

## 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