Evaluating the Impact of a Community Education Program on Dementia and IDD: Adapted NTG Curriculum in Arizona

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Summary
In Fall 2016, the Sonoran Center for Excellence in Disabilities initiated the Identify and Address Alzheimer’s and Dementia in Adults through Prevention and Training (I-AADAPT) project. The goal was to develop local capacity for providing Dementia Education of Intellectual and Developmental Disabilities and bring the Dementia Capable Care Training developed by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) to Arizona. The I-AADAPT project team adapted the NTG curriculum to meet the needs of specific local audiences and implemented the curriculum via 27 workshops across Arizona. This study provides the preliminary results of pre- and post-workshop evaluations (N=260) of the I-AADAPT family and community provider designed curriculum.

Background
- As the life expectancy of individuals with intellectual and developmental disabilities (IDD) increases, the risk of experiencing age-related conditions, such as dementia, increases.
- Underlying life-long cognitive and behavioral conditions pose unique challenges in detecting age related health conditions.
- Health Care Advocacy can be complex but is essential to ensure proper treatment and support to promote the well-being of individuals with IDD and their caregivers.

I-AADAPT:
- Six I-AADAPT core team members were certified as NTG affiliated trainers.
- The NTG curriculum was adapted and implemented between June 2017 and September 2018. The I-AADAPT curriculum consisted of:
  
<table>
<thead>
<tr>
<th>Training Type</th>
<th>Length</th>
<th># of classes/ # of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/Direct Care Provider</td>
<td>4-9h</td>
<td>8 classes/ n =97</td>
</tr>
<tr>
<td>DDD staff</td>
<td>6-9h</td>
<td>10 classes/ n = 71</td>
</tr>
<tr>
<td>Combined for Rural Areas</td>
<td>7-9h</td>
<td>4 classes/ n = 71</td>
</tr>
<tr>
<td>Health Care Professionals</td>
<td>1-1h</td>
<td>5 classes/ n = 83+</td>
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</tbody>
</table>

Current Study:
Examines the impact of I-AADAPT *Family/Direct Care provider and DDD staff trainings on participants’ awareness and knowledge of Alzheimer’s disease and related Dementias in individuals with IDD.

Methods
a) Pre- and post-workshop surveys on participants’ awareness and knowledge of Alzheimer’s disease and related dementias (10 items; 0= not at all to 4= very much; Total score range: 0 to 40; n = 260)
b) Follow-up semi-structured interviews (n=3).

Results
- **Participant Type:**
  - Family, n=16; Direct Care Providers, n=59; Support Coordinators, n=74; Nurse, n=4; Family & Care Provider, n=10; Division of Developmental Disability Staff/Supervisors, n=41; Others, n=56
  - a) Paired T-tests results reveal that the I-AADAPT workshops had significant impact on overall scores of participants’ awareness and knowledge:
    
    | Pre, M= 18.7, SD= 10.6 | Post, M= 33.7, SD= 6.5, t(259) = -23.32, p < .000, d = 1.71 |
    
    b) Φ represents most improved items/larger effect size

<table>
<thead>
<tr>
<th>Question Categories</th>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>df</th>
<th>Cohen’s D</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Warning signs</td>
<td>-1.29</td>
<td>1.10</td>
<td>-18.87</td>
<td>259</td>
<td>1.39</td>
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<tr>
<td>2. Ruling out other conditions</td>
<td>-1.71</td>
<td>1.27</td>
<td>-21.74</td>
<td>259</td>
<td>1.67</td>
</tr>
<tr>
<td>3. Functional changes</td>
<td>-1.16</td>
<td>1.15</td>
<td>-16.13</td>
<td>255</td>
<td>1.15</td>
</tr>
<tr>
<td>5. NTG Dementia screening tool</td>
<td>-2.27</td>
<td>1.36</td>
<td>-26.36</td>
<td>250</td>
<td>2.09</td>
</tr>
<tr>
<td>6. Health care advocacy</td>
<td>-1.32</td>
<td>1.31</td>
<td>-16.09</td>
<td>253</td>
<td>1.18</td>
</tr>
<tr>
<td>7. Quality care tips</td>
<td>-1.24</td>
<td>1.27</td>
<td>-14.71</td>
<td>226</td>
<td>1.14</td>
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<tr>
<td>8. Communication tips</td>
<td>-1.60</td>
<td>1.24</td>
<td>-20.61</td>
<td>253</td>
<td>1.56</td>
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<tr>
<td>9. Environment tips</td>
<td>-1.65</td>
<td>1.29</td>
<td>-20.48</td>
<td>252</td>
<td>1.58</td>
</tr>
<tr>
<td>10. Care planning</td>
<td>-1.68</td>
<td>1.22</td>
<td>-21.70</td>
<td>252</td>
<td>1.62</td>
</tr>
</tbody>
</table>

- c) Follow-up semi-structured interviews (n = 3) provide some insights; tangible content of training topics brought immediate impact, such as NTG dementia screening tool and care planning book:
  - “I used the NTG tool and identified over 30 of my recipients that are Down syndrome and over the age 50...I came to the workshop because some of our clients were showing signs of Alzheimer’s.”
  - “I am in a process of making a future plan for [him], I am now communicating with the home nurse. In the future, I might need more help taking care of him.”

Conclusions/Implications
- What we learned from I-AADAPT activities:
  a) Health care advocacy is crucial for individuals with IDD to ensure they receive equitable care and to support quality living within their community throughout their lifespan.
  b) Clinician, Health Care Provider and Aging Agency’s trainings are necessary to improve partnership for Dementia/IDD/Aging health care advocacy
  c) The NTG education curriculum, especially with tangible screening tool and Dementia Capable Care educational materials, empower family members and providers to advocate for health care needs with health care professionals.
  - Particularly, providers are eager for more information and practical tools whereas many family members are hesitant to be directly involved.
  d) Culturally sensitive educational materials are needed (e.g., Native American, and Spanish speaking communities)

Our Next Steps
- Hosted a NTG Dementia Capable Care Phoenix Workshop in September 2018:
  - 40 members from across Arizona participated (e.g., Yuma, Flagstaff, Sierra Vista, Tuba City, and Tucson)
  - 29 new NTG affiliated trainers are certified
  - Formed I-AADAPT Task Force with 30 members to expand knowledge and network as well as address local needs (e.g., system change, education/training, practical guidelines, bridging aging and IDD, cultural competency, and others)

- b) Identify I-AADAPT Task Force priority items and sub-committees by hosting task group meetings.
  - c) Seek and obtain funding for the Task Force activities

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