

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:

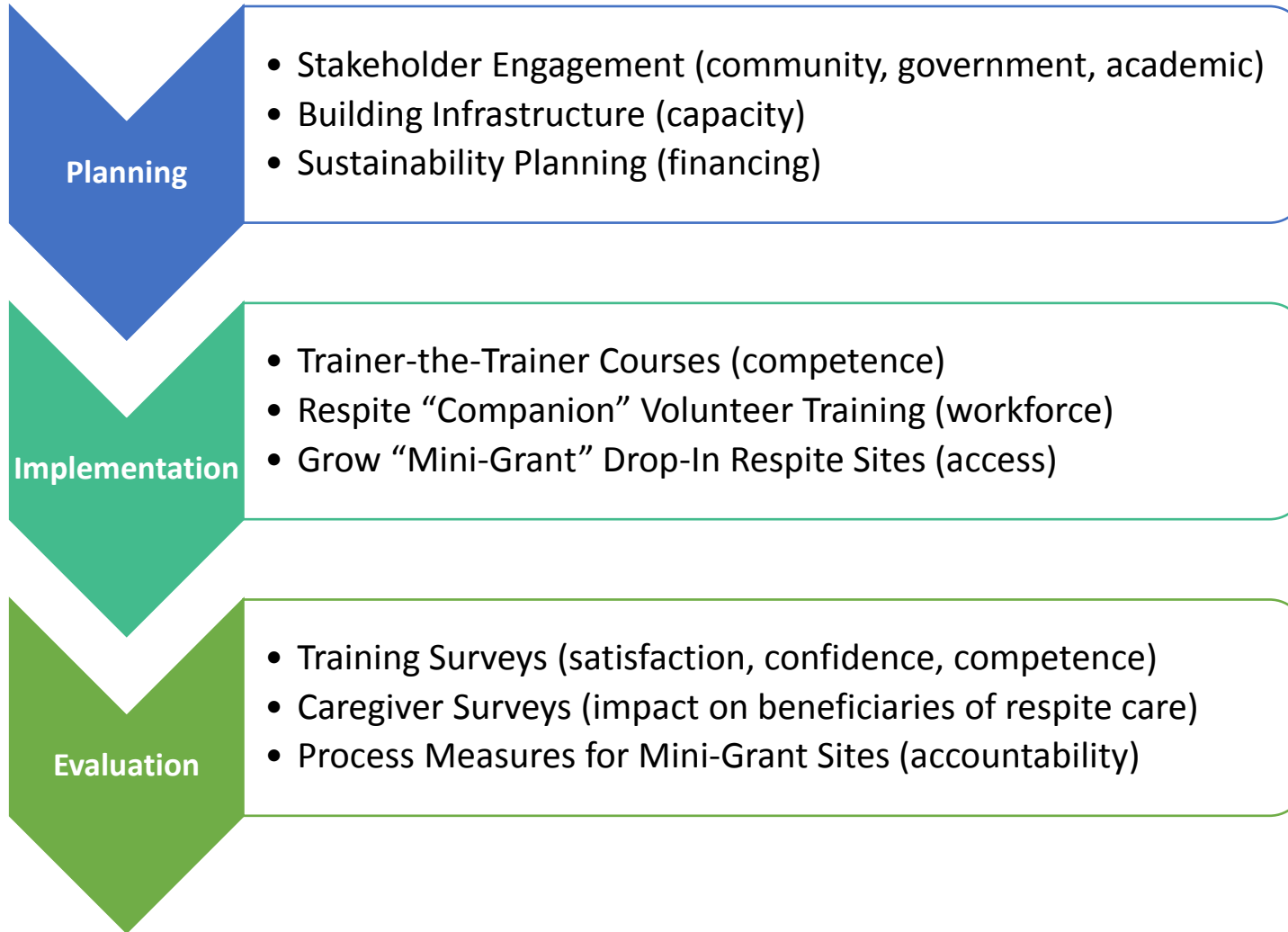
- New York State Office for the Aging (NYSOFA)
- New York State Caregiving and Respite Coalition (NYSCRC)
- New York State's ADRC (NY Connects)
- Monroe County Office for the Aging (MCOFA)
- Lifespan of Greater Rochester, Inc. (Lifespan)

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



Positioning for Future Research



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/>



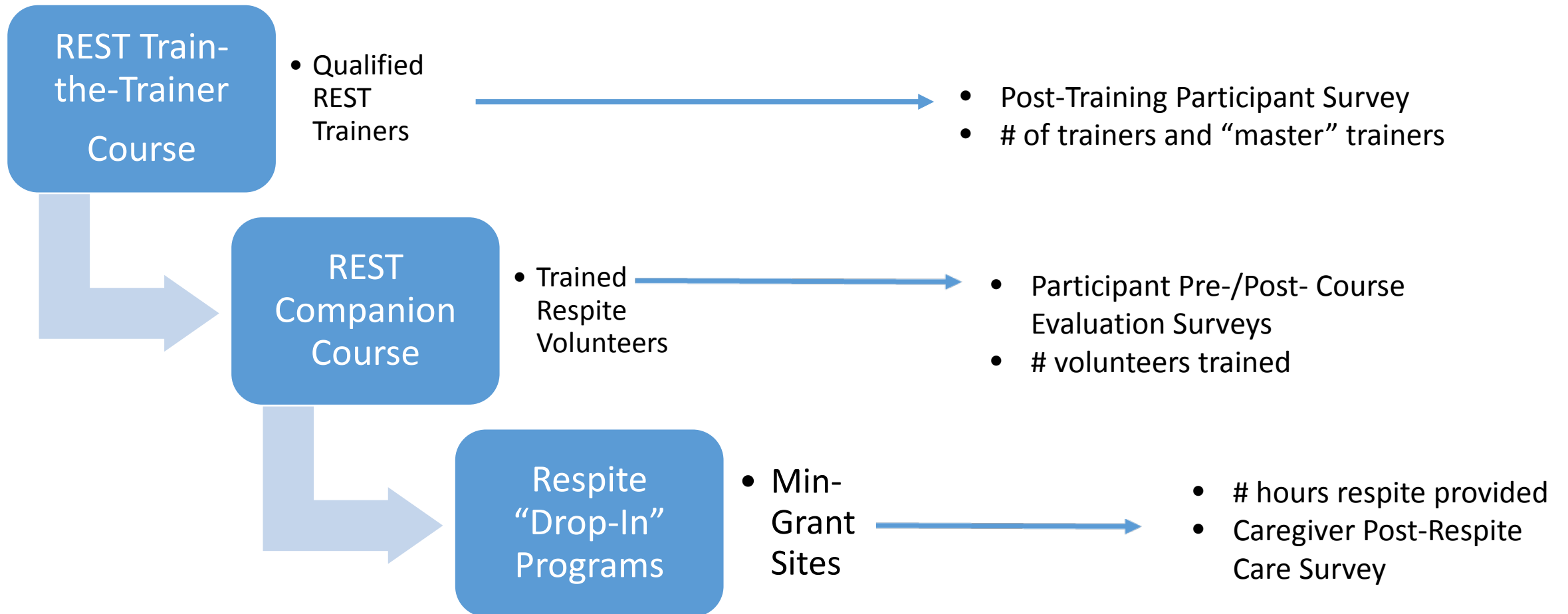
REST Trainings - New York State dissemination

- **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

Evaluation Strategy



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

Rate your level of skill/knowledge/understanding in each of the following areas	Mean Change Score*
The roles and responsibilities of a respite worker	+1.9
Establishing good communication and trust with the family	+1
Gathering information from the family to set up respite arrangements	+1.34
Determining care recipients interests and abilities	+1.6
Strategies for communicating with care recipients	+1.7
Adapting activities to care recipients needs	+1.7
Understanding challenging behaviors	+1.65
Dealing with injuries and emergency situations	+1.58
Signs of caregiver stress and coping strategies	+1.42
Respecting different family situations and cultures	+1.2
Keeping family information confidential	+.4
Preventing the spread of germs	+.74

Scale of 1 (very low) to 5 (very high) *

REST Companion Course (Respite Volunteers) Pre-/Post-Surveys Course Evaluation

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

*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

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

*Sites on pause due to COVID-19 Pandemic

Post-Respite Care Survey

Please complete this form at the conclusion of the Respite Program provided by <Provider Name>. All surveys are confidential. We do not need your name on this form.

1. Have you felt a reduction in care-giving stress because of having respite care?
 Yes No

Please explain:

2. Regarding the use of respite services, do you feel ...? (Check all that apply)

- More comfortable accepting help from others
 More comfortable having respite workers provide support at home
 More comfortable with respite support outside of home
 That respite workers have provided competent care
 That I should have used respite supports earlier
 Other (Please Describe)

3. How much do you agree with the following statement: I used my respite plan to do something I enjoyed and felt that the respite was "time well spent"?

- | Completely Disagree | | | | | | | Completely Agree | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|------------------|--|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | |

4. Has respite allowed you to spend time in the various activities that you enjoy (e.g., going to religious services, socializing with others, going out for a meal) or spend time on hobbies or activities you like to enjoy alone (e.g., reading or gardening)? Yes No

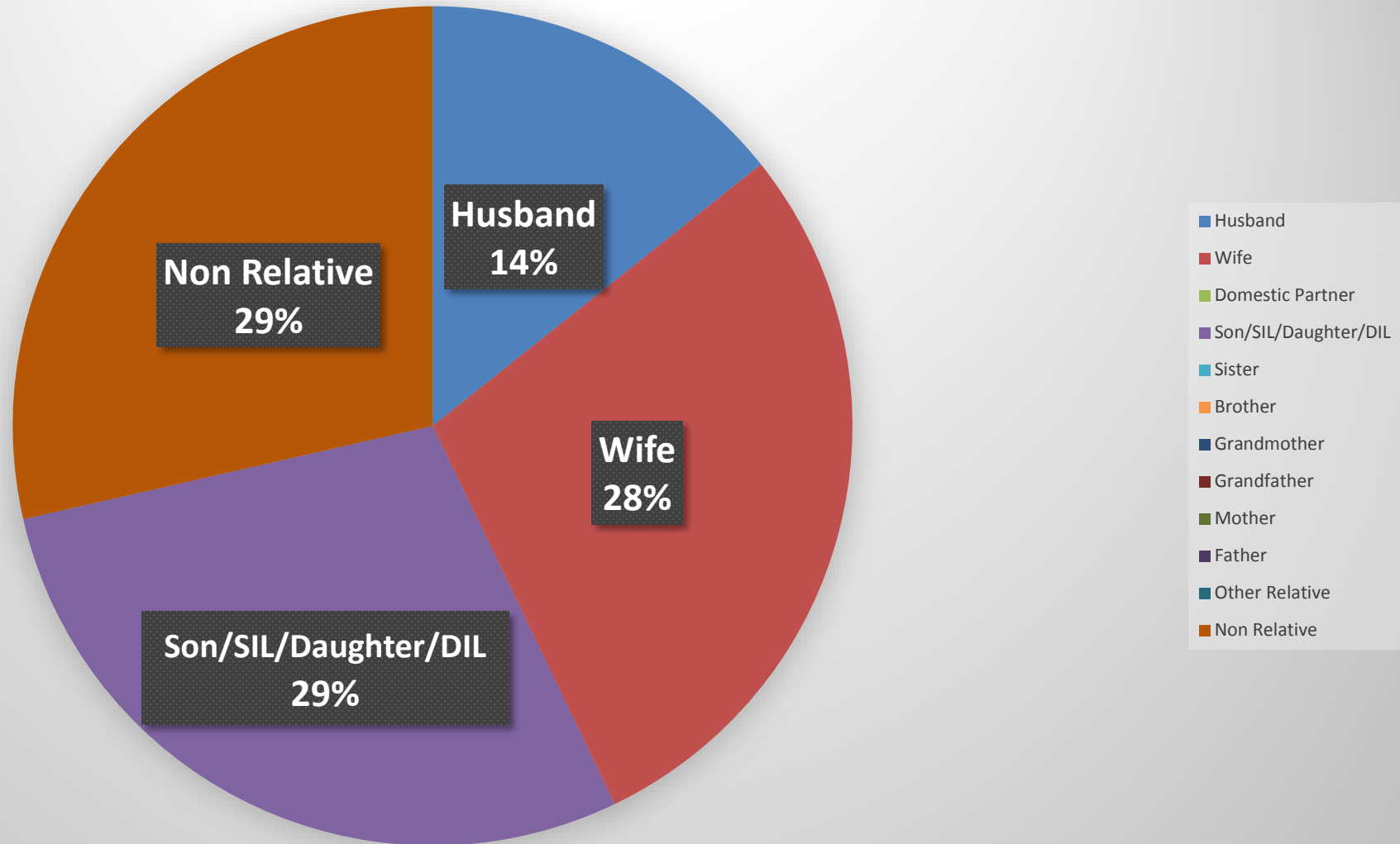
5. Has the use of respite made a positive difference to you and your family? Yes No

Caregiver Post-Respite Care Survey

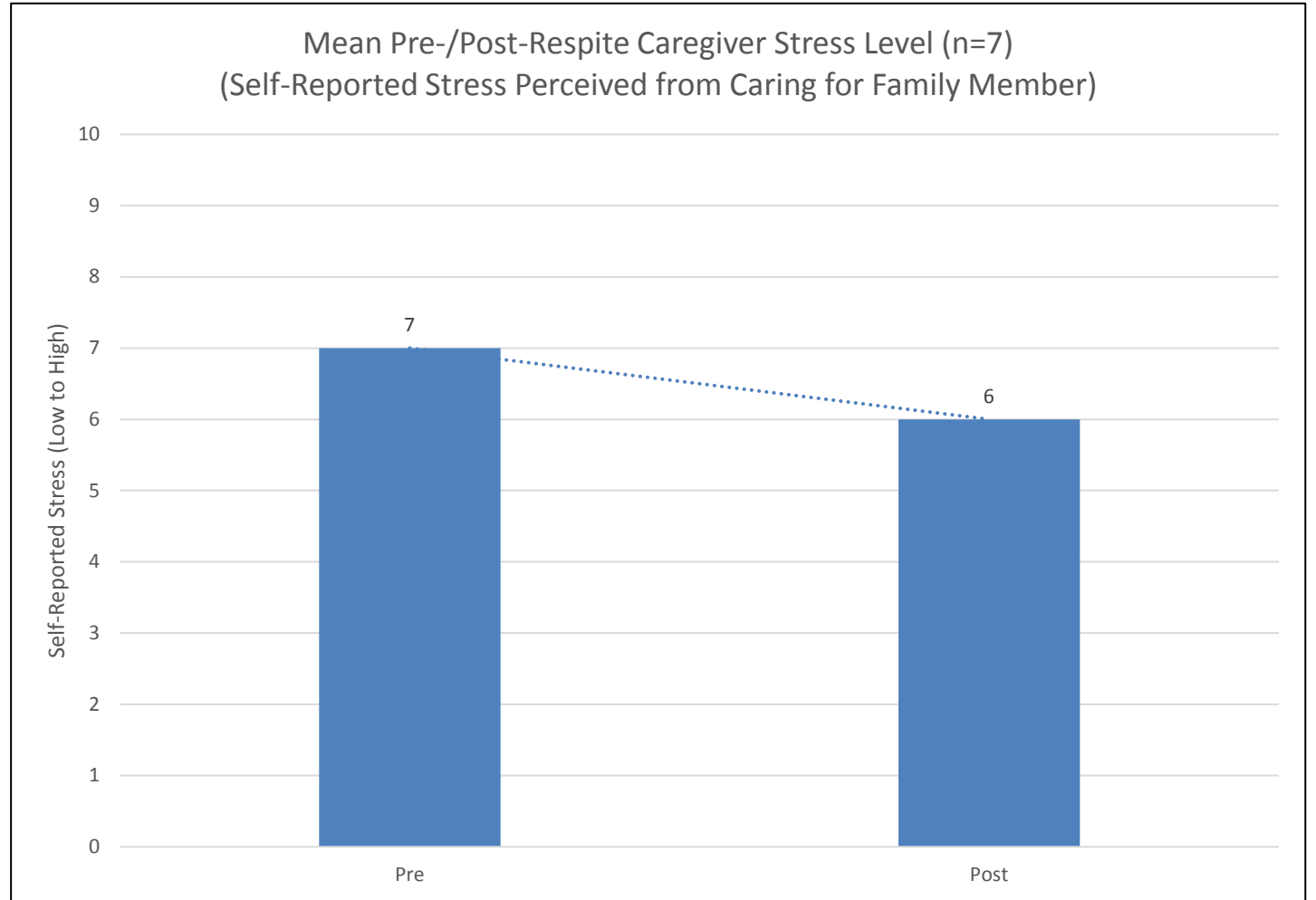
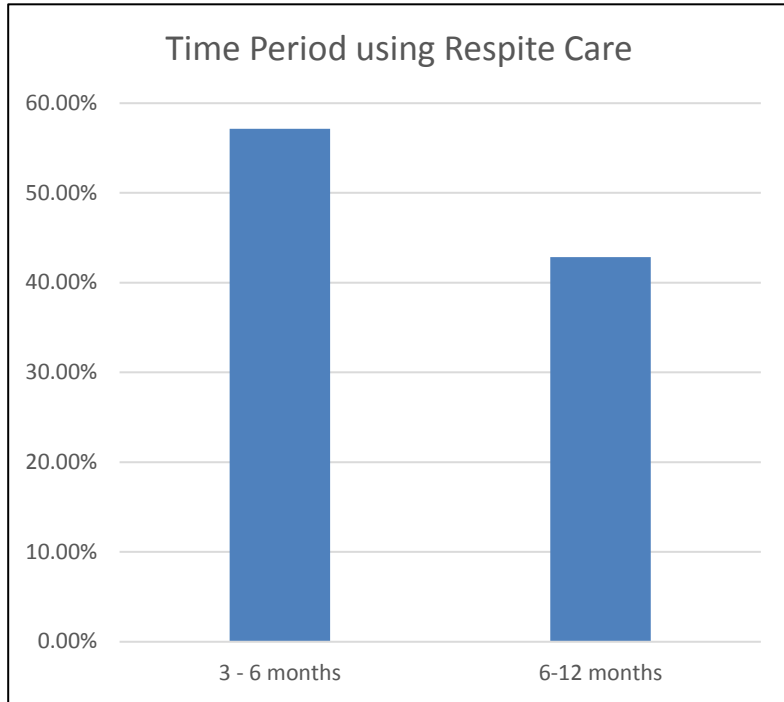
- Target: Caregivers who's loved one or family member was a respite recipient
- Created/modified from prior ARCH Respite Tools
- Pilot tested at respite mini-grant sites
- Evaluation/perception of respite recipients
- 80% indicate they have no-one to fill in for them as a caregiver in an emergency
- 100% of respondents indicate they have felt a "reduction in care-giving stress because of having respite care"

Post-Respite Survey: Caregiver Demographics

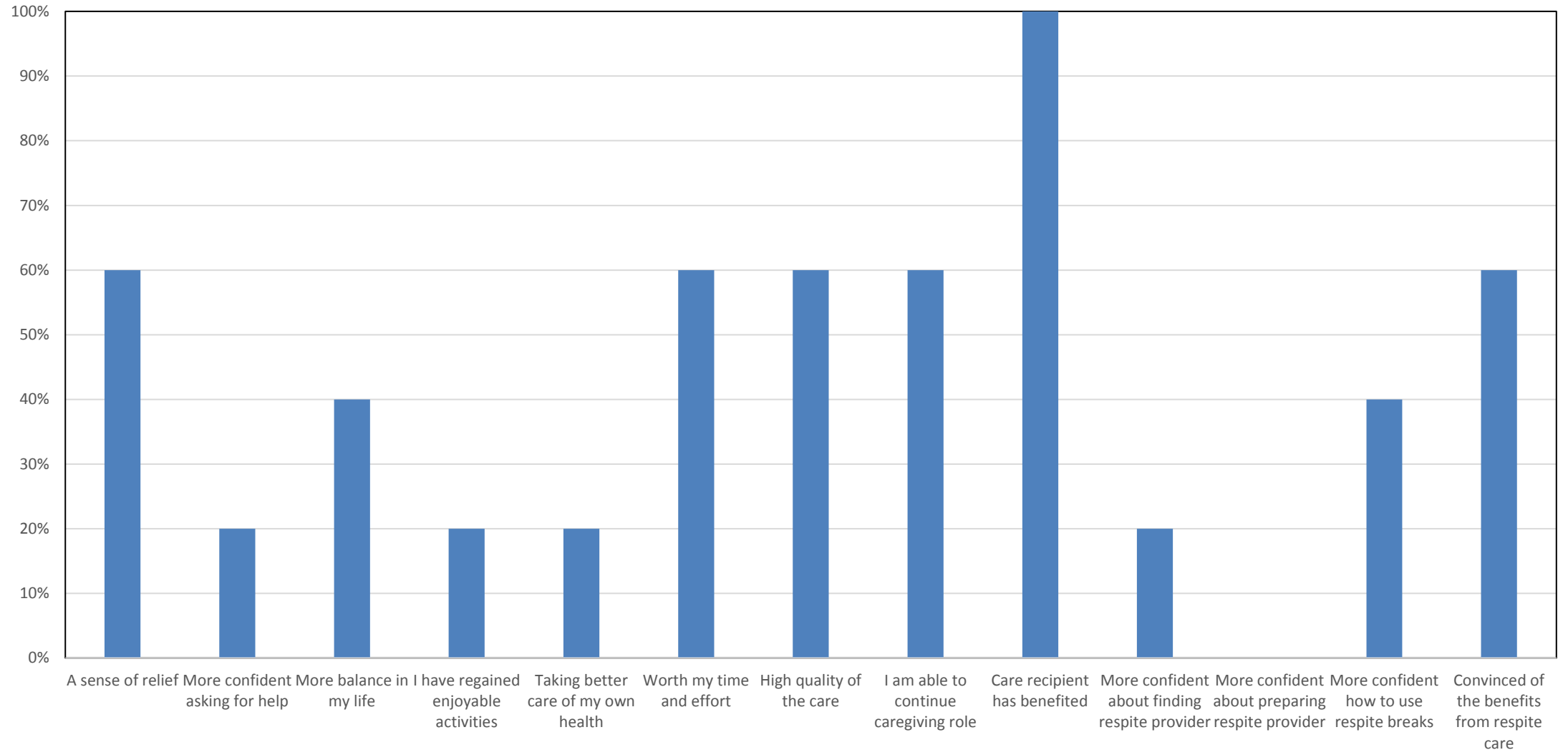
Relationship of Caregiver to Respite Recipient



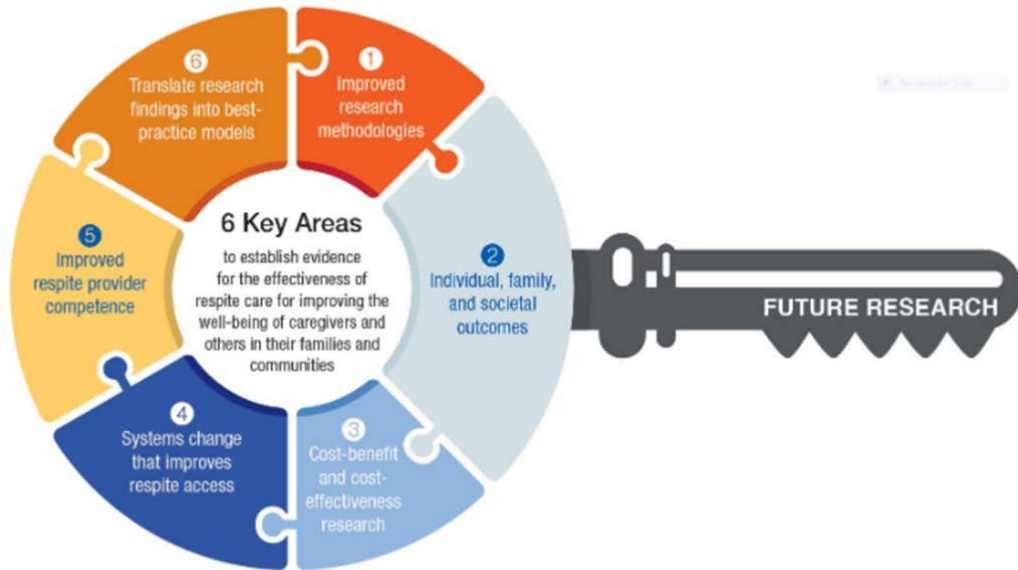
Post-Respite Caregiver Survey



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