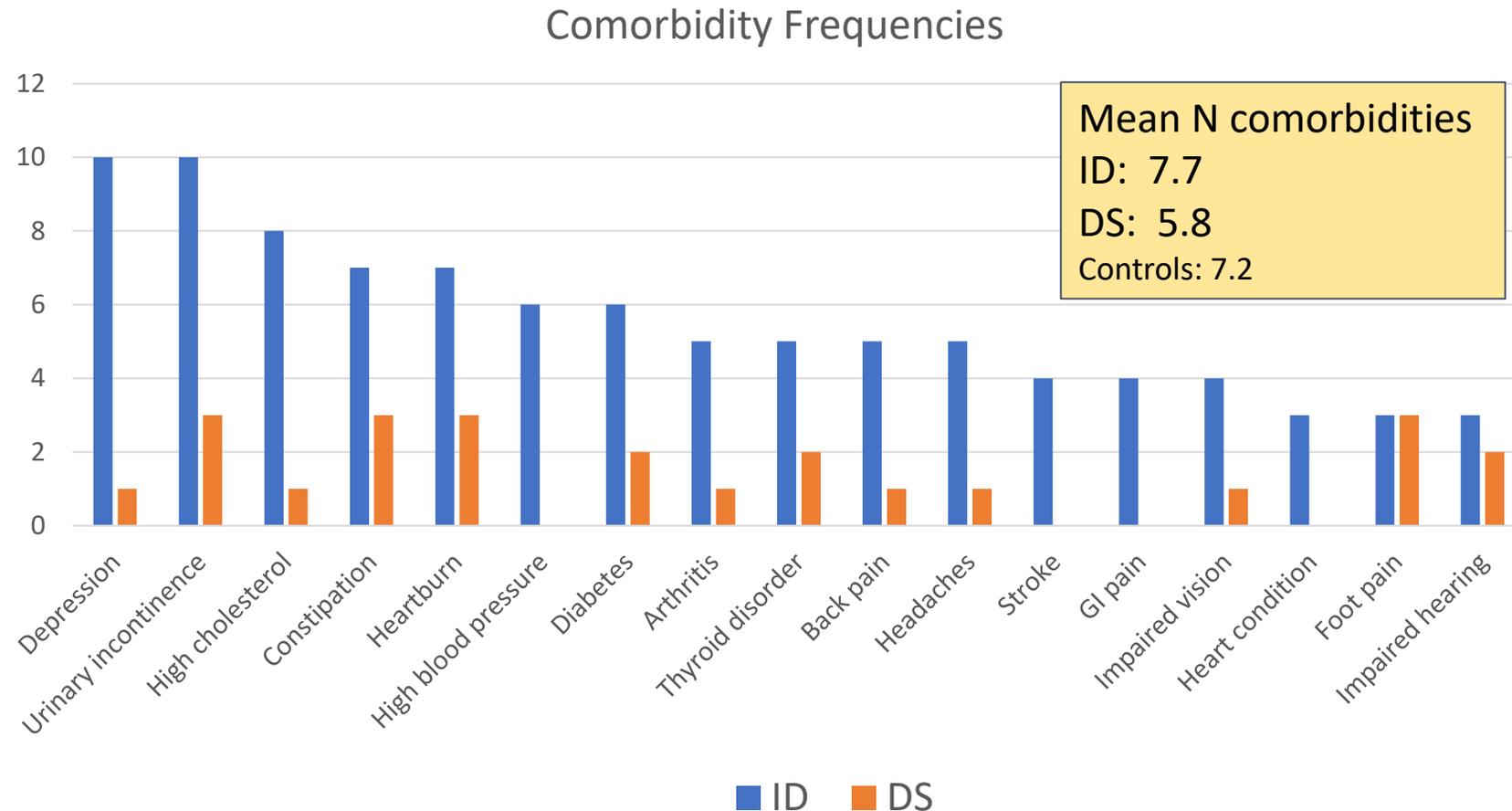
Mean N comorbidities
ID: 7.7
DS: 5.8
Controls: 7.2

Legend: ID, DS

Categories (left to right): Depression, Urinary incontinence, High cholesterol, Constipation, Heartburn, High blood pressure, Diabetes, Arthritis, Thyroid disorder, Back pain, Headaches, Stroke, GI pain, Impaired vision, Heart condition, Foot pain, Impaired hearing

5 most prevalent comorbidities among **ID residents**
- Depression
- Urinary incontinence
- High cholesterol
- Constipation
- High blood pressure, diabetes

5 most prevalent comorbidities among **DS residents**
- Urinary incontinence
- Constipation
- Heartburn
- Foot pain
- Diabetes, thyroid disorder, impaired hearing

Data drawn from the NTG-EDSD (Esralew et al., 2017)

Wichita Project

AADS dementia symptom related Items – DS vs ID

Behaviors occurring at minimum 2-3 times in past 2 weeks

AADS: Assessment for Adults with Developmental Disabilities (Oliver et al., JARID, 2011)

$N_{DS}=6; N_{ID}=14$

Results

- Recognition of earlier cognitive decline was reflected in age admission patterns for adults with Down syndrome (DS)

- Ages of adults with DS while in residence trended upward in general compared to adults with ID, who died earlier while in residence and were replaced with younger age adults with ID

- There were less comorbidities noted in adults with DS – which could be a function of earlier age of onset

- There were some differences observed in the functional status and behaviors expressed, e.g., adults with DS were less alert to surroundings

- Adults with DS, were admitted at earlier age and possibly earlier in the disease course, and thus tended to survive longer while in residence – compared to adults with ID who remained in other settings longer before being admitted and generally were more prone to die sooner

Implications in general for group homes

Information on progression timelines can aid agencies with residence resource planning and assignment of staff and clinical resources

Knowledge drawn for how different etiologies have various presentations can help with planning home admissions and providing for LOS (dementia care protocols and individualized care planning)

By tracking the health and function longitudinally, outcome information can pinpoint markers that are associated with premorbid dementia and can help health providers maintain surveillance over select functions and health conditions of those adults already affected

Screening instruments, incorporating markers, can more precisely be used to identify at-risk adults for dementia and aid providers in designing remediation programs earlier

Knowing about probabilities of occurrence of co-conditions can help with medical management and with providing accommodations for non-dementia related effects