

Title VI - Caregiver Definitions

Who Are Caregivers?

In Indian Country, the most likely caregivers are family members, friends of the family, neighbors, or members of a church or social club who are close to the person needing care.

Many caregivers do not identify themselves as such since caring for elders is a traditional activity in Indian Country; caregivers see themselves as simply doing what needs to be done.

Meeting the Needs of Your Caregivers

- It is important to recognize that the services available through this program include services **for the caregiver**, not for the elder who needs care.
- If caregivers are supported while they do their work, they can provide care longer and better. This support can help the elder, but services must be directed to the caregiver.
- **If an elder doesn't have a caregiver, Title VI part C resources are not available to them.**

Title VI, Part C—Caregiver Support Services

- Must also have a Part A/B grant
- Services are for two types of **unpaid** caregivers:
 - ❑ **informal provider of care to a frail older individual or to an individual with Alzheimer's disease or a related disorder** (for instance family, friends, or other relatives caring for an older individual)
 - ❑ **older relative caregivers** (for instance grandparents raising grandkids, or an elder caring for an adult with a disability)
- Program services are for the **caregiver**; not for the elder who receives the care

What do we mean by "frail"?

- "Frail" means that the older individual is functionally impaired because the individual—
 - is unable to perform at least two activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision
 - Activities of daily living are: Eating, Bathing, Dressing, Transferring (from bed to chair), Toileting, Walking or Moving Around
 - due to a cognitive or other mental impairment, requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or to another individual.

Title VI - Caregiver Definitions

Title VI, Part C—Adult Family Caregiver: Defined

(3) The term “family caregiver” means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction [OAA Section 302 (3)].

This person must be 18 years or older. Would provide care or support to an Elder or an individual of any age with Alzheimer’s disease and related disorders (such as dementia)

Title VI, Part C—Older Relative Caregiver: Defined

Older Relative Caregiver means a caregiver who—

- (A)(i) is age 55 or older; and
- (ii) lives with, is the informal provider of in-home and community care to, and is the primary caregiver for, a child or an individual with a disability

The older relative caregiver must be 55 years or older and provides care either to a child (such as a grandchild), or an individual with a disability – more on these two below.

Title VI, Part C – Older Relative Caregiver: Grandparents Raising Grandchildren

(B) in the case of a caregiver for a child—

- (i) is the grandparent, step grandparent, or other relative (other than the parent) by blood, marriage, or adoption, of the child; and
- (ii) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregivers of the child; and
- (iii) has a legal relationship to the child, such as legal custody, adoption, or guardianship, or is raising the child informally;

Title VI, Part C—Older Relative Caregiver: Caring for Someone with a Disability

(C) in the case of a caregiver for an individual with a disability, is the parent, grandparent, or other relative by blood, marriage, or adoption, of the individual with a disability.

Title VI - Caregiver Definitions

Title VI, Part C – Required Services

1. Information to caregivers about available services
2. Assistance to caregivers in gaining access to the services
3. Individual counseling, organization of support groups, and caregiver training to assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles
4. Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
5. Supplemental services, on a limited basis, to complement the care provided by caregivers

Required Service 1: Information

- Information and assistance services may be one way to identify caregivers as it is often the first thing a caregiver seeks is information about caregiver services or assistance in getting the service.
- Caregivers may need information about services, equipment, and the illness or condition their loved one is experiencing.

Required Service 2: Assistance Services

- Assistance may be direct assistance with:
 - Paperwork, finding resources, or helping them access programs that can provide assistance with Medicare, Medicaid, yard work or heavy chores, housecleaning, or other tasks.
- Your Title VI, Part A program may be able to provide the services identified.
 - Remember that assistance under the Caregiver Support Program is to assist the caregiver in accessing the service, not providing the service.

Required Service 3: Caregiver Counseling, Training, and Support Groups – Counseling

- Caregivers may need to learn new skills about helping with activities of daily living, medical treatments and prescription drugs, or changes that occur as their loved one ages and their illness progresses.
- Caregivers may need counseling and training about the best way to take care of themselves and training in how to perform some caregiver responsibilities, such as getting an elder out of bed.

Required Service 3: Caregiver Counseling, Training, and Support Groups – Training

- Training required by the OAA includes health, nutrition, and financial literacy, and training in making decisions and solving problems relating to their caregiving roles.
- Training can be about general things such as communication with elders with dementia (including Alzheimer's Disease), end-of-life signs, or incontinence or as specific as catheter care, tube feeding, or filling insulin syringes.
- It is important that the person doing the training be qualified to provide it.

Title VI - Caregiver Definitions

Required Service 3: **Caregiver Counseling, Training, and Support Groups** – *Support Groups*

- In a support group, members provide each other with various types of nonprofessional, nonmaterial help for a particular shared issue.
- The help may take the form of providing relevant information, relating personal experiences, listening to others' experiences, providing sympathetic understanding and establishing social networks.
- Some programs have used a Caregiver Stress Test to help open up the discussion.
- Confidentiality is an important aspect of support groups.

Required Service 4: **Supplemental Services**

- Include such things as:
- Home Modification/Repairs: Putting in ramps or handrails into an Elder's home.
- Consumable Items: Incontinence supplies, Ensure, school supplies, uniforms for school or sports, cleaning supplies, etc...
- Lending Closet: Clothing exchange; Durable Medical Equipment (chair lifts, wheelchairs, walkers, emergency response systems), anything lent on a short-term basis.
- Financial Support: limited (emergency) help with utility bills
- Homemaker/Chore/Personal Care Service: chopping wood, mowing a lawn, snow clearing.

Required Service 5: **Respite**

- Respite care is care provided to caregivers so that they can have a break (preference to caregivers of the frail or grandparents raising grandchildren).
- Respite care can be provided in the home of the elder or the caregiver or it can be provided at an out-of-home setting such as the respite person's home, senior center, or day care center.
- Some programs provide the care by giving the caregiver a voucher and allowing them to choose their own provider and circumstances.

Respite Policy Considerations

- If the respite provider is not a family member, you will want to check your tribe's policies about background checks.
- It is important to develop policies on:
- Who can provide respite – will you allow spouses or children, relatives vs paid providers,
- How are you going to pay for respite – volunteer-based or paid (rate of pay)
- How you are going to pay for respite – agency-based model, give money directly to family, voucher program
- Other issues – service limits, service locations (at home or facility-based), service hours (weekdays/weekends/overnights)

Title VI - Caregiver Definitions

Coordinating Caregiver Programs

- If there is another program providing a required service for caregivers in your community, you do not have to provide it with your funds, but must coordinate with the program to ensure caregivers can use the program.
- The OAA also requires coordination with Title III programs.
- Area Agencies on Aging can assist with information or application assistance, trainings, and supplemental services
- Do you currently coordinate with the AAA responsible for your planning and service area?

Remember...

- Program services are for the **caregiver**; not for the elder who receives the care.
- While there may be a need to find a caregiver for a person who lives alone and does not have a family caregiver, a grantee **cannot hire a caregiver for them with their Title VI Part C funds**.

Caregiver Resources

There is a wealth of information on the Internet designed to assist family members and caregivers of older adults. Here are a few useful links to get you started.

- [National Alzheimer's Call Center](#)
The National Call Center is available to people in 56 states and territories, 24/7, 365 days a year, to provide expert advice, care consultation, information, and referrals and can help with questions about memory problems, how to deal with challenging behaviors, and tips for taking care of someone with Alzheimer's disease or other forms of dementia.
- [ARCH –The National Respite Locator Service](#)
This service helps parents, caregivers, and professionals find respite services in their state and local area that match their specific needs.
- [Ask Medicare](#)
This initiative offers information, tools and materials to assist the caregiver and their loved ones in making informed healthcare decisions.
- [Family Caregiver Alliance](#)
This site features information on programs at national, state and local levels that support and sustain caregivers.
- [National Alliance for Caregiving](#)
This site features publications and resources for caregivers, including the Family Care Resource Connection, where you can find reviews and ratings of more than 1,000 books, videos, websites and other materials on caregiving.