

**Supporting Statement for Alzheimer’s disease Programs Standardized Data Collection**  
**OMB control number 0985-0022**  
**Expiration 12/30/2020**

**A. Justification**

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

The Alzheimer’s and Dementia Program Data Reporting Tool (ADP-DRT) is needed in order to:

- 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 Program 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 Alzheimer’s and Dementia Program Data Reporting Tool (ADP-DRT) (OMB#0985-0022) was extended, with modifications, for June 22, 2017 through December 30, 2020. The ADP-DRT collects information about the delivery of supports and services by ACL Alzheimer’s Disease 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.

The Older American’s Act requires ACL to evaluate “demonstration projects that support the objectives of this Act, including activities to bring effective demonstration projects to scale with a prioritization of projects that address the needs of underserved populations, and promote partnerships among aging services, community-based organizations, and Medicare and Medicaid providers, plans, and health (including public health) systems. (Section 201 (42 U.S.C. 3011) Sec. 127. Research and Evaluation).

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

- A. The number of persons with Alzheimer’s disease or related dementia or at high risk of dementia and/or their caregivers served by the program and their respective demographic characteristics.
- B. The number of professionals trained in dementia education, care and best practices.
- C. Information about grant funds spent on direct services, program administration

- costs and general organizational administrative costs.
- D. The provision of direct services to persons with Alzheimer’s disease or related dementia or at high risk of dementia and/or their caregivers.

The following changes of the currently approved ADP-DRT have been made:

1. All worksheets
  - a. Added language indicating that all numbers reported should be cumulative and unduplicated from the grant start date.
  - b. Added language indicating “Do not add or modify rows or columns.”
  - c. Added language and a link directing users to a document that provides definitions and answers to frequently asked questions (FAQs).
2. The Person with Dementia and Caregiver demographics worksheet:
  - a. Within the category Living Arrangement, divided the category Does Not Live Alone into two: 1) Lives with a Caregiver and 2) Lives with Someone Who is Not a Caregiver. This helps to address the common situation where the person with dementia’s living companion has their own impairment or limitation that prevents them from providing care.
3. The Professional Training worksheet
  - a. Changed header from Persons Trained to Professionals Trained, By Function to emphasize that this worksheet should not include general outreach and education and that grantees should categorize respondents by function rather than by credential.
  - b. Changed the category Health Educators, Interventionists to Other Dementia-Related Program Providers with examples illustrating the types of providers intended. This change was made based on grantee feedback that the term “interventionist” is not meaningful to respondents.
  - c. Changed the category Health Care Providers to Medical Care Providers to better distinguish from other types of health care roles.
  - d. Added a category for Allied Health Professionals to better capture professionals such as occupational therapists who are frequently part of Alzheimer’s grant projects.
  - e. Added a category for Volunteers who are delivering direct services through the project.

- f. For the category First Responders, added note in parentheses to clarify that this may include both paid and unpaid responders.
  - g. Added a category for financial professionals.
  - h. Removed the example “banks” from the Community business category and replaced it with “hairdressers” because “banks” now fit within the new Financial professionals category
  - i. Added a category for Students who are preparing for dementia-related work
  - j. Added a category for Profession Missing
  - k. Added a row for Total Professionals Trained
4. Services & Expenditures worksheet
- a. Category divided into two: Total Units of Direct Service Delivered was divided into 1) Total Units of Direct Service Delivered, Persons with Dementia and Caregivers and 2) Total Units of Direct Service Delivered, Professionals Trained
  - b. Category added – one category was added to the Expenditures data to indicate the Percentage of Total Budget Spent on Other Programmatic Expenses. This was added to clarify the data collection for grantees, who often overlooked this category in their calculations.
  - c. Removed two lines that included statutory requirement information related to ADSSP and ADI-SSS grants. Because no new grants are being funded in these areas, the information is no longer relevant. Slightly edited notes to clarify expenditure requirements and where more information can be found.

## **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 related dementia and long-term care issues; current and future ACL Alzheimer’s Disease 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 ADP-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 and state Alzheimer plans;

- 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 and public health programs to compare operation of their Alzheimer's programs to other states and organizations and advocate for more effective program structure and sustainable funding to embed these model supports and services into state and local 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 ADP-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 grantees 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. Data are aggregated and analyzed by ACL contractors and made available to grantees and the general public.

ACL is aware that different grantees have different capabilities in using data forms. ACL will continue to work with ACL Alzheimer's Disease 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 ACL Alzheimer's Disease Program grantees.

### **5. Impact on Small Businesses or Other Small Entities**

No small businesses will be involved in this work.

### **6. Consequences of Collecting the Information Less Frequently**

Grantees will submit data semi-annually. To 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 not achieving the direct service spending requirements (at least 50% of funds spent on direct service) that are outlined in the program announcements.

#### **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 July 16, 2020, Vol. 85, No. 137; pp.43241-43242. ACL received the below outside consultation post on the NADRC site during the comment period. ACL provided an acknowledgment of comment.

A 30-day Federal Register Notice published in the *Federal Register* on October 23, 2020, Vol. 85, No. 206; pp. 67549-67550.

#### **Comments on Proposed Collection: Alzheimer’s and Dementia Program Data Reporting Tool (ADP-DRT) OMB #0985-0022**

##### **General**

It would be helpful if the explanation of categories and definitions for all data elements were part of this information collection (ie, PRA process). It is difficult to comment on estimated burden and utility of the information collection when the information being collected hasn’t been fully explained. Also, definitions and data elements should be synchronized or crosswalked to those in the American Community Survey or another national collection to facilitate analyses across data collections.

##### **PLWD & CG served**

CG data points - It is important to get a more fulsome profile of the caregivers to assess the impact caregiving has on their lives, their families, and those they care for. Understanding this data collection may not be for this purpose, a few extra data points could shed help expand the CG profile: employment status, # of chronic diseases, # of people cared for, # recent traumas experienced (eg, emotional, physical, etc.), etc.

There are sections on race and ethnicity. It’s not clear what is meant by “Minority Status” or why it’s needed. This section should be deleted to reduce burden.

Living arrangement – This section describes who the PLWD lives with but doesn’t identify where the person is living. It would be helpful to know whether these individuals are living in a private home setting, an institutional setting such as a nursing home, supportive housing, or if they are experiencing homelessness. It would also be helpful to know where they are receiving most of their care – ie, in the home or outside of the home. Where people are receiving their care is relevant to the workforce and services needed to support them.

##### **Professionals Trained**

The note at the bottom states, “Persons trained should not include.... Caregivers...” but there are caregivers who are trained and licensed and some family caregivers who receive stipends from Medicaid and other programs.

It’s not clear if they would be excluded. Also, in the middle of the sheet there’s a section on “Total Units of Direct Service Delivered.” How does this relate to Professionals Trained? This heading may belong to the last worksheet.

##### **Services & Expenditures**

Assuming that grantees can accurately report these totals if they have more granular data, there wouldn’t be much more burden added if grantees reported the details behind “Total Units of Direct Service Delivered.” This should be broken out by service/expenditure type. Also, there should be separate column for PLWD and for CG. As noted

previously, direct services for PLWD should be separated from direct services for the CG to get a better understanding the impact AD caregiving on family members.

**9. Explanation of any Payment or Gift to Respondents**

Not applicable

**10. Assurance of Confidentiality Provided to Respondents**

Information provided for the ADP-DRT data collection requirement will be submitted in aggregate format, which means no individual or personal information will be transmitted. There are no assurances of confidentiality. Aggregate data will be used to inform: ACL, other federal agencies, Congress, state agencies on aging, ACL Alzheimer’s Disease Program grantees, and other relevant stakeholders about the progress being made and services provided through the ACL Alzheimer’s Disease Program.

**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 grantee data submission. At the end of FY 2020, there will be a total of 88 grantees administering a total of 90 grants. Based on reports from a sample of grants, there are approximately 2 local program sites per grant. ADP-DRT related data entry by local program sites requires an average of 6.06 hours of time annually per local program site. This equates to an annual total of 1,090.8 hours total across the 90 grants (6.06 hours x 2 sites x 90 grants = 1,090.8 hours).

Based on reports from a sample of grants, grantees spend an average of 13.86 hours annually per grant gathering internal data and/or data from local program sites and submitting the data to ACL. Data is collected internally by the grantee and/or sent to the grantees from the local program sites and aggregated into the ADP-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 ADP-DRT Excel workbook. Regardless of collection method, grantees ensured that cumulative, aggregate data are submitted to ACL using the ADP-DRT.

A fair estimate for the average amount of grantee staff time spent annually gathering the local program site data, correcting mistakes, entering it into the ADP-DRT and submitting the report to ACL is 13.86 hours per grant. This equates to an annual total of

1,247.4 hours total across the 90 grants (13.86 hours x 90 grants = 1,247.4 hours).

Thus, the average time spent reporting for a single grant annually equals:  
 6.06 hours (local program site 1) + 6.06 hours (local program site 2) + 13.86 hours (grantee) = 25.98 hours per grant.

Type of Respondent	Form Name	No. of Respondents	Frequency of Response	Average Time per Response (in hours)	Total Burden Hours (Annual)
Local Program Site	ADSSP-DRT	180	2	3.03	1,090.8
Grantee	ADSSP-DRT	90	2	6.93	1,247.4
<b>Total</b>		270			2,338.2

**12B. Costs to Respondents**

Documentation (local level)

3.03 hours x 2 (semi-annual reports) = 6.06 hours annually

6.06 hours annually x \$24.26 per hour = \$147.02 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>

\$147.02 x 180 local program sites = \$26,463.60 annually

Preparing ADP-DRT (grantee level)

6.93 hours x 2 (semi-annual reports) = 13.86  
 13.86 hours x \$47.62 per hour (average salary reported among ACL ADP project directors) = \$660.01 per grant annually x 90 grants = \$59,401.18 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

1 Bureau of Labor Statistics, U.S. Department of Labor, *Occupational Outlook Handbook*, Social Workers, on the Internet at <https://www.bls.gov/ooh/community-and-social-service/social-workers.htm> (visited May 07, 2020).

Data Entry by Local Program Site Staff	180	6.06	\$24.26	\$147.02	\$294.04
Data Preparation for submission by Grantee Staff	90	13.86	\$47.62	\$660.01	\$660.01

Total Annual Costs to All Respondents: \$26,463.60 (local) + \$59,401.18 (grantee) = \$85,864.78.

**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 14 @ 2 percent time	\$2,600
Contract	\$22,111.67 <sup>2</sup>
<b>TOTAL</b>	<b>\$24,711.67</b>

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

There is a program change increase of 1346 annual burden hours. The annual reporting burden hour estimates have increased from 983 to 2,329.

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

- The new estimates are for 90 grants, rather than the 38 grants from the previous ADP-DRT approval, a 136% increase in the number of grants.
- Although, for data set approved in 2016, it was anticipated that grantee respondents would spend 25.88 hours reporting annually, the actual number of hours spent (local partners and grantee combined), as reported by the current ADP grantees consulted, was 19.92 hours annually per grant.

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

- The new estimates are for 90 grants, rather than the 38 grants from the previous ADP-

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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 ADP-DRT and data analysis (including quality checks, tabulation and creating reports), based on contractual amounts available for data support.



DRT approval. This also include data collection from 180 local partners, rather than 76 local partners from the previous ADP-DRT approval

- The pay grades and pay rates for local partner and grantee staff increased between 2016 and 2020.
- The annualized cost to the federal government increased due to increased contractor costs to analyze the data of the increased in the number of grantees and a pay grade increase for the federal project officer.

**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.