Practice Research and Evaluation

Moderated by Casandra Firman, MS
ARCH National Respite Network
Presenters

Thomas V Caprio, MD, Professor of Medicine/Geriatrics, Psychiatry, Dentistry, Clinical Nursing, and Public Health Sciences, University of Rochester Medical Center

Sarah Swanson, MPH, Assistant Professor Community and Family Resource Specialist, Munroe-Meyer Institute, University of Nebraska Medical Center

Susan Jenkins, PhD, Director, Office of Performance and Evaluation, Center for Policy and Evaluation Administration for Community Living U.S. Department of Health and Human Services
Expanding a Volunteer Respite Workforce to Provide Support to Caregivers in New York State

Thomas V. Caprio, MD, MPH, MS, CMD, HMDC, FACP, AGSF, FAAHPM
Professor of Medicine/Geriatrics, Psychiatry, Dentistry, Nursing, & Public Health Director, Finger Lakes Geriatric Education Center Program Evaluator, Lifespan Respite Initiative
University of Rochester Medical Center (Rochester, New York)

September 30, 2020
**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)
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>Area</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>+.4</td>
</tr>
<tr>
<td>Preventing the spread of germs</td>
<td>+.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
<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 Respite Hours</strong></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

**Relationship 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**

- 3 - 6 months: 60.00%
- 6 - 12 months: 40.00%

**Mean Pre-/Post-Respite Caregiver Stress Level (n=7)**

(Self-Reported Stress Perceived from Caring for Family Member)

- Pre: 7
- Post: 6

Self-Reported Stress (Low to High)
A sense of relief
More confident
More balance in
I have regained
Taking better care of my own
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.
Summary of Respite Research

By: Sarah Swanson, MPH
August, 2020

- Impacts of Providing Respite
- Systems Change that Improves Respite Access
- Respite Provider Competence
Evaluation Framework

Families Together and Out of Institutional Care

- Need
- Access
- Caregiver Outcomes
- System Outcomes
- Cost Effectiveness
Evaluation

Family Caregiver Outcomes

- Year One- one program (N=26)
- Year Two- multiple programs (N=73)
- Year Three- multiple programs (N=78)

Other

- Respite Providers
- Focus groups with families, Respite Coordinators
- Employer Engagement
- Respite Provider Training Program
Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families

2015-2017
Nebraska Lifespan Respite - a Best Practice State

- Established by State legislation in 1999
- Lifespan Respite Network: Coordinated regional infrastructure
- Lifespan Respite Subsidy Program
- Basis for federal Respite Care Act
Impacts of Providing Respite
Family Caregiver Satisfaction with Respite 2015-2017

Family Caregivers were Highly Satisfied with the Respite Care Provided

- With the respite care provided to the care recipient:
  - Strongly Disagree: 8%
  - Disagree: 3%
  - Agree: 52%
  - Strongly Agree: 37%

- With the ease of finding a respite care provider:
  - Strongly Disagree: 21%
  - Disagree: 26%
  - Agree: 31%
  - Strongly Agree: 22%

- The overall level of respite care services received:
  - Strongly Disagree: 11%
  - Disagree: 11%
  - Agree: 39%
  - Strongly Agree: 39%

(N=176)
Decreased Stress

Caregiver Stress Decreased with Respite Services

- Before Respite
- Receiving Respite
- If Respite Ended

<table>
<thead>
<tr>
<th>Stress Level</th>
<th>Before Respite</th>
<th>Receiving Respite</th>
<th>If Respite Ended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all Stressed</td>
<td>10%</td>
<td>3%</td>
<td>2%</td>
</tr>
<tr>
<td>Slightly Stressed</td>
<td>35%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Moderately Stressed</td>
<td>42%</td>
<td>20%</td>
<td>8%</td>
</tr>
<tr>
<td>Very Stressed</td>
<td>31%</td>
<td>36%</td>
<td>36%</td>
</tr>
<tr>
<td>Extremely Stressed</td>
<td>9%</td>
<td>4%</td>
<td>57%</td>
</tr>
</tbody>
</table>

n=149
Family Caregivers Reported Large Decreases in Anxiety and Irritability/Anger

- Anxiety
- Fatigue
- Irritability or anger
- Sleep Problems
- Sadness or depression
- Lack of motivation or focus
- Headache
- Muscle tension or pain
- Restlessness
- Change in sex drive
- Stomach upset
- Chest pain

Comparison of symptoms before and after respite care (N=26)

- With respite
- Before respite
Year 2 - (2016)

Family Caregivers Experienced Reduced Health Symptoms While Receiving Respite

- Fatigue
- Anxiety
- Sadness or depression
- Irritability or anger
- Sleep problems
- Headache
- Muscle tension/pain
- Lack of motivation or focus
- Restlessness
- Change in sex drive
- Stomach upset
- Chest pain

N=73

With respite vs. Before respite
Year 3 - (2017)

Respite Care Resulted in Fewer Health Symptoms Reported by Family Caregivers

- Fatigue
- Sleep problems
- Anxiety
- Irritability or anger
- Headache
- Sadness or depression
- Muscle tension/pain
- Lack of Motivation
- Restlessness
- Stomach upset
- Change in sex drive
- Chest pain

N=78

With Respites	Before Respites
Level of Strain in Relationship with Spouse Decreased

(1=Not at all Strained to 5=Extremely Strained)

Year One:
- Before Respite: 3.64
- With Respite: 2.64
- If Respite Ended: 3.62

Year Two:
- Before Respite: 3.48
- With Respite: 2.54
- If Respite Ended: 3.72

Year Three:
- Before Respite: 3.15
- With Respite: 2.09
- If Respite Ended: 3.44

N=175
Relationship Strain with Care Recipient Decreased When Respite was Provided

(1=Not at all Strained to 5=Extremely Strained)

Year One:
- Before Respite: 3.69
- With Respite: 2.54
- If Respite Ended: 3.88

Year Two:
- Before Respite: 2.74
- With Respite: 1.91
- If Respite Ended: 3.16

Year Three:
- Before Respite: 3.01
- With Respite: 2.13
- If Respite Ended: 3.36

N=175
Mental Health

Percentage of Family Caregivers Self-Reporting Depressive Symptoms

- In the last month, one week or more feeling sad or depressed: 30%
- In the last year, 2 weeks of feeling sad or depressed: 36%
- 2 years or more feeling sad or depressed most days: 41%

N=123
Caregiving Impact on Employment

30% Resulted in being late or missing work

73% Missed 1-5 days

11% Missed 5-10 days

8% Missed 10-15 days

8% Missed 15+ days
Possible out-of-home placement consideration decreased

Source: 2016 Family Caregiver Survey
Respite Providers

Year Two  (N=80)

29% from an agency
71% independent providers

Greatest Challenge:
• Low wages
• Gap in services for rural vs. urban regions.
• Training and strategies are needed for serving care recipients with mental health and behavioral concerns
Respite Provider Competence

6 Key Areas:
1. Improved research methodologies
2. Individual, family, and societal outcomes
3. Cost-benefit and cost-effectiveness research
4. Systems change that improves respite access
5. Improved respite provider competence
6. Translate research findings into best-practice models

Future Research
Respite Service Learning Certificate Program

2019-2020
Student Manual

Authored By:
Ellen Bennett, MS; Sarah Swanson, MPH & Kim Falk, BS

Training Included:
- Online Respite Provider Orientation
- Structured Respite Service Learning
- Home Based Respite

Certificate of Achievement in Direct Workforce with Specialization in Home-Based Respite Care

Presented to:

Recipient

Date

Presenter Signature
Presenter Signature

Helping People Live Better Lives
Systems Change that Improves Respite Access
Responsiveness to Evaluation

Lifespan Respite Subsidy Program

- $1000 Exceptional Circumstances or Crisis Respite funding
Respite Employer Engagement Coordinator

Problems:
Lack of understanding of “Respite”
Uniformed about Needs of Working Family Caregivers

Solution:
Outreach through University System
Outreach to employers
RESPITE EMPLOYER ENGAGEMENT

140

756 Respite Brochures Requested
Reached over 8000 Employees
150 follow-up contacts

Orientations Attended

80

Employers
RESPITE EMPLOYER ENGAGEMENT: Next Steps

Wisconsin Survey

- Survey working family caregivers
- 25 questions
- 10 minutes

This survey has been adapted from the University of Wisconsin-Madison Division of Extension.
RESPITE EMPLOYER ENGAGEMENT: Next Steps

National Core Indicators (NCI)

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**Are you using respite resources to allow for breaks from caregiving?**

- Yes, friends/family members help me take a break from caregiving
- Yes, I use respite services paid with respite funding
- Yes, I use self-pay respite services

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7. Please rate your experiences for the following items.

<table>
<thead>
<tr>
<th></th>
<th>Not at all stressed</th>
<th>Slightly stressed</th>
<th>Moderately stressed</th>
<th>Very stressed</th>
<th>Extremely stressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before receiving respite, how “stressed” were you as a result of caring for your family member?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Now that you are receiving respite care services, how “stressed” are you as a result of caring for your family member?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>If respite care were to end, how “stressed” would you be as a result of caring for your family member?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
National Family Caregiver Support Program: Evaluation Findings

Susan Jenkins, PhD
US Administration on Aging
September 30, 2020
Overview

- Overview of the National Family Caregiver Support Program (NFCSP)
- The NFCSP Evaluation
- Next Steps
  - Older Americans Act (OAA) Reauthorization
  - ACL’s Learning Agenda
Overview of the NFCSP

• Established in 2000

• Provides grants to states and territories to fund supports that help informal caregivers care for older adults in their homes for as long as possible

• These services work in conjunction with other state and community-based services to provide a coordinated set of supports.
Overview of the NFCSP

NFCSP grantees provide five types of services:

- information to caregivers about available services
- assistance to caregivers in gaining access to the services
- individual counseling, organization of support groups, and caregiver training
- respite care; and
- supplemental services, on a limited basis
The NFCSP Evaluation: Purpose

• Help ACL understand which kinds of services are most helpful for caregivers and identify any unmet needs of caregivers and gaps in support for them;

• Assess the impact of services on caregivers’ ability to continue to provide homebased caregiving as needed; and

• Examine the relationship between caregiver outcomes and key processes and characteristics of the Area Agencies on Aging managing and/or providing NFCSP services.
The NFCSP Evaluation: Methodology

• Survey of a nationally representative sample of client caregivers, a Comparison group of caregivers who do not receive NFCSP services, and a sample of care recipients (CRs) of caregivers in the two groups.

• Survey data coupled with the AAA-level data collected during the process evaluation allow for the investigation into what types of organizational structures, approaches, and strategies for delivering services are associated with optimal caregiver-level outcomes.

• The team attempted phone interviews with each caregiver three times: (1) baseline in Winter 2016, (2) 6-month follow-up in Summer 2017, and (3) 12-month follow-up in Winter 2017.
The NFCSP Evaluation:  
Selected Findings

Table 5-19.  Respite care hours and the odds ratio of a more favorable response to Continued caregiving (N = 447 caregivers)

<table>
<thead>
<tr>
<th>Variables (reference category)</th>
<th>Odds ratio</th>
<th>P-value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite care hours per week</td>
<td>1.047</td>
<td>0.000</td>
<td>1.024</td>
<td>1.073</td>
</tr>
<tr>
<td>Control Variables:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CR Age (&lt; 65 years old)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 to &lt;75</td>
<td>0.607</td>
<td>0.359</td>
<td>0.195</td>
<td>1.699</td>
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<td>75 to &lt;80</td>
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<td>0.180</td>
<td>0.151</td>
<td>1.357</td>
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<td>80 to &lt;85</td>
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<td>0.182</td>
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<td>85 to &lt;90</td>
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<td>0.749</td>
<td>0.271</td>
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<tr>
<td>90+</td>
<td>0.374</td>
<td>0.068</td>
<td>0.121</td>
<td>1.034</td>
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<tr>
<td>Caregiver Race (Non-Hispanic White)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>1.518</td>
<td>0.168</td>
<td>0.847</td>
<td>2.787</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.382</td>
<td>0.404</td>
<td>0.655</td>
<td>3.024</td>
</tr>
<tr>
<td>Non-Hispanic Other</td>
<td>1.394</td>
<td>0.364</td>
<td>0.689</td>
<td>2.910</td>
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<tr>
<td>Living with CR</td>
<td>0.455</td>
<td>0.014</td>
<td>0.238</td>
<td>0.844</td>
</tr>
<tr>
<td>Count of ADL’s Needing Help Daily (No ADLs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1.571</td>
<td>0.175</td>
<td>0.819</td>
<td>3.032</td>
</tr>
<tr>
<td>2</td>
<td>1.995</td>
<td>0.039</td>
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<td>3</td>
<td>2.592</td>
<td>0.005</td>
<td>1.340</td>
<td>5.069</td>
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<tr>
<td>4</td>
<td>1.505</td>
<td>0.199</td>
<td>0.807</td>
<td>2.817</td>
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<tr>
<td>5</td>
<td>1.428</td>
<td>0.276</td>
<td>0.753</td>
<td>2.719</td>
</tr>
</tbody>
</table>
The NFCSP Evaluation: Selected Findings

Table 7-9. Comparison of receipt of respite care or educational services provided by family, friends, or neighbors

<table>
<thead>
<tr>
<th>Services by family/friend</th>
<th>NFCSP caregivers (N = 617)</th>
<th>Non-NFCSP caregivers (N = 951)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Yes</td>
<td>Mean amount</td>
</tr>
<tr>
<td>Respite care</td>
<td>54.0</td>
<td>9.77 hrs./week</td>
</tr>
<tr>
<td>Educational</td>
<td>18.6</td>
<td>5.11 sessions</td>
</tr>
</tbody>
</table>

Table 7-10. Comparison of receipt of respite and educational services provided by different sources: NFCSP versus non-NFCSP caregivers

<table>
<thead>
<tr>
<th>Services by non-NFCSP organization</th>
<th>NFCSP caregivers (N = 617)</th>
<th>Non-NFCSP caregivers (N = 951)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Yes</td>
<td>Mean amount</td>
</tr>
<tr>
<td>Respite care</td>
<td>20.0</td>
<td>14.51 hrs./week</td>
</tr>
<tr>
<td>Educational services</td>
<td>21.7</td>
<td>6.99 sessions</td>
</tr>
</tbody>
</table>
The NFCSP Evaluation: Selected Findings

Figure ES-2. Changes in adjusted mean Zarit Caregiver Burden scores for Program and Comparison caregiver groups
The NFCSP Evaluation

• Complete information is available at: https://acl.gov/programs/program-evaluations-and-reports
Next Steps: OAA Reauthorization

The Older Americans Act, which funds ACL’s National Family Support Program was reauthorized in January through 2024. The Act mentions caregivers in several places including with regard to:

- Ensuring that they are consulted for the development of objectives, priorities, and a long-term plan for supporting State and local efforts involving education about prevention of, detection of, and response to negative health effects associated with social isolation among older individuals.
- Increasing business acumen, capacity building, organizational development, innovation, and other methods of growing and sustaining the capacity of the aging network to serve older individuals and caregivers most effectively.
- There is additional focus on caregiver assessment of needs, identification of best practices, promoting quality and continuous improvement in the support provided to family caregivers and older relative caregivers.
Next Steps: ACL Learning Agenda

• A systematic way to identify the data agencies will collect, use, or acquire, as well as the methods and analytical approaches to facilitate the use of evidence in policy making.

• They encourage the use of data to improve agency operational and programmatic outcomes and develop appropriate policies and regulations supporting successful mission accomplishment.
Next Steps: ACL Learning Agenda

**Priority Question:** What is the efficacy and effectiveness of ACL programs and initiatives?

**Sub-question:** Is ACL being effective in its caregiver support programs?
Next Steps: ACL Learning Agenda

Current Efforts:

• Evaluation of Home and Community-Based Support Services for Older American Indians, Alaska Natives, and Native Hawaiians (process and outcome evaluations scheduled for completion in summer 2021)

• Supporting Families Community of Practice (CoP) Evaluation (retrospective evaluation scheduled for completion in fall 2020)
Next Steps: ACL Learning Agenda

New Efforts:

- A topical module to the National Survey of Older Americans Act
- A process evaluation of the National Aging Network and its return on investment, planned for fall 2020 through fall 2024, will focus on identifying members of the aging network and their work beyond that funded by ACL.
- A fidelity evaluation of ACL’s evidence-based programs, planned for fall 2020 through fall 2022, will focus on the adherence of programs to the implementation standards for evidence-based programming awards funded through the OAA.
- A flexible evaluation and research support contract, planned from fall 2020 through fall 2025, will allow OPE to plan and implement a series of studies about the efficacy and effectiveness of ACL’s suite of grants and initiatives focused on supporting caregivers across the lifespan.
Thank you

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