

Understanding How Families Access and Use Long-Term Care Services

ASPE Generic Information Collection Request
OMB No. 0990-0421

Supporting Statement – Section A

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Program Official/Project Officer

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Section A – Justification

1. Circumstances Making the Collection of Information Necessary

Background

Long term care is assistance with daily activities provided to people with functional limitations because of physical, cognitive, or mental disability. These services include health and social services that may be provided in a number of settings including at-home, in adult day care centers, residential care settings, and nursing homes. Although the majority of long term care is provided informally by family members and friends, this project will focus on how families identify and access paid care supports. Most paid long term care is financed by Medicaid, which provides coverage for people who have limited financial resources and have a significant level of disability. However, almost one-quarter of long term care for older adults is paid out-of-pocket. For middle-income or wealthier adults, the likelihood that they will pay out of pocket for their care needs is even greater.

Individuals and their families may turn to many places for information, including family and friends, geriatric case managers, hospital discharge planners, providers and a growing array of internet services and resources. They also seek out information from government resources both on-line (such as Nursing Home Compare) and within their communities such as the local Aging and Disability Resource Center (ADRC) or Area Agencies on Aging. Long term care decisions are complex and multi-layered (Maloney & Finn, et al, 1996), involve numerous cost and quality assessments (Castle, 2003) and are often made at a time of crisis with little advance thought to preferences (Kane & Kane, 2001). Consequently some researchers have concluded that consumers are decidedly at a disadvantage when it comes to choosing a long term care service, provider or care setting that best meets their needs (Lubalin and Harris-Kojetin, 1999, Hibbard and Peters, 2003).

The federal government provides some information on long term care. The Administration on Aging (AOA) within the Administration for Community Living (ACL) supports a national network of area agencies on aging (AAAs) that are designed to provide information on services and supports available in each community and assist in decision making. The [Eldercare Locator](#) can help families find the nearest AAA. Information on nursing facilities or home healthcare agencies, including information on the quality of services, is available from Center for Medicare and Medicaid Services' [Nursing Home Compare](#) or [Home Health Compare](#) websites.

In 2005, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) undertook a study to understand how families choose a nursing home. The resulting study (available at: <http://aspe.hhs.gov/daltcp/reports/2006/chooseI.htm>) found that location is the most important factor families consider when searching for a nursing home for a loved one. Additional important factors include experiences of family and friends, cost, and appearance of the facility.

In July 2015, ASPE conducted a series of electronic focus groups with Americans aged 40-70 to gather information about the process and dynamics of finding long-term care for a family member. We obtained OMB approval through this mechanism. Participants noted challenges with the process, although these challenges were not universal and did not always occur in the same part of the process. Physicians were cited as a frequent source of information, although participants were divided over whether physicians provided useful information on services. Respondents felt that it would be useful to have one source of information, localized for each community, with quality information on services.

Little is known, however, about the processes that families and older adults go through to gather information, make decisions, and access long term care generally when a loved one needs assistance. The purpose of this data collection is to examine where families gather information, how they make decisions, and how well these arrangements work. Findings from the proposed data collection described in this Generic Information Collection package will address the research questions listed below:

1. Where do consumers turn for information and education on how to find and choose long term care services?
2. How satisfied are consumers with the information provided, the resources available to them, the process of making these connections and the follow-up if any that was provided to them?
3. How do factors such as community location and available resources, family dynamics, the urgency and nature of the care need, finances and other considerations play in the process of finding options and selecting care?
4. What specific public and private information sources do people use? How do they learn about those resources and how do they evaluate their experiences with them?
5. What improvements are needed to better support families in finding services to meet long term care needs?
6. If there are community resources which professional feel are available and valuable, but which were not used or considered, why did this occur and how can visibility be improved for these resources?
7. How useful are federal resources and how can they be improved to better understand the needs of older adults and their families?

The data will be collected through four (4) in-person focus group sessions conducted in three distinct market areas within Pennsylvania. Participants will be recruited so that they represent a balance of geographic areas and demographic characteristics within each community. Recruitment screening protocols are established by the Contractor and approved by ASPE. Recruitment is conducted by trained professionals who will recruit from a sample of adults ages 40 to 70 who indicate that they have a family member who has used long term care within the last two years.

Overview of the Data Collection System – The data collection will be conducted through four moderated in-person focus groups. The focus groups will be structured with a session moderator and will follow a detailed discussion guide. Participation in the focus groups (and subsequent information provided by participants) will be completely voluntary. No personal identifying information will be collected. The questions to be posed by the moderator have been developed and revised prior to the session (see Attachment A) by the Contractor and approved by ASPE staff. The moderator is a subject matter expert in the topic as well as an experienced professional moderator who has worked previously with ASPE and other government entities in similar research. ASPE staff will be able to assist the moderator by providing additional probing questions or asking for details on the information provided by the participants as needed. The data will be collected qualitatively from the audio and written transcripts of the focus groups.

The Contractor will analyze the data qualitatively by reviewing the digital video capture, audio and written transcripts and developing both a topline and in-depth report. The focus group findings will be used to identify predominant themes with regard to factors that facilitate or impede the process of finding long term care for consumers, examining in particular community and demographic factors that play important roles in the process. The Contractor will note if particular issues (for example, challenges in finding information on home health aides or selecting a suitable dementia care placement) are raised more often, or are of greater importance, to the focus group participants. The analysis will also identify differences in how information is sought for meeting care needs when the need for care is sudden vs. gradual, when caregivers are local vs. long-distance, and as income, education and other factors vary. The pros and cons of relying on internet-based resources, and public sector resources, will also be a focus of the data analytics.

The findings from the focus groups will not be generalizable. The method of data collection was chosen due to the exploratory nature of this inquiry. Through the focus groups, the ASPE staff and their Contractor will be able to collect nuanced and detailed information about the on-the-ground experiences and challenges to accessing long term care.

Items of Information to be Collected –

- What is the impetus for families beginning to look for services and supports for their loved one?
- Where/from whom do families first seek information on these services?
- What is the process that families go through in determining what services to use? Who is involved or assisted in the decision making?
- What are the key pieces of information that consumers use when making decisions about services and supports?

- How useful and/or relevant was the information available from government (i.e., federal, state, and local sources) and non-government organizations when making decisions?
- What additional information would be useful when families are evaluating long term care options?
- What community-specific characteristics influence the process and outcomes for families seeking care? What are the roles of public agencies, providers, on-line resources, or other community players in this process? How and why does the family experience differ from one community compared with another community in the same state?
- How do the experiences and outcomes vary based on characteristics of the population seeking care or the circumstances under which care is being sought?
- How could the process of looking for long term care be improved?

2. Purpose and Use of the Information Collection

There are currently no federal efforts underway that focus on understanding how families gather information, make decisions, and access long term care. The purpose of this project is to examine where families gather information, how they make decisions, and how well these arrangements work. Specifically, research questions for this current project include, but are not limited to:

1. Where do consumers turn for information and education on how to find and choose long term care services?
2. How satisfied are consumers with the information provided, the resources available to them, the process of making these connections and the follow-up if any that was provided to them?
3. How do factors such as community location and available resources, family dynamics, the urgency and nature of the care need, finances and other considerations play in the process of finding options and selecting care?
4. What specific public and private information sources do people use? How do they learn about those resources and how do they evaluate their experiences with them?
5. What improvements are needed to better support families in finding services to meet long term care needs?
6. If there are community resources which professional feel are available and valuable, but which were not used or considered, why did this occur and how can visibility be improved for these resources?
7. How useful are federal resources and how can they be improved to better understand the needs of older adults and their families?

The current Generic Information Collection request will address the above questions. The focus group findings will be used to identify predominant themes with regard to factors that facilitate or impede the process of finding long term care for consumers, examining in particular community and demographic factors that play important roles in the process. The Contractor

will note if particular issues (for example, challenges in finding information on home health aides or selecting a suitable dementia care placement) are raised more often, or are of greater importance, to the focus group participants. The analysis will also identify differences in how information is sought for meeting care needs when the need for care is sudden vs. gradual, when caregivers are local vs. long-distance, and as income, education and other factors vary. The pros and cons of relying on internet-based resources, and public sector resources, will also be a focus of the data analytics. The information will be used to inform future ASPE research projects and potentially identify ways in which federal resources and programs can more effectively meet consumers care needs.

All information or data collected will be kept secure and will be used only to inform the overall findings of the project. No personally identifiable information will be collected.

3. Use of Improved Information Technology and Burden Reduction

Experienced professional focus group recruiters will be used to streamline the process of identifying willing participants from among those who fit the criteria for participation. They are able to move through the screening questions efficiently to reduce the time and effort for the prospects considering participation. Providing follow-up materials by mail with “day of” details and a reminder phone call also eases the burden on participants.

Respondents are recruited from a large panel of participants, using the recruitment parameters and focus group participation time limits outlined in the Recruitment Screener. From this known sample, individuals are identified fulfill the participation requirements (most notably having a family member who used long term care within the past two years) and who consents to participate in one of the focus groups. Therefore, the sample for this data collection will be a sample of convenience. This method was chosen to reduce the overall burden on respondents and to gather as many perspectives as possible in the shortest amount of total time. The benefit of an in-person focus group compared with online research, is the ability to delve more fully on key topics, provide a more supportive environment in which participants can open up about difficult personal issues regarding their long term care experience and at the same time design the groups to be representative of the specific communities in which they are being convened. Because of the small sample size, focus groups are not nationally representative but the information they provide is directional and informative.

4. Efforts to Identify Duplication and Use of Similar Information

Over the past year, ASPE staff has scanned the literature and met with experts in the field to understand what information is available on how families access long term care. To our knowledge, no other similar efforts exist.

5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this data collection.

6. Consequences of Collecting the Information Less Frequently

This request is for a one time data collection. There are no legal obstacles to reduce the burden. Without this information, the Department of Health and Human Services would have very limited information about the processes that families go through, including the challenges they face, when looking for care.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

There are no special circumstances with this information collection package. This request fully complies with the regulation 5 CFR 1320.5 and will be voluntary.

8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

This data collection is being conducted using the Generic Information Collection mechanism through ASPE – OMB No. 0990-0421.

9. Explanation of Any Payment or Gift to Respondents

We will not be providing any remuneration or incentive to respondents. We believe this will have a detrimental effect on recruitment.

10. Assurance of Confidentiality Provided to Respondents

The Privacy Act does not apply to this data collection. Participants will not be asked about, nor will they provide, individually identifiable information.

11. Justification for Sensitive Questions

No information will be collected that are of personal or sensitive nature.

12. Estimates of Annualized Burden Hours and Costs

The estimate for burden hours is based on a two (2)-hour focus group discussion with up to 10 participating individuals in each of the four focus groups.

Estimates for the median hourly wage for respondents are based on the Department of Labor (DOL) 2014 estimates for all occupations: http://www.bls.gov/oes/current/oes_nat.htm#00-0000. The average hourly wage rate in 2014 of \$22.71 was used as an hourly wage estimate for or all 40 respondents. Table A-12 shows estimated burden and cost information.

Table A-12: Estimated Annualized Burden Hours and Costs to Respondents

Type of Respondent	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
Focus Group Participants	40	1	2	80	22.71	\$1,816.80
TOTALS	40	40		80		\$1,816.80

13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers

There will be no direct costs to the respondents other than their time to participate in the data collection.

14. Annualized Cost to the Government

The estimated cost of these focus groups to the government as part of this contract is \$40,000 which includes contractor and government full time equivalent staff time.

Table A-14: Estimated Annualized Cost to the Federal Government

Staff (FTE)	Average Hours per Collection	Average Hourly Rate	Average Cost
Social Science Analyst, GS 14	4	56.57	\$226.28
Social Science Analyst, GS 12	4	43.92	\$175.68
Estimated Total Cost of Information Collection			\$401.96

15. Explanation for Program Changes or Adjustments

This is a new data collection.

16. Plans for Tabulation and Publication and Project Time Schedule

The qualitative information gathered from the focus groups will be summarized by the Contractor in both a top line and final report on the focus groups. After each group session, ASPE staff will be consulted to provide input and direction to enhance subsequent sessions. The results will identify common themes, common processes, and unique situations. Findings will be shared with leadership in ASPE, ACL and CMS. The focus group transcripts will not be made public.

The focus groups will be convened during the first and/or second weeks in June 2016. Findings from the focus groups, including verbatim comments to illustrate key findings and session transcripts will be provided within two (2) weeks of completing each group. Upon completion of all the groups, the project team will prepare a Focus Group Report that summarizes methodology, findings, limitations and implications. This Report will be compiled into the Final Report for the project to be delivered on or before September 30, 2016.

17. Reason(s) Display of OMB Expiration Date is Inappropriate

We are requesting no exemption.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification. These activities comply with the requirements in 5 CFR 1320.9.

LIST OF ATTACHMENTS – Section A

Note: Attachments are included as separate files as instructed.

- A.** Draft Focus Group Discussion Guide
- B.** Recruitment Screener