Expanding a Volunteer Respite Workforce to Provide Support to Caregivers in New York State

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Lifespan Respite Care Programs are coordinated systems of accessible, community-based respite care services for family caregivers of children or adults of all ages with care needs.

• Goal: build a statewide, integrated, sustainable Lifespan Respite Program that is fully integrated into the New York State Long Term Services and Supports System (LTSS).

• Objectives:
  1. Expand respite capacity to help to fill gaps in needed respite care
  2. Raise awareness of and access to available respite care statewide
  3. Develop a volunteer respite pool statewide through sustainable training initiatives using a train-the-trainer model
Funding: AoA/ACL 90LI0023 and 90LRLI0012

Project Partners:

- New York State Office for the Aging (NYSOFA)
- New York State Caregiving and Respite Coalition (NYSCRC)
- New York State’s ADRC (NY Connects)
- Monroe County Office for the Aging (MCOFA)
- Lifespan of Greater Rochester, Inc. (Lifespan)

HRSA Funded GWEP

- University of Rochester Geriatric Workforce Enhancement Program (HRSA U1QHP28738)
- Finger Lakes Geriatric Education Center (FLGEC)
- Focus on caregiver education and training

*A Federal, State, Aging Services Network/Community, Academic, Faith-Based Partnership with a shared goal of improving access to Respite Services*
Methodology

Planning
- Stakeholder Engagement (community, government, academic)
- Building Infrastructure (capacity)
- Sustainability Planning (financing)

Implementation
- Trainer-the-Trainer Courses (competence)
- Respite “Companion” Volunteer Training (workforce)
- Grow “Mini-Grant” Drop-In Respite Sites (access)

Evaluation
- Training Surveys (satisfaction, confidence, competence)
- Caregiver Surveys (impact on beneficiaries of respite care)
- Process Measures for Mini-Grant Sites (accountability)

Positioning for Future Research

6 Key Areas
1. Translate research findings into best-practice models
2. Improved research methodologies
3. Improved respite provider competence
4. Systems change that improves respite access
5. Cost-benefit and cost-effectiveness research
6. To establish evidence for the effectiveness of respite care for improving the well-being of caregivers and others in their families and communities

Individual, family, and societal outcomes
REST (Respite, Education, and Support Tools)

- REST is an evidenced-based, professionally designed Train-the-Trainer course that provides respite education to those who then go out and train others
- Goal is to develop a workforce of **REST Companions** (a.k.a. respite care workers, volunteers, or providers)
- Targets: training for senior services and healthcare organizations, Area Agencies on Aging, faith-based organization, adult day care, and other social service organizations.

http://restprogram.org/
REST Trainings - New York State dissemination

- 6 REST “master” trainers developed – first in New York
- 262 REST trainers across all of New York can now offer REST companion courses to interested organizations
- 242 volunteer respite companions
- 10,273 hours of respite with 730 caregivers served
- People come to training from a cross section of county agencies, faith based communities, colleges & universities and other human services organizations
- Participants attend 2-day training and then are poised to offer REST companion courses in their communities to work toward supporting caregivers
REST Trainer and Companion Courses

**Activity**

- **REST Train-the-Trainer Course**
  - Qualified REST Trainers

- **REST Companion Course**
  - Trained Respite Volunteers

- **Respite “Drop-In” Programs**
  - Min-Grant Sites

**Evaluation Strategy**

- **Post-Training Participant Survey**
  - # of trainers and “master” trainers

- **Participant Pre-/Post- Course Evaluation Surveys**
  - # volunteers trained

- **# hours respite provided**
  - Caregiver Post-Respite Care Survey
REST Train-the-Trainer Evaluations (Sept 2019- August 2020)

Post-Training Participant Survey Ratings

Agreement Scales (1-5 higher better) mean scores

- Content: 4.81
- Instructor: 4.90
- Materials: 4.67
- Overall Workshop Rating: 4.70
REST Companion Course (Respite Volunteers)  
Pre-/Post-Surveys Course Evaluation

<table>
<thead>
<tr>
<th>Rate your level of skill/knowledge/understanding in each of the following areas</th>
<th>Mean Change Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>The roles and responsibilities of a respite worker</td>
<td>+1.9</td>
</tr>
<tr>
<td>Establishing good communication and trust with the family</td>
<td>+1</td>
</tr>
<tr>
<td>Gathering information from the family to set up respite arrangements</td>
<td>+1.34</td>
</tr>
<tr>
<td>Determining care recipients interests and abilities</td>
<td>+1.6</td>
</tr>
<tr>
<td>Strategies for communicating with care recipients</td>
<td>+1.7</td>
</tr>
<tr>
<td>Adapting activities to care recipients needs</td>
<td>+1.7</td>
</tr>
<tr>
<td>Understanding challenging behaviors</td>
<td>+1.65</td>
</tr>
<tr>
<td>Dealing with injuries and emergency situations</td>
<td>+1.58</td>
</tr>
<tr>
<td>Signs of caregiver stress and coping strategies</td>
<td>+1.42</td>
</tr>
<tr>
<td>Respecting different family situations and cultures</td>
<td>+1.2</td>
</tr>
<tr>
<td>Keeping family information confidential</td>
<td>+0.4</td>
</tr>
<tr>
<td>Preventing the spread of germs</td>
<td>+0.74</td>
</tr>
</tbody>
</table>

Scale of 1 (very low) to 5 (very high) *
## REST Companion Course (Respite Volunteers) Pre-/Post-Surveys Course Evaluation

<table>
<thead>
<tr>
<th>Rate your level of concern about each of the following areas of respite work</th>
<th>Mean Change in Level of Concern*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will I know how to deal with an emergency?</td>
<td>-1.3</td>
</tr>
<tr>
<td>Will I be able to meet the care recipient’s needs?</td>
<td>-.86</td>
</tr>
<tr>
<td>Will I put myself at risk for becoming ill?</td>
<td>-1.23</td>
</tr>
<tr>
<td>Will it be difficult to keep family information confidential?</td>
<td>-.34</td>
</tr>
<tr>
<td>Will I be asked to take on more than I can handle?</td>
<td>-1.2</td>
</tr>
<tr>
<td>Will I have the support and resources I need?</td>
<td>-2.2</td>
</tr>
</tbody>
</table>

*Scale of 5 (very concerned) to 1 (not at all concerned)

**Post Survey: Mean Overall Course Rating from Participants (1 Low-5 High): 4.8**
Respite Mini-Grant Program

• A **Statewide Respite Mini-Grant Program** was initiated Summer 2016 through the New York State Office for the Aging (NYSOFA) and the New York Caregiving and Respite Coalition (NYSCRC)

• Since September 2016 awards have been made to 13 applicants (most implementing REST training)

• The mini-grant efforts focused upon ongoing communication, data collection, and working with the sites for sustainability
## Respite Mini-Grant Sites

<table>
<thead>
<tr>
<th>Respite Site</th>
<th>Region</th>
<th>Target Population</th>
<th># New Respite Companion Volunteers</th>
<th>Estimated Hours of Respite Services Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mercy Care</td>
<td>North Country</td>
<td>Older Adults</td>
<td>10</td>
<td>648</td>
</tr>
<tr>
<td>UCP</td>
<td>North Country</td>
<td>Older Adults</td>
<td>Not Reported</td>
<td>60</td>
</tr>
<tr>
<td>BHSN CRC</td>
<td>North Country</td>
<td>Older Adults</td>
<td>6</td>
<td>1000</td>
</tr>
<tr>
<td>Parma Baptist</td>
<td>Western New York</td>
<td>Early Stage Dementia</td>
<td>Not Reported</td>
<td>84</td>
</tr>
<tr>
<td>Baker United Methodist</td>
<td>Western New York</td>
<td>Early Stage Dementia</td>
<td>18</td>
<td>420</td>
</tr>
<tr>
<td>SUNY Geneseo</td>
<td>Finger Lakes</td>
<td>Early Stage Dementia</td>
<td>17</td>
<td>650</td>
</tr>
<tr>
<td>Faith in Action</td>
<td>Finger Lakes – Steuben County</td>
<td>Early Stage Dementia</td>
<td>33</td>
<td>600</td>
</tr>
<tr>
<td>LTI</td>
<td>Long Island</td>
<td>Kinship Care</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>Interfaith Works of CNY</td>
<td>Central NY</td>
<td>Senior Companion Program</td>
<td>9</td>
<td>425</td>
</tr>
<tr>
<td>Wayne County Action Program</td>
<td>Wayne County</td>
<td>RSVP</td>
<td>0*</td>
<td>0*</td>
</tr>
<tr>
<td>YesterYears Social Adult Day Care</td>
<td>Broome County</td>
<td>Rural Seniors</td>
<td>10</td>
<td>5311</td>
</tr>
<tr>
<td>PSS</td>
<td>New York City</td>
<td>Dementia Friendly Community Programs</td>
<td>0*</td>
<td>0*</td>
</tr>
<tr>
<td>Catskill Neighbors</td>
<td>Ulster, Delaware, and Greene Counties</td>
<td>Senior Companion Volunteers</td>
<td>0*</td>
<td>0*</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td></td>
<td></td>
<td><strong>105 Volunteers</strong></td>
<td><strong>9223</strong> Respite Hours</td>
</tr>
</tbody>
</table>

*Sites on pause due to COVID-19 Pandemic
Caregiver Post-Respite Care Survey

• Target: Caregivers who’s loved one or family member was a respite recipient

• Created/modified from prior ARCH Respite Tools

• Pilot tested at respite mini-grant sites

• Evaluation/perception of respite recipients

• 80% indicate they have no-one to fill in for them as a caregiver in an emergency

• 100% of respondents indicate they have felt a “reduction in care-giving stress because of having respite care”
Post-Respite Survey: Caregiver Demographics

Realationship of Caregiver to Respite Recipient

- Husband: 14%
- Wife: 28%
- Son/SIL/Daughter/DIL: 29%
- Non Relative: 29%
Post-Respite Caregiver Survey

Time Period using Respite Care

Mean Pre-/Post-Respite Caregiver Stress Level (n=7)
(Self-Reported Stress Perceived from Caring for Family Member)
A sense of relief
More confident
More balance in
my life
I have regained
enjoyable activities
Taking better care of my own health
Worth my time and effort
High quality of the care
I am able to continue caregiving role
Care recipient has benefited
More confident about finding respite provider
More confident about preparing respite provider
More confident how to use respite breaks
Convinced of the benefits from respite care

Caregiver Survey: Perceived Outcomes of Drop-In Respite Care
(n=7 respondents)
Lessons Learned – Caregiver Focused Initiatives

• Leveraging new or evolving state and/or local caregiver initiatives can increase the breath and depth of evaluation and support sustainability

• Many (“mission driven”) partner and community-based organizations are not as familiar with data management and outcome assessment

• Academic institutions (and faculty) can add expertise in program evaluation and survey design/methods to enhance the measurement and reporting of outcomes