Family Support Interventions: Crossing Networks of Aging and Developmental Disabilities

IASSID SIRG on Aging Roundtable

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Gerontology is a more comprehensively researched field; what can disability learn from the most recent aging literature?

What strategies have both aging and disability employed to effectively translate interventions to community settings?
Majority live at home with family (60% in the US) (Braddock et al., 2012)

Long waiting list for services (Braddock et al., 2012)

Some families face higher levels of depression, health issues, financial strain, and poorer access to health care (Yamaki, Hsieh, & Heller, 2009)

Need for support interventions
General Aging

- Adult offspring and spouses most often provide care (National Alliance for Caregiving, 2009)

- High rates (over 2/3) of caregiving burden and depression (NAC, 2009)

- Worries about person’s health and uncertainty about ones ability to provide care

- Decades of caregiving support research
Research Questions

1. What types of interventions and outcomes?
2. What are the innovative approaches being used?
3. What are the gaps in the research?
Methods for Caregiving: Scoping Reviews

Disability Reviews
- Literature from 1991 through 2011
- MEDLINE, PsychInfo, and CINAHL databases
- Journal articles written in English on interventions for adults with developmental disabilities
- Subject: family caregiving

Aging Reviews
- Literature from 2007 through 2012
- MEDLINE, PsychInfo, and CINAHL databases
- Journal articles written in English on interventions for older adults
- Subject: family caregiving
Caregiving Review Results: Types of Interventions

Developmental Disability
- Support & Therapy: 36%
- Education and Training: 21%
- Financial & Home Supports: 29%
- Care Coordination: 14%
- Other: 0%

Aging
- Support & Therapy: 31%
- Education and Training: 39%
- Financial & Home Supports: 6%
- Care Coordination: 13%
- Other: 11%
Family Caregiving: Results

- Disability review had greater emphasis on positive outcomes, future planning.
- Aging review had stronger research designs, greater breadth of research.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Aging n-64</th>
<th></th>
<th>Developmental Disability n-14</th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percentage</td>
<td>Frequency</td>
<td>Percentage</td>
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<tr>
<td>Research Design</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>RCT</td>
<td>29</td>
<td>45%</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>quasi-experimental</td>
<td>5</td>
<td>8%</td>
<td>0</td>
<td>6%</td>
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<tr>
<td>No comparison group, multiple observations</td>
<td>19</td>
<td>30%</td>
<td>5</td>
<td>36%</td>
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<tr>
<td>cross-sectional</td>
<td>5</td>
<td>36%</td>
<td>5</td>
<td>36%</td>
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<tr>
<td>Other</td>
<td>11</td>
<td>17%</td>
<td>3</td>
<td>21%</td>
</tr>
<tr>
<td>Type of intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>government programs: care coordination</td>
<td>8</td>
<td>13%</td>
<td>2</td>
<td>14%</td>
</tr>
<tr>
<td>government programs: waivers &amp; financial assistance</td>
<td>4</td>
<td>6%</td>
<td>3</td>
<td>21%</td>
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<tr>
<td>government programs: respite</td>
<td>2</td>
<td>3%</td>
<td>1</td>
<td>7%</td>
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<tr>
<td>Psychosocial: education and training</td>
<td>24</td>
<td>38%</td>
<td>3</td>
<td>21%</td>
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<tr>
<td>psychosocial: support &amp; therapy</td>
<td>19</td>
<td>30%</td>
<td>5</td>
<td>36%</td>
</tr>
<tr>
<td>other</td>
<td>7</td>
<td>11%</td>
<td>0</td>
<td>0%</td>
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</table>

Findings: Types of Outcomes

<table>
<thead>
<tr>
<th></th>
<th>Aging n-64</th>
<th>Percentage</th>
<th>Developmental Disability n-14</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health (depression, anxiety, stress)</td>
<td>38</td>
<td>59%</td>
<td>8</td>
<td>57%</td>
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<tr>
<td>Caregiving Appraisal (burden, satisfaction, stress)</td>
<td>52</td>
<td>81%</td>
<td>10</td>
<td>71%</td>
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<tr>
<td>out-of-home placement</td>
<td>4</td>
<td>6%</td>
<td>1</td>
<td>7%</td>
</tr>
<tr>
<td>health (disease specific, health behaviors)</td>
<td>11</td>
<td>17%</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>employment and productivity</td>
<td>0</td>
<td>0%</td>
<td>2</td>
<td>14%</td>
</tr>
<tr>
<td>future planning</td>
<td>6</td>
<td>9%</td>
<td>7</td>
<td>50%</td>
</tr>
<tr>
<td>access to supports</td>
<td>9</td>
<td>14%</td>
<td>6</td>
<td>43%</td>
</tr>
<tr>
<td>care recipient outcomes</td>
<td>12</td>
<td>19%</td>
<td>9</td>
<td>64%</td>
</tr>
</tbody>
</table>
I/DD Family Support Interventions

Psychosocial Interventions
- Support and therapy groups
- Psycho-educational groups

Public Policies
- Support coordination
- Financial and home support
Psycho-educational  (Smith, Majesky, & McClenny, 1996)
- Liked networking
- Families who resided with relative wanted more information on future planning

Support and Education  (Mengel, Marcus, & Dunkle, 1996)
- Shared coping strategies
- Continued meeting
Efficacy Trials: *Future is Now* (Heller & Caldwell, 2006; Factor et al., 2012)

- Randomized one year –pre-post test
- Key outcomes
  - Developed Special Needs Trust
  - Made residential plans
  - Developed a Letter of Intent
  - Caregiving burden decreased
  - For adult with ID more daily choice making and fewer unmet leisure needs
“Options for Older Families” with intensive case coordination (Bigby, Ozanne, & Gordon, 2002)

- Access to discretionary funds
- Resulted in proactivity and prevention
- Increased access to supports and services and better planning for the future
- Increased knowledge and self-confidence in navigating services and increased use of services
I/DD Policies: Illinois Home Based Support Services Program

- Model self-directed program since 1990
  - Adults with developmental disabilities at home
  - Randomly selected through “lottery” from waiting list
- Individualized monthly budget of $1,637 (3 x SSI)
  - Respite and personal assistance services
  - Hire workers (including family members)
  - Home modifications
  - Day program and employment services
  - Transportation
Outcomes (Heller & Caldwell, 2006; Caldwell & Heller, 2003, 2007)

For individuals with disabilities:
- Greater community participation
- Greater employment and higher wages
- More opportunities for those from lower-income families to make daily choices

For families:
- More satisfaction with services
- Fewer unmet service needs
- Better mental health for poorer families
- More social participation
Placement Over 8 Year Period

- At Home: 70 (Waiting List), 81 (Consumer-Directed Program)
- Institution: 16 (Waiting List), 10 (Consumer-Directed Program)
Aging Family Support Interventions

- **Psychosocial Interventions**
  - Support and therapy groups
  - Psycho-educational groups

- **Public Policies**
  - Support coordination
  - Financial and home support

- **Other**
  - Expressive writing
  - Creative movement
  - Benefit-finding (focusing on the positive aspects)
Aging: Support Groups

Psycho-educational

- Coping with end of life (Bowman, 2009)
- Use of religion and spirituality (Bormann, 2009)
- Dyadic counseling, skill building, and singing (Camic, 2011)
- Less depression and burden in most studies

Support and Education (Mengel, Marcus, & Dunkle, 1996)

- Taught cognitive strategies (Burgio, 2009)
- Improved confidence in caring ability and use of coping strategies (DuCharme, 2011)
Aging: Support Coordination

- Transition support from hospital (Ghatak, 2011)
- Coordination within computer database (Judge, 2011)
- Changes in emergency healthcare (Knowles, 2011)
- Resulted in caregivers’ increased facility with care models and improved service satisfaction
National Family Caregiver Support Programs including activities for person and respite for caregivers (Park, 2008)

Improved caregiver appraisal and mental health

6 month delay in nursing home placement (Andren, 2008)
What Disability Can Learn From Aging: Findings from Caregiving Reviews

- Greater breadth of research and wider variety of programs
- Greater use of theoretical approaches; e.g., Gitlins (2010) use of environmental fit within home environments
- Unique strategies (singing, creative movement)
- Use of technology (tele-video and tele-counseling)
- Smoother transitions in care
- Translational approaches to tailor to particular communities, such as veterans
What Aging Can Learn from Disability: Findings from Caregiving Reviews

- Less emphasis on negative outcomes, beyond “burden” and “stress” to identify positive outcomes, such as access to employment or independence.
- More focus on building independence and self-determination of care recipient—holistic perspective on family.
Needed I/DD Interventions

- More attention to siblings
- More involvement of the person with ID in planning for the future
- Public policies that support families in continued care
- Long-term supports out of the family home
- Support for caregivers with ID
Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function

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