

Alzheimer's Disease Supportive Services Program Template for Data Collection Information

This form can be used by grantees to collect data on primary caregivers and persons with dementia. Grantees may choose to collect additional elements.

PRIMARY CAREGIVER

Primary Caregiver – the person who provides the most care to 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. While some people with dementia have more than one (1) caregiver, for the purposes of this data collection, only collect data from the one (1) 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.

Date: _____

Unique Identifier: _____

Age: Under 60 60+

Gender: Female Male

Geographic Location: Urban Rural

Caregiver Relationship to Person with Dementia:

- Spouse Unmarried partner Child
 Other relative Non-relative Parent

Ethnicity of Caregiver:

_____ Hispanic or Latino
_____ Not Hispanic or Latino

Race of Caregiver: (Mark One or More)

- White
 American Indian/Alaska Native
 Asian
 Black/African-American
 Native Hawaiian/Other Pacific Islander

Veteran Status of Caregiver:

- Veteran
 Non-Veteran

PERSON WITH DEMENTIA

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.

Date: _____

Unique identifier: _____

Age: Under 60 60+

Gender: Female Male

Geographic Location: Urban Rural

Ethnicity of Person with Dementia:

_____ Hispanic or Latino

_____ Not Hispanic or Latino

Race of Person with Dementia: (Mark One or More)

- White
- American Indian/Alaska Native
- Asian
- Black/African-American
- Native Hawaiian/Other Pacific Islander

Veteran Status of Person with Dementia:

- Veteran
- Non-Veteran

SERVICES PROVIDED:

Date: _____

Indicate services provided to primary caregiver or person with dementia. Units of service provided should reflect non-duplicative services provided to either member of the dyad.

Unique identifier: _____

Period for which services provided: _____ to _____.

Direct Services – ADSSP-Specific

Service Units Provided

- Adult Day Care _____
- Companion Services _____
- Home Health Care _____
- Personal Care _____
- Respite _____
- Short-term Care in Health Facility _____

Total Direct Service Units: _____

Attendance (for Evidence-Based Projects Only)

Unique identifier: _____

Date (M/D/Y): _____ (Session 1) Attended

Date (M/D/Y): _____ (Session 2) Attended

Date (M/D/Y): _____ (Session 3) Attended

Total Sessions Attended: _____ out of _____

Completed Intervention (circle one): Yes No