Short Breaks, Big Impact: Delivering Education and support to those offering a break to caregivers

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Wendy Berk, M.S., REST Program Analyst
40 million

Number of family caregivers of adults in the U.S.

(Valuing the Invaluable: 2015 Update, AARP Public Policy Institute)
37 billion

Number of family caregiving hours provided in a single year

(Valuing the Invaluable: 2015 Update, AARP Public Policy Institute)
$470 billion

Estimated economic value of unpaid family caregiving

(Valuing the Invaluable: 2015 Update, AARP Public Policy Institute)
ECONOMIC VALUE OF FAMILY CAREGIVING

The economic value of family caregiving is as big as the world’s largest company, and bigger than Medicaid and out-of-pocket (OOP) spending on health care.

Economic Value in Billions

- Walmart: $477
- Family Caregiving: $470
- Total Medicaid: $449
- OOP Spending on Health Care: $339
- Total Medicaid LTSS: $123

(AARP Public Policy Institute, 2015)
55% of caregivers feel overwhelmed by loved one’s care needs

25 to 50% of caregivers meet criteria for major depression

*compared 6.7% in general adult population

(Family Caregiver Alliance, 2006)

(Anxiety and Depression Association of America, retrieved 2016)
Figure 1. 
Population Aged 65 and Over for the United States: 2012 to 2050 

(U.S. Census, 2014)
How can the challenges of family caregiving be relieved?
Move loved one to assisted living or skilled nursing?
90%
RESPITE HELPS!

Caregivers

Families

Care Receivers

(Cohen and Warren, 1985)
WHAT IS RESPIE?

Dictionary definition of “Respite”
A short period of time when you are able to stop doing something that is difficult or unpleasant or when something difficult or unpleasant stops or is delayed
(Merriam-Webster, 2016)

Respite Care
Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.
(ARCH – Access to Respite Care and Help)
CAREGIVER TRAINING PROGRAMS

- Focus on teaching the caregiver how to take care of their loved one
- Hospitals refining transition-to-home programs training medical tasks

Caregivers are learning needed skills to care for their loved ones. But who is helping the caregiver stay afloat?
REST TO THE RESCUE!

Caregivers reach out to:

• Faith-based organizations
• County Senior Services
• Volunteer Organizations
REST Companions are trained in “Soft Skills”
KEY COMPONENTS OF REST

10 Core Competencies aligned with the National Respite Guidelines (ARCH)

What is Respite?  The Role of the Respite Worker
Coping Strategies  Caregiver Assessment  Confidentiality
Communication  Tips
First Visit  Leisure Activities
Valuing Differences  Caregiver Thoughts
Activities
Universal Precautions
Crisis Intervention  Handling Injuries
Understanding Behaviors

Creates a STANDARDIZED Respite Training
CUSTOMIZABLE CURRICULUM
Make REST YOUR Training!

- Trainer Stories
- Policies and Procedures
- REST Companion™ Resources
- Community Resources
- Enhanced Population-specific Education
- Forms
ONGOING SUPPORT TOOLS
To Mobilize REST SUCCESSFULLY

- Trainer Development/Collaboration
- Quarterly Conference Calls
- Monthly R.A.N. Report
- Local and National Workgroups
- Customized Marketing/Support Materials
- Grant Support
- Robust Website
## REST MOBILIZATION

<table>
<thead>
<tr>
<th>Course</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Train-the-Trainer</strong></td>
<td>• Prepared to train unlimited REST Companions</td>
</tr>
<tr>
<td><strong>Course</strong></td>
<td>• Two-Day Interactive Course</td>
</tr>
<tr>
<td></td>
<td>• Full Instructor Kit to run Companion Courses</td>
</tr>
<tr>
<td></td>
<td>• 13.5 CEs for nurses &amp; social workers</td>
</tr>
<tr>
<td><strong>Companion Course</strong></td>
<td>• Prepared Respite Workers/Volunteers</td>
</tr>
<tr>
<td></td>
<td>• 8-Hour Companion Course – Independent Respite 7.0 CEs</td>
</tr>
<tr>
<td></td>
<td>• 4-Hour REST Essentials™ – Supervised Group Respite  4.0 CEs</td>
</tr>
<tr>
<td></td>
<td>• REST Essentials™ Online Course: 1.5 CEs</td>
</tr>
<tr>
<td><strong>Master Trainer</strong></td>
<td>• Sustainable Statewide Program</td>
</tr>
<tr>
<td><strong>Course</strong></td>
<td>• Qualified REST Trainers can become Master Trainers</td>
</tr>
<tr>
<td></td>
<td>• Unlimited REST Train-the-Trainer Events with Trainer stipend</td>
</tr>
</tbody>
</table>
TRAIN-THE-TRAINER MODEL

1 Master Trainer → 10 Trainers → 200 REST Companions™ → Families Served

UNLIMITED FAMILIES SERVED
REST PROGRAM IN ACTION

REST Trainers in 29 States
473 REST Trainers Nationwide
4,910 REST Companions Nationwide
OUTCOMES EVALUATION
EVALUATION QUESTIONS

Were the appropriate respite skills, knowledge, and confidence gained during the REST companion workshops?

Were skills, knowledge, and confidence retained six months later?
Were REST companions providing respite to families six month later?

How do family caregivers feel about the respite they receive from REST companions?
EVALUATION QUESTION

Were the appropriate respite skills, knowledge, and confidence gained during the REST companion workshops?

- Pre-post Companion Workshop Survey
- Post-Workshop Core Competency Assessment
1,108 COMPANION WORKSHOP PARTICIPANTS

**What is Your Experience Providing Respite Care?**

- Never provided respite: 42.0%
- Provided, but not in past year: 30.7%
- Currently providing respite: 27.3%

**Do You Have a Professional Care Background?**

- No: 54.6%
- Yes: 45.4%
1,108 COMPANION WORKSHOP PARTICIPANTS

**How Often Will You Be Able to Serve?**

- Less than once per month: 17.0%
- 1 to 3 days per month: 31.1%
- 1 to 2 days per week: 28.1%
- 3 to 5 days per week: 23.8%

**Preferred Respite Assignment (Check all that apply)**

- Aging: 74.3%
- Developmentally disabled: 36.9%
- Veterans: 31.8%
- Other: 13.6%
WORKSHOP – SKILLS/KNOWLEDGE GAINED

Rate Your Skill/Knowledge in Each of the Following Areas - Change from Pre to Post Workshop

<table>
<thead>
<tr>
<th>Skill/Knowledge</th>
<th>Pretest Avg</th>
<th>Posttest Avg</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>The roles and responsibilities of a respite worker</td>
<td>3.44</td>
<td>4.52</td>
<td>1.09</td>
</tr>
<tr>
<td>Gathering info from family to set up respite arrangements</td>
<td>3.54</td>
<td>4.52</td>
<td>0.99</td>
</tr>
<tr>
<td>Adapting activities to care recipient needs</td>
<td>3.50</td>
<td>4.44</td>
<td>0.94</td>
</tr>
<tr>
<td>Dealing with injuries and emergency situations</td>
<td>3.45</td>
<td>4.36</td>
<td>0.91</td>
</tr>
<tr>
<td>Determining care recipient interests and abilities</td>
<td>3.62</td>
<td>4.52</td>
<td>0.91</td>
</tr>
<tr>
<td>Strategies for communicating with care recipients</td>
<td>3.60</td>
<td>4.49</td>
<td>0.90</td>
</tr>
<tr>
<td>Signs of caregiver stress and coping strategies</td>
<td>3.49</td>
<td>4.34</td>
<td>0.85</td>
</tr>
<tr>
<td>Understanding challenging behaviors</td>
<td>3.55</td>
<td>4.32</td>
<td>0.76</td>
</tr>
<tr>
<td>Respecting different family situations and cultures</td>
<td>4.04</td>
<td>4.62</td>
<td>0.58</td>
</tr>
<tr>
<td>Establishing good communication and trust with the family</td>
<td>4.10</td>
<td>4.65</td>
<td>0.55</td>
</tr>
<tr>
<td>Preventing the spread of germs</td>
<td>4.23</td>
<td>4.77</td>
<td>0.53</td>
</tr>
<tr>
<td>Keeping family information confidential</td>
<td>4.54</td>
<td>4.82</td>
<td>0.28</td>
</tr>
</tbody>
</table>
WORKSHOP – SKILLS/KNOWLEDGE GAINED

Predictive Validity

Rate Your Skill/Knowledge in Each of the Following Areas - By Experience

<table>
<thead>
<tr>
<th>Currently providing respite</th>
<th>Provided, but not in past year</th>
<th>Never provided respite</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pretest Average</td>
<td>Posttest Average</td>
<td>Change</td>
</tr>
<tr>
<td>4.08</td>
<td>4.62</td>
<td>0.54</td>
</tr>
<tr>
<td>3.96</td>
<td>4.57</td>
<td>0.61</td>
</tr>
<tr>
<td>3.39</td>
<td>4.46</td>
<td>1.07</td>
</tr>
</tbody>
</table>

Rate Your Skill/Knowledge in Each of the Following Areas - By Professional Care Background

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pretest Average</td>
<td>Posttest Average</td>
</tr>
<tr>
<td>3.42</td>
<td>4.42</td>
</tr>
<tr>
<td>4.15</td>
<td>4.68</td>
</tr>
</tbody>
</table>
## WORKSHOP – CONFIDENCE GAINED

### Level of Concern About Each of the Following Areas of Respite Work - Change from Pre to Post Workshop

<table>
<thead>
<tr>
<th>Concern Area</th>
<th>Pretest Avg (Range 1-5)</th>
<th>Posttest Avg (Range 1-5)</th>
<th>Change (Range 1-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will I know how to deal with an emergency?</td>
<td>3.08</td>
<td>2.45</td>
<td>-0.63</td>
</tr>
<tr>
<td>Will I be able to meet the care recipient's needs?</td>
<td>3.05</td>
<td>2.48</td>
<td>-0.57</td>
</tr>
<tr>
<td>Will I have the support and resources I need?</td>
<td>2.72</td>
<td>2.19</td>
<td>-0.54</td>
</tr>
<tr>
<td>Will I be asked to take on more than I can handle?</td>
<td>2.58</td>
<td>2.10</td>
<td>-0.48</td>
</tr>
<tr>
<td>Will I put myself at risk for becoming ill?</td>
<td>2.42</td>
<td>2.00</td>
<td>-0.42</td>
</tr>
<tr>
<td>Will it be difficult to keep family information confidential?</td>
<td>1.87</td>
<td>1.74</td>
<td>-0.13</td>
</tr>
</tbody>
</table>
WORKSHOP – CONFIDENCE GAINED

*Predictive Validity*

<table>
<thead>
<tr>
<th>Level of Concern About Each of the Following Areas of Respite Work - By Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently providing respite</td>
</tr>
<tr>
<td>Provided, but not in past year</td>
</tr>
<tr>
<td>Never provided respite</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Concern About Each of the Following Areas of Respite Work - By Professional Care Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>
## WORKSHOP – CORE COMPETENCY

<table>
<thead>
<tr>
<th>Question</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. What can build trust with a family to whom you are providing respite?</td>
<td>97.3%</td>
</tr>
<tr>
<td>10. What is the most important precaution for preventing the spread of germs?</td>
<td>95.8%</td>
</tr>
<tr>
<td>3. When communicating with an individual in your care, it is helpful to…</td>
<td>94.4%</td>
</tr>
<tr>
<td>7. What should you do first if a medical emergency arises while providing respite care?</td>
<td>93.7%</td>
</tr>
<tr>
<td>5. What is a good question to ask yourself when planning activities?</td>
<td>93.2%</td>
</tr>
<tr>
<td>2. An effective volunteer respite worker…</td>
<td>90.8%</td>
</tr>
<tr>
<td>6. Which of the statements about understanding challenging behaviors is TRUE?</td>
<td>88.0%</td>
</tr>
<tr>
<td>1. Your goal as respite worker is to…</td>
<td>76.9%</td>
</tr>
<tr>
<td>8. What can you do to help when a caregiver seems stressed out?</td>
<td>70.0%</td>
</tr>
<tr>
<td>4. A leisure interests survey can be used to help the respite volunteer…</td>
<td>68.3%</td>
</tr>
</tbody>
</table>
WORKSHOP – CORE COMPETENCY

Core Competency Assessment - By Respite Experience

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently providing respite</td>
<td>86.8%</td>
</tr>
<tr>
<td>Provided, but not in past year</td>
<td>88.1%</td>
</tr>
<tr>
<td>Never provided respite</td>
<td>85.9%</td>
</tr>
</tbody>
</table>

Core Competency Assessment - By Professional Care Background

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>87.2%</td>
</tr>
<tr>
<td>No</td>
<td>86.3%</td>
</tr>
</tbody>
</table>
WORKSHOP – PARTICIPANT RATINGS

What do you like best about the workshop?
• Group activities, discussions, and opportunities to share experiences.
• Resources and quality of information provided in the training materials.
• Instructors perceived as qualified, knowledgeable, and effective.

What can be done to improve the workshop?
• Adjust the length of the workshop. Some feel it is too long, others feel it is too short.

Response: New 4-hour course called REST Essentials™. Covers 10 core competencies. Only for individuals providing respite in a supervised, group setting.
EVALUATION QUESTIONS

Were skills, knowledge, and confidence retained six months later?
Were REST companions providing respite to families six months later?

Companion six month post-workshop phone interview
219 COMPANION INTERVIEWS – 6M FOLLOW UP

Workshop Ratings at Six Months

- Skills/Knowledge: 87.9%
- Confidence: 89.8%
- Well Trained: 87.9%
219 COMPANION INTERVIEWS – 6M FOLLOW UP

Have you provided respite since the workshop?

- Yes: 33%
- No: 67%

73 out of 218 companions provided respite since workshop
18 never served before (new recruits)

Hours served in 2017 via independent program tracking

3233

<table>
<thead>
<tr>
<th># Families Served</th>
<th>Before Workshop</th>
<th>After Workshop</th>
<th>Currently Serving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>1.78</td>
<td>1.83</td>
<td>1.80</td>
</tr>
<tr>
<td>Mode</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hours Per Month</td>
<td>Range Mean Total</td>
<td>1 to 96</td>
<td>17</td>
</tr>
</tbody>
</table>
How do family caregivers feel about the respite they receive from REST companions?

Online Family Caregiver Survey
103 FAMILY CAREGIVERS RECEIVING RESPITE

- Perceived stress
- Health problems
- Social opportunity
- Placement risk

Before respite | Receiving respite | If respite lost
---|---|---
1=Not At All | 5=Extremely

Graph showing changes in perceived stress, health problems, social opportunity, and placement risk before, during, and after respite.
103 FAMILY CAREGIVERS RECEIVING RESPITE

Number of stress related symptoms

Before respite: 5.2
Receiving respite: 3.1
103 FAMILY CAREGIVERS RECEIVING RESPITE

Care recipient's opinion of respite experience

- Extremely positive: 26%
- Very positive: 56%
- Moderately positive: 12%
- Slightly positive: 4%
- Not at all positive: 3%
To learn more about REST visit our website at: www.restprogram.org

Are you interested in:

Hearing more about our Research?

• Lynn Ackerman
  Lead Researcher
  lackerman@ackermanresearch.com

Attending or Hosting a Training?

• Kelly Fitzgerald
  REST Training Development Manager
  kfitzgerald@restprogram.org

Information on Mobilizing REST through your State?

• Lois Sheaffer
  Director of REST
  lsheaffer@restprogram.org
Creating an international network of organizations that prepares individuals to support caregivers through respite.