Alzheimer's and Dementia Program Data Reporting Tool (ADP-DRT) Data Collection Terms

Definition of Terms

The Administration for Community Living's (ACL's) Alzheimer's and Dementia Program (ADP), includes the Alzheimer's Disease Program Initiative. The required data collection for this program includes reporting basic demographic information, numbers and types of professionals trained, hours of direct service specific to the project, and direct service and administrative expenditures.

Although ACL encourages discussion among grantees regarding the procedures states and communities might adopt to collect required data, grantees are ultimately responsible for developing their own data collection protocols.

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.

Person Living with Dementia and Caregiver - Characteristics

Participants should ideally be given the opportunity to select the demographic categories that apply to them and except for Race, should choose only one response within each demographic category

Program Participants

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 of an individual living with dementia or who is responsible for directing and managing the care of an individual 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 persons living 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 Identity

- Woman
- Man
- Non-binary An umbrella term for gender identities that lie outside the gender binary
- Use a different term
- Prefer not to answer
- Gender Missing: Includes missing data and gender identity not specified by participant

Transgender

- Yes
- No
- Prefer not to answer
- Transgender missing: Includes missing data and transgender not specified by participant

Transgender – A person whose current gender identity is different from the sex they were assigned at birth

Sexual orientation

- Lesbian or gay
- Straight, that is, not gay or lesbian
- Bisexual
- Use a different term
- Don't know
- Prefer not to answer
- Sexual orientation missing: Includes missing data and sexual orientation not specified by participant

Lesbian or gay – Sexually oriented toward people of the same, usually binary, gender

Straight, that is, not gay or lesbian – Sexually oriented toward people of a different, usually binary, gender

Bisexual – Sexually oriented toward both men and women

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
- Non-Hispanic or Latino
- Ethnicity Missing: Includes missing data and ethnicity not specified by participant

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."

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
- Asian or Asian American
- Black or African American
- Middle Eastern North African
- Native Hawaiian or Other Pacific Islander
- White
- Some Other Race
- Race Missing: Includes missing data and race not specified by participant

American Indian or Alaska Native—A person having origins in any of the original peoples of North and South 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.

Middle Eastern North African—A person having origins in Algeria, Bahrain, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Qatar, Saudi Arabia, Syria, Tunisia, United Arab Emirates or Yemen.

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 original peoples of Europe.

Some Other Race—Participant identifies with a race not listed.

Minority Status

- Minority
- Not Minority
- Minority Status Missing: Includes missing data and status not specified by 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. Note that this category integrates data from Ethnicity and Race Status and therefore **must be entered by program staff, NOT by the participant.**

Intellectual & Developmental Disability

- Persons with IDD
- Persons without IDD
- IDD status missing

IDD—Intellectual and developmental disability. Intellectual disability starts any time before a child turns 18 and is characterized by differences with both intellectual functioning or intelligence (the ability to learn, reason, problem solve, and other skills); and adaptive behavior, which includes everyday social and life skills. The term "developmental disabilities" is a broader category of often lifelong challenges that can be intellectual, physical, or both. The term "IDD" is often used to describe situations in which intellectual disability and other disabilities are present. https://www.nichd.nih.gov/health/topics/idds/conditioninfo

Military Status

A person who has served in the military is an individual who is a former member of any of the U.S. Armed Forces.

- Served in the military
- Has not served in the military
- Military Status Missing: Includes missing data and status not specified by participant

Relationship to Caregiver

Relationship data is in reference to 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 in reference to who a person living with dementia lives 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 an 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:

- Any IDD providers
- 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 services delivered to persons living with dementia, caregivers, and other community members, and training provided to professionals. Outreach activities such as health fairs or brief telephone referral contacts should <u>not</u> be counted as direct services. Please note, in most cases one unit of direct service equals 1 hour.

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 service could be counted.

Administrative Expenses

Administrative expenses are the direct and indirect costs related to (1) routine grant administration and monitoring (for example, receipt and disbursal 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, meeting about workplan objectives, translating evidence-based research protocols, outreach and recruitment, marketing, developing a curriculum, and evaluation and information dissemination.

Calculating Percentage of Total Budget Spent

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

Direct Service Expenses

Total Grant Funds Spent on Direct Services to Date
Total Grant Funds Spent for Your Grant to Date

Administrative Expenses

<u>Total Grant Funds Spent on Administrative Expenditures to Date</u> Total Grant Funds Spent for Your Grant to Date

Other Programmatic Expenses

<u>Total Grant Funds Spent on Other Programmatic Expenses to Date</u>
Total Grant Funds Spent for Your Grant to Date