

## Definitions of Data Collection Terms

The ACL's ADP requires data collection on people served, professionals trained, and direct services provided. Specifically, grant programs are required to report basic demographic information, numbers and types of professionals trained, units of direct service specific to the project, and expenditures for direct service, administrative, and other programmatic expenses.

**All data are reported cumulatively from the beginning of the grant project. Grantees may choose to collect and share additional data in their narrative report but, at minimum, must submit the required data set** using the ADP-DRT Data Collection Reporting Form found online at <https://nadrc.acl.gov/node/106>. Data must be submitted on a semiannual basis as a "Grant Note" in GrantSolutions and with the final grant report.

*Please note that name, Social Security number, or any other type of identifying participant information should not be reported to ACL.*

If you have any questions or concerns about data collection or reporting, please contact your assigned National Alzheimer's and Dementia Resource Center technical assistance staff member.

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### Person Living with Dementia and Caregiver – Characteristics

Participants should be given the opportunity to select the demographic categories that apply to them, except for Minority Status which must be assigned by project staff, not by the participant. Participants should choose only one response within each demographic category, except for Race where they can choose all responses that apply.

#### Person Living with Dementia (PLWD)

The person with diagnosed or undiagnosed Alzheimer's disease or a related dementia. Related dementias include, but are not limited to, vascular dementia, Lewy Body dementias, frontotemporal degeneration disorders, Parkinson's disease, mixed dementia, and normal pressure hydrocephalus.

#### Caregiver (CG)

The person who provides care to a person living with dementia or who is responsible for directing and managing the care of a person living with dementia. This definition refers to unpaid caregivers, such as family or friends, rather than paid caregivers, such as certified nursing assistants or personal care attendants. Some people with dementia have more than one caregiver; for the purposes of this data collection, collect data from only the caregivers receiving direct services as part of the ACL grant project as defined later in this document.

## Age

- Under 60
- 60+
- Age Missing—Includes missing data and age not specified by participant

## Gender

- Female
- Male
- Gender Missing—Includes missing data and gender not specified by participant

## Geographic Location

- Urban—A central place and its adjacent densely settled territories with a combined minimum population of 50,000
- Rural—Not urban
- Geographic Location Missing—Includes missing data and location not specified by participant

## Ethnicity

- Hispanic or Latino—A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term “Spanish origin” can be used in addition to “Hispanic or Latino.”
- Not Hispanic or Latino
- Ethnicity Missing—Includes missing data and ethnicity not specified by participant

## Race Status

Important: Respondents should ideally be given the opportunity for self-identification and must be allowed to designate all categories that apply to them.

- American Indian or Alaska Native—A person having origins in any of the original peoples of North America (including Central America) and who maintains tribal affiliation or community attachment
- Asian or Asian American—A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam
- Black or African American—A person having origins in any of the black racial groups of Africa
- Native Hawaiian or Other—Pacific Islander A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands
- White—A person having origins in any of the peoples of Europe, the Middle East, or North Africa
- Race Missing—Includes missing data and race not specified by participant

## Minority Status

Important: This category integrates data from Ethnicity and Race Status and therefore must be entered by program staff, NOT by the participant.

- Minority—Minority populations are defined as Hispanic or Latino, American Indian or Alaska Native, Asian or Asian American, Black or African American, or Native Hawaiian and Pacific Islander
- Not Minority
- Minority Status Missing—Includes missing data and status not specified by participant

## Military Status

- Served in the military—A person who has served in the military is an individual who is a former member of any of the U.S. Armed Forces
- Has not served in the military
- Military Status Missing—Includes missing data and status not specified by participant

## Relationship to Caregiver

Relationship to caregiver data is about the connection between the person living with dementia and his or her caregiver.

- Spouse or Partner
- Parent
- Other Caregiver
- No Caregiver
- Relationship Missing—Includes missing data and relationship not specified by participant

## Living Arrangement

Living arrangement data is about who a person living with dementia resides with and the identification of a caregiver, a person who provides care of an individual living with dementia. A person living with dementia who does not live alone may live with a caregiver or with someone who is not a caregiver.

- Lives alone, has an identified caregiver
- Lives alone, no identified caregiver
- Lives with a caregiver
- Lives with someone who is not a caregiver
- Living Arrangement Missing—Includes missing data and living arrangement not specified by participant

## Professional Training

This category enables the grant program to quantify training of health care and other community service providers across all grants.

Professionals trained may include the following:

- Information and referral providers, Options Counselors
- Case managers, care coordinators, discharge planners
- Other dementia-related program providers (e.g., caregiver skills trainers, support group facilitators, adult day services staff)
- Direct care workers (e.g., certified nursing assistants, personal care attendants, companions)
- Medical care providers (e.g., physicians, nurse practitioners, physician assistants)
- Allied health providers (e.g., occupational therapists, pharmacists, dietitians)
- Volunteers (e.g., Meals on Wheels, friendly visitors)
- First responders (paid and unpaid)
- Legal professionals
- Financial professionals (e.g., bank tellers, financial planners)
- Community businesses (e.g., retail store employees, café baristas, hairdressers)
- Clergy, other members of faith community
- Students preparing for dementia-related work
- Other
- Profession missing

## Services and Expenditures

### Direct Services

Direct services include both services delivered to people living with dementia and caregivers and professional training. Outreach activities such as health fairs or brief telephone referral contacts should not be counted as direct services. Please note, one unit of direct service equals 1 hour, except for durable goods.

Grant projects should avoid duplicative counting of services. For example, if a person living with dementia attended 1 hour of adult day care for both the purpose of socialization for the person living with dementia and to provide respite for their caregiver, only one unit of direct service can be counted.

### Administrative Expenses

Administrative expenses are the direct and indirect costs related to (1) routine grant administration and monitoring (for example, receipt and disbursement of program funds, preparation of routine programmatic and financial reports, and compliance with grant conditions and audit reports); and (2) contract development, solicitation, review, and monitoring of contracts.

### Other Programmatic Expenses

Other programmatic expenses include costs associated with substantive programmatic work such as revising the work and evaluation plans, program planning meetings, translating evidence-based research protocols, outreach and recruitment, marketing, developing a curriculum, and evaluation and information dissemination.

## Calculating Percentage of Cumulative Grant Funds Spent

Percentage of cumulative grant funds spent is calculated using total grant funds spent to date for the grant project, including both federal and match funds, as the denominator.

### *Direct Service Expenses*

Total Grant Funds (Federal and Match) Spent on Direct Services to Date

Total Grant Funds (Federal and Match) Spent to Date

### *Administrative Expenses*

Total Grant Funds (Federal and Match) Spent on Administrative Expenditures to Date

Total Grant Funds (Federal and Match) Spent to Date

### *Other Programmatic Expenses*

Total Grant Funds (Federal and Match) Spent on Other Programmatic Expenses to Date

Total Grant Funds (Federal and Match) Spent to Date

### Public Burden Statement:

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless such collection displays a valid OMB control number (OMB 0985-0022). Public reporting burden for this collection of information averages and estimate of seven hours per response, including time for gathering, maintaining the data, completing, and reviewing the collection of information. The obligation to respond to this collection is required to retain or maintain benefits under the statutory authority [Section 201 (42 U.S.C. 3011) Sec. 127.].