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]

**Family care**
- [living with family, other relatives, or other family members of carers]

**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

**Sheltered dementia care**
- [assisted living, dementia care homes]

**Carer supports**

**Small personalized care settings**
Prevalent models of group home-based dementia care

**AGING-IN-PLACE**
- single care home and stable stay

**IN-PLACE-PROGRESSION**
- multiple care homes & movement with progression

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, T4; †T1
First Year – ‘T1’

What were the residents of the three homes like in the first year?
<table>
<thead>
<tr>
<th>House #1</th>
<th>Age (mean)</th>
<th>Sex</th>
<th>Down syndrome</th>
<th>IQ</th>
<th>BMI (mean)</th>
<th>Dementia stage</th>
<th>Dementia years</th>
<th>Co-morbidities</th>
</tr>
</thead>
<tbody>
<tr>
<td>House #1</td>
<td>58.0</td>
<td>2: ♀</td>
<td>Yes: 2</td>
<td>Mod: 5</td>
<td>30.04 obese</td>
<td>Mod: 5</td>
<td>1-3yr: 3</td>
<td>3-5yr: 2</td>
</tr>
<tr>
<td></td>
<td>3: ♂</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House #2</td>
<td>61.6</td>
<td>5: ♂</td>
<td>Yes: 2</td>
<td>Mod: 3 Sev:2</td>
<td>26.56 overweight</td>
<td>Mod: 3 Sev: 2</td>
<td>1-3yr: 3</td>
<td>3-5yr: 2</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House #3</td>
<td>55.8</td>
<td>4: ♀</td>
<td>Yes: 1</td>
<td>Mild: 1 Mod: 2 Sev: 2</td>
<td>32.86 obese</td>
<td>Mod: 3 Sev: 2</td>
<td>1-3yr: 5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1: ♂</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Age: mean age; Down Synd: 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**

<table>
<thead>
<tr>
<th></th>
<th><strong>Dementia Group Homes (n=15)</strong></th>
<th><strong>Control Adults w/ID (n=15)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>59.1</td>
<td>59.1</td>
</tr>
<tr>
<td>Sex (males)</td>
<td>60%</td>
<td>60%</td>
</tr>
<tr>
<td>Down syndrome present</td>
<td>33.4%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Mean Weight (lbs/kg)</td>
<td>166.3/74.4</td>
<td>181.7/82.4</td>
</tr>
<tr>
<td>Mean BMI</td>
<td>29.82</td>
<td>34.76</td>
</tr>
<tr>
<td>IQ – Moderate/Severe</td>
<td>66.7/27.7%</td>
<td>53.3/26.7%</td>
</tr>
<tr>
<td>Co-morbidities (Average #)</td>
<td>8.6</td>
<td>4.8</td>
</tr>
<tr>
<td>Mean CAS-ID (min/day)/(hr/day)</td>
<td>275.9m/4.6h</td>
<td>167.2m/2.8h</td>
</tr>
<tr>
<td>Mean Health Now Score</td>
<td>2.3 (F-G)</td>
<td>3.2 (V-VG)</td>
</tr>
<tr>
<td>Health year ago (About same or Better)</td>
<td>53.0%</td>
<td>86.7%</td>
</tr>
<tr>
<td>T</td>
<td>Age</td>
<td>Sex</td>
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<tr>
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</tr>
<tr>
<td>House 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>$X=60.2$</td>
<td>51-68</td>
</tr>
<tr>
<td></td>
<td>$X=62.8$</td>
<td>53-70</td>
</tr>
<tr>
<td></td>
<td>House 2</td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>$X=61.6$</td>
<td>49-76</td>
</tr>
<tr>
<td></td>
<td>$X=63.2$</td>
<td>50-78</td>
</tr>
<tr>
<td></td>
<td>House 3</td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>$X=55.8$</td>
<td>44-70</td>
</tr>
<tr>
<td></td>
<td>$X=57.5$</td>
<td>45-72</td>
</tr>
</tbody>
</table>

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)
# Group Home Residents (T1/T5)

<table>
<thead>
<tr>
<th>House</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
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</tr>
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<tr>
<td></td>
<td>T</td>
<td>Age</td>
<td>Sex</td>
<td>Down Synd</td>
<td>IQ</td>
<td>BMI</td>
<td>Dem stage</td>
<td>Dem years</td>
<td>Dem symp</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House 1</td>
<td>T1</td>
<td>$X=60.2$</td>
<td>2: ♀</td>
<td>Yes: 2</td>
<td>Mod: 5</td>
<td>$X=30.04$ obese</td>
<td>Mod: 5</td>
<td>1-3yr: 3</td>
<td>3-5yr: 2</td>
</tr>
<tr>
<td></td>
<td>T5</td>
<td>$X=63.8$</td>
<td>2: ♀</td>
<td>NC</td>
<td>NC</td>
<td>$X=32.2$ obese</td>
<td>Mod: 5</td>
<td>1-3yr: 1</td>
<td>3-5yr: 3</td>
</tr>
<tr>
<td>House 2</td>
<td>T1</td>
<td>$X=61.6$</td>
<td>5: ♂</td>
<td>Yes: 2</td>
<td>Mod: 3</td>
<td>$X=26.56$ overweight</td>
<td>Mod: 3</td>
<td>1-3yr: 3</td>
<td>3-5yr: 2</td>
</tr>
<tr>
<td></td>
<td>T5</td>
<td>$X=57.2$</td>
<td>4: ♂</td>
<td>Yes: 3</td>
<td>NC</td>
<td>$X=30.6$ Obese</td>
<td>Mod: 3</td>
<td>3-5yr: 4</td>
<td>5+yr: 1</td>
</tr>
<tr>
<td>House 3</td>
<td>T1</td>
<td>$X=55.8$</td>
<td>4: ♂</td>
<td>Yes: 1</td>
<td>Mild: 1</td>
<td>$X=32.86$ obese</td>
<td>Mod: 3</td>
<td>1-3yr: 5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>T5</td>
<td>$X=59.2$</td>
<td>4: ♂</td>
<td>NC</td>
<td>NC</td>
<td>$X=29.9$ overweight</td>
<td>Mod: 3</td>
<td>1-3yr: 1</td>
<td>3-5yr: 4</td>
</tr>
</tbody>
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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
NTG Guidelines that can help

www.aadmd.org/ntg

Coming soon

Guidelines for community dementia-capable home settings

Applicable to living settings for adults with intellectual and developmental disabilities affected by dementia
The NTG is Supported by the American Academy of Developmental Medicine and Dentistry and the University of Illinois at Chicago’s RRTC on Developmental Disabilities and Health

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