



# U.S. Department of Health and Human Services Administration on Aging



## ADDGS Data Collection Definitions

Please note that this information is to be reported to the Project Officer of the Alzheimer's Disease Demonstration Grants to States (ADDGS) project on an annual basis. Grantees should develop the data collection protocols they see fit and can, for example, ask their sub-contractors or partners to report data on a more ongoing basis throughout the year.

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### ***Primary Caregiver & Person with Dementia Characteristics-*** ***The following terms are located on pages 1 & 2 of the ADDGS Data Collection Forms.***

#### **Program Participants**

**Primary Caregiver** – the person most responsible for 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. While some people with dementia have more than 1 caregiver, for the purposes of this data collection, only collect data from the 1 person most responsible for the care of the person with dementia. In states with consumer direction, the primary informal caregiver may also be a paid caregiver.

**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, and Creutzfeldt-Jakob Disease.

#### **Geographic Location**

**Urban** – a central place and its adjacent densely settled territories with a combined minimum population of 50,000

**Rural** – not urban or frontier

**Frontier** –Determined by population density and distance in miles and travel time from a market service area, such as a store, gas station, or health clinic; based on matrix developed by the Frontier Education Center. List of U.S. frontier counties: <http://www.frontierus.org/index.htm?p=2&pid=6003&spid=6019>

#### **Race/Ethnicity Status**

The following reflects the requirements of the Office of Management and Budget (OMB) for obtaining information from individuals regarding race and ethnicity. It constitutes what OMB classifies as the “**two-question format.**” When the questions on race and ethnicity are administered, respondents are to be asked about their ethnicity and race as **two separate questions**. Respondents should ideally be given the opportunity for self-identification and are to be allowed to designate all categories that apply to them. Consistent with OMB requirements, the following are the race and ethnicity categories to be used for information collection purposes:

**Ethnicity -**

- Hispanic or Latino
- Not Hispanic or Latino

**Hispanic or Latino** – a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.

**Race -**

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

**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, for example, 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.

**“(Alone)”** – when appended to a racial category (e.g., “White (Alone)”) means that the individual only designated one race category.

## **Utilization & Service Expenditures-**

**The following terms are located on page 3 of the ADDGS Data Collection Forms.**

### **Program Participants**

**Participant/Client** – the ADDGS program considers the primary caregiver and the person with dementia to be a single (1) participant/client unit.

**Primary Caregiver** – the person most responsible for the care of an individual with dementia. This definition refers to informal caregivers, such as family or friends, rather than formal caregivers, such as healthcare professionals. While some people with dementia have more than 1 caregiver, for the purposes of this data collection, only collect data from the 1 person most responsible for the care of the person with dementia. In states with consumer direction, the primary informal caregiver may also be a paid caregiver.

**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, and Creutzfeldt-Jakob Disease.

### **Direct Services –ADDGS Specific**

**In the ADDGS statute, 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 state must implement at least one to meet the 50% direct service requirement. For our purposes, only those direct services identified in the ADDGS statute as direct services are recorded as “direct services.” Many states also provide other services through their ADDGS grant, in addition to the required direct service. These services are called “other ADDGS services.” For example, some states do outreach, support groups, or training for home health aides through their ADDGS grant. These would be categorized under “other ADDGS services.” Please note that “other ADDGS services” only refers to services provided through the ADDGS grant and does not refer to services a participant/ client receives through other sources.**

**Additionally, the following two 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 1 unit equals 1 hour with a few exceptions. Please round the service units up or down to the nearest whole unit. Remember to input data under the relevant or appropriate category regardless of whether the service principally exists to benefit the caregiver or the person with dementia.**

**Adult Day Care – (1 hour)** an organized program that takes place outside of the home and provides care for the person with dementia in a congregate setting. Services are supervised and includes social engagement and/or health care for elders who require skilled services or physical assistance with activities of daily living. Also called Adult Day Services.

**Companion Services – (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. Also called Homemaker Services

**Home Health Care - (1 hour)** in-home assistance that addresses medical needs, such as administering medications and physical therapy. Also called Health Maintenance Care.

**Personal Care – (1 hour)** in-home assistance with daily living activities, including bathing, dressing, eating, meal preparation, and light housekeeping. Also called Personal Assistance.

**Respite “Other” (as approved) – (1 hour)** services that offer temporary, substitute supports for people with dementia in order to provide a brief period of relief or rest for caregivers and are *not* adult day care, companion services, home health care, or personal care. Also called In-home or Non-Institutional Caregiver Respite Care.

**Short Term Care in Health Facility – (1 day/24 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. Also called Institutional Caregiver Respite Care.

#### **Other ADDGS Services –**

**Case Management – (1 hour)** one-to-one, on-going contact in which advocacy, service coordination, and assistance with service awareness/attainment for the person with dementia or their caregiver is provided. Also called System Navigation.

**Mental Health Services – (1 contact)** counseling or crisis intervention provided by a professional to people with dementia or caregivers either individually or in groups.

**Information & Referral Services/Helpline - (1 contact)** service that: (a) provides individuals with information on services available within their communities; (b) links individuals to the services and opportunities that are available within their communities; (c) to the maximum extent practicable, establishes adequate follow-up procedures. Internet web site “hits” are to be counted only if information is requested and supplied.

**Outreach - Participant/Client - (1 activity)** a single activity or intervention, of any given length, for the purpose of identifying potential participant/clients to encourage their use of existing services and benefits.

**Outreach – Professional - (1 activity)** a single activity or intervention, of any given length, for the purpose of identifying potential professionals or partnering agencies to encourage their use of existing services and benefits. This includes outreach to faith-based organizations and physicians.

Note: the service units for Information & Referral Services/Helpline and outreach are individual, one-to-one contacts between a service provider and potential participant/clients, professionals, or partnering agencies. An activity that involves multiple current or potential participant/clients, professionals, or partnering agencies (e.g., publications, publicity campaigns, and other mass media activities) should not be counted as a unit of service. Such services might be termed public information and reported in the “Other Service – Not Above” category.

**Training – Participant/Client - (1 activity)** an intervention, which may vary in length, provided to participant/clients to increase skills, knowledge, and understanding of dementia and related topics.

**Training – Professional – (1 activity)** an intervention, which may vary in length, aimed to increase skills, knowledge, and dementia-related capabilities of people who work directly or indirectly with people with dementia or their caregivers. Types of professionals include but are not limited to: administrators, home health aides, hospice workers, occupational therapists, physical therapists, physicians, nurses, social workers, and volunteers.

**Support Groups – (1 hour)** facilitated gatherings of caregivers, family, friends, or others affected by a disease or condition that are generally led by a non-professional for the purpose of discussing issues related to the disease. This is not the same as “Training – Participant/Client” as a support group is more for sharing experiences than increasing skills or knowledge.

**Transportation - (1 way trip)** transportation from one location to another so that a participant/client can attend or receive services; does not include any other activity.

**Other Service – Not Above** - (1 hour) service provided using ADDGS funds that does not fall into the previously defined services categories.

### **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 socialization and to provide respite for the caregiver, only one (1) unit of Adult Day Service would be counted.

**Unduplicated Persons Served** – total count of client/participants (caregivers and/or people with dementia) served through the ADDGS program. Please note that to avoid duplicative counting, if the person with dementia attends one hour of adult day care services for both the purpose of socialization and to provide respite for the caregiver, this would count as only one (1) person served.

**ADDGS Expenditures** – outlays/payments made by the ADDGS state grantee and their sub-grantees using ADDGS federal funds and state-provided match to provide ADDGS services.

**Total Service Expenditures** – ADDGS expenditures (federal and state-matching funds) plus any other funds administered by ADDGS state grantee and their sub-grantees on behalf of the ADDGS grant.

**Program Income Received** – money received by the ADDGS state grantee and all ADDGS sub-grantees such as voluntary contributions or payments for ADDGS services received or provided as a result of the grant project during the grant period. This does not include required state-matching grant funds or any additional funding obtained through grants or other organizational mechanisms.

**Number of Providers (Unduplicated)** – a total count of providers who provide services through ADDGS grant. This does not include the ADDGS state grantee.

### **Service Mode Types-**

**Service Mode** - the mechanism through which a service is provided. For example, personal care (the service) may be provided through an Area Agency on Aging (the service mode). **Please select all applicable service modes that apply for the services you provide. For example, codes for “Adult Day Care” may be 3 (AAA), 4 (Consumer Directed Care), and 9 (National Family Caregiver Support Program). Similarly, codes for “Outreach – Participant/Client” may be 2 (Alzheimer’s Association), 3 (AAA), and 10 (Service Provider). Some services may have just one code.**

**Ageing & Disability Resource Center** – Please code ADRCs under this code rather than under the “Government (state or local)” code.

**Alzheimer's Association** - includes local chapters and national office. Please code Alzheimer’s Associations under this code rather than under the “Service Provider” code

**Area Agency on Aging** – Please code AAAs under this code rather than the “Government (state or local)” code.

**Faith Based Organization** – includes faith based communities such as churches, temples, and mosques and faith based social services agencies such as Catholic Charities or Lutheran Social Services.

**Consumer Directed Care/Vouchers** – program whereby families are given a specified budget (cash or vouchers) to purchase services they need, such as adult day care, respite, and home modifications. Consumers ultimately make decisions about type, amount, and timing of care. Include this service mode type if the specified service can be purchased by the family through a consumer-directed care option.

**Government (Federal)** –includes partnership with federal government through other grants such as Real Choice Systems Change and Medicaid waiver grants. Aging and Disability Resource Centers (ADRCs) and National Family Caregiver Support Program (NFCSP) grants should not be counted here since they have separate codes.

**Government (State or Local)** – state or local offices of the government, including local and state Medicaid offices. This code *only* includes the state grantee that is receiving the ADDGS grant if they are directly providing services to families as part of their grant. Area Agencies on Aging should not be counted here since they have a separate code.

**Long-Term Care Facility** – includes skilled nursing, assisted living, residential care, and other facilities providing long-term, out-of-home services for people with dementia.

**National Family Caregiver Support Program** – Please use this code if the specified service is offered through a joint effort with the NFCSP.

**Service Provider** – non-profit or for-profit organizations providing services to individuals with dementia, caregivers, professionals, and other organizations. This code includes but is not limited to: senior centers, adult day care centers, home health agencies, personal care agencies, and companion agencies.

**University or School** – institutes of education that are associated with the ADDGS program.

**Volunteer** - an uncompensated or minimally compensated individual who provides services or support on behalf of older individuals or agencies (e.g., AAAs, Alzheimer's Association chapters, Senior Companion program etc.)

**Other (please specify)** - provider or partner providing services through the ADDGS program that does not fall into the previously defined categories.



## ***Accomplishments and Collaborations-***

***The following terms are located on page 4 of the ADDGS Data Collection Forms.***

This section asks for narrative descriptions of your project's single greatest accomplishment and single strongest collaboration achieved through the ADDGS grant in the year reported. This section will not require additional data tracking and should be considered a space to reflect on and describe the year's greatest accomplishments and collaborations.

Please describe the single greatest accomplishment in the top box, and describe the single strongest collaboration in the second box. The third box is optional and can be used to describe either an accomplishment or collaboration. Use the "Accomplishment and Collaboration Types" and their codes on the right side of the page to fill in the area entitled "Enter Code." There are currently only two codes for collaborations: 1 (Federal) or 2 (Non-federal).

**Collaboration - Federal** –includes collaboration with federal government through non-ADDGS federal grants such as Real Choice Systems Change, Medicaid waivers, and National Family Caregiver Support program grants.

**Collaboration - Non-federal** – collaboration with state or local offices of the government, including local and state Medicaid offices and Area Agencies on Aging, as well as with community agencies and organizations.

**Materials Development** – development of items such as brochures, Public Service Announcements, videotapes, manuals for the purpose of large scale distribution, or relevant staff or participant/client trainings.

**Policy Development** – program components that affect the development, implementation, and/or assessment of policy at the organizational, local, or state level

**Public Education/Awareness** – program components aimed at educating and increasing awareness of the general public. This includes but is not limited to media campaigns, widely-disseminated materials, attendance at health fairs, and participation in community events for the purposes of highlighting ADDGS program.

**Service (Direct Service defined by ADDGS statute)** - includes those services that **can** be used to meet the 50% direct service requirement – adult day care, companion services, home health care, personal care, respite "other," and short term care in health facility. See above for full definitions.

**Service (Other ADDGS)** - those services that **can not** be used to meet the 50% direct service requirement, including but not limited to: case management, information & referral/Helpline, mental health services, outreach for participants/clients or professionals, training for participants/clients or professionals, support groups, and transportation. See above for full definitions of these services.

**Sustainability** – efforts made to ensure the long-term presence and success of the ADDGS program in part or in whole.

**Training/Education** - program components aimed at educating and increasing awareness of selected groups, including but not limited to: caregivers, physicians, home health aides, and other informal and formal care providers.

**Other – Please specify** –accomplishment or collaborator that does not fall into the previously defined categories.