

**DESIGNING AND VALIDATING A STRESS QUESTIONNAIRE ON INFORMAL  
CAREGIVERS: BASELINE DATA FROM TELEPHONE INTERVIEWS WITH  
CAREGIVERS FROM THE FAMILY CAREGIVER SUPPORT PROGRAM AT THE  
DURHAM COUNCIL FOR SENIOR CITIZENS**

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### **Abstract**

Daily caregiving can impact a caregiver's emotional and physical health. Some caregivers receive a break in providing care through respite care programs. The Durham Council of Senior Citizens provides respite care to participants in their Family Caregiver Support Program. The Council of Senior Citizens lacks a method to evaluate stress in their caregivers. Validated instruments that measure stress in the caregiver population include the Zarit Burden Interview (Zarit, Reever, Bach-Peterson, 1980) and the Caregiver Burden Scale (Montgomery, Borgatta, and Borgatta, 2000). The purpose of this study is to design and validate a questionnaire for informal caregivers at the Council for Senior Citizens. The results indicate the Zarit Burden Interview is a valid instrument in measuring stress in this population. No statistically significant relationships concerning participant stress were detected through the administration of the Caregiver Burden Scale. Due to the small population examined, further research is recommended to determine if the Caregiver Burden Scale should be continued as an element of the Family Caregiver Support Program Questionnaire.

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## Table of Contents

|   | Page |
|---|------|
| List of Tables.....   | 5    |
| List of Figures.....  | 6    |
| List of Abbreviations.....  | 7    |
| Introduction.....   | 8    |
| Methods.....  | 13   |
| Hypothesis.....   | 15   |
| Results.....  | 16   |
| Discussion.....   | 23   |
| Recommendations.....  | 26   |
| Appendix 1: Family Caregiver Support Program Questionnaire.....                 | 28   |
| Appendix 2: Department of Aging and Adult Services Form 101.....                | 35   |
| Appendix 3: Information to be abstracted from Client Registration Form DAAS 101 | 39   |
| Works Cited.....  | 42   |

## List of Tables

|  | Page |
|--|------|
| Table 1: Family Caregiver Support Program Questionnaire: Baseline Interview Metrics.....   | 15   |
| Table 2: Descriptive Statistics of the Zarit Burden Interview, Caregiver Burden Scale, and Question 38.....  | 17   |
| Table 3: Correlation Coefficients of the Zarit Burden Interview, and the Caregiver Burden Scale to Question 38.....  | 18   |
| Table 4: Descriptive Statistics of the Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL) Index Scores.....                                   | 21   |
| Table 5: Total Length of Caregiving.....   | 21   |
| Table 6: Correlation Coefficients of the Zarit Burden Interview and Question 38 to Instrumental Activities of Daily Living (IADL) –Activities of Daily Living (ADL) Index..... | 21   |
| Table 7: Examination of Relationship between Zarit Burden Interview, Question 38 and Caregiver Burden Scale to Length of Caregiving.....                                       | 21   |
| Table 8: Department of Aging and Adult Services From 101 Summary.....  | 23   |
| Table 9: Satisfaction with Caregiver Program.....  | 25   |

## List of Figures

|  | Page |
|--|------|
| Graph 1: Stress Rating on Date DAAS Form Initially Completed and on Date of Baseline Interview .....                 | 19   |
| Graph 2: Family Caregiver Support Program Questionnaire Completers: Relationship of Care Recipient to Caregiver..... | 22   |

## List of Abbreviations

|   | Abbreviation |
|---|--------------|
| Activities of Daily Living.....                     | ADL          |
| Caregiver Burden Scale.....                         | CBS          |
| Council for Senior Citizens.....                    | CSC          |
| Department of Aging and Adults .....                | DAAS         |
| Family Caregiver Support Program.....               | FCSP         |
| Family Caregiver Support Program Questionnaire..... | FCSPQ        |
| Instrumental Activities of Daily Living.....        | IADL         |
| Zarit Burden Interview.....                         | ZBI          |

## Introduction

Over 22 million Americans act as informal caregivers everyday to elderly or disabled people over 18 years old (Office of Women's Health, 2008). An informal caregiver is defined as someone who provides "extraordinary, uncompensated care, predominantly in the home setting, involving significant amounts of time and energy for months or years, requiring the performance of tasks that may be physically, emotionally, socially, or financially demanding" (Biegel, Sales, and Schultz, 1991). Formal caregivers are those who receive training and certification prior to providing care. Some characteristics of these informal caregivers are:

- Women (approximately 60% of caregivers are women)
- Middle-aged (40-64 years old)\* as defined by Collins Dictionary (1999)
- Aging (approximately 13% are over 65 years)
- Currently employed (almost 60% work).

*Office of Women's Health, 2008*

Daily caregiving impacts a person emotionally and physically due to the demands of caregiving. A recent study analyzed data from 23 studies on caregiver stress from the last 30 years and found that caregivers have 23% more stress hormones and a 15% lower level antibody response than non-caregiver controls (Vitaliano, Zhang, and Scanlan, 2003). Other studies indicate that caregivers are at a higher risk for mortality than non-caregiver controls (Schulz and Beach, 1999), and experience higher levels of depression and anxiety (Beeson, Horton-Deutsch, Farran, Neundorfer, 2000). As the American population ages, more and more people will serve as informal caregivers to grandparents, elderly parents, companions, and even their children. It is necessary to understand reasons why and how providing care to someone impacts the caregiver's



health, quality of life and well being. In addition, it is necessary to find ways that society can help people take care of their loved ones in their homes by helping them manage their stress.

One way to alleviate stress from constant caregiving is through respite care, where the primary caregiver takes a break for a period of time while someone else provides care for the loved one. There are many options of respite care in the United States such as: adult day care; in home respite care; short term nursing homes; and day hospitals (Office of Women's Health, 2008). The Family Caregiver Support Program (FCSP) at the Council for Senior Citizens (CSC) in Durham, North Carolina offers respite care and educational programs to individuals who are primary caregivers of adults who need constant caregiving. The goal of the respite care program within the FCSP is to reduce caregiver' stress and burden of care by providing respite care on a regular basis. As a participant in this program, each caregiver qualifies for six hours of respite care per month from an outside agency. This program, in its sixth year, presently lacks a method or tools to evaluate self-reported level of caregiver stress. The purpose of this study is to design and validate a questionnaire to measure stress over time in informal caregivers at the CSC. Benefits of creating a measurement tool include accountability for measuring the impact of the respite care program on caregiver stress, capability to generate a focused needs assessment for future CSC programs, and opportunities to improve the program.

### ***Designing the Questionnaire***

To evaluate the Family Caregiver Support Program, an extensive literature search was conducted to determine the availability of any instruments that measure stress over time in caregivers. Currently, there are no instruments that measure stress over time. The Family

Caregiver Support Program Questionnaire (Appendix 1) was developed using the following caregiver stress measurement instruments: Zarit Burden Interview (Zarit, Reever, Bach-Peterson, 1980) and the Caregiver Burden Scale (Montgomery, Borgatta, and Borgatta, 2000). The Family Caregiver Support Program Questionnaire also includes demographic elements and specific questions related to the CSC program (e.g., *Have you attended an educational program for caregivers at the Council for Senior Citizens?*). The question “*On a scale of 1 to 5, with 1, not at all, and 5, extremely, how would you rate how stressful caregiving is for you?*” was included to validate the ZBI and the CBS with this population of informal caregivers.

The Zarit Burden Interview is the most widely used scale in measuring the burden on caregivers and is available in 27 languages. The original ZBI was introduced in 1980 as a 29 – item Likert Scale instrument (Zarit, Reever, Bach-Peterson, 1980) that has been modified to a 22-item Likert Scale (Zarit, Orr, and Zarit, 1985) and now is also available as a 12-item Likert Scale (Bédard, et al, 2001). The shorter version of the scale (12-item) is more suited for diagnostic groups of cognitively impaired older adults, and can be used for cross-sectional, longitudinal, and intervention studies (Bédard, et al, 2001). The score for the ZBI ranges from 0-88 for the 22-item scale and 0-48 for the 12-item scale. In general, a higher score on the ZBI indicates a higher level of stress and burden. Specifically, a score of 17 or higher on the 12-item ZBI scale may indicate a higher burden (Bédard, et al, 2001). Examples of questions from the ZBI include “*DO YOU FEEL that because of the time you spend with your relative that you don't have enough time for yourself?*” and “*DO YOU FEEL stressed between caring for your relative and trying to meet other responsibilities (work/family)?*” While Zarit, Reever, and Bach-Peterson do not

explain why the words “DO YOU FEEL” are capitalized, it is theorized that these words are capitalized for emphasis so the caregiver can provide an honest opinion to rate their stress level.

The Caregiver Burden Scale is evaluated with three burden scores: Objective Burden, Subjective Demand Burden, and Subjective Stress Burden. This 14-item instrument is quick and easy to use. The Objective Demand score measures “perceived infringement or disruption of tangible aspects of a caregiver's life” (Montgomery, Borgatta, and Borgatta, 2000). Subjective Demand score is defined as the extent to which the caregiver perceives care responsibilities to be overly demanding (Montgomery, Borgatta, and Borgatta, 2000). And the Subjective Stress Burden score measures the emotional impact of caregiving responsibilities (Montgomery, Borgatta, and Borgatta, 2000). Objective Burden scores range from 6-30; Subjective Demand Burden scores range from 4-20; Subjective Stress Burden scores range from 4-20. Higher scores on these three burden scales indicate higher levels of stress. Questions include “*Do you have personal privacy? Do you have attempts by your relative to manipulate you? Do you have time to spend in recreational activities?*” The advantage of three different burden scores is the ability to distinguish the different types of burden to help design the most effective and appropriate types of intervention (Montgomery, Borgatta, and Borgatta, 2000). While some variables on the Zarit Burden Interview and CBS overlap, such as questions on privacy, stress, and social life, questions on the ZBI are more general than the CBS. For example, the ZBI asks “*DO YOU FEEL that your social life has suffered because you are caring for your relative?*”, while the CBS is more specific and asks questions such as “*Do you have vacation activities and trips?*”, “*Do you have time for recreational activities and trips?*” and also asks “*Do you have time for*

*friends and other relatives.”* Therefore, the questions on the ZBI are more broad and general, than the CBS.

The Family Caregiver Support Program Questionnaire is based on the 12-item Zarit Burden Interview for the ease of caregivers answering the questions in a telephone interview. In order to measure stress over a specific period of time, the question on the ZBI *“Circle the response that best describes how you feel”* was revised to *“Please answer the following questions about how you felt in the last two weeks.”* Additionally, for the Caregiver Burden Scale, the question, *“Since you began caregiving, how has assisting or having contact with the person for whom you care affected the following aspects of your life?”* on the FCSPQ was revised to *“In the last two weeks, how has assisting or having contact with the person for whom you care affected the following aspects of your life?”* The interval of 2-weeks was added to the ZBI and the CBS so that all caregivers could answer the question within a standard timeframe. The CBS was also selected for inclusion in the FCSPQ to help the Council for Senior Citizens determine the areas of burden for future programs.

Therefore, stress can be potentially measured by three different scores in the Family Caregiver Support Program Questionnaire:

1. Zarit Burden Interview Score: A score of 17 or higher on this scale suggests a high level of stress and burden (Scores can range from 0-48).
2. Caregiver Burden Scale (Scores in three areas: Objective Burden, Subjective Demand Burden, Subjective Stress Burden): High scores on each of these burden scales suggest a high level of stress and burden (Scores can range from 4-30).

3. Question 38: *On a scale of 1 to 5, with 1 not at all and 5, extremely, how would you rate how stressful caregiving is for you?* A score of 3 or higher on this scale suggests a high level of burden.

## Methods

IRB approval was obtained to contact caregivers who participate and receive respite services in the Family Caregiver Support Program at the Council of Senior Citizens in Durham North Carolina, using the Family Caregiver Support Program Questionnaire (University of North Carolina Institutional Review Board Approval #08-1349). The IRB approval was sought to contact these caregivers at a baseline interview and a 3-month interview. Results from the 3-month interviews are not presently available for summarization and analysis.

- *Inclusion criteria:* All caregivers in the FCSP at the CSC in Durham, North Carolina.
- *Exclusion criteria:* No exclusions

Caregivers were contacted for baseline interviews from October 2008 until January 2009. All caregivers were sent letters notifying them of an upcoming telephone survey of the Family Caregiver Support Program by postal mail from the Program Director. Each caregiver was consented prior to administering the telephone questionnaire. Consent was also obtained from the caregivers to abstract information from their respective Department of Aging and Adult Services (DAAS) 101 Form. This form documents the care recipient's Instrumental Activities of Daily Living and Activities of Daily Living. IADL are "home management and support tasks, such as bill paying" (North Carolina Department of Health and Human Services, 2009). ADL "refers to six activities - bathing, dressings grooming), mobility (ambulation/transfers), eating,

toileting and bowel/bladder incontinence that reflect a person's capacity for self-care" (North Carolina Department of Health and Human Services, 2009). According to the NC Division of Aging and Adult Services, caregivers would qualify for respite services if the care recipient has severe IADL impairment in four activities and has three deficits in ADLs (North Carolina Department of Health and Human Services, 2009). For this research project, the scores for IADL and ADL impairments were combined to create a composite IADL-ADL Index. Therefore, a composite score of 7 or higher would indicate a person qualifies for caregiver services. The purpose for abstracting data from the DAAS Form 101 is to determine if there are any notable differences in levels of the composite IADL-ADL Index or in the length of care compared to the caregiver reported level of stress. The DAAS Form 101 is provided in Appendix 2. In addition, other information about the caregiver was also abstracted from this form (e.g., *How many hours of care do you provide in a day? Are you a long distance caregiver?*).

Table 1 provides a summary of the baseline interview metrics. Thirty nine caregivers were contacted; 18 caregivers completed the Family Caregiver Support Program Questionnaire; a response rate of 46%. According to the Journal of Marketing Research, the response rate to this questionnaire is greater than that reported by a meta-analysis of 12 telephone questionnaire studies (1983). Of the non-completers only two caregivers refused to complete the questionnaire. The total of questionnaires not completed equaled 19. Reasons for not completed questionnaires include *Unable to Contact* and *Hospitalizations*.

| <b>Table 1</b>  |       |       |
|---|-------|-------|
| <i>Family Caregiver Support Program Questionnaire: Baseline Interview Metrics</i> |       |       |
| Interviews  | Total |       |
| Attempted   | 39    |       |
| Completed   | 18    | (46%) |
| Refused   | 2     | (5%)  |
| Not Done  | 19    | (49%) |

### Hypothesis

*Three primary hypotheses were examined:*

1. The Zarit Burden Interview should correlate with Question 38: *“On a scale of 1 to 5, with 1 not at all and 5, extremely, how would you rate how stressful caregiving is for you?”* In addition, Question 38 should also correlate with each burden score (Objective Burden, Subjective Demand Burden, Subjective Stress Burden) of the Caregiver Burden Scale.
2. Caregivers who provide care to people with high Instrumental Activities of Daily Living-Activities of Daily Living Index (IADL-ADL Index) or for a longer length of time will have more stress as measured by the Zarit Burden Interview, the three burden scores in the Caregiver Burden Scale, or by Question 38 than those caregivers of individuals with low IADL-ADL Index scores. Longer length of care, as measured by the Question 5 *“How long have you been providing care”* should be positively correlated with more stress as measured by the ZBI , CBS, and Question 38.
3. Caregivers who provide care to their parents will be more stressed than caregivers who are spouses as documented by the Zarit Burden Interview or the burden scores in the

Caregiver Burden Scale or Question 38, *How stressful is caregiving for you.*

## **Results**

### ***Caregiver Summary:***

The mean age of caregivers in the study group is 65.7 years old. Sixty three percent of caregivers were female, which is similar to the data from the Office of Women's Health (2008). Mean age of care recipients is 79.3 years old. Fifteen out of the 18 (85%) caregivers live with their care recipient. Two caregivers (11%) reported providing care to more than one person in the household. Fifty-six percent of caregivers are retired, which is higher than the data from the Office of Women's Health (2008). Of those who are currently retired, 20% retired early due to the need to provide care. Almost 45% of these caregivers reported their health as "fair" or "poor." Thirty-one percent reported their health as "Good" or "Very Good." Only 25% reported their health as "Excellent." Almost 40% of caregivers reported that they have a physical impairment and of these caregivers, 71% reported this impairment limits their activity in caregiving. According to Vitaliano, Zhang, and Scanlan, caregivers have a slightly higher risk of health problems than non-caregiver controls (2003). In addition, the authors found a 63% higher risk of death among caregivers than non-caregiver controls in an average of four years (Vitaliano, Zhang, and Scanlan, 2003). The authors controlled for various factors such as gender and disease.

### ***Evaluation of Hypothesis 1: Association of Stress Measures***

A score of 17 on the Zarit Burden Interview indicates a high burden of stress (Bédard, et al, 2001). Of the interviewed caregivers, the scores ranged from 11 to 40, with a mean ZBI score



of 25, well above the threshold of 17 for this scale (see Table 2). The results for Question 38: “On a scale of 1 to 5, with 1 not at all and 5, extremely, how would you rate how stressful caregiving is for you?” for those interviewed revealed that no caregivers reported less than a value of 2 (slightly stressful), 31% reported 3 (moderately stressful), 44% reported 4 (quite a bit stressful), and 25% reported 5 (extremely stressful) as their level of stress. The most frequently observed response was “quite a bit stressful” (median=4.0). Table 2 provides the mean and related descriptive statistics for the ZBI, the burden scores in the CBS, and the mean score for Question 38.

The Zarit Burden Interview had a highly statistically significant positive correlation with the Question 38 ( $R=.67$ ,  $p\text{-value}=0.045$ , Table 3). Table 3 provides the correlation coefficients among the ZBI to Question 38, and to the three burden scales from the Caregiver Burden Scale with Question 38. In addition, Question 38 was not significantly correlated with the Objective Burden, Subjective Demand Burden, or the Subjective Stress Burden scores of the CBS.

**Table 2**

***Descriptive Statistics of the Zarit Burden Interview, Caregiver Burden Scale, and Question 38***

| Scale   | N    | Mean  | Median | Std | Min  | Max  |
|---|------|-------|--------|-----|------|------|
| Zarit Burden Interview                                  | 18.0 | 25.0  | 26.5   | 7.5 | 14.0 | 40.0 |
| Caregiver Burden Scale: <i>Objective Burden</i>         | 15.0 | 21.2  | 20.0   | 2.5 | 18.0 | 25.0 |
| Caregiver Burden Scale: <i>Subjective Demand Burden</i> | 14.0 | 12.5  | 12.5   | 2.0 | 10.0 | 17.0 |
| Caregiver Burden Scale: <i>Subjective Stress Burden</i> | 15.0 | 12.2  | 12.0   | 2.1 | 8.0  | 18.0 |
| Question 38: <i>How stressful is caregiving for you</i> | 16.0 | 2.94* | 4.0    | 0.7 | 3.0  | 5.0  |

\* Not at all = 0, Slightly = 1, Moderately = 2 (31%), Quite a bit = 3 (44%), Extremely = 4 (25%)

| <b>Table 3</b><br><b><i>Correlation Coefficients of the Zarit Burden Interview, and the Caregiver Burden Scale to Question 38</i></b> |  |         |
|---|--|---------|
| Scale   | Correlation<br>coefficient to<br>Question 38 | p-value |
| Zarit Burden Interview  | 0 .67  | 0.0045* |
| Caregiver Burden Scale: <i>Objective Burden</i>   | 0.32   | 0.25    |
| Caregiver Burden Scale: <i>Subjective Demand Burden</i>   | 0.21   | 0.25    |
| Caregiver Burden Scale: <i>Subjective Stress Burden</i>   | 0.15   | 0.22    |

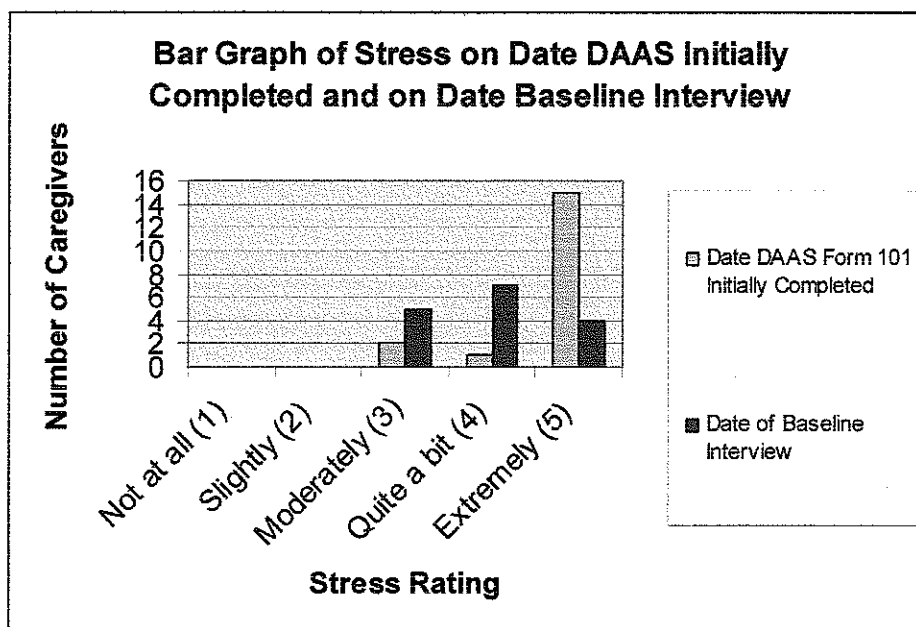
\* Statistically significant p-value <0.010

Finally, an important finding was found when analyzing the data of stress on the Department of Aging and Adult Services Form 101 and at the time of the baseline interview. Table 2 provides the mean and related descriptive statistics for the ZBI, the burden scores in the CBS, and the mean score for the Question 38. Graph 1 provides the rating of stress on the date the Department of Aging and Adult Services Form was completed by the Program Director and the rating of stress on the date of the baseline interview. Fifteen caregivers indicated their stress as “Extreme” at the time of the DAAS form was completed; however, the number who rated their stress as “Extreme” at the time of the baseline interview dropped to only 25% or four caregivers. Although more analysis is needed to investigate this finding, this suggests that the respite program as provided by the Family Caregiver Support Program does provide stress relief to caregivers. These results should be viewed with caution since the average number of days between date DAAS Form 101 completion and date of the baseline interview was 97 days, with a range of 17 days to 438 days. Since there is such a wide variation between the assessments, we

cannot attribute the observed decline in self-reported caregiver stress due to the respite program alone.

Graph 1

*Stress Rating on Date DAAS Form Initially Completed and on Date of Baseline Interview*



### ***Evaluation of Hypothesis 2: Impact of Recipient IADL-ADL Index and Length of Time Providing Care***

No statistically significant relationship was found between the care recipient's Instrumental Activities of Daily Living and the Activities of Daily Living) Index scores, as abstracted from the Department of Aging and Adult Form 101, with the Zarit Burden Interview or the burden scores in the Caregiver Burden Scale or Question 38. The majority of the care recipients were documented as being dependent on their caregivers for support with activities of daily living. Mean IADL-ADL Index was 11.7 with a standard deviation of 1.1. An index score for the IADL-ADL of seven or higher would indicate a person qualifies for caregiving services.

There is little variation in the IADL-ADL Index scores in the study group and subsequently no significant relationship was able to be detected between impact of IADL-ADL Index and caregiver stress as measured by the ZBI or Question 38. Table 4 provides the descriptive statistics for IADL-ADL Index levels and Table 5 provides the correlation coefficient of the ZBI and Question 38, *How stressful is caregiving* compared to IADL-ADL Index scores. The Caregiver Burden Scales were not considered for this evaluation, since these measures were not found to be indicative of the level of stress for this study population.

More than 80% of caregivers interviewed reported having provided care for more than one year. No statistically significant relationship was found between length of caregiving with the Zarit Burden Interview, or the three burden scales in the Caregiver Burden Scale, or Question 38, *How stressful is caregiving* (Table 6). Because the majority of caregivers have provided care for more than a year (median value of 4, > 1 year), there is little variation in length of caregiving which subsequently limits the ability to detect statistically significant relationships between length of care and caregiver stress. Expanded categories beyond the present should be included for future examination of these measures. Table 4 provides descriptive statistics on Instrument Activities of Daily Living and Activities of Daily Living Index. Table 5 provides information on the total length of care for caregivers. Table 7 provides details concerning the statistical comparisons of the length of care relative to the Zarit Burden Interview, Question 38, and the three burden of stress of Caregiver Burden Scale.

**Table 4*****Descriptive Statistics of the Instrumental Activities of Daily Living and Activities of Daily Living Index Scores and Length of Care***

| Variable       | N    | Mean | Median | Std | Min | Max  |
|----------------|------|------|--------|-----|-----|------|
| IADL-ADL Index | 13.0 | 11.7 | 12.0   | 1.1 | 4.0 | 13.0 |

**Table 5*****Total Length of Caregiving***

|                | < 1 month | 1-6 months | 7-12 months | > 1 year | Data not available |
|----------------|-----------|------------|-------------|----------|--------------------|
| Length of Care | 0         | 0          | 2 (11%)     | 13 (72%) | 3 (17%)            |

**Table 6*****Correlation Coefficients of the Zarit Burden Interview and Question 38 to Instrumental Activities of Daily Living-Activities of Daily Living Index Scores***

| Scale   | Correlation coefficient<br>to IADL | p-value |
|---|------------------------------------|---------|
| Zarit Burden Interview                                  | -0.23                              | 0.47    |
| Question 38: <i>How stressful is caregiving for you</i> | -0.13                              | 0.69    |

**Table 7*****Examination of Relationship between Zarit Burden Interview, Question 38 and Caregiver Burden Scale to Length of Care***

| Scale   | Cochran-Mantel-<br>Haenszel Statistic (df) | Cochran-Mantel<br>-Haenszel p-value |
|---|--|-------------------------------------|
| Zarit Burden Interview                                  | 0.3314 (1)                                 | 0.56                                |
| Question 38: <i>How stressful is caregiving for you</i> | 1.5734 (2)                                 | 0.45                                |

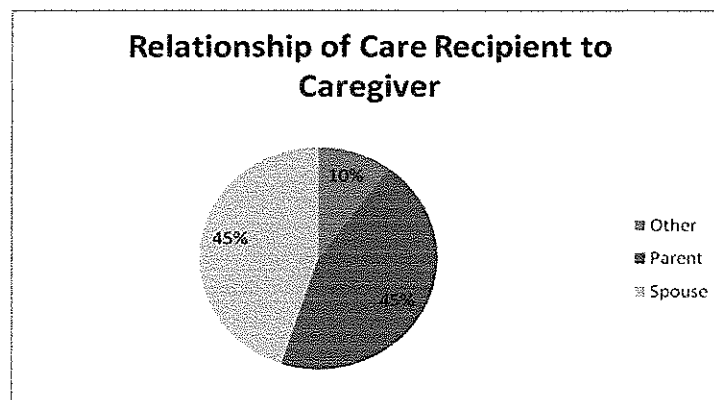
| <i>Correlation Coefficients of the Caregiver Burden Scale to Length of Care</i> |  |         |
|---|--|---------|
| Scale   | Correlation coefficient<br>to Length of Care | p-value |
| Caregiver Burden Scale: <i>Objective Burden</i>                                 | 0.14   | 0.62    |
| Caregiver Burden Scale: <i>Subjective Demand Burden</i>                         | 0.04   | 0.90    |
| Caregiver Burden Scale: <i>Subjective Stress Burden</i>                         | -0.22  | 0.43    |

### ***Evaluation of Hypothesis 3: Relationship of Caregiver to Recipient***

No statistically significant relationship was found between the caregiver's relationship to the care recipient and the reported stress scores of the Zarit Burden Interview, or the three burden scales in the Caregiver Burden Scale, or Question 38, *How stressful is caregiving*. Graph 1 provides a summary of the relationships of caregivers to care recipients in this study. In general, providing care to a person is very stressful, regardless of this person is a parent or a spouse or child. Further analysis could not be performed on the relationships of caregivers to care recipients due to the small sample size. Table 8 provides a summary of the Department of Aging and Adult Services 101 Form. These data indicate that this study group is mostly composed of middle-aged, married, African American women, who provide care to someone older.

### **Graph 2**

#### ***Relationship of Care Recipient to Caregiver***



**Table 8*****Department of Aging and Adult Services Form Summary***

| Variable                     | Value    |
|------------------------------|----------|
| Women Caregivers             | 61%      |
| Working Full Time Caregivers | 39%      |
| African American Caregivers  | 61%      |
| Married Caregivers           | 61%      |
| Mean Caregiver Age           | 64 years |
| Mean Care Recipient Age      | 79 years |

**Discussion**

The purpose of the Family Caregiver Support Program Questionnaire is to measure stress in an informal caregiver population over time. As mentioned in the introduction, informal caregivers are those who provide “extraordinary, uncompensated care, predominantly in the home setting, involving significant amounts of time and energy for months or years, requiring the performance of tasks that may be physically, emotionally, socially, or financially demanding” (Biegel, Sales, and Schultz, 1991). The FCSQ includes two instruments commonly used to measure stress in caregivers, the Zarit Burden Interview and the Caregiver Burden Scale. Limitations of this study include low participation (response rate of 46%). The ZBI was found to be statistically significant with Question 38, “*On a scale of 1 to 5, with 1 not at all and 5, extremely, how would you rate how stressful caregiving is for you?*” However, none of the three burden scores of the CBS revealed a statistically significant association with Question 38. The data from this study suggests that the ZBI is a valid instrument in measuring stress in informal caregivers who provided cared to someone for more than one year,

While some questions on the Zarit Burden Interview and the Caregiver Burden Scale (CBS) are similar, the CBS may be more appropriate for screening and intervening with newer caregivers. For example, the ZBI asks “*DO YOU FEEL that you don't have as much privacy as you would like because of your relative?*” and the CBS asks “*Do you have personal privacy?*” However, possible responses are slightly different. The ZBI questions a caregiver’s burden at the current time. However, the CBS asks a person to compare their stress from a prior time. The choices are “*A lot less,*” “*A little less,*” “*The same,*” “*A little more,*” and “*A Lot more.*” For caregivers who have provided care for some time, it is hypothesized there maybe little variation in their levels of burden in day-to-day routines such as changes in manipulation of care recipient, vacation activities or trips, or tension in life over a two week period. Therefore, the CBS may be more appropriately used to measure changes in burden levels in newer caregivers who may need assessment and placement into support programs based on their answer to questions related to the burdens of Objective Demand, Subjective Demand, or Subjective Stress.

The Zarit Burden Interview is an appropriate tool to measure stress in a new or an experienced caregiver because it asks simply “*Please answer the following questions about how you feel in the last 2 weeks.*” The choices are “*Never/Rarely,*” “*Sometimes,*” “*Quite Frequently,*” and “*Nearly Always.*” These choices provide a person an opportunity to measure how they feel; it does not ask them to measure a *difference* in how they felt from before which may also introduce recall bias. The ZBI is a quick tool to measure stress in caregivers. The Caregiver Burden Scale which requires more thought and consideration is better suited to measure differences in burden levels in caregivers who come to the Council for Senior Citizens for initial help.



The information from the Department of Aging and Adult Form 101 (DAAS) allows us to measure differences in stress between the dates of completing the application for enrollment in the Family Caregiver Support Program to the date of the baseline interview. There was an observed difference in levels of stress or self reported health ratings at the time of completing the DAAS Form 101 and the time of the baseline interview (see Figure 2). This suggests that the current respite program does provide some relief in caregiving. However, the program as presently offered may not suffice since the median rate of stress at the baseline interview revealed a value of 4, “Quite a bit” stressed (see Table 2). It is interesting to note that the caregivers, on average, are very satisfied with the Council for Senior Citizens Caregiver Program, as reported by a median score of 5 (Extremely satisfied) and a mean score of 4.1 for the question *“On a scale of 1 to 5, with 1 not at all, and 5 extremely satisfied, how would you rate how satisfied you are with the caregiver program?”* (Table 9) This suggests that the caregivers appreciate very much any assistance in caregiving. Almost 90% of the caregivers in this program are the primary caretakers of their loved ones.

**Table 9**

**Satisfaction of the Caregiver Program, Question 42***“On a scale of 1 to 5, with 1 not at all, and 5 extremely satisfied, how you would rate how satisfied you are with the caregiver program?”*

| Satisfaction          | Value |
|-----------------------|-------|
| Not at all satisfied  | 0%    |
| Slightly satisfied    | 0%    |
| Moderately satisfied  | 33%   |
| Quite a bit satisfied | 6%    |
| Extremely satisfied   | 44%   |
| No response received  | 17%   |

It remains disconcerting to confirm the level of stress and burden these caregivers feel. According, to Bourgeois, Schulz, and Burgio (1996), respite interventions may not provide adequate amount of relief. The Council of Senior Citizens provides only six hours of respite care per month for a caregiver which may not be sufficient time to relax. Classes offered at the Council of Senior Citizens include monthly educational programs (e.g., Taking Care of YOU, Identifying and Reducing Personal Stress, Communication Feelings, Needs and Concerns). However, only 20% of the caregivers interviewed attended an educational program at the Council for Senior Citizens. One frequently noted barrier to attending a class was *“Who will take care of my loved one while I attend this class?”*.

### **Recommendations**

With the findings from the baseline questionnaire, it appears the Caregiver Burden Scale does not provide an accurate measure of stress of caregivers already in the respite program who have provided care for at least 12 months. However, this may be due to small sample size of this study. Further research is warranted, but the data from the baseline questionnaire strongly suggests that the Zarit Burden Interview is a more accurate measure for caregiver stress. Therefore, at this time, it is suggested that the Council for Senior Citizens modify the current Family Caregiver Support Questionnaire by removing the Caregiver Burden Scale (questions 24-37.) The ZBI scores and Question 38 correlate at a significant level, suggesting that the ZBI is a valid measure for measuring stress and burden in caregivers. However, there was no significant relationship between Questions 38 and the CBS scores. The CBS may be more appropriate for initial assessment for newer caregivers who are new participants in this program. Further research is needed to determine the reliability of the ZBI in measuring stress over time. Analysis

on the 3 month follow up questionnaire is forthcoming. These data will help determine the reliability of the ZBI across time.

In addition, it is also suggested that the CSC conduct the Family Caregiver Support Questionnaire on an annual basis to measure the stress of the caregivers. By conducting annual questionnaires, the CSC will be able to measure the short and long term objectives for this program: to reduce self-reported caregiver stress. In addition, findings from these annual surveys will aid the CSC in modifying the current program or creating additional interventions to reduce caregiver stress and burden. Results from this survey could also be used in grant proposals for additional funding for the Family Caregiver Support Program. As documented in this paper, caregivers face high levels of stress and burden. Any time away from caregiving provides time for a person to relax, although it may be only for a short time. Perhaps additional funding dollars could provide the CSC with the financial resources to offer more respite hours to caregivers on a monthly basis. Finally, if the results from the 3 month interview find the ZBI a reliable tool in measuring stress in caregivers, then the modified Family Caregiver Support Program Questionnaire (without the Caregiver Burden Score) could be used as a model for other respite programs that want to measure stress in caregivers, who have been providing care for 12 months or more.

Appendix 1:  
**Council for Senior Citizens**  
**Summary Form**  
***Stress Inventory- Family Caregiver Support Program***

Interval    ☐ Baseline

---

**Questionnaire Status**

☐ Complete

**Reasons Incomplete or Not Done**

☐ Incomplete →→→→→→→→→→→→→→→→→→ ☐ Refused

☐ Not Done →→→→→→→→→→→→→→→→→→ ☐ Too ill/deaf

☐ Unable to locate

☐ Death

☐ Other \_\_\_\_\_

**Source**

☐ Caregiver

**Interviewer Initials**

\_\_\_\_\_

---

Questionnaire Entered By: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
          M M/ D D Y Y Y Y

Questionnaire QC By: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
          M M/ D D Y Y Y Y

**Council for Senior Citizens**  
**Stress Inventory- Family Caregiver Support Program**

Interval    ☐ Baseline

---

*The purpose of this questionnaire is to understand how caring for someone may impact stress level. We understand that you are currently receiving respite care for someone you care for through an agency. Please answer the following questions about you, the caregiver. There are no wrong or right answers. Your answers will remain confidential and will not be released to anyone outside the research staff. This questionnaire will take approximately 10-15 minutes.*

Today's Date:     /     /      
                  MM   D D   Y Y Y Y

---

**Demographics**

**1. Your Current Working Status**

- ☐ Working Full Time
- ☐ Working Part Time
- ☐ Unemployed / Looking for Work
- ☐ Retired
- ☐ Disabled
- ☐ Other \_\_\_\_\_

**2. Do you feel your work is stressful?**

- ☐ No
- ☐ Yes → → → → → → → → → Does this impact your life at home? ☐ No

☐ Yes → → →

If yes, please describe  
how:

---

**3. Currently, how many people do you provide care for (not including yourself)?**

- ☐ 1
- ☐ 2
- ☐ >3

**4. What is your relationship to the person your provide care for? Please check all that apply.**

- ☐ Parent
- ☐ Spouse/Significant Other
- ☐ Child
- ☐ Sibling
- ☐ Uncle/Aunt
- ☐ Grandparent
- ☐ Grandchild
- ☐ Other \_\_\_\_\_

5. How long have been providing care? (note: if you are currently the caregiver for more than one person, please check the longest time you have provided this type of care. )

- ☐ <1 month
- ☐ 1-6 months
- ☐ 7-12 months
- ☐ >1 year

6. Do you receive any service or assistance with care giving? Check all that apply.

☐ No

☐ Yes→→→→→→→→→ What services?

- ☐ In home respite care
- ☐ Short term respite care(≤7 day)
- ☐ Long term respite care (>7days)
- ☐ Formal care giving
- ☐ Financial assistance
- ☐ Help with household chores
- ☐ Adult day care
- ☐ Transportation assistance
- ☐ Private paid care giving (not through Council)
- ☐ Other\_\_\_\_\_

7. Do you feel you need any additional services?

☐ No

☐ Yes→→→→→→→→→ What services?

Check all that apply.

- ☐ In home respite care
- ☐ Short term respite care (≤7 day)
- ☐ Long term respite care (>7days)
- ☐ Formal care giving
- ☐ Financial assistance
- ☐ Help with household chores
- ☐ Adult day care
- ☐ Transportation assistance
- ☐ Private paid care giving (not through Council)
- ☐ Other\_\_\_\_\_

8. Do you live with the person you provide care for?
- ☐ No
  - ☐ Yes→→→→→→→→→ Including the person you provide care for, and yourself, how many people live in your home? \_\_\_\_\_ # of people
9. Does anyone else provide assist you in providing care for this person?
- ☐ No
  - ☐ Yes→→→→→→→→→ Are you the primary care giver? ☐No  
☐Yes
10. Is your current monthly household income more, less or about the same as a year ago?
- ☐ More
  - ☐ Less
  - ☐ About the same
  - ☐ Don't know
  - ☐ Prefer not to answer
11. How well does your household's income meet your household's basic needs (i.e., food, clothing, shelter, and medical expenses, including medicines)?
- ☐ Not at all
  - ☐ Somewhat
  - ☐ Adequately
  - ☐ More than adequately
  - ☐ Don't know
  - ☐ Prefer not to answer

Please answer the following questions about how you feel in the last 2 weeks.  
(Zarit Burden Scale)

| Question   | Never/Rarely             | Sometimes                | Quite Frequently         | Nearly Always            |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| 12. DO YOU FEEL that because of the time you spend with your relative that you don't have enough time for yourself?      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. DO YOU FEEL stressed between caring for your relative and trying to meet other responsibilities (work/family)?       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. DO YOU FEEL angry when you are around your relative?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. DO YOU FEEL that your relative currently affects your relationship with family members or friends in a negative way? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. DO YOU FEEL strained when you are around your relative?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. DO YOU FEEL that your health has suffered because of your involvement with your relative?                            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. DO YOU FEEL that you don't have as much privacy as you would like because of your relative?                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. DO YOU FEEL that your social life has suffered because you are caring for your relative?                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. DO YOU FEEL that you have lost control of your life since your relative's illness                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. DO YOU FEEL uncertain about what to do about your relative?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. DO YOU FEEL you should be doing more for your relative?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. DO YOU FEEL you could do a better job in caring for your relative?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



**In the last 2 weeks**, how has assisting or having contact with the person for whom you care affected the following aspects of your life? (**Caregiver Burden Assessment**)

| <b>Question</b>   | <b>A lot less</b>        | <b>A little less</b>     | <b>The same</b>          | <b>A little more</b>     | <b>A Lot more</b>        |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 24. Do you have time to yourself?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. Do you have stress in your relationship with your relative?                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. Do you have personal privacy?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. Do you have attempts by your relative to manipulate you?                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. Do you have time to spend in recreational activities?                                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. Do you have unreasonable requests made of you by your relative?                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30. Do you have tension in your life?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. Do you have vacation activities and trips?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. Do you have nervousness and depression concerning your relationship with your relative? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. Do you have feelings that you are being taken advantage of by your relative?            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. Do you have time to do your own work and daily chores?                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 35. Do you have demands made by your relative that are over and above what s/he needs?      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. Do you have anxiety about things?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. Do you have time for friends and other relatives  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

38. On a scale of 1 to 5, with 1 not at all and 5, extremely, how would you rate how stressful caregiving is for you?

| 1                    | 2                  | 3                    | 4                     | 5                   |
|----------------------|--------------------|----------------------|-----------------------|---------------------|
| Not at all stressful | Slightly stressful | Moderately stressful | Quite a bit stressful | Extremely stressful |

Please answer the following questions about **YOUR** overall health.

39. In general would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

40. Do you have an impairment that limits your activity?

- ☐ No
- ☐ Yes → → → → → Does this impact your ability to provide care? → → ☐ No  
☐ Yes

If yes, please describe how:

41. Have you attended an educational program for caregivers at the Council for Senior Citizens?

- ☐ No → → Do you plan to attend caregiver education programs in the future?  
☐ No  
☐ Yes
- ☐ Yes → → → → → Please list below:

Title/Topic: \_\_\_\_\_ (When: \_\_\_\_\_)

Were you satisfied with this program?

- ☐ No
- ☐ Yes

Title/Topic: \_\_\_\_\_

When: \_\_\_\_\_

Were you satisfied with this program?

- ☐ No
- ☐ Yes

42. On a scale of 1 to 5, with 1 not at all and 5, extremely, how would you rate how satisfied you are with the caregiver program?

| 1                    | 2                  | 3                    | 4                     | 5                   |
|----------------------|--------------------|----------------------|-----------------------|---------------------|
| Not at all satisfied | Slightly satisfied | Moderately satisfied | Quite a bit satisfied | Extremely satisfied |

Appendix 2:  
Department of Aging and Adult Services Form 101 (DAAS Form 101)

| CLIENT REGISTRATION FORM DAAS 101 (Long Form)  |  |  |   |   |   |
|--|--|--|---|---|---|
| NC Department of Health and Human Services • Division of Aging and Adult Services  |  |  |   |   |   |
| <i>Check the applicable category or categories below and follow corresponding directions.</i> <ul style="list-style-type: none"> <li>HCCBG – congregate nutrition (180), congregate supplemental meals (182), NSIP-only congregate meals (181) Sections I, II, and VII only</li> <li>HCCBG – general (250) or medical (033) transportation complete Sections I and VII only</li> <li>Family Caregiver Support Program (services 820, 830, 840, 850); and HCCBG Respite Services (in-home aide respite (235, 236, 237, 238), group respite (309) and institutional respite (210)) Sections I, VI, and VII (caregiver information) and Sections III, IV, and V (care recipient information)</li> <li>HCCBG – Care management (610), home-delivered meals (020), NSIP-only home-delivered meals (021), home-delivered supplemental meals (022) complete Sections I, II, IV, V (if appropriate), VI (if appropriate), and VII</li> <li>For all other HCCBG services complete Sections I, IV, V (if appropriate), VI (if appropriate), and VII</li> </ul>   |  |  |   |   | <b>Service Codes</b><br><br><div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div> <div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div> <div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div> <div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div> |
| <b>Region Code</b> _____   |  | <b>Provider Code</b> _____   |   |   |   |
| <b>1. Client (Caregiver) Status:</b> <i>Check the appropriate box. More than one box may be appropriate.</i><br><input type="checkbox"/> New Registration/Activate (complete all per instructions above)<br><input type="checkbox"/> Waiting for Service: service codes: _____ (complete Section I - unit based services only)<br><input type="checkbox"/> Inactive <input type="checkbox"/> applies to client/caregiver    OR <input type="checkbox"/> applies to care recipient<br><div style="display: flex; justify-content: space-between; padding: 0 20px;"> <div style="width: 45%;"> <input type="checkbox"/> adult care home/assisted living<br/> <input type="checkbox"/> alternative living arrangement<br/> <input type="checkbox"/> death<br/> <input type="checkbox"/> hospitalization<br/> <input type="checkbox"/> other (specify) _____                 </div> <div style="width: 45%;"> <input type="checkbox"/> moved<br/> <input type="checkbox"/> improved function/need eliminated<br/> <input type="checkbox"/> service not needed/wanted<br/> <input type="checkbox"/> illness<br/> <input type="checkbox"/> nursing home placement                 </div> </div> <input type="checkbox"/> Change (complete Section I, Items 2, 4, 5 and any changed items.) |  |  |   |   | <b>Date</b><br><br><div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div> <div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div> <div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div>   |
| <b>2. Name</b> Last _____ First _____ M.I. _____   |  |  | <b>4. Last 4 Digits SSN</b><br><div style="border-bottom: 1px solid black; height: 15px; width: 100%;"></div>   |   |   |
| <b>3. Street Address</b> Line 1 _____  |  |  | <b>5. Date of Birth</b> MM ____ DD ____ YYYY ____   |   |   |
| <b>Mailing Address</b> Line 2 _____  |  |  | <b>6. Phone #</b><br>_____ - _____<br><input type="checkbox"/> No phone   |   |   |
| City _____ State _____ Zip _____   |  | County _____   |   |   |   |
| <b>7. Sex</b> <i>(check one)</i><br><input type="checkbox"/> Female<br><input type="checkbox"/> Male   | <b>8. At/Below Poverty Level</b> <i>(check one)</i><br><input type="checkbox"/> Yes<br><input type="checkbox"/> No | <b>9. Marital Status</b> <i>(check one)</i><br><input type="checkbox"/> single (never married)<br><input type="checkbox"/> married<br><input type="checkbox"/> single (divorced/widowed)<br><input type="checkbox"/> refused to answer | <b>10. Household size</b> <i>(check one)</i><br><input type="checkbox"/> lives alone <input type="checkbox"/> 2 in home<br><input type="checkbox"/> 3 or more in home<br><input type="checkbox"/> group/shared home<br><input type="checkbox"/> refused to answer |   |   |
| <b>11. Race</b> <i>Ask: What is your race?</i><br>a. Black or African-American<br>b. Asian<br>c. American Indian or Alaska Native<br>d. White<br>e. Native Hawaiian/other Pacific Islander<br>f. Unknown/refused<br>g. Other (specify) _____   |  | Check one race which client most closely identifies<br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>            | Check all that apply<br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/><br><input type="checkbox"/>  | <b>12. Hispanic/Latino</b> <i>(check one)</i><br>Ask: Are you of Hispanic or Latino origin?<br><input type="checkbox"/> Yes <input type="checkbox"/> No<br><i>(a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture of origin, regardless of race)</i> |   |
| <b>14. Overall Functional Status:</b> <input type="checkbox"/> Well <input type="checkbox"/> At-risk <input type="checkbox"/> High Risk <i>(If Section IV is required, do not complete.)</i>   |  | <b>13. Primary Language Spoken</b> <i>Ask: What language do you speak in your home?</i><br>Language _____  |   |   |   |

**Section II: Required only for clients of HCCBG congregate meals, home-delivered meals, supplemental meals, NSIP-only meals and care management.**

| <b>15. Nutrition Health Score</b>   |  | Refused to Answer        |
|---|--|--------------------------|
| a. Do you have an illness or condition that made you change the kind and/or amount of food you eat? | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| b. How many meals do you eat per day?   | #  |                          |
| c. How many servings of fruit per day?  | #  |                          |
| d. How many servings of vegetables per day?   | #  |                          |
| e. How many servings of milk/dairy products per day?  | #  |                          |
| f. How many drinks of beer, liquor, or wine do you have every day or almost every day?              | #  |                          |
| g. Do you have tooth/mouth problems that make it hard for you to eat?                               | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| h. Do you always have enough money or food stamps to buy the food you need?                         | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| i. How many meals do you eat alone daily?   | #  |                          |
| j. How many prescribed drugs do you take per day?   | #  |                          |
| k. How many over-the-counter drugs do you take per day?   | #  |                          |
| l. Have you lost 10 or more pounds in the past 6 months without trying?                             | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| m. Have you gained 10 or more pounds in the past 6 months without trying?                           | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| n. Are you physically able to shop for yourself?  | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| o. Are you physically able to cook for yourself?  | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |
| p. Are you physically able to feed yourself?  | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> |

**Section III: Complete on the care recipient (not caregiver) for HCCBG respite (in-home aide respite, group respite and institutional respite) & Family Caregiver Support Program.**

**CARE RECIPIENT #1** (For additional service recipients, attach an additional DAAS-101, Section III, IV, and V.)

|   |  |      |       |      |                                   |
|---|--|------|-------|------|-----------------------------------|
| <b>16. Name</b>   |  | Last | First | M.I. | <b>Last 4 Digits SSN</b><br>_____ |
| <b>Street Address</b> Line 1  |  |      |       |      |                                   |
| <b>Mailing Address</b> Line 2   |  |      |       |      |                                   |
| <b>Date of Birth</b>  |  | City | State | Zip  | MM DD YYYY                        |
| <b>17. Is care recipient a person with severe disabilities?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No  |  |      |       |      |                                   |
| <b>18. Does care recipient live in same household as caregiver?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No  |  |      |       |      |                                   |
| <b>19. Care recipient marital status: (check one)</b> <input type="checkbox"/> single (never married) <input type="checkbox"/> single (divorced/widowed)<br><input type="checkbox"/> married <input type="checkbox"/> refused to answer |  |      |       |      |                                   |

**Section IV: Complete for all clients/recipients except congregate nutrition, transportation or minor relative children without severe disabilities for FCSP.**

**20. Does client (care recipient) have significant memory loss or confusion?** <sup>3</sup> ☐ Yes ☐ No

| <b>21. Number of IADL (Instrumental Activities of Daily Living)</b> | Client (care recipient) can carry out the following tasks without help. |                          | If the answer to items a - h in question #21 or items a - f #22 is "no" then select one of the following: |   |  |   |
|---|---|--------------------------|---|---|--|---|
|   | YES   | NO                       | Client (care recipient) cannot do and has someone unpaid who assists.                                     | Client (care recipient) cannot do and has someone paid who assists. | Client (care recipient) cannot do and has both unpaid & paid assistance. | Client (care recipient) has no one who assists. |
| a. Prepare meals  | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| b. Shop for personal items  | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| c. Manage own medications   | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| d. Manage own money (pay bills)                                     | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| e. Use telephone  | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| f. Do heavy housework   | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| g. Do light cleaning  | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| h. Transportation ability   | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                        |
| Total "no" column = IADL Impairments                                |   |                          |   |   |  |   |

| <b>22. Number of ADL (Activities of Daily Living)</b>            |                          |                          |                          |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Eat   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Get dressed   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Bathe self  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Use the toilet  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Transfer into/out of bed/chair                                | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Ambulate (walk or move about the house without anyone's help) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Total "no" column = ADL Impairments                              |                          |                          |                          |                          |                          |                          |

**23. How many unpaid caregivers involved in care including primary caregiver?** Enter # \_\_\_\_\_  
 (If answer to this question is "0" skip to Section VII.)

**Section V: Complete for HCCBG respite, FCSP, and others responding with "1" or more in # 23.**

**24. How many hours per day of help, care, or supervision does care recipient need?**  
a. # of daily hours needed \_\_\_\_\_ b. If not daily, # of hours per week needed \_\_\_\_\_

**25. How many hours per day of help, care, or supervision does primary caregiver provide?**  
a. # of daily hours provided \_\_\_\_\_ b. If not daily, # of hours per week provided \_\_\_\_\_

**26. Primary caregiver's relationship to care recipient: (check one)**

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> wife                      | <input type="checkbox"/> granddaughter/granddaughter-in-law | <input type="checkbox"/> grandmother    |
| <input type="checkbox"/> husband                   | <input type="checkbox"/> grandson/grandson-in-law           | <input type="checkbox"/> grandfather    |
| <input type="checkbox"/> daughter/ daughter-in-law | <input type="checkbox"/> niece                              | <input type="checkbox"/> aunt           |
| <input type="checkbox"/> son/son-in-law            | <input type="checkbox"/> nephew                             | <input type="checkbox"/> uncle          |
| <input type="checkbox"/> sister                    | <input type="checkbox"/> mother                             | <input type="checkbox"/> other relative |
| <input type="checkbox"/> brother                   | <input type="checkbox"/> father                             | <input type="checkbox"/> non-relative   |

**Section VI: Complete for all caregivers. Questions 27-30 should be answered only by caregiver.**

**27. Primary caregiver's self-reported health on scale of 1 (poor) to 5 (excellent) (Choose one.)**

|                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1                        | 2                        | 3                        | 4                        | 5                        |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**28. Primary caregiver: How stressful for you is caregiving on a scale from 1 (not at all/very low) to 5 (very high) (Choose one.)**

|                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1                        | 2                        | 3                        | 4                        | 5                        |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**29. Primary caregiver's paid employment status:**

- |  |  |   |   |
|--|--|---|---|
| <input type="checkbox"/> Full-time                       | <input type="checkbox"/> Part-time             | <input type="checkbox"/> Quit due to caregiving               | <input type="checkbox"/> Is not/was not working |
| <input type="checkbox"/> Retired early due to caregiving | <input type="checkbox"/> Retired/full benefits | <input type="checkbox"/> Lost job/dismissed due to caregiving |   |

**30. Is the primary caregiver a long distance caregiver?** ☐ Yes ☐ No

**Section VII: REQUIRED FOR ALL CLIENTS.**

I, the client, understand the information contained on this form will be kept confidential unless disclosure is required by court order or for authorized federal, state or local program reporting and monitoring. I understand that any entitlement I may have to Social Security benefits or other federal or state sponsored benefits shall not be affected by the provision of the aforementioned information. My signature authorizes the providing agency to begin the service(s) requested.

DATE: \_\_\_\_\_ CLIENT (Caregiver) SIGNATURE: \_\_\_\_\_

DATE: \_\_\_\_\_ AGENCY EMPLOYEE SIGNATURE: \_\_\_\_\_

**EMERGENCY CONTACT PERSON**

Name: \_\_\_\_\_

Phone (day): \_\_\_\_\_ (evening): \_\_\_\_\_

☐ Refused to provide emergency contact information

**Provider Use Only**

|   |                      |
|---|----------------------|
| Registration Update _____ / _____ / _____ | Staff Initials _____ |
| Registration Update _____ / _____ / _____ | Staff Initials _____ |
| Registration Update _____ / _____ / _____ | Staff Initials _____ |

Appendix 3:  
Information to be abstracted from Client Registration Form DAAS 101

| Question                    | Caregiver  | Recipient of Care   |
|-----------------------------|--|---|
| 1. Age (calculate from DOB) | _____  | _____   |
| 2. Gender                   | <input type="checkbox"/> Male<br><input type="checkbox"/> Female   |   |
| 3. At/below poverty level   | <input type="checkbox"/> No<br><input type="checkbox"/> Yes  |   |
| 4. Marital Status           | <input type="checkbox"/> Single/never married<br><input type="checkbox"/> Married/living as married<br><input type="checkbox"/> Divorced or Widowed<br><input type="checkbox"/> Refused to answer  | <input type="checkbox"/> Single/never married<br><input type="checkbox"/> Married/living as married<br><input type="checkbox"/> Divorced or Widowed<br><input type="checkbox"/> Refused to answer |
| 5. Race                     | <input type="checkbox"/> Black or African-American<br><input type="checkbox"/> Asian<br><input type="checkbox"/> American Indian or Alaskan Native<br><input type="checkbox"/> White<br><input type="checkbox"/> Native Hawaiian/other Pacific Islander<br><input type="checkbox"/> Unknown or Refused<br><input type="checkbox"/> Other _____ |   |

6. Is care recipient a minor child with mental retardation or developmental disability?

- ☐ No  
☐ Yes

7. Does care recipient have significant memory loss or confusion?

- ☐ No  
☐ Yes

Information to be abstracted from Client Registration Form DAAS 101 cont

| Number of IADL<br>(Instrumental Activities of Daily Living)    | If the answer to items 49-56 or items 58-63 are "no" then select one of the following: |    |  |  |   |   |
|--|--|----|--|--|---|---|
|  | Client (care recipient) can carry out the following tasks without help.                |    | Client (care recipient) cannot do and has someone unpaid who assists | Client (care recipient) cannot do and has someone paid who assists | Client (care recipient) cannot do and has both unpaid and paid assistance | Client (care recipient) has no one to assist. |
|  | YES  | NO |  |  |   |   |
| 8. Prepare meals prepare                                       |  |    |  |  |   |   |
| 9. Shop for personal items                                     |  |    |  |  |   |   |
| 10. Manage own medications                                     |  |    |  |  |   |   |
| 11. Manage own money (pay bills)                               |  |    |  |  |   |   |
| 12. Use telephone  |  |    |  |  |   |   |
| 13. Do heavy housework   |  |    |  |  |   |   |
| 14. Do light cleaning  |  |    |  |  |   |   |
| 15. Transportation ability                                     |  |    |  |  |   |   |
| <b>16. Total "no column"=IADL impairments</b>                  |  |    |  |  |   |   |
| 17. Eat  |  |    |  |  |   |   |
| 18. Get dressed  |  |    |  |  |   |   |
| 19. Bathe self   |  |    |  |  |   |   |
| 20. Use the toilet   |  |    |  |  |   |   |
| 21. Transfer into/out of toilet                                |  |    |  |  |   |   |
| 22. Ambulate (walk or move about the house without one's help) |  |    |  |  |   |   |
| Total "no column"=ADL impairments                              |  |    |  |  |   |   |

23. How many hours per day of help, care or supervision does care recipient need?

\_\_\_\_\_ hours \_\_\_\_\_ if not daily , # of hours per week needed

24. How many hours per day of help, care, or supervision does primary caregiver provide?

\_\_\_\_\_ hours \_\_\_\_\_ if not daily , # of hours per week needed

25. Is the primary caregiver a long distance caregiver? ☐ No ☐ Yes



26. House hold size \_\_\_\_\_

27. Household size

- ☐Lives alone
- ☐2 in home
- ☐3 in home
- ☐Group/share home
- ☐Refused to answer

28. Care recipient a person with severe disabilities?

- ☐No ☐Yes

29. Does care recipient live in the same household as caregiver (# 18)

- ☐No ☐Yes

30. How many unpaid caregiver involved in care including primary caregiver? (#23)

\_\_\_\_\_

31. Primary caregiver's relationship to care recipient

- Wife
- Husband
- Daughter/daughter-in law
- Son/son in law
- Sister
- Brother
- Grand-daughter/grand-daughter in law
- Grand-son/grand son in law
- Niece
- Newpew
- Mother
- Father
- Grandmother
- Grandfather
- Aunt
- Uncle
- Other relative

32. Primary caregiver's self-reported health on a scale of 1 to 5 \_\_\_\_\_

33. Primary caregiver: How stressful is care giving on a scale of 1 to 5 (#29) \_\_\_\_\_

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