

Memo

To: Elyse Greenwald, OMB  
 From: Heather Menne and Susan Jenkins, ACL  
 Re: Non-Substantive Modifications to the Information Collection Tools for the *National Family Caregiver Support Program (NFCSP) Outcome Evaluation*  
 Date: April 14, 2017; revised May 18, 2017

**BACKGROUND:**

In March 2016, OMB Control Number 0985-0052 was given for the information collected titled: *National Family Caregiver Support Program (NFCSP) Outcome Evaluation*. As noted in Table 1, the baseline information collection with National Family Caregiver Support Program Clients (a), Care Recipients of NFCSP Clients (d), Comparison group non-NFCSP family caregivers (f), and Comparison group or care recipients (i) is complete, and the 6-month and 12-month information collections are still upcoming (Table 1).

<b>Table 1. Information Collection Status for the <i>National Family Caregiver Support Program (NFCSP) Outcome Evaluation (OMB 0985-0052)</i></b>	
<b>Respondents/Timeframe</b>	<b>Status</b>
<b>a) National Family Caregiver Support Program Clients - Baseline</b>	Complete
<b>b) National Family Caregiver Support Program Clients - 6 month follow-up</b>	Non-substantive Modification
<b>c) National Family Caregiver Support Program Clients - 12 month follow-up</b>	Non-substantive Modification
<b>d) Care Recipients of NFCSP Clients - Baseline</b>	Complete
<b>e) Care Recipients of NFCSP Clients - 12 month follow-up</b>	No modifications
<b>f) Comparison group non-NFCSP family caregivers - Baseline</b>	Complete
<b>g) Comparison group non-NFCSP family caregivers- 6 month follow-up</b>	Non-substantive Modification
<b>h) Comparison group non-NFCSP family caregivers- 12 month follow-up</b>	Non-substantive Modification
<b>i) Comparison group of care recipients - Baseline</b>	Complete
<b>j) Comparison group of care recipients - 12 month follow-up</b>	No modifications

Although the tools were all tested prior to initial administration, during the base line data collection with both program clients and comparison group members, it became clear that there were some questions that could be clarified. Specifically, questions about the extent to which respondents might be receiving services needed to be revised to ensure that respondents to the 6 month and 12 month follow up surveys are properly categorized as service recipients or comparison group members. These modifications are all “conditional” items, meaning they may or may not be asked of respondents based on their prior responses. More specifically, they are conditional items for caregivers that respond “no” to receiving services.

## DESCRIPTION OF THE PROPOSED NON-SUBSTANTIVE CHANGES

The changes apply to two of the 13 sections of the approved survey. Below is a brief description of the proposed changes and Table 2 includes two sections of the caregiver information collection tools where modifications would occur as well as notes about the changes.

In brief, the non-substantive modifications requested are:

### Section on Caregiver Services

- New conditional item #8b: this item is only asked if the respondent responds “no” to the prior item. Due to some confusion among respondents about who provides them a program service, this new conditional item #8b will clarify the source of a program service.
- New conditional item #9: this item is only asked if the respondent responds “no” to the 2 prior items. Responses to this question (which are only asked of those who indicate no to 2 prior questions) will provide clarifying information to their response.
- New conditional item #16b: this item is only asked if the respondent responds “no” to the prior item. Due to some confusion among respondents about who provides them a program service, this new conditional item #16b will clarify the source of a program service.
- New conditional item #17: this item is only asked if the respondent responds “no” to the 2 prior items. Responses to this question (which are only asked of those who indicate no to 2 prior questions) will provide clarifying information to their response.

### Section on Knowledge and Use of Formal Services

- New conditional item #6a: this item is only asked if the response to the preceding item is “c: individual counseling, support groups, and caregiver education and training” or “d: respite care.” The focal services of the evaluation are “individual counseling, support groups, and caregiver education and training” and “respite care;” therefore, this new conditional item will clarify and confirm whether the respondent gave a consistent response to earlier items asking about their receipt of these specific program services.

<b>Table 2. Modifications for 6- and 12-Month Follow-up Information Collection</b>	
<b>Section Items (wording changes and new items are in blue)</b>	<b>Changes for follow-up tools</b>
<p><b>Section on Caregiver Services (CSV)</b></p> <ol style="list-style-type: none"> <li>1. 1410_ListedCG. You are listed as someone who currently provides care. Are you still a caregiver for an adult? (if response is NO – ask the “why not caregiver” questions and end survey)</li> <li>2. What is the name of the person you care for?</li> <li>3. What is your relationship to [CARE RECIPIENT]?</li> <li>4. What is [CARE RECIPIENT]’s gender</li> <li>5. What is [CARE RECIPIENT]’s age?</li> <li>6. How long have you been the caregiver for [CARE RECIPIENT]? <i>Years? Months?</i></li> </ol> <p><i>Intro to all Caregivers:</i> I'd like to ask you some questions about the Family Caregiver services that you may have received from {ADM.DispProviderAgency}. These are services that help you provide care at home for {ADM.TPIdentifier}. For example, caregiver services can be: - Information about available services;</p>	

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<p>- Assistance in accessing supportive services;</p> <p>- Individual counseling, support groups, and education/training to assist you in making decisions and solving problems relating to your caregiving role,</p> <p>- Respite care to temporarily relieve you from your caregiving responsibilities; and</p> <p>- supplemental services such as home modifications; nutritional supplements; assistive devices such as walkers, canes or crutches; Emergency response systems; Specialized equipment, such as CPAP, apnea machines, hospital bed, WanderGuard or receiving a voucher, Money or a stipend.</p> <p>7. <b>1720_ReceiveSupServiceNum</b>. For how long have you been receiving caregiver support services from {ADM.DispProviderAgency}?</p> <p><i>"We would like to ask you questions about any respite care that you may have received from {ADM.DispProviderAgency}. Respite care allows you a brief period of rest or relief while temporary care is provided to [CARE RECIPIENT] either in your house or someplace else."</i></p> <p><b>8a. (a) 1740_AgencyRespite</b>. In the past 6 months, that is since {Holds the display of the month, in words, that is 6 months before the month the interview is taking place. For example, if interview is taking place in July, display "February"} have you received respite care from {ADM.DispProviderAgency}?</p> <p><b>8b.</b> (If NO to 8a above). In the past 6 months, did you use a voucher, allowance or budget from ADM.DispProviderAgency to purchase respite care from an organization or provider of your choice?</p> <p>(If no to both 8a and 8b)</p> <p>9. Why did you not receive respite care through ADM.DispProviderAgency during the past 6 months?</p> <p>a. You didn't know about this service from this agency (if Yes then skip to item 12, NO then 9b)</p> <p>b. You didn't need the service from this agency (If YES then skip to item 12, NO then 9c)</p> <p>c. You were previously not satisfied with the service and did not request again from this agency (if YES then skip to item 12, NO then 9d)</p> <p>d. Prior to 6 months ago, you used all your allotted respite hours for the year from this agency. (If YES, then skip to item 12, NO then 9e)</p> <p>e. You wanted to receive respite care from this agency, but they didn't have the staff or resources to provide during the past 6 months. (For example, you are on a waiting list or you were told that they couldn't provide any type of respite care until a future date. (yes then item 12, NO then 9f)</p> <p>f. Specify Other _____</p> <p>10. (if yes to #8a or 8b) Which type of respite care did you receive from Provider X? Did you receive ....</p> <p>a. In-home</p> <p>b. Adult daycare</p>	<p>This item (#7) is for Program caregivers only.</p> <p>New: ask items 8a and 8b, 9 or 10-11 of both Program and Comparison caregivers. For comparison caregivers, use the AAA/ Provider associated with care recipient.</p> <p><b>Add new conditional item #8b.</b></p> <p><b>Add new conditional item #9.</b></p>

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<p>c. Overnight respite care in a facility  d. Overnight respite in the home  e. Some other kind of respite care</p> <p>10a. How many hours per week of respite care do you usually receive from ADM.DispProviderAgency?</p> <p>11. How helpful are these services to you as a caregiver? Would you say ....  a) Very helpful  b) Somewhat helpful  c) Unsure  d) Somewhat unhelpful  e) Not at all helpful  f) Refused or DK</p> <p>12. <b>FamilyRespite</b>. In the past 6 months, that is since &lt;February&gt;, have you received respite care from a family member, friend, neighbor, or other volunteers? (26)  12a. (If yes). <b>1920_FamilyInHome</b>. Which type of respite care did you receive?  12b. In home where you could take a break  12c. Overnight respite  12d. Some other kind of respite</p> <p>13. How many hours per week of respite care do you usually receive in total from a family member, friend or neighbor? (0 – 72 hours)</p> <p>14. Overall, how helpful are these services to you as a caregiver?</p> <p>15. <b>SCV2000. RespiteOtherSource</b>. In the past 6 months, have you received respite care from a source other than from {ADM.DispProviderAgency}, family, friends, neighbors or other volunteers?</p> <p><i>“NEXT I AM GOING TO ASK YOU QUESTIONS ABOUT SERVICES RELATED TO CAREGIVER EDUCATION, TRAINING, INDIVIDUAL COUNSELING, AND SUPPORT GROUPS. THESE SERVICES ARE INTENDED TO STRENGTHEN YOUR ABILITY AND SKILL AT MAKING DECISIONS AND SOLVING PROBLEMS IN YOUR ROLE AS A CAREGIVER.”</i></p> <p><b>16a AgencyEducation</b>. In the past 6 months, have you received caregiver education, training, counseling, or support group services from ADM.DispProviderAgency?</p> <p><b>16b</b>. (If NO to above). In the past 6 months, did you use a voucher, allowance or budget from ADM.DispProviderAgency to purchase caregiver education, training, counseling or support group services by from an organization or provider of your choice?</p> <p>(If no to both 16a and 16b)</p> <p><b>17</b>. Why did you not receive caregiver education, training, counseling or support group services through ADM.DispProviderAgency during the past 6 months?</p>	<p>Add new conditional item #16b</p>

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<p>a. Didn't know about this service from this agency (if Yes then skip to item 21, NO then 17b)</p> <p>b. Didn't need the service from this agency during the past 6 months (If YES then skip to item 21, NO then 17c)</p> <p>c. I have not been satisfied with the service and did not request again from this agency (if YES then skip to item 21, NO then 17d)</p> <p>d. I wanted these services, but there were no classes, courses, or sessions offered from this agency. (if YES or NO, then 17e.)</p> <p>e. I wanted individual counseling, but was unable to get an appointment through this agency.</p> <p>f. Other specify _____</p> <p>If yes to #16a or 16b, Which type:</p> <p>18. Did you receive caregiver education or training, such as classroom or on-line courses?</p> <ul style="list-style-type: none"> <li>How many times did you attend an individual caregiver education or training sessions?</li> </ul> <p>19. Did you attend individual counseling sessions [provided by {ADM.DispProviderAgency}] to assist with your specific caregiving situation?</p> <ul style="list-style-type: none"> <li>How many sessions?</li> </ul> <p>20. Did you attend any caregiver support groups?</p> <ul style="list-style-type: none"> <li>How many sessions?</li> </ul> <p>20. <b>AgencyHelpful</b> How helpful are these services to you as a caregiver? Would you say . . .</p> <p>21. <b>2340_FamilyEducation</b>. In the last 6 months, have you received caregiver education, support, or training informally from a family member, friend, neighbor, or volunteer from a place of worship?</p> <p>22. <b>2380_FamilySupport</b>. In the past 6 months that is &lt;since February&gt;, how many times have you received this education, training or support? (40) Would you say ....</p> <ul style="list-style-type: none"> <li>a) 1-3</li> <li>b) 4-6</li> <li>c) 7-9</li> <li>d) 10 or more</li> </ul> <p>23 <b>2400_OtherEducation</b>. In the last 6 months, that is &lt;since February&gt;, have you received caregiver education, training, counseling or support group services from a source <u>other than</u> from (ADM.DispProviderAgency), family, friends, neighbors, or other volunteers?</p> <p>24. Which of the following types of education, training, counseling or support group services did you receive from <b>any other source</b> in the past 6 months?</p> <ul style="list-style-type: none"> <li>a) <b>2420_OtherEducationType</b>. Caregiver education or training such as classroom or online courses? (if yes, how many times)</li> </ul>	<p>Add new conditional item #17</p>

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<p>b) 2460_OtherCounseling. Individual counseling? (if yes, how many sessions)</p> <p>c) 2500_OtherSupportGroup. In the past 6 months, have you attended caregiver support group sessions provided by any other source?</p> <p>25. (If yes to 2500). In the past 6 months, How many caregiver support group sessions have you attended provided by another source? Would you say .....</p> <p>a) 1-3</p> <p>b) 4 to 6</p> <p>c) 7-9</p> <p>d) 10 or more?</p> <p>e) Don't know or Refused</p> <p>26. 2540_OtherHelp. How helpful are these services to you as a caregiver? Would you say ....</p> <p>a) Very helpful</p> <p>b) Somewhat helpful</p> <p>c) Unsure</p> <p>d) Somewhat unhelpful</p> <p>e) Not at all helpful</p> <p>f) Refused or DK</p>	
<p><b>Section on Knowledge and Use of Formal Services Available (KNS)</b></p> <p>Read "The next set of questions is about other services, not respite care and not education, training or support groups, that you, the caregiver, or [CARE RECIPIENT] is receiving."</p> <p>1. In the last 6 months, have you as the <b>caregiver or [CARE RECIPIENT]</b> received any of the following services offered by <b>any organization</b> with paid staff? This includes services paid for by Medicaid or Medicare, but not services provided by volunteers.</p> <ul style="list-style-type: none"> <li>• 1520_HelpApplying. Assistance that connects you to resources for caregivers such as applying for and receiving caregiver services?</li> <li>• Case management, such as coordination and care management?</li> <li>• Training on attending to recipient's medical needs such as wound care, injections, and medications</li> <li>• Legal assistance</li> <li>• Incontinence supplies</li> <li>• Home modification such as grab bars or ramps?</li> <li>• Nutritional supplements such as Ensure or Boost</li> <li>• Transportation</li> <li>• Home-delivered meals</li> <li>• Congregate meals, meals at a center for example</li> <li>• mental and behavioral health services for [CARE RECIPIENT]</li> <li>• 1740_HomemakerServ. Homemaker services</li> <li>• Home health aide that was not respite care</li> <li>• KNS1780_OtherServ. In the last 6 months, what other services have you as a caregiver or [CARE RECIPIENT] received from any paid agency or organization? <ul style="list-style-type: none"> <li>• Specify Otherservicesos _____</li> </ul> </li> </ul> <p>2. 1804_HelpNotReceive. In the last 6 months, was there a time when you needed</p>	

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<p>assistance from PROVIDER X or an organization to understand resources available or to apply for services, but you didn't get the help you need with this? (74) YES or NO</p> <p>1805_HelpNotReceivedOS. If yes, specify _____</p> <p>3. 1820_Voucher. In the last 6 months, have you received a voucher, cash, or individual budget from your local AAA or community service organization that allows you to purchase goods or services for [CARE RECIPIENT]? When we say voucher or budget payment, we mean that you were given an allowance where you can decide by yourself what to buy or whom to hire. (75) (Y/N)</p> <p>4. 1804_HelpNotReceive. Have you tried to obtain any caregiving support services from a community organization such as a business or agency but were not able to receive them? (Y/N)</p> <p>(4a) If NO, what were the reasons? (76)</p> <ol style="list-style-type: none"> <li>Were you are on a waiting list?</li> <li>Did the services cost too much?</li> <li>1900_NotHaveSrv. Your local agency doesn't have the services you need?</li> <li>Was there some Other reason? (ObtainOtherOS. SPECIFY) _____</li> </ol> <p>5. 1960_ReceiveAllHelp. As [CARE RECIPIENT]'s Caregiver, are you receiving all the help that you need?</p> <ul style="list-style-type: none"> <li>Yes, definitely; Yes, probably; Not sure; No, probably not; No, definitely not</li> </ul> <p>6. 1980_AgencyMostHelpful. Now, thinking back to all the services that you received only from AGENCYPROVIDER, which service is most helpful for you? _____ (only if necessary, read list)</p> <ol style="list-style-type: none"> <li>INFORMATION ABOUT AVAILABLE SERVICES</li> <li>ASSISTANCE ACCESSING SUPPORTIVE SERVICES</li> <li>INDIVIDUAL COUNSELING, SUPPORT GROUPS, AND CAREGIVER EDUCATION AND TRAINING</li> <li>RESPIRE CARE</li> <li>SUPPLEMENTAL SERVICES, ON A LIMITED BASIS</li> </ol> <p><i>There is help text available on the screen so data collectors know what is included under each of these responses.</i></p> <p><b>6a) If YES to c or d to 6 above AND caregiver responded NO to receiving NFCSP respite (#8 on page 1) and Educ/counseling (#16 on page 3) then ask:</b>  <b>"When was the last time that you received this service or a voucher for this service from AgencyProvider?"</b></p> <p><b>Responses options for July interview:</b></p> <ol style="list-style-type: none"> <li>Since April of this year? Y/N If No,</li> <li>Since the new year, in 2017, but before April? Y/N If No,</li> </ol>	<p>Add new conditional item #6a</p>

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c. During the last half of 2016, last July - December? Y/N If No, d. Earlier than July 2016? Y/C	

**DESCRIPTION OF HOW THE REVISED SURVEY ITEMS WERE TESTED BEFORE BEING PROPOSED AS NONSUBTANTIVE CHANGES**

Between baseline and 6-month interviewing, the contractor (Westat) has programmed and tested 5 new questions that are being added to the instrument to improve and clarify necessary information about the participants' use of NFCSP caregiver services.

This process included:

- Preparing the specifications for the programmer
- Translating the new items from the specifications into Spanish
- Programming the new items of the questionnaire into Computer-assisted Telephone Interviewing (CATI)
- Testing the new items and the entire questionnaire.

During programming, the Telephone Research Center staff performs "specification verification" by re-checking the wording of the questions for grammatical errors and syntax errors. If errors are found, they contact project staff to update the questionnaire and the specifications.

Most recently, the five new items were tested by Westat TRC and Project team members. During testing, the TRC provides on-line access of the CATI instrument to a handful of testers. In that way, staff can review not only the content of the questionnaires but also the actual mode of administration. Testers have access to a full load of cases that we use to enter 'mock' interviews. For these interviews, we follow a variety of scenarios that cover all likely paths through the questionnaire. Based on feedback, we revise and finalize the CATI versions of the surveys instruments. Our primary tester for the six-month changes was Norma Neuberg, a Westat manager with 30 years of experience as tester for TRC studies. She is bilingual in English and Spanish. She is very experienced in following questionnaire specifications, using the knowledge acquired over the years as translator, tester, and data manager for the AOA study.

There were 3 testing release phases. After each phase, minor wording changes are performed to improve flow and clarity of the questions. Sixty-four (64) cases were worked in testing, and multiple paths were tested within each case. Westat has completed final testing of the caregiver survey. Interviewers are fully trained in procedures to administer the informed consent, contact caregivers, gain participation in the survey, and administer the survey instrument. These are the same interviewers that did the baseline collection; they are familiar with the survey.