

## National Family Caregiver Support Program (NFCSP) Outcome Evaluation

November 28, 2018

### Responses to attendee questions posed during the webinar

Question	Response
<p>Did you keep any data on those who identified at the second point as no longer being caregivers whether it was because the care recipient had transitioned into a facility or if there was another reason? Such as caregiver burden? Impact on caregiver employment?</p>	<p>Yes, at follow-up interviews, caregivers were asked if they were still the Care Recipient's (CR) caregiver. One-third of all caregivers reported that they were no longer CR's caregiver (N=379). We offered them reason categories. Of those who stopped, 39% stopped because of CR's death, 24% because of CR's institutionalization, 2% because the CR does not need care anymore, 6% because someone else became the CR's caregiver, and the remaining 28% either responded said "for another reason" or did not provide a reason. We did not ask if they stopped due to the impact of caregiving..</p> <p>Report section 5.1.7.</p>
<p>When was the Zarit burden measurement done? At the first point or second?</p>	<p>The four Zarit Burden items were collected at baseline, 6-month follow-up, and 12-month follow-up.</p>
<p>We hope to learn what percentage of the caregivers evaluated were caring for a person living with ADRD.</p>	<p>Among all caregivers at baseline, 52.2% responded "Yes" to "<i>Has a doctor ever told you or CR that he (or she) had Alzheimer's disease, dementia, or other type of memory problem?</i>"</p> <p>Report section 5.2.2</p>
<p>Would the appropriateness of HME be a factor in caregiver burden? For example, use of a floor bed vs standard bed. Policies/practices concerning accessibility of "right" equipment are underappreciated in SO many caregiver studies.</p>	<p>Assistive devices and technologies can be an important component of providing care to individuals with physical limitations. Having the correct equipment in place is critical. Under the NFCSP, states and AAAs are able to develop their own policies and procedures for determining which types of equipment will be provided and under what circumstances.</p>
<p>Did I understand that individuals receiving HCBS were referred to NFCSP but the reverse was not occurring? Do other states allow individuals on HCBS receive NFSCP at the same time?</p>	<p>Yes, caregivers receiving HCBS at baseline were more likely to start NFCSP services, but caregivers using NFCSP at baseline only had a slight (not significant) increased likelihood of using HCBS in the future.</p> <p>Each state/AAA is responsible for developing policies and procedures for implementing and administering all programs funded by the Older Americans Act, including the NFCSP. In this regard, states may permit a family caregiver to receive services under the NFCSP as well as other HCBS if they meet the eligibility criteria for the program and there is a demonstrated need.</p>

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For all of the results that were statistically significant (e.g., $p < .05$ ) will effect sizes be included in the final report? Effect size information will help to quantify the degree of difference that is "real"	Where appropriate, the report does provide various effect size indices such as odds ratios, correlation coefficients, and beta weights for both statically significant and non-significant results. This will enable readers to evaluate the magnitude of effects and relative contribution of factors of interests in a model, regardless of p-values and sample sizes used in various analyses. Further, the report provides standard deviations, standard errors, and confidence intervals, as needed, so that readers can gauge the amount variation for statistics and parameter estimates.
Will the assessment tools be shared?	Yes, assessment tools were collected during the Process Evaluation. These are available <a href="#">here</a> and <a href="#">here</a> .
Could you please share the specific education & training programs that Title 3 is funding that address specific care needs or legal/financial matters?	At the present time, we are not aware of specific programs funded under Title III that address legal and/or financial matters. ACL currently funds the Women’s Institute for a Secure Retirement (WISER) to conduct financial literacy training targeted primarily to women and we recently awarded a grant to the Alzheimer’s Association to begin developing tools and training on financial literacy and preparedness for family caregivers, however that project is brand new and just getting started.
Did the evaluation only look at caregivers caring for older adults or did the evaluation also look at the other populations covered under NFCSP (grandparents caring for children and caregivers of adults with disabilities)?	<p>The NFCSP outcome evaluation described in this report focused on these two groups of caregivers:</p> <ol style="list-style-type: none"> <li>1. Adult family members or other informal caregivers age 18 and older providing care to individuals age 60 and older, and</li> <li>2. Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer’s disease and related disorders.</li> </ol> <p>The evaluation did not include:</p> <ul style="list-style-type: none"> <li>• Older relative caregivers (excluding parents) age 55 and older providing care to children under age 18, and</li> <li>• Older relative caregivers (including parents) age 55 and older providing care to adults ages 18 to 59 with disabilities.</li> </ul>
Do you have a sense of what caregiver assessment tools were being used. For example, T-Care or something developed in house by the AAA's?	T-Care is being used extensively in several states, including Washington State, Michigan and Georgia. However most states and AAAs seem to be using assessment instruments of their own design, often incorporating scales and measures that have been tested and determined reliable. As part of the Process Evaluation completed in 2016, ACL collected examples of assessment instruments in use by states and AAAs. Those examples are posted on ACL’s web site, <a href="#">here</a> and <a href="#">here</a> .
Kate said that results did not show a significant effect of NFCSP on the five outcomes. What were the 5 outcomes being referred to?	The five caregiver outcome measures that were focused on in this evaluation were: mental health, physical health, caregiver burden, caregiver satisfaction, and caregiver confidence. Among the full sample (not restricted to 4+ hours of weekly respite or at least one reported use of an educational service) program impacts were not found. Although still not statistically significant, a minimum amount of NFCSP respite care had a positive impact on caregiver burden trends and educational services had a positive impact on caregiver confidence trends.

Question	Response
<p>How do define HCBS as used in this presentation? And isn't it possible that by virtue of asking a caregiver to identify their mental/physical/ burden status allows them to come to terms with the burden--permission to express burden. And then perhaps the burden remains there but doesn't worsen with services?</p>	<ol style="list-style-type: none"> <li>1. Caregivers were asked if they received these 14 categories of services that were considered HCBS: Help with applying for services; Case management; Training on attending to recipient's medical needs; Legal assistance; Incontinence supplies, home modification such as grab bars, ramps; Nutritional supplements such as Ensure or Boost; Transportation; Home delivery meals; Congregate meals; Mental health services; Homemaker services; Home health aide that was not respite care; Any other services.</li> <li>2. Yes, there could be "survey bias" that may enhance or diminish an individual's perception of burden or well-being. However, there should not be any systematic bias that differs between the Program and Comparison caregivers.</li> </ol> <p><i>Report Section 7.4</i></p>
<p>In the report did you distinguish the results of the Zarit burden measurement at each measurement point as opposed to blending those results as one?</p>	<p>The Burden scores were not blended or averaged across the timeframes. For the DiD analysis, we measured the change in burden from Time 1 (baseline) to Time 2. For each caregiver, Time 2 indicated either 6-month or 12-month measurement, specific to each caregiver's latest completed survey.</p>