

Supporting Statement for Alzheimer’s Disease Supportive Services Program Standardized Data Collection

A. Justification

1. Circumstances Making the Collection of Data Necessary

The revised Alzheimer’s Disease Supportive Services Program Data Reporting Tool (ADSSP-DRT) is needed in order to:

- Comply with the reporting requirements in the Public Health Services Act (PHS);
- Collect data for performance measures used in the justification of the budget to Congress and by program, state and national decision makers.
- Effectively manage the Alzheimer’s Disease Supportive Service Program (formerly known as the Alzheimer’s Disease Demonstration Grants to the States) at the federal, state and local levels.
- Advocate at the federal and state levels for more effective and efficient supports and services for persons with Alzheimer’s disease and their caregivers.

In 2007, AoA developed an ADSSP Data Collection Reporting Tool (ADSSP-DRT) and supporting documents (OMB#0985-0022). The ADSSP-DRT collects information about the delivery of supports and services by ADSSP state grantees, including basic demographic information about service recipients and spending on direct services and administrative expenses. The ADSSP-DRT was approved for use from June 7, 2007 through June 7, 2010.

This request is to extend, with some modifications, the use of the ADSSP-DRT from June 7, 2010 through June 7, 2013.

The current ADSSP-DRT and supporting documents are available at:

http://www.adrc-tae.org/tiki-index.php?page=OMB_ADDSPData

The revised ADSSP-DRT and supporting documents are available at:

http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/docs/ADSSP.pdf

The Public Health Services Act (PHS) requires AoA to “provide for an evaluation of each demonstration project for which a grant is made” under the Alzheimer’s demonstration projects and “submit to the Congress a report describing the findings made as a result of the evaluations”

(Section 280c-5d).

To fulfill the evaluation requirements and allow for optimal federal and state-level management of the program, specific information identified in the statute must be collected from grantees, including the following:

- A. The number of persons with Alzheimer’s disease and/or their family caregivers served by the program and their respective demographic characteristics. Section 280c-3 (3) requires that grantees “improve access...to home or community-based services [for persons with Alzheimer’s disease and/or their family caregivers]... particularly those individuals who are members of racial or ethnic minority groups, who have limited proficiency in speaking the English language”.
- B. The provision of direct services to persons with Alzheimer’s disease and/or their family caregivers. Section 280c-3 (2) requires that “home health care, personal care, day care, companion services, short-term care in health facilities, and other respite care” be provided.
- C. Information about federal funds spent on direct services and administrative costs. Section 208c-5c requires that “no more than 10 percent of the grant will be expended for administrative expenses with respect to the grant” and Section 208c-3b requires that grantees “expend not less than 50 percent of the grant on the provision of [direct services]”, including those listed in Section 280c-3 (s) (i.e. home health care, personal care, day care, companion services, short-term care in health facilities, and other respite care).

The following revisions of the currently approved ADSSP-DRT have been made:

1. From the Primary Caregiver demographics sheet:
 - a. Condensed the Age of the Person with Dementia into 2 categories to be consistent with other AoA data collection protocols.
 - b. Excluded the Frontier category from Geographic Location. The ADSSP legislation identifies that those who live in rural areas as a target population. Grantee respondents participating in the focus groups reported that calculating whether or not an area was frontier was difficult and burdensome. Under the definition on the “ADSSP Definitions for Data Collection” supplemental document, frontier would be included with the rural category.
 - c. Removed the following from the Relationship to Person with Dementia: Husband; Wife; Significant Other; Son/Son-In-Law; Daughter/Daughter-in-Law; and Sibling. These categories have been condensed to the following: Spouse; Unmarried Partner; Parent; other relative; and Non-Relative. The rationale behind this is that: husband or wife can both be captured by Spouse; Unmarried Partners are often identified as primary caregivers¹ and may not be captured by the Spouse

¹LGBT In the Aging Network. Accessed July 2, 2010 at: <http://www.asaging.org/networks/lain/lgainlinks.cfm?>

category; and the Other Relative category will include Son/Son-In-Law; Daughter/Daughter-in-Law; and Sibling.

- d. Removed Estimated Years of Caregiving. This is not required by law. Further, grantee respondents who participated in focus groups and expert consultants did not identify this as useful data.
 - e. Removed from the total number of caregivers, estimated number receiving any services through Title III of the Older Americans Act. This is not required by the ADSSP legislation and may be difficult to answer for those not familiar with Older Americans Act (OAA) Title III programs.
 - f. Added Unique Identifier field. This will be a number assigned to the program participant(s) to ensure that respondents are not counted twice.
2. From the Person with Dementia demographics sheet:
- a. Condensed the Age of the Primary Caregiver into 2 categories. The intent of this is to be consistent with other AoA data collection protocols.
 - b. Excluded the Frontier category from Geographic Location. The ADSSP legislation identifies that those who live in rural areas as a target population. Grantee respondents participating in the focus groups reported that calculating whether or not an area was frontier was difficult and burdensome. With the definition for given on the “ADSSP Definitions for Data Collection” supplemental document, frontier would be included with the rural category.
 - c. Removed the estimated number of Persons with Dementia receiving any services through Title III of the Older Americans Act. This is not required by the ADSSP legislation and may be difficult to answer for those not familiar with Older Americans Act (OAA) programs Title III programs.
 - d. Added Unique Identifier field. This will be a number assigned to the program participant(s) to ensure that respondents are not counted twice.
3. From the Services and Expenditures sheet:
- a. The Total Units of Direct Service have not been broken down into categories (i.e. adult day care; companion services; home health care; personal care; respite “other” (as approved); and short-term care in a health facility). A description of these services has already been provided to grantee respondents in the “ADSSP Definitions for Data Collection” supplemental document. Moreover, the ADSSP legislation does not require that AoA report a break down of these services by specific category.
 - b. Removed Unduplicated Persons Served. This is already captured in the caregiver and person with dementia sheets.
 - c. Removed Program Income Received. This is not a required data element in the ADSSP legislation and is already included in the SF-269² reports submitted to the AoA Office of Grants.
 - d. Removed Other ADDGS Services and Service Mode Types. These are not

[category=CAREGIVE](#)

² White House. Accessed July 2, 2010 from www.whitehouse.gov/OMB/grants/sf269.pdf

required by the ADSSP legislation and grantee respondents participating in focus groups have identified these as confusing.

4. The Development and Accomplishments sheet has been removed completely. This information is already captured in the semi-annual Program Progress Reports required for all ADSSP grantees³.

Two (2) items have been added to the ADSSP-DRT: Veteran Status and the Number of Entrants and Completers for evidence-based Alzheimer's disease programs:

1. Veteran status. Currently there are over 500,000 veterans diagnosed with Alzheimer's disease or related dementias.⁴ Providing quality care to this population is challenging because of the wide range of medical and social services needed. Data suggests that the VA serves a disproportionate number of low income persons, African-Americans and persons living in rural areas⁵, all of whom are target populations served by ADSSP programs which focus on hard-to-reach and underserved persons.

Family caregivers of veterans with dementia are often older spouses who are socially isolated lacking support, information and training.⁶ ADSSP programs provide these caregivers and their extended families with evidence-based caregiver interventions and a home and community-based service system that help veterans with dementia live at home and avoid unnecessary institutionalization.

2. The Number of Entrants and Completers for evidence-based Alzheimer's disease programs. Under the ADSSP, a portion of grants AoA awards are for the translation of evidence-based programs into community settings. Evidence-based program entrants are those individuals who begin the evidence-based intervention; those who finish the program (i.e. are considered to have attended enough of the sessions to make it possible to attribute any improvement in outcomes to the intervention) are program completers. In order for AoA to identify program implementation problems and provide appropriate technical assistance, it is important that any that any significant disparities between the number of program participants and program completers be identified as early as possible.

3 Guidelines for Preparing Program Progress Reports. Accessed July 2, 2010 from: http://www.aoa.gov/AoARoot/Grants/Reporting_Requirements/docs/2008_ADSSP_Reporting_Requirements.pdf

4 Office of Assistant Deputy Under Secretary for Health. Projections of the prevalence and incidence of dementias including Alzheimer's disease for the total, enrolled, and patient veteran populations age 65 and over. Washington, DC: Department of Veterans Affairs; 2004.

5 Krishnan LL, Petersen NJ, Snow AL, et al. "Prevalence of dementia among Veterans Affairs medical care system users," *Dementia and Geriatric Cognitive Disorders* 2005;20:245-253.

6 Maslow K, Skalny MA, Looman W. "Partners in Dementia Care: A Chronic Care Networks for Alzheimer's Alzheimer's Disease (CCN/AD) Project: Final Report," Alzheimer's Association, April 2005.

To develop the initial ADSSP-DRT and supporting documents, AoA worked closely with experts in the field of Alzheimer's disease and long-term care, as well as ADSSP program grantees. Likewise, AoA worked closely with these stakeholders to develop the revised ADSSP-DRT and supporting documents for this submission.

2. Purpose and Use of the Information Collection

Information from the revised ADSSP-DRT will be provided to: federal and state legislators; state agencies on aging; national, state and local organizations with an interest in Alzheimer's disease and long-term care issues; current and future ADSSP grantees; and private citizens who request it. Information will be posted on AoA's website, as well as a technical assistance website maintained by an AoA contractor.

Information that has been collected with the current ADSSP-DRT to date has been used:

- By AoA, to advocate within the Department on specific issues affecting persons with Alzheimer's disease and/or their family caregivers, pin-point areas where technical assistance to the states is indicated, and prepare planning and reporting documents;
- By AoA, to identify those states that have had success in serving disparate populations and work with grantees to develop materials that enable current and future grantees to learn from and replicate these practices; and
- By AoA, state, and local level managers of aging programs to compare operation of their ADSSP programs to other states and advocate for more effective program structure and sustainable funding to embed these model supports and services into state systems

Examples of products developed through this data collection are available at:

<http://www.adrc-tae.org/tiki-index.php?page=AboutADSSP> and

http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/index.aspx

3. Use of Improved Information Technology and Burden Reduction

In the initial approval for the ADSSP dataset, contract funds were included to develop an electronic system to capture and analyze the data. However, upon further analysis by AoA and feedback from ADSSP grantees, it was determined that the cost of maintaining an entirely new data system would not be an effective use of scarce federal and state funds, and might increase burden hours at the state level. As a result, the new electronic data system was not implemented; instead, grantees collected data using the approved ADSSP-DRT excel spreadsheets and submitted the spreadsheets, by e-mail, to AoA. State data were then aggregated and analyzed by AoA contractors and made available to the states and general

public, as planned in the initial approval.

For this revised dataset, a web-based form will be developed by an AoA contractor for grantees to enter data directly into a database. This existing database, which is maintained by an AoA contractor, can be easily adapted for use with the new ADSSP data set. As a result, developing an ADSSP web-based form will be less labor intensive and costly than developing an entirely new system. Because there will be no user fees associated with the use of the tools, states will have the flexibility to determine how the data is entered and by whom. For example, some states may choose to have local sites enter the data at the community level, while others may prefer to enter the data at the state level.

AoA is aware that different states have different capabilities in using web-based data forms. It is understood that, after the approval of the revised data set, AoA will need to work with ADSSP grantees to ensure easy access to the web-based form and provide regular training to ensure minimal burden. Once launched, the grantees will be trained in the use of the forms by an AoA contractor via a webinar that will be taped. The training webinar will be available on the reporting page of the ADSSP website for grantees to download and view at any time. Any new grantee will be directed to review the webinar online, as well as receive one to one technical assistance as needed.

4. Efforts to Identify Duplication and Use of Similar Information

All information in the currently approved data tool and proposed in this revision is unique to the ADSSP program grantees.

5. Impact on Small Businesses or Other Small Entities

No small businesses will be involved in this study.

6. Consequences of Collecting the Information Less Frequently

ADSSP grantees will submit data semi-annually. To meet the statutory requirements and execute program management functions, availability of current data is critical. The average project period for current grantees is approximately 24 months. If data was only submitted annually or once throughout the project period, AoA would be unable to promptly identify grantees in need of technical assistance to reach their goals (numbers served, numbers of underserved populations reached, etc.) and identify grantees who are exceeding the spending limits (no more than 10% of federal funds spent on administration) and not achieving the direct service spending requirements (at least 50% of federal funds spent on direct service) that are required by law.

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

None of the listed circumstances applies to this submission.

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

In December 2009, AoA initiated a review of the current ADSSP-DRT to ensure the acceptability of these items for evaluating the program and minimizing burden for respondents.

First, a review of the currently approved ADSSP-DRT and supporting documents was solicited from a group of experts in the fields of Alzheimer's disease and long-term care who were familiar with the history and goals of the ADSSP. Several suggestions for the improvement of the existing ADSSP-DRT were provided, reviewed by AoA, and incorporated into the tool and supporting documents.

Feedback on the current and revised tool and supporting documents was then solicited, by e-mail, from all current ADSSP grant project directors (N = 47); two e-mails soliciting feedback were sent over the course of three (3) weeks. Seven (7) grantees responded in written form and/or by telephone. AoA then reviewed this input and, again, modifications were made to fine tune the tool and supporting documents.

The result of this input is the revised ADSSP-DRT and supporting documents. As with the current ADSSP-DRT, AoA will work with ADSSP grantees to ensure easy access to a reporting system and offer regular training in using the tool to ensure minimal burden.

Between December 2009 and May 2010, the following ADSSP grant project directors provided feedback about the current and revised tool, including:

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Between November 2009 and December 2009, experts in the fields of Alzheimer's disease and/or long-term care provided feedback on the current tool,

including:

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A 60-day Federal Register Notice was published in the *Federal Register* on March 15, 2010, vol. 75, 49; pp. 12241 and is attached. There was one public comment received pertaining to the categories for race. In the revised tool and supporting documents, the race and ethnicity categories were condensed into one category. The comment suggested that the revised tool retain race and ethnicity as two distinct categories, which is consistent with the OMB data collections. As a result, the tool was revised to separate the race and ethnicity categories and make them consistent with other AoA and OMB data collections.

9. Explanation of any Payment or Gift to Respondents

Not applicable

10. Assurance of Confidentiality Provided to Respondents

Information provided for the ADSSP data collection requirement will be submitted in aggregate format, which means no individual or personal information will be transmitted. Confidentiality will not be compromised. Aggregate data will be used to inform: AoA, other federal agencies, Congress, state agencies on aging, ADSSP state grantees, and other relevant stakeholders about the progress being made and services provided through the ADSSP.

11. Justification for Sensitive Questions

The report does not include questions of a sensitive nature.

12. Estimates of Annualized Burden Hours and Costs

12A. Estimated Annualized Burden Hours

The estimated hourly burden for this revised ADSSP-DRT is based on the number of persons served in the most recent ADSSP grantee data submission. In FY2008, there were 28 grantees; their most recent reports, submitted 9/30/09, show 3,954 unduplicated persons served. Based on the average time reported by a sample of ADSSP state project directors to enter a case locally (60 minutes), total documentation time is calculated by multiplying total cases (3,954) by 60 minutes, totaling 237,240 minutes, which equates to 3,954 hours of paid and volunteer time ($237,240/60 = 3,954$). However, about 95% of the information entered for a typical case is for use at the state level (e.g. other participant demographics, use of other services, outcomes, etc.) and is not required for the ADSSP-DRT. Therefore, 5% of the 3,954 hours – 197.7 hours – is required to enter data needed for the ADSSP-DRT report annually. This equates to 7.06 hours per state ($197.7/28 =$ approximately 7.06)

Based on reports from a sample of ADSSP state project directors, states spent an average of 8 hours annually gathering data from local program sites and submitting the data to AoA. Data was submitted to the states from the local implementation sites and aggregated into the ADSSP-DRT excel spreadsheet. States differed in their methods of collecting data from local sites. In some states, local agencies reported aggregate data using state-specific electronic data reporting systems; in other states, local sites reported aggregate data on the ADSSP-DRT excel spreadsheet. Irrespective of collection method, states ensured that cumulative, aggregate data was submitted to AoA on the ADSSP-DRT spreadsheet.

Therefore, a fair estimate for the average amount of state staff time spent gathering the local data, correcting mistakes, entering it into the ADSSP-DRT and submitting the

report to AoA is 8 hours per state. This equates to a total of 224 hours total across the 28 states (8 x 28= 224).

Thus, the average time spent reporting annually equals:
 $197.7 \text{ (local)} + 224 \text{ (state)} = 421.7$; $421.7/28 =$ approximately 15 hours

We propose to increase the frequency of reporting from annually to semi-annually (see item15 for explanation). As of the end of FY 2010, a total of 47 grantees will be submitting data, so the anticipated annual burden would be $15 \times 2 = 30$ hours; $30 \text{ hours} \times 47 \text{ grantee respondents} = 1,410$ hours annually.

| Type of Respondent | Form Name | No. of Respondents | Frequency of Response | Average Time per Response (in hours) | Total Burden Hours (Annual) |
|--------------------|-----------|--------------------|-----------------------|--------------------------------------|-----------------------------|
| State Government | ADSSP-DRT | 47 | 2 | 15 | 1,410 |

12B. Costs to Respondents

Documentation (local level)

$7.06 \text{ hours} \times 2 \text{ (semi-annual reporting)} = 14.12 \text{ hours annually}$

$14.12 \text{ hours annually} \times \$15.65 \text{ per hour} = \$220.98 \text{ per state annually}$. This estimate is based on the projected salary for a local government social service worker 2010-2011 according to the U.S. Bureau of Labor Statistics⁷ (\$32,560 per year, divided by 52 weeks in a year, divided by 40 hour work week).

$\$220.98 \times 47 \text{ states} =$ approximately \$10,386 annually

Preparing ADSSP-SRT (state level)

$8 \times 2 \text{ (semi-annual reporting)} = 16$
 $16 \text{ hours} \times \$38 \text{ per hour (average state salary reported among ADSSP state project directors providing feedback)} = \$608 \text{ per state annually} \times 47 \text{ states} = \$28,576$ annually

| Type of Respondent | Total Burden Hours Per Respondent | Hourly Wage Rate | Total Annual Cost Per Respondent |
|--------------------|-----------------------------------|------------------|----------------------------------|
| | | | |

⁷ U.S. Bureau of Labor Statistics (2010). Occupational Outlook Handbook, Accessed May 12, 2010 from www.bls.gov/oco/ocos067.htm#earnings

| | | | |
|---------------------------|---------------------------------|---------|----------|
| Data Entry by Local Staff | 14.12 | \$15.65 | \$220.98 |
| ADSSP State Staff | 16.00 | \$38.00 | \$608.00 |
| Total | 30.12 or approximately 30 hours | | \$828.98 |

Total Annual Costs to All Respondents: \$828.28 x 47 = approximately \$38,962

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

There are no other costs to respondents or record-keepers or capital costs.

14. Annualized Cost to the Federal Government

| | |
|---|--|
| One GS 11-6 @ ten percent time Contract | \$7,287.60 \$15,000.00 ⁸ |
| TOTAL | \$22,287.60 |

15. Explanation for Program Changes or Adjustments

The annual reporting burden hour estimates have increased from 950 hours to 1410 hours. The following reasons account for the change in burden hour estimates:

- The new estimates are for 47 grantee respondents, rather than the 38 grantee respondents from the original ADSSP-DRT approval.
- Although, for the current data set, it was anticipated that grantee respondents would spend 25 hours spent reporting annually, the actual number of hours spent, as reported by the current ADSSP state grantees consulted, was 15 hours annually.
- The frequency of data reporting will increase from annually to semi-annually.

The annual reporting burden for grantees is anticipated to be 30 hours (15 twice yearly x 2). This is likely an over-estimate because several items included in the current tool are not included in the revised tool. Refinements have also been made to the supporting documents in order to streamline the data collection template and data definitions.

The proposed move from annual to semi-reporting came as a result of a re-evaluation of the ADSSP-DRT by AoA, experts in the field of Alzheimer’s disease and long-term care, and current ADSSP state grantees. Based on the collection experiences over the past three years, AoA and the expert reviewers believe that more frequent data collection

⁸ An AoA contractor provided this estimate, which includes the following tasks: semi-annual trainings of grantees on the use of the ADSSP-DRT; maintenance of a web platform; and data analysis (including tabulation and creating reports), based on contractual amounts available for data support...

would be helpful in order to comply with the requirements of the PHS Act, for federal level advocacy and for management of the program; all ADSSP state grantees consulted believed that more up-to-date information would be helpful for state-level advocacy.

16. Plans for Tabulation and Publication and Project Time Schedule

Data will be due semi-annually and reviewed by an AoA contractor. If inconsistencies are noted states will be asked to correct and resubmit their reports. Once all reports are in and verified, the data will be aggregated and analyzed by the contractor. Based on previous data collections, this process will take three to four months. When the national data is finalized, the information will be posted on the ADSSP website, which is available to the public. The contractor will provide AoA and state grantees access to the data in charts, graphs and other summaries depicting the national data and each state's data. A report, summarizing the findings and lessons learned, will be submitted to Congress no later than 6 months after each data submission.

OMB approval for an additional three (3) years is requested.

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

Not applicable – display is not inappropriate.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.

B. Statistical Methods (used for collection of information employing statistical methods)

These collections do not employ statistical methods.