

Definition of Terms

Grant ID and Report Dates

Grantee Name—the name of the agency or organization that was awarded the grant

Grant ID—the 8-digit ID number assigned to each grantee

Reporting period—the grant's start date (#6 on the Notice of Award form) through the last date of the reporting period (the format should be: mm/dd/yyyy – mm/dd/yyyy)

Report submission date—the date the report was uploaded to GrantSolutions

Person with Dementia and Caregiver Characteristics

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

Program Participants

The number of participants reported should be unduplicated. For example, a caregiver who receives three types of direct service should be counted as one participant, not three.

Person with Dementia—a person with diagnosed or undiagnosed Alzheimer's disease or a related dementia. Related dementias include, but are not limited to: Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, Parkinson's disease, Normal Pressure Hydrocephalus and Creutzfeldt-Jakob disease.

Caregiver— any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, a person with dementia. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care. This definition refers to informal caregivers, rather than formal caregivers, such as paid healthcare professionals. In states with consumer direction, an informal caregiver may also be a paid caregiver.

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 geographic location not specified by participant

Race

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

- White–Non-Hispanic
- White–Hispanic
- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- Persons Reporting Some Other Race
- Persons Reporting 2 or More Races
- Race Missing: Includes missing data and race not specified by participant

White—a person having origins in any of the peoples of Europe, the Middle East, or North Africa.

American Indian or Alaskan 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—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.

Veteran Status

A veteran is an individual who is a former member of the US Armed Forces.

- Veteran
- Non-Veteran
- Veteran Status Missing: Includes missing data and status not specified by participant

Relationship

Relationship data is in reference to the connection between the person with dementia and their primary caregiver.

- Spouse or partner
- Parent
- Other caregiver
- No caregiver
- Relationship Missing: Includes missing data and relationship not specified by participant

Living Arrangement

Living arrangement refers to the person with dementia

- Lives alone
- Does not live alone
- Living arrangement missing: Includes missing data and living arrangement not specified by participant

Professional Training

Persons Trained

The number of persons reported should be unduplicated. For example, a nurse who participates in two different trainings is counted as one participant, not two.

Persons trained refers to persons who are taught specific knowledge, skills, or behaviors that are intended to be used in the course of their **paid employment**. Not included are trainings for family caregivers or general community presentations.

- Information and referral providers, options counselors
- Case managers, care coordinators, discharge planners
- Direct care workers (certified nursing assistants, personal care attendants, companions)
- Health care providers (physicians, nurse practitioners, nurses)
- Health educators, interventionists (providing training to PWD or caregivers)
- First responders
- Clergy, other members of faith community
- Legal professionals
- Community businesses (banks, retail stores, pharmacies, restaurants, etc)
- Other

Information and referral providers, options counselors—educate consumers about community services and supports and make appropriate referrals. Options counselors provide support to persons with dementia and their caregivers in decision making about care options.

Case managers, care coordinators, discharge planners—activities include assessment, planning, coordination of patient care between multiple parties, connecting patients and their families with options and services to meet comprehensive health needs, and assistance in developing a healthcare plan after being discharged from the hospital. Generally, services are more comprehensive and provided over an extended period of time.

Direct care workers (certified nursing assistants, personal care attendants, companions)—provide assistance with bathing, dressing, eating, meal preparation, light housework, shopping, transportation, or companionship, either in the home, a residential facility, or a healthcare facility.

- **Certified Nursing Assistant (CNA) services:** help with healthcare needs under the supervision of a nurse
- **Companion services:** Help with supervision, recreational activities or visiting
- **Personal care services:** Help with bathing, dressing, toileting, exercising or other personal care
- **Homemaker services:** Help with housekeeping, shopping or meal preparation

Health care providers (physicians, nurse practitioners, nurses, allied health professionals)—provide health care in settings such as primary care clinics, hospitals, rehabilitation centers, long-term care facilities, etc. Does not include CNAs; see “direct care workers” above.

Health educators, interventionists (provide training to PWD or caregivers)—conduct psychoeducational programs for persons with dementia and/or caregivers, either one-on-one or in a group setting

First responders—police officers, EMTs, paramedics, or fire fighters

Clergy, other members of faith community—leaders or practitioners of various faiths trained to identify persons with possible dementia and connect them to local resources

Legal professionals—attorneys, judges or paralegals

Community businesses (banks, retail stores, pharmacies, restaurants, etc)—members of the local business community trained to identify persons with possible dementia and connect them to local resources

Other

Services, Expenditures, & Participation

Direct Services

There are 6 specified direct services (adult day care, companion services, home health care, personal care, respite, and short term care in health care facility) of which a grantee must implement at least one to meet the programmatic direct service requirement.

The following sections contain service definitions and service units. A unit of service is defined as a specific event or a predetermined period of time spent providing a specific service. Please note that in most cases one (1) unit equals one (1) hour.

To avoid duplicative counting of services, if a person with dementia attended one (1) hour of adult day care for both the purpose of socialization for the person with dementia and to provide respite for their caregiver, only one (1) unit service could be counted.

Adult Day Care—(unit = 1 hour) an organized program that takes place outside of the home and provides care for the person with dementia in a congregate setting, but is not a residential setting. Services are supervised and include social engagement or health care for elders who require skilled services or physical assistance with activities of daily living. These services may be also referred to as Adult Day Services and Adult Day Health Services.

Companion Services—(unit = 1 hour) companion services include non-medical care, supervision and socialization provided to a participant/client. Companions may assist or supervise the individual with such tasks as meal preparation, laundry, light housekeeping, and shopping. Companion services are typically provided in a participant/client's home but may include time spent accompanying participant/client to access services outside of the home. These services may be also referred to as Homemaker Services.

Home Health Care—(unit = 1 hour) in-home assistance that addresses medical needs, such as administering medications and physical therapy. These services may be also referred to as Health Maintenance Care.

Personal Care—(unit = 1 hour) in-home assistance with daily living activities, including bathing, dressing, eating, meal preparation, and light housekeeping. These services may be also referred to as Personal Assistance.

Respite—(unit = 1 hour) an interval of rest or relief OR the result of a direct dementia-specific service or supportive intervention that generates rest or relief for the caregiver and/or care recipient.

Short Term Care in Health Facility—(unit = 1 hour) services provided on a short/long term basis in a residential or assisted living facility, nursing home, or other long-term care institution because of the absence/need for relief of the regular caregiver. These services may be also referred to as Institutional Caregiver Respite Care.

Expenditures

Spending Requirements for Funds Spent on Direct Service Expenses and Administrative Expenses –

When calculating funds spent on direct service expenses and administrative expenses, the “grant funds” and “budget” apply to the total approved budget, including both the federal share and the state match portion.

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.

Administrative expenses do not include costs associated with substantive programmatic work.

Examples of expenses that are not considered administrative include: project planning and implementation (e.g. project protocols, staff training, etc.); salary, fringe, etc. for staff

delivering direct services; the evaluation and analysis of participant outcomes; and the dissemination of project materials and findings.