



Lifespan Respite Program Data Collection Tool Pilot Discussion

Welcome!

Come in. Take a seat.

Think about your response to this question:

If your state Lifespan Respite team were to compete on America's Got Talent, what would you choose for your talent and why?





Agenda

- Introductions and Overview
- Key Findings from Initial Submissions
- Ease and Burden Results
- Next Steps



Thank you!

The Lifespan Respite Data Collection Tool provides ACL more specific data than what is currently collected in the semi-annual reports. It also supports your program monitoring efforts! Thank you for being a part of this pilot.



Introductions

America's
got **Talent**
LIFESPAN RESPITE EDITION!



KEY FINDINGS FROM INITIAL SUBMISSIONS

Lifespan Respite Program Outcomes

- 34 outcomes across 7 states
 - Average 5 outcomes per state
 - Range is 2 – 8 outcomes
 - Median is 5 outcomes
- Average reported achievement across all outcomes is 54%

Outcome 1: Grantees meet the project outcomes identified in their workplan.
Indicator: Semi-annual and final progress made towards achievement of outcomes and indicators.

Reporting Period: to
mm/dd/yy mm/dd/yy

Instructions:

- 1) State your outcomes and objectives from your workplan. Most grantees identify 3-5 outcomes with 3-5 objectives each. There is no expectation to use all fields provided.
- 2) Put an x in one of the boxes to the right of each objective describing your progress.

Measurable outcomes and their objectives	Achieved	Partially Achieved	Collecting Baseline	Not achieved	Not scheduled	Deleted/ Modified
	Objective 1.1					
Objective 1.2						
Objective 1.3						
Objective 1.4						
Objective 1.5						
Objective 1.6						
Objective 1.7						
Objective 1.8						
Objective 1.9						

Outcome Completion
 The charts below will auto fill as you enter data into the outcome table.

Total % of Outcomes Achieved: #DIV/0!

A. Number of checkmarks (not counting deleted/modified)	0.00
B. The number of checkmarks in the "achieved" column.	0.00
C. Total number of partially achieved & collecting baseline.	0.00
D. Number of partially achieved & collecting baseline X .5	0.00
E. Sum of B and D	0.00
F. Percentage of outcome completion	#DIV/0!



Menti Question

What best describes your state's ability to complete the Outcomes portion of the data collection tool?



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Stakeholder Involvement

Outcome 2: Grantees have a coordinated state-wide system of accessible respite. Indicators: 2.1 - The number of stakeholders who actively promote, fund, provide or otherwise support respite services.							
Reporting Period: 09/01/18 to 02/28/19 <i>mm/dd/yy mm/dd/yy</i>							
Section 1: During this reporting period, how many Lifespan Respite partners/coalition members/stakeholders in your state did the following? Put a number in the blue-shaded fields.							
Partners/Coalition Members/Stakeholders	Attended at least one coalition meeting (state or local) or any formal or informal meeting held to promote the lifespan respite program.	This individual or the agency they represented promoted Lifespan Respite awareness (e.g., presented at conference, shared info. in a	This individual or the agency they represented contributed in-kind resources to support Lifespan Respite (not for direct respite services)	This individual or the agency they represented provided financial assistance or vouchers for direct Lifespan Respite services	This individual or the agency they represented provided respite or facilitated respite (i.e., linked caregivers with volunteer respite	This individual or the agency they represented has an MOU, contract, or written agreement with the Lifespan Respite grantee related to the	totals:
Family Caregivers of adults							0
Family Caregivers of children							0
Family Lifespan Caregiver (a caregiver of both children and adults)							0
Paid or Volunteer Respite Provider for adult							0
Paid or Volunteer Respite Provider for children							0
Paid or Volunteer Lifespan Respite Provider (provides respite for both children and adults)							0
Legislators and other policy makers							0
Private health and long-term sector (hospitals, medical provider, home health agencies, etc.)							0
Private, nonprofit children's, aging, and disability groups.							0
Private sector businesses and employers (not health and long-term sector, or nonprofit)							0
Education community							0
Charitable foundations							0
Faith and Volunteer Communities							0
Agencies serving Veterans and military families							0
ADRCs							0
State and Local Government Agencies (other than grantee agency)							0
Others							0
Totals	0	0	0	0	0	0	0



Stakeholder Involvement

- The most involvement from family caregivers is:
 - attending coalition meetings
 - promoting Lifespan Respite awareness
 - contributing in-kind resources to support Lifespan Respite
 - providing/facilitating Lifespan Respite.



Stakeholder Involvement

- Major contributors to promoting Lifespan Respite awareness are:
 - family caregivers
 - private health and long-term sector (hospitals, medical provider, home health agencies, etc.)
 - ADRCs
 - education community
 - private sector businesses and employers
 - private, nonprofit children's, aging and disability groups
 - state/local government agencies (other than grantee agency).

Lifespan Respite Funding:

1068 Caregivers Received Planned Respite

- **Average funding for indirect or direct respite: \$167,610**
 - Range across 6 states is \$56,810-\$288,980
 - Funding came mainly from state and other federal resources or a foundation
- **Average amount of direct respite services paid for with mini-grants, contracts, or vouchers: \$58,360**
 - Range across 7 states is \$11,250 - \$189,980

Section 2, A: Financial contributions, including cash and in-kind equivalents, received for direct or indirect services. Put a dollar amount in the blue-shaded fields.

Enter the amount of funding received for each category. Funds must be for Lifespan Respite grant activities. Funds must have been received during this reporting period. There is no need to identify each source of funding, just the total dollar amount.

Count funds that flow through the LR grantee or primary partners that the LR grantee facilitated for Lifespan Respite activities. Estimate the monetary equivalent of in-kind goods or services. For example, the in-kind dollar amount of an hour of respite provided by a volunteer should be based on what it would cost for a paid provider of the same service. You may not be aware of all funds, but as time progresses, the Lifespan Respite Grantee will become aware of more.

	Amount Received
Other Federal	\$
State	\$
Local/Communities	\$
Foundation	\$
In-kind	\$
Other	\$
Total:	0



Menti Question

What best describes your state's ability to complete the Stakeholder Involvement and Program Funding portions?



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Care Recipients and Caregivers

Outcome 2: Grantees have a coordinated state-wide system of accessible respite.

Indicators: 2.3 - The number of caregivers receiving respite.

2.4 - The number of organizations connecting caregivers with a single point of contact for respite information and services.

Reporting Period: 09/01/18 to 02/28/19
09/01/18 02/28/19

Instructions: In the shaded spaces below, enter the number of individuals who received respite through vouchers, direct payments, or other provisions facilitated by the Lifespan Respite grantee. Note the distinctions between caregivers and care recipients.

Care Recipients	Care Recipients, Total Unduplicated Count <input type="text"/>	Care Recipient Age	Care Recipient Military Status	Care Recipient Race
	Special Need of Care Recipients	Under 18 <input type="text"/>	Served in military (active or retired) <input type="text"/>	American Indian or Alaska Native <input type="text"/>
	Cognitive impairment and/or Dementia <input type="text"/>	18-24 <input type="text"/>	Has not served in military <input type="text"/>	Asian or Asian American <input type="text"/>
	Intellectual/Developmental Disabilities (IDD) <input type="text"/>	25-39 <input type="text"/>	Military status missing <input type="text"/>	Black or African American <input type="text"/>
	Mental Illness (MI) and/or Substance Use Disorder <input type="text"/>	40-64 <input type="text"/>		Native Hawaiian or other Pacific Islander <input type="text"/>
	Physical Disabilities <input type="text"/>	Over 65 <input type="text"/>		White <input type="text"/>
	Traumatic Brain Injury (TBI) <input type="text"/>	Age missing <input type="text"/>		Race missing <input type="text"/>
	Other: <input type="text"/>		Care Recipient Gender	
	Describe others: <input type="text"/> sciatica, bursitis, Multiple Sclerosis, pulmonary fibrosis		Female <input type="text"/>	Care Recipients Ethnicity
	Special need missing <input type="text"/>		Male <input type="text"/>	Hispanic or Latino <input type="text"/>
		Other <input type="text"/>	Not Hispanic or Latino <input type="text"/>	
		Gender Missing <input type="text"/>	Ethnicity missing <input type="text"/>	

Family Caregivers	Caregivers, Total Unduplicated Count <input type="text" value="50"/>	Caregivers Age	Caregiver Military Status	Caregivers Race
	Caregivers' Relationship to Care Recipient	Under 18 <input type="text"/>	Served in military (active or retired) <input type="text"/>	American Indian or Alaska Native <input type="text"/>
	Parent <input type="text"/>	18-24 <input type="text"/>	Has not served in military <input type="text"/>	Asian or Asian American <input type="text"/>
	Spouse or partner <input type="text"/>	25-39 <input type="text"/>	Military status missing <input type="text"/>	Black or African American <input type="text"/>
	Child <input type="text"/>	40-64 <input type="text"/>		Native Hawaiian or other Pacific Islander <input type="text"/>
	Court appointed legal Guardian <input type="text"/>	Over 65 <input type="text"/>		White <input type="text"/>
	Siblings <input type="text"/>	Age missing <input type="text"/>		Race missing <input type="text"/>
	Grandparent <input type="text"/>		Caregivers Gender	
	Other <input type="text"/>		Female <input type="text"/>	Care Recipients Ethnicity
	Describe others: <input type="text"/>		Male <input type="text"/>	Hispanic or Latino <input type="text"/>
Relationship missing <input type="text"/>		Other <input type="text"/>	Not Hispanic or Latino <input type="text"/>	
		Gender missing <input type="text"/>	Ethnicity missing <input type="text"/>	



2476 Individuals were Served during this Reporting Cycle

Care Recipients

- **Total:** 1256 **Gender:** 43% Male
- **Race:** 31% White, 28% African American (34% missing data)
- **Ethnicity:** 46% Not Hispanic or Latino (37% missing data)
- **Age:** 38% are 18 and under, 26% are over 65 (13% missing data)
- **Military:** 1% served (active or retired), 37% of data missing

Caregivers

- **Total:** 1220 **Gender:** 65% Female
- **Race:** 33% White, 30% African American (29% missing data)
- **Ethnicity:** 49% Not Hispanic or Latino (35% missing data)
- **Age:** 41% are 40-64, 15% are over 65 and 15% are 25-39 (24% missing data)
- **Military:** 3% served (active or retired), 45% missing data
- **Caregiver Relationship:** 36% parent, 14% spouse/partner, 23% missing data

Training and Marketing

Training/Workshop/classes provided by LR Grantee or partner on their behalf.

- * Training must be **related to respite**.
- * Training may have been held in partnership with others.
- * Counts of attendees may be duplicated. (An attendee might attend multiple events.)
- * A keynote presentation at a conference would not count as a training. A workshop on a topic related to respite, such as, "how to choose a respite provider", or "identifying funding sources for respite" or ongoing classes would count as trainings.

Number of remote (web-based or conference call) trainings, classes or workshops:

Number of face-to-face trainings, classes or workshops:

Attendee count at in-person trainings/workshops or web-based trainings:

Caregivers	<input type="text" value="0"/>
Providers	<input type="text" value="0"/>
Volunteers	<input type="text" value="0"/>
Other stakeholders	<input type="text"/>
Role of attendee missing	<input type="text" value="0"/>

How many emergency respite services has the LR grantee identified in the state?

Does your state currently have a Lifespan Respite Website?

Yes *No*

Count of website views this reporting period:

Does your state have a system that provides caregivers with a single point of contact (i.e. ADRC/NWD, 211, website, etc.) for respite information and services?

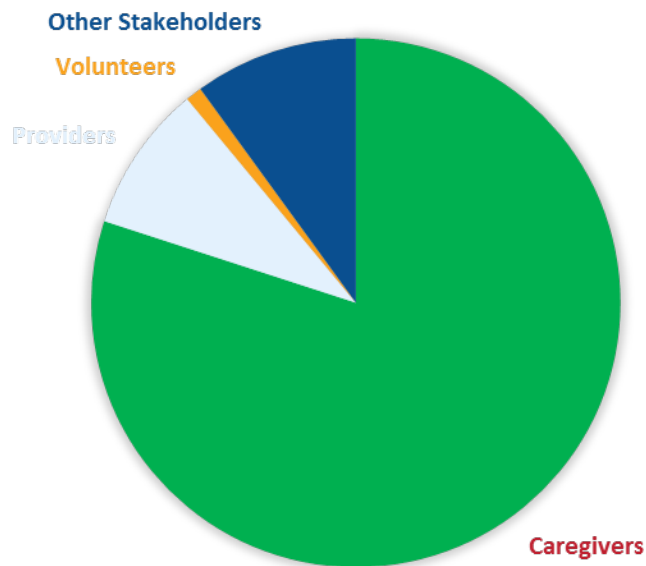
Yes *No*

If yes, please indicate the system you use:



A total of 141 trainings, classes, and workshops were provided across six states for 3252 individuals.

**ATTENDEES FOR FACE-TO-FACE
(PERCENTAGE ACROSS STATES)**





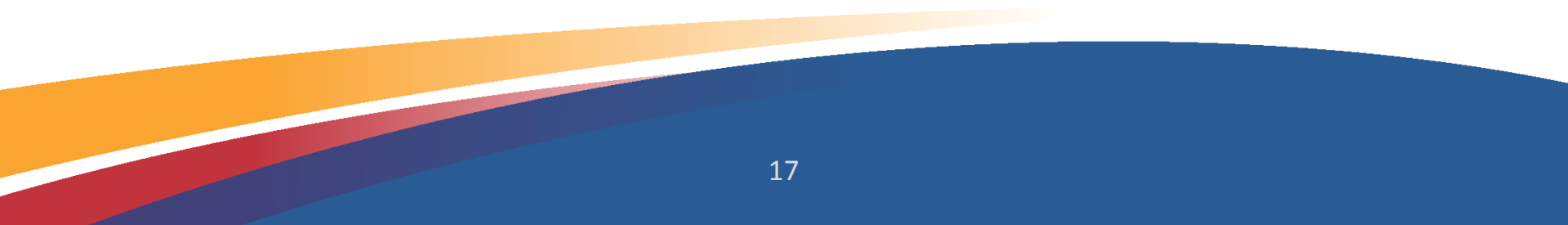
Menti Question

What best describes your state's ability to complete Care Recipient/Caregiver, Training/Workshop sections?



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Ease and Burden



Time spent gathering data

- Average is 14.5 hours
- Range is from 3 hours to 38 hours

Time spent entering data

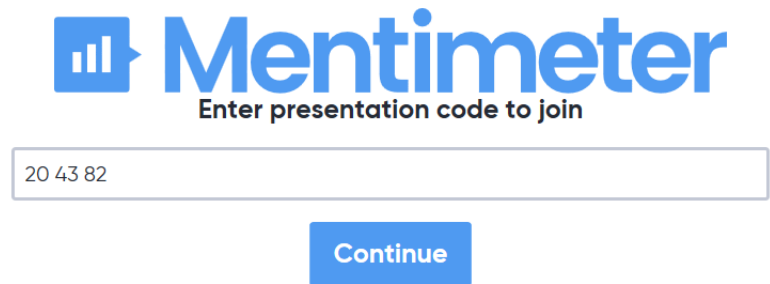
- Average is 2.5 hours
- Range is from 30 minutes to 4 hours





Menti Question

Does the average time spent collecting and entering data seem achievable for future submissions?



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Next Steps

Pilot states to:

- Continue to submit the data collection tool semi-annually
- Modify existing processes to support data collection and submission process
- Reach out for support from ACL, as needed

ACL and Lewin to:

- Begin process of obtaining approval for wider use of the data collection tool
- Identify data collection tool prototype development specifications



Menti Question

If you could change one thing about the data collection tool that would make it better, what would it be?



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