Specialized Supportive Services for Adults with Intellectual and Developmental Disabilities (IDD) and Alzheimer’s Disease and Related Disorders (ADRD)

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Project Director
Seven Hills RI
Grant number 90AL0014-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services
Overarching Project Goal

- Engage key community stakeholders including Alzheimer’s and Developmental Disability (DD) provider organizations, self-advocates, and others throughout Rhode Island in order to strengthen and expand the current dementia-capable system of care for older adults with IDD and ADRD, and their caregivers.
Timeline

Funding Period: 9/1/15 - 8/31/18

Planning Phase

9/1/15 - 12/31/15

Implementation Phase

1/1/16 - 8/31/18
Partners

- National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
  - Collaborate with SHRI to provide a statewide two-day workshop and a third day train-the-trainer workshop using its national curriculum, will provide technical assistance to SHRI on the project, and will sit on the Project’s Advisory Board.

- Alzheimer’s Association of Rhode Island (AARI)
  - Collaborate with SHRI to provide ADRD related trainings for staff and caregivers, will provide technical assistance to SHRI on the project, and will sit on the Project’s Advisory Board.

- Healthcentric Advisors
  - Collaborate with SHRI to serve as the evaluator, informing the development and implementation of the program evaluation, quality assurance program, and “Lessons Learned” document. They will also work closely with the Project Director to adhere to all semi-annual grant reporting and will sit on the Project’s Advisory Board. Efforts also include marketing of events.
Additional Stakeholders

- Advocates in Action
- American Nurses Association of Rhode Island
- Charter Care
- Community Provider Network
- RI Developmental Disabilities Nurses Association
- RI Department of Health
- John Stoukides, MD
- LeadingAge Rhode Island
- Senior Agenda Coalition
- RI Department of Behavioral Healthcare, Developmental Disabilities and Hospitals
- RI Disability Law Center
- RI Governor’s Council on Disability
- RI Governor’s Long-Term Care Coordinating Council
- PACE
- University Centers on Excellence in Developmental Disabilities - Paul V. Sherlock Center on Disabilities at Rhode Island College
- Visiting Rehab Services
Target Population

- Over 4000 adults supported by RI DD Provider organizations annually and their paid and family caregivers
- Adults with I/DD living in the community who have not previously accessed DD supports
Purpose and Goals

**Purpose:**
Details how we identify, collect, and analyze the defined metrics that assess each proposed intervention’s impact and determine whether or not the program achieved its anticipated outcomes

**QA program - to track adherence to program deliverables and anticipated outcomes**

**Objectives and activities:**

1) Promote and provide person- and family-centered care and training to improve care for and prepare individuals living with moderate to severe impairment and their caregivers for the future

- Resource Guide
- Legal and Financial Planning workshop
- Support groups

2) Improve the quality and effectiveness of programs and services dedicated to individuals aging with IDD and ADRD, or those at high risk of developing ADRD

- Expansion of SHRI’s Adult Day Health (ADH) program to include Alzheimer’s Certification
- NTG Educational and “Train-the-Trainer” workshops
- Support adults with IDD, with evidence-informed interventions, MUSIC & MEMORY℠ and Geri-Care ™

3) Deliver Behavioral Symptom Management Training and expert consultation to family caregivers

- Access to a full-time Clinical Specialist at SHRI
- Educational workshops on Behavioral Symptom Management
Methods
Methods

**Process Measures**
- Collected to track reach/impact for all trainings and workshops

**Demographic Data**
- Collected from training and workshop participants and individuals with IDD and ADRD who received interventions through the grant

**Proximal/Outcome Measures**
- Collected to assess impact of grant interventions on participant satisfaction, knowledge, caregiver stress/burden and the dementia attitude scale for providers/clinicians

**Developed/adapted surveys to:**
- elicit both qualitative and quantitative data from program participants
- evaluate the efficacy of intervention strategies
- collect information on barriers or successes throughout the project

**Evidence-based surveys were included where available:**
- Caregiver Stress
- Caregiver Burden
- Dementia Attitude Scale (DAS)

**Demographic Information:** for grant activity participants and individuals with IDD/ADRD
To sustain our efforts we sought to educate:

- Current caregivers (paid and unpaid) and professionals in the DD field
- Professionals not specializing in the DD field
- Those who provide education
- Funding source
- Managed care organization and 3rd party payers
Results
Results

Total Project Reach

Selected Outcomes

• National Task Group Training: Knowledge Gained
• National Task Group Training: Dementia Attitude Scale
• Support Group: Caregiver Strain Index (Post)
• Music and Memory Intervention
• Qualitative Data
## Project Reach: September 2015 - May 2018

<table>
<thead>
<tr>
<th>Grant Activity</th>
<th>Caregivers &amp; Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Task Group (NTG) Training</td>
<td>754</td>
</tr>
<tr>
<td>Support Groups</td>
<td>59</td>
</tr>
<tr>
<td>Behavioral Self-Management Educational Series (includes Legal and Financial Planning workshops)</td>
<td>127</td>
</tr>
<tr>
<td>Behavioral Symptom Management Training</td>
<td></td>
</tr>
<tr>
<td>Geri-care Trained</td>
<td></td>
</tr>
<tr>
<td>Music and Memory Training</td>
<td>47 individuals</td>
</tr>
<tr>
<td></td>
<td>14 sites/facilities</td>
</tr>
<tr>
<td>Miscellaneous Trainings (powerful tools for caregivers)</td>
<td>177</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Grant Activity</th>
<th>Individuals with IDD &amp; ADRD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music and Memory Participants &amp; Occupational Therapy Assessments</td>
<td>142</td>
</tr>
</tbody>
</table>
NTG Training: Overall Knowledge Increase in Caring for Adults with IDD and Dementia

Pre- vs Post-Test

Pre Average: 82.09%
Post Average: 96.37%
NTG Training - Changes in Dementia Attitude Scale
Pre- vs Post-Test

- I am not very familiar with ADRD
  - Pre: 33.26%, Post: 26.47%
  *decreased response rate is better

- I am frustrated because I do not know how to help people with ADRD
  - Pre: 29.66%, Post: 19.58%
  *decreased response rate is better

- I feel confident around people with ADRD
  - Pre: 84.36%, Post: 90.20%

- I feel relaxed around people with ADRD
  - Pre: 83.42%, Post: 89.52%
“I will be more knowledgeable to teach caregivers about the population we serve surrounding Alzheimer's”

“I will take this knowledge to better understand and educate my CNA to better understand the resident with dementia”

“[allow me to] assess individuals more adequately”

“[allow me to] make environmental changes to meet the individual needs”

“Supporting them with health advocacy; importance of through assessment, differential diagnosis modifying environments”

“Excellent training; great awareness if only we could be make more medical providers to create more awareness and understanding of ID and dementia”

“Highly recommend this training to other healthcare professionals”

“This training/seminar is very useful and informative”
### Post-Support Group-Caregiver Strain Index (N=29), through Feb 2018

<table>
<thead>
<tr>
<th>Strain</th>
<th>On a Regular Basis</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel completely overwhelmed</td>
<td>48.3</td>
<td>51.7</td>
</tr>
<tr>
<td>Caregiving is a financial strain</td>
<td>55.2</td>
<td>44.8</td>
</tr>
<tr>
<td>There have been work adjustments</td>
<td>20.7</td>
<td>79.3</td>
</tr>
<tr>
<td>Upsetting to find person I care for changed</td>
<td>48.3</td>
<td>51.7</td>
</tr>
<tr>
<td>Some behavior is upsetting</td>
<td>55.2</td>
<td>44.8</td>
</tr>
<tr>
<td>There have been emotional adjustments</td>
<td>37.9</td>
<td>62.1</td>
</tr>
<tr>
<td>There have been other demands on my time</td>
<td>72.4</td>
<td>27.6</td>
</tr>
<tr>
<td>There have been changes in personal plans</td>
<td>73.9</td>
<td>24.1</td>
</tr>
<tr>
<td>There have been family adjustments</td>
<td>40.3</td>
<td>58.6</td>
</tr>
<tr>
<td>Caregiving is confining</td>
<td>74.1</td>
<td>25.9</td>
</tr>
<tr>
<td>Caregiving is a physical strain</td>
<td>55.2</td>
<td>44.8</td>
</tr>
<tr>
<td>Caregiving is inconvenient</td>
<td>62.1</td>
<td>37.9</td>
</tr>
<tr>
<td>My sleep is disturbed</td>
<td>48.3</td>
<td>51.7</td>
</tr>
<tr>
<td>Support Groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“The speaker was amazing and friendly, connected to the staff and was supported very informative and responsive to every question asked”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It was a positive meeting we were able to bring our concerns to the table with honesty”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Need more and more”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Very informative”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Music and Memory Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of unique patients</td>
<td>59 patients</td>
</tr>
<tr>
<td>Gender</td>
<td>56% Female</td>
</tr>
<tr>
<td></td>
<td>44% Male</td>
</tr>
<tr>
<td>Average Age</td>
<td>65 years old</td>
</tr>
<tr>
<td>Age Range</td>
<td>23 - 97 years old</td>
</tr>
<tr>
<td>Average number of sessions per patient</td>
<td>7 sessions</td>
</tr>
<tr>
<td>Number of facilities involved</td>
<td>14 facilities</td>
</tr>
<tr>
<td>(Group homes, assisted living centers, personal homes)</td>
<td></td>
</tr>
</tbody>
</table>
Change Reported Post Music And Memory Intervention

- Negative Change: 76%
- No effect/Stayed the same: 22%
- Positive Change: 2%
Nearly 51% of respondents said that if a person has possible cognitive impairment, there is a standard protocol in their organization for supplying the information to service providers, case managers, and eligibility determination staff.

46% of respondents reported that if a person is identified with possible dementia or cognitive impairment, there is a standard protocol in their organization for a referral to a physician or clinic for a diagnostic evaluation.

67% of respondents said staff in their organization receive formal training on dementia and cognitive impairment.
Key Takeaways

- Far reach in the Rhode Island developmental disability and healthcare communities
- Positive event and training feedback
- Innovative patient-centered approaches to treatment
- Where do we go from here?
  - Use more focused interventions with goals that are not that easy to reach
  - Healthcare workforce- how we can we help foster practice change in these settings?
  - How can we continue to care for a changing population
Please describe at least one way that you intend to change your clinical approach/practice.

- Observant of communication provided by individual, evaluations of medical concerns, completing screening at baseline to be preventative.
- Ruling out all medical possibilities so there is no misdiagnosis.
- Consider how we can implement the screening tool on a more wide-scale approach especially with some of our older clients with challenging behaviors.
- I will perform a better diagnostic workup. I will also utilize the screening tool.
- All behaviors are communication---Investigate!
- Reintroduce hospice and their role.
- Start with history, medical and medication check.
- Share info and resources with caregivers and families.
Barriers

- Difficult to get the buy in from other agencies
  - Seemingly distrusted “free”
  - Difficult for the agency to arrange to have staff out of circulation for 2-3 days for training
  - Once they are on board, be sure to have more than 1 contact person---turnover is frequent and sometimes involved out main contact

- Difficult to maintain trainers r/t busy schedules, budget cuts, LIFE!
  - Returned to contracting with NTG to do their full curriculum; by the end of the 3 years, only 3 of the nurse trainers could remain committed to continued training

- Delays in publication of Resource Guide, Supplements and Webinars
  - Too much review; too many reviewers
Barriers

- Among survey respondents, the majority were Clinical or Professionals (41%) and Paid Direct Care workers (25%).
- Remaining participants were managers/administrators (11%), Case managers/care coordinators (11%), health educators (7%), and family members (7%).
- The majority of participants were female (77%) and 45 was the average age.
Sustainable Efforts

- Free Resource Guides and Supplements online and via USB flash drive
  - Model being replicated by several projects in other states
- Free online learning activities (also linked on USB flash drive and promoted on Project Partner websites)
  - Proposed to BHDDH as “suggested training” for all new staff
- RIGEC funding shortened NTG material for BHDDH
- 54 new Regional Trainers
  - 49 fully funded by grant; 5 partially funded by grant
- Increased awareness among DD providers and professionals
Questions?