

# Lifespan Respite Mini-Grant Program: Results from Caregiver Survey (Attachment B)<sup>1</sup>

## Data Collection Method

Upon registration into the Lifespan Respite Mini-Grant Program, caregivers completed a “Pre-Respite Form”. The form consisted of a demographics questionnaire and a 16-item Caregiver Burden Assessment. Scores on the 16-item form can range from 0 (no burden) – 16 (high burden). After the respite funds were used, the same caregivers also completed a “Post-Respite Form”. The post form contained the Caregiver Burden Assessment along with a 4-item satisfaction questionnaire that asked the caregivers how satisfied they were with the respite received through the program.

## Demographics

A total of 235 caregivers were provided respite paid for by the Lifespan Respite Mini-Grant Program, of those, 88 caregivers completed at least the Lifespan Respite Mini-Grant Program pre-respite form. There was a high return rate of the post-respite form, where 90% (n = 79) of the caregivers that completed the pre-respite form also completed the post-respite form. The age range of caregivers was 32 – 87 years old, with the average caregiver age of 56.61 years. The majority of caregivers were female (79%), white (72%), and married (65%). Furthermore, 63% had at least “some college” education and 53% had an annual household income greater than or equal to \$30,000. The relationship of the caregiver to the care recipient was primarily made up of a parent-child dyad, where 44% of the respondents were children caring for their parent and 22% were parents caring for their children. The care recipient age range was 4 – 103 years old, where the average age was 65.68 years.

## Outcomes

### *Program Satisfaction*

First we examined Program Satisfaction. All 100% of the caregivers who completed the post-respite survey indicated that they were at least “somewhat” satisfied with the respite services they received from the mini-grant program. Ninety-six percent of the caregivers said they were either “Very Satisfied” or “Extremely Satisfied” with the respite services. When asked if they would apply for the respite services again, all of the caregivers, except one, stated that, “Yes, they would apply again.”

For the following statement, “I used my respite to do something I enjoyed and it was time well spent”, 86% of the caregivers either “Agreed a little” or “Completely Agreed” with that statement. Finally, when asked the following question, “Did your respite provider talk with you about what you wanted to do with the respite and help with a plan?” 87% of the caregivers

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said “Yes”. Overall, the caregivers stated that were satisfied with the respite services and they would apply for them again if available.

When examining the data, we noticed one particular “outlier”. Specifically, the one caregiver that said they would not apply for respite again also stated that they used the respite services so they could “Go to work”, rather than using the services to do something enjoyable. This same individual also stated that their provider who offered the respite did not talk with them and help them develop a plan of how to use their respite services effectively. They also were the only caregiver to “Completely Disagree” with the following statement, “I used my respite to do something I enjoyed and it was time well spent.” This begs the question that if the Service Provider spoke with this caregiver and instructed him/her on how to maximize your respite time towards something more enjoyable, rather than work, would their response have been different and more positive?

### *Caregiver Burden*

A Repeated Measures ANOVA was conducted to determine whether the changes in caregiver burden from pre- to post-respite was significant. A significant change was found where there was a 35% decrease in caregiver burden. Specifically, average burden at the pre-respite assessment was 7.02 and at the post-respite assessment it dropped to an average score of 4.53. Next we examined changes in scores from pre- to post-respite for each different type of caregiving dyad (e.g. spouse-spouse, parent-child, etc.). As can be seen in table 1, average scores for caregiver burden declined from pre- to post-respite across all caregiving types. A Repeated Measures ANOVA was run to examine whether there were significant differences in pre-post respite scores as a function of caregiving dyad. One of the caregiving types, Grandparent (CG) – Grandchild (CR), was excluded from the analysis because there was only one participant in this dyad and that participant did not complete the post-respite form, consequently there was no pre-post respite data. A second caregiver type, Friend (CG) – Friend (CR), was excluded from the analysis because only one of the caregivers completed the post-respite assessment.

Table 1  
Average Changes in Caregiver Burden by Caregiver-Care Recipient Relationship

Caregiver (CG) – Care Recipient (CR)	N	Pre-Respite Mean	Post-Respite Mean
Child (CG) – Parent (CR)	39	7.64	4.76
Parent (CG) – Child (CR)	19	4.47	2.77
Spouse (CG) – Spouse (CR)	15	8.67	5.20
Grandchild (CG) – Grandparent (CR)	5	9.00	7.00
Niece/Nephew (CG) – Aunt/Uncle (CR)	4	8.00	5.50
Sibling (CG) – Sibling (CR)	3	4.67	2.33
Friend (CG) – Friend (CR)	2	7.00	1.00*
Grandparent (CG) – Grandchild (CR)	1	0.00	-

**Note:** Scores on the 16-item form can range from 0 (no burden) – 16 (high

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burden), where a decrease in score equates to a decrease in caregiver burden

\*Only one caregiver in this dyad completed the post-respite form therefore it could not be included in the Repeated Measures ANOVA analysis

The next set of analyses examined changes in caregiver burden as a function of the caregiver-care recipient dyad. Demonstrated in Table 1, the sample size for the dyads Niece/Nephew-Aunt/Uncle, Grandchild-Grandparent, Sibling-Sibling, and Friend-Friend were relatively small compared to the other three dyad groups, consequently we collapsed these dyads into one group labeled "Other". The "Other" group (n = 13) had an average caregiver burden score of 7.00 at pre-respite and average score of 4.83 at post-respite. The subsequent analyses compared pre-post respite scores for the following four groups: Child-Parent, Parent-Child, Spouse-Spouse, and Other. The only significant difference between the four dyad groups was that the Parent (CG) – Child (CR) dyad has significantly lower pre- and post-respite burden scores.

The final set of analyses examined whether changes in scores on the Caregiver Burden Assessment were significantly different as a function of the self-report data on satisfaction of the respite service. A Repeated Measures ANOVA was conducted to examine whether or not the provider discussing respite planning with the caregiver had an effect on the caregiver burden scores. An effect was found such that average caregiver burden scores significantly declined from pre- to post-respite only for those caregivers that talked to their provider about respite planning. Burden scores did decline for those caregivers that did not receive consultation from their provider on respite planning, but the decline was not significant. Specifically, on average, those that received counseling had an average decline in burden of 3.10, while those that did not receive counseling had an average decline of only 0.60 on the Caregiver Burden Scale.

Given that there was not a comparison group in the study, we cannot say that the significant decrease in caregiver burden was a direct result of the respite program, but we can hypothesize that the respite service provided with these Lifespan Respite funds along with the "Consultation" has a positive effect on the caregiver.