

# Supporting Statement for Alzheimer's Disease Supportive Services Programs Standardized Data Collection

## A. Justification

### 1. Circumstances Making the Collection of Information Necessary

The Alzheimer's and Dementia Program Data Reporting Tool (ADP-DRT) (previously entitled: 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 ACL's Alzheimer's Disease Supportive Service Program (ADSSP) and Alzheimer's Disease Initiative - Specialized Supportive Services Project (ADI-SSS) 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.

The ADSSP Data Collection Reporting Tool (ADSSP-DRT) (OMB#0985-0022) was extended, with modifications, for August 31, 2013 through December 31, 2016. The ADSSP-DRT collects information about the delivery of supports and services by ACL Alzheimer Program grantees, including basic demographic information about service recipients and spending on direct services and administrative expenses.

This request is to modify the tool name and extend, with modifications, the use of the tool beginning January 1, 2017 through December 31, 2020.

This request is to also extend use of the ADP-DRT to include ACL grantees of the Alzheimer's Disease Initiative - Specialized Supportive Services (ADI-SSS) project. ADI-SSS projects are financed solely by Prevention and Public Health Funds. Similar in scope to ADSSP, ADI-SSS projects are designed to fill gaps in dementia-capable home and community based services (HCBS) for persons living with or those at high risk of developing Alzheimer's disease and related dementias (ADRD) and their caregivers by providing quality, person-centered services that help them remain independent and safe in their communities.

The current ADSSP-DRT (revised June 2013) is available at:

[http://nadrc.acl.gov/sites/default/files/uploads/docs/ADSSP\\_DataCollectionReportingForm.xlsx](http://nadrc.acl.gov/sites/default/files/uploads/docs/ADSSP_DataCollectionReportingForm.xlsx)

The proposed ADP-DRT (revised November 2016) is available at:

[https://nadrc.acl.gov/sites/default/files/uploads/docs/Proposed%20ADP-DRT%20Update%2011\\_30\\_2016.xlsx](https://nadrc.acl.gov/sites/default/files/uploads/docs/Proposed%20ADP-DRT%20Update%2011_30_2016.xlsx)

The Public Health Services Act (PHS) requires ACL to “provide for an evaluation of each demonstration project for which a grant is made” under the Alzheimer’s demonstration projects. (Section 280c-5d). Recipients of ADI-SSS are subject to the same evaluation requirements as ADSSP grantees.

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 changes of the currently approved ADSSP-DRT have been made:

1. All worksheets
  - a. Added fields for Grantee name, Grant ID, Reporting period dates, and Report submission date. This allows accurate identification of which grant submitted the data for which reporting period.

2. The Person with Dementia demographics sheet and Caregiver demographics sheets:
  - a. These two worksheets have been combined into one. This simplifies data entry for grantees. Change #2b has made it possible to combine the two worksheets.
  - b. Changed how Age demographics are tracked. Previously, age data were entered in columns, to allow cross-tabs with all other variables such as gender and geographic location (for example, Females Under 60 and Females 60+). Age will now be tracked in rows, which simplifies tracking of demographic data for grantees.
  - c. Race categories have been simplified. White-Hispanic and White Non-Hispanic have been combined into one category: White. Persons reporting some other race has been removed. Persons reporting 2 or more races have been removed. These changes reflect the OMB standards for race and ethnicity.
  - d. Relationship data categories have been simplified. Spouse and unmarried partner have been combined into one category: Spouse or partner. Parent and child data have been combined into one category: Parent. Other relative and non-relative have been combined into one category: Other caregiver. A category has been added: No caregiver. These changes allow us to simplify data tracking for grantees and accommodate changes in the types of persons being served more frequently by grantees, including those with dementia who do not have a caregiver.
  - e. Renamed Veteran Status categories. Previous categories included: Veteran, Non-veteran, Veteran status missing. New categories include: Served in the military, Has not served in the military, and Military status missing. These changes are intended to help fully capture the number of veterans being served, as many grantees and participants may misinterpret the word “veteran” to mean only those who have served in a war.
  - f. Created new category, Living Arrangement. One of the focus areas for ADI-SSS grants is persons with dementia who live alone. Adding this category enables the grant programs to better track how many persons with dementia being served are living alone, with or without an involved caregiver. Categories include: Lives alone, has an identified caregiver; Lives alone, no identified caregiver; Does not live alone; and Living arrangement missing.
3. The Professional Training worksheet was added
  - a. Added new data to be collected - Number of Persons Trained. Improving the dementia capability of health care and other community service providers has become an increased focus of ADSSP grants. This involves a greater emphasis on training professionals. Adding this category will enable the grant program to quantify training activities.

#### 4. Services, Expenditures and Participation worksheet

- a. Categories removed – Total federal funds spent on direct services and Total federal funds spent on administrative services. The dollar amounts that grants are spending on various components of their projects are reported through the federal cash transaction quarterly reports.
- b. The category Percentage of Federal Funds Spent on Direct Service Expenses was changed to Percentage of Funds Spent on Direct Services Expenses. This change was made to more accurately reflect the statutory spending requirements that apply to both the federal share and the state match portion of the budget.
- c. The category Percentage of Federal Funds Spent on Administrative Expenses was changed to Percentage of Funds Spent on Administrative Expenses. This change was made to more accurately reflect the statutory spending requirements that apply to both the federal share and the state match portion of the budget.
- d. Narrative categories have been updated to clarify the budget requirements for both ADSSP and ADI-SSS grants. These requirements have been broken out into two different rows.
- e. Participant Entrant and Completers data has been removed. The requirement to report on this data applied only to grants focused on implementing Evidence-Based Interventions. This type of grant is no longer being funded, thus this requirement no longer applies.

## **2. Purpose and Use of the Information Collection**

Information from the ADP-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 ACL Alzheimer Program grantees; and private citizens who request it. Information will be posted on ACL's National Alzheimer's and Dementia Resource Center (NADRC) website (<http://nadrc.acl.gov/>).

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

- By ACL, 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, such as the US National Alzheimer's Plan;
- By ACL, 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 ACL, state, and local level managers of aging programs to compare operation of their Alzheimer 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://nadrc.acl.gov/>

### **3. Use of Improved Information Technology and Burden Reduction**

Grantees collect data using the approved ADSSP-DRT excel spreadsheets and submit the data to ACL. There are no user fees associated with the use of the tools and 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. State data are aggregated and analyzed by ACL contractors and made available to the states and general public.

ACL is aware that different states have different capabilities in using data forms. ACL will continue to work with ACL Alzheimer Program grantees to ensure easy access to the form and provide regular training to ensure minimal burden. Current grantees have been trained in the use of the forms by an ACL contractor. Any new grantee receives 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 and ADI 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 and ADI 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 31 months. If data was only submitted annually or once throughout the project period, ACL 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 ADSSP 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**

A 60-day Federal Register Notice was published in the *Federal Register* on August 23, 2016, Vol. 18, No. 136; pp. 57591. There was one public comment received pertaining to the categories for living arrangements. The comment suggested that the category needed to have a clear definition. As a result, the tool was revised by condensing the categories and ACL will provide an update to its definition of terms.

**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: ACL, other federal agencies, Congress, state agencies on aging, ACL Alzheimer Program grantees, and other relevant stakeholders about the progress being made and services provided through the ACL Alzheimer Programs.

**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 ADP-DRT is based on the number of persons served in the most recent ADSSP and ADI grantee data submission. At the end of FY 2016, there will be a total of 36 grantees administering a total of 38 grants. Based on reports from a sample of ADSSP and ADI grants, there are approximately 2 local program sites per grant. ADSSP-DRT related data entry by local program sites requires an average of 9.34 hours of paid and volunteer time annually per local program site. This equates to a total of 709.84 hours total across the 38 grants (9.34 hours x 2 sites x 38 grants = 709.84 hours).

Based on reports from a sample of ADSSP and ADI grants, grantees spend an average of 7.2 hours annually per grant gathering data from local program sites and submitting the data to ACL. Data is submitted to the grantees from the local program sites and aggregated into the ADSSP-DRT. Grantees differ in their methods of collecting data from local sites. Some grantees have local sites report aggregate data using state-specific electronic data reporting systems; other grantees have local sites report aggregate data on the ADSSP-DRT. Regardless of collection method, grantees ensured that cumulative, aggregate data was submitted to ACL using the ADSSP-DRT.

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 ACL is 7.2 hours per grant. This equates to a total of 273.6 hours total across the 38 grants (7.2 hours x 38 grants = 273.6 hours).

Thus, the average time spent reporting for a single grant annually equals: 709.84 hours (local partner) + 273.6 hours (grantee) = 983.44 hours; 983.44 hours/38 grants = approximately 25.88 hours per grant.

<b>Type of Respondent</b>	<b>Form Name</b>	<b>No. of Respondents</b>	<b>Frequency of Response</b>	<b>Average Time per Response (in hours)</b>	<b>Total Burden Hours (Annual)</b>
<b>Local Program Site</b>	ADSSP-DRT	76	2	4.67	709.84
<b>Grantee</b>	ADSSP-DRT	38	2	3.6	273.6
<b>Total</b>					983.44

## **12B. Costs to Respondents**

### Documentation (local level)

4.67 hours x 2 (semi-annual reports) = 9.34 hours annually

9.34 hours annually x \$22.07 per hour = \$206.13 per local respondent annually. This estimate is based on the projected salary for a local government social service worker, according to the U.S. Bureau of Labor Statistics<sup>1</sup> (\$45,900 per year, divided by 52 weeks in a year, divided by 40 hour work week).

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<sup>1</sup> Bureau of Labor Statistics, U.S. Department of Labor, *Occupational Outlook Handbook, 2016-17 Edition*, Social Workers, on the Internet at <http://www.bls.gov/ooh/community-and-social-service/social-workers.htm> (visited May 03, 2016).

\$206.13 x 76 local sites = \$15,665.88 annually

Preparing ADSSP-DRT (grantee level)

3.6 hours x 2 (semi-annual reports) = 7.2

7.2 hours x \$35.27 per hour (average salary reported among ADSSP project directors) = \$253.94 per grant annually x 38 grants = \$9,649.72 annually

Type of Respondent	No. of Respondents	Total Annual Burden Hours Per Respondent	Hourly Wage Rate	Total Annual Cost Per Respondent	Total Annual Cost Per Grant
Data Entry by Local Site Staff	76	9.34	\$22.07	\$206.13	\$412.26
Data Preparation for submission by Grantee Staff	38	7.2	\$35.27	\$253.94	\$253.94

Total Annual Costs to All Respondents: \$15,665.88 (local) + \$9,649.72 (grantee) = \$25315.60.

**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 13 @ 2 percent time	\$2,580
Contract	\$9,110 <sup>2</sup>
<b>TOTAL</b>	<b>\$11,690.00</b>

**15. Explanation for Program Changes or Adjustments**

The annual reporting burden hour estimates have decreased from 1176 hours to 983.44.

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<sup>2</sup> An ACL contractor provided this estimate, which includes semi-annual trainings for grantees on the use of the ADSSP-DRT and data analysis (including tabulation and creating reports), based on contractual amounts available for data support.

The following reasons account for the change in burden hour estimates:

- Although, for data set approved in 2013, it was anticipated that grantee respondents would spend 39 hours reporting annually, the actual number of hours spent (local and state combined), as reported by the current ADSSP and ADI grantees consulted, was 16.54 hours annually per grant
- The 39 hours annual burden hour estimate from 2013 was an over-estimate because data provided from grantees were based on the 2010 version. Several items included in the 2010 tool were not included in the 2013 revised tool. The 2016 revision includes fewer items than the 2013 revision.

The following reasons account for the change in burden cost estimates:

- The new estimates are for 38 grants, rather than the 30 grants from the previous ADSSP-DRT approval.
- The pay rates for both local and grantee staff increased between 2013 and 2016.
- The annualized cost to the government decreased due to decreased contractor costs through the elimination of maintenance for a data collection web platform.

#### **16. Plans for Tabulation and Publication and Project Time Schedule**

Data will be due semi-annually and reviewed by an ACL contractor. If inconsistencies are noted, grantees 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 National Alzheimer's and Dementia Resource Center (NADRC) website, which is available to the public. The contractor will provide ACL and grantees access to the data in charts, graphs and other summaries depicting the national data and each state's data.

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.