

Alzheimer's Disease Supportive Services Program Data Collection Terms and FAQs

Definition of Terms

Alzheimer's Disease Supportive Services Program (ADSSP) data collection includes reporting basic demographic information, hours of direct service specific to the project, direct service and administrative expenditures, and—for ADSSP evidence-based projects—program entrants and completers.

Although the Administration on Aging (AoA) encourages discussion among grantees regarding the procedures states might adopt to collect the required data, grantees are ultimately responsible for developing their own data collection protocols.

States may choose to collect and share additional data but, at a minimum, must submit the required data set using the ADSSP Data Collection Reporting Form found online at http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/ADSSP_DataCollectionReportingForm.xlsx. Data must be submitted on a semiannual basis as a "Grant Note" in GrantSolutions and with the final grant report.

For exemptions, please see the Frequently Asked Questions section of this document.

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

If you have any questions or concerns about data collection or reporting, please contact your ADSSP National Resource Center liaison.

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

Person With Dementia—the person with diagnosed or undiagnosed Alzheimer's disease or a related dementia. Related dementias include Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal Dementia, Parkinson's disease, Normal Pressure Hydrocephalus, and Creutzfeldt-Jakob Disease.

Primary Caregiver—the person who provides the most care of an individual with dementia or who is most responsible for directing and managing the care of an individual with dementia. This definition refers to informal caregivers, such as family or friends, rather than formal caregivers, such as paid healthcare professionals. Although some people with dementia have more than one caregiver, for the purposes of this data collection, only collect data from the one person who most closely fits the role of primary caregiver. In states with consumer direction, the primary informal caregiver may also be a paid caregiver.

Age Range

- Under 60
- 60+

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

Relationship

Relationship data refers to the connection between the person with dementia and his or her primary caregiver.

- Spouse
- Unmarried Partner
- Parent
- Other Relative
- Non-Relative
- Relationship Missing: Includes missing data and relationship not specified by participant

Ethnicity

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

Race Status

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 Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- Person Reporting Some Other Race
- Person Reporting Two 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 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—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 U.S. Armed Forces.

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

Services, Expenditures, and Participation

Direct Services—ADSSP Specific

In the ADSSP statute, there are six 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 state must implement at least one to meet the 50% direct service requirement. For reporting purposes, only those direct services identified in the ADSSP statute are recorded as “direct services.”

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 unit equals one hour. For consumer-directed services, please see the FAQs to determine the process for determining units of service. Please round the service units up or down to the nearest whole unit.

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 also be referred to as Adult Day Services and Adult Day Health Services.

Companion Services (unit = 1 hour)—companion services include nonmedical 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 the participant/client to access services outside of the home. These services may also be 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 also be 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 also be 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 or care recipient.

Short-Term Care in Health Facility (unit = 24 hours)—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 also be referred to as Institutional Caregiver Respite Care.

Units, Expenditures, and Related Definitions

Units—a specific event or a predetermined period of time spent providing a specific service. Please note that to avoid duplicative counting, if the person with dementia attended one hour of adult day care for both the purpose of home health care and to provide respite for the caregiver, only one unit of adult day service would be counted.

Total Federal Funds Spent on Direct Service Expenditures—expenditures of federal grant funds administered by ADSSP state grantees and their subgrantees on behalf of the ADSSP grant.

Total Federal Funds Spent on Administrative Expenditures—expenditures of federal grant funds administered by ADSSP state grantees and their subgrantees on behalf of the ADSSP grant.

Percentage of Federal Funds Spent on Direct Service Expenditures =

$$\frac{\text{Total Federal Funds Spent on Direct Service Expenditures}}{\left(\text{Total Federal Funds Spent on Direct Service} + \text{Total Federal Funds Spent on Administrative Services} \right)} \times 100$$

Percentage of Federal Funds Spent on Administrative Expenses =

$$\frac{\text{Total Federal Funds Spent on Administrative Expenditures}}{\left(\text{Total Federal Funds Spent on Direct Service} + \text{Total Federal Funds Spent on Administrative Services} \right)} \times 100$$

For Evidence-Based Programs Only

Program Entrants and Completers

Program Entrants—the number of caregivers or persons with dementia or caregiver/person with dementia dyads who enroll and begin the intervention.

Completers—the number of caregivers or persons with dementia or caregiver/person with dementia dyads who complete the intervention. Completion of the intervention is defined as participation in two-thirds or more of the program sessions.

Alzheimer's Disease Supportive Services Program Data Collection Frequently Asked Questions (FAQs)

Question: Who do I collect demographic information for? Do I have to collect it for every person who comes to a support group or training?

Answer: The grantee is only required to collect demographic information on those persons with dementia and caregivers who are receiving Alzheimer's Disease Supportive Services Program (ADSSP) direct services.

Question: My project is required to provide some services through a consumer-directed option. How do I enter/track/report data when people buy tangible items, such as Depends or groceries or even something larger?

Answer: When consumers receive a voucher or cash, grantees may not have a detailed accounting of how the funds are spent. AoA recommends that states report their hours of service in two ways. First, if grantees have detailed information on the services purchased, they should report them as they would any other service. However, if states do not have detailed information on service use, please divide the value of the cash or voucher by the average national cost of home health aide services as reported by MetLife in its 2009 survey, which is \$21 per hour, and report the number of hours as respite care.¹ Tangible items, such as disposable diapers, should be counted in the same way as cash; that is, \$21 dollars of tangible items equals one unit of direct service.

Question: What can be considered an administrative expense?

Answer: 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); salary, fringe, etc. for staff delivering direct services; the evaluation and analysis of participant outcomes; and the dissemination of project materials and findings.

Question: My project has used federal funds for activities that do not fall into the categories of direct or administrative expenses. How do I calculate the percentage of federal funds spent on direct and administrative services?

Answer: If your project included the use of federal funds for activities other than those defined as direct or administrative, please add the "other" services paid for with federal funds to the denominator in your calculations.

E.g. Percentage of Federal Funds Spent on Administrative Expenses =

$$\frac{\text{Total Federal Funds Spent on Administrative Expenditures}}{\left(\frac{\text{Total Federal Funds Spent on Direct Service} + \text{Total Federal Funds Spent on Administrative Services} + \text{Total Federal Funds Spent on Other Services}}{\text{Total Federal Funds Spent on Other Services}} \right)} \times 100$$

¹ MetLife. (2009). *Market Survey of Long-Term Care Costs*. Westport, CT: Metlife Mature Market Institute.

Question: My project works with people with dementia who have multiple caregivers. How do I indicate this on the data?

Answer: Because of the potentially large number of people involved with the care of a person with dementia and the complexities of identifying them, AoA is only asking that grantees collect information on the “primary caregiver.” As noted in the document “ADSSP Definitions for Data Collection,” AoA defines “primary caregiver” as “the person who provides the most care of an individual with dementia or who is most responsible for directing and managing the care of an individual with dementia.” This definition refers to informal caregivers, such as family or friends, rather than formal caregivers, such as paid healthcare professionals. Although some people with dementia have more than one caregiver, for the purposes of this data collection, only collect data from the one person who most closely fits the role of primary caregiver. In states with consumer direction, the primary informal caregiver may also be a paid caregiver.

Question: My project has a caregiver who is caring for multiple family members with dementia. How do I indicate this on the data?

Answer: Please consider the combination of the person with dementia and the caregiver to be a dyad, so if a caregiver is caring for two people with dementia, there are two dyads.

Assuming both people with dementia are receiving ADSSP services, the grantee would enter the same caregiver information for each person with dementia that the grant is serving.

Question: What do I do if I still have questions about data collection and/or reporting?

Answer: Please contact your ADSSP National Resource Center liaison.