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Authorized Signature

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**Topic:** Other

**Due Date:** 7/1/2012

**Subject:** OAA Family Caregiver Support Program

**Applies to (check all that apply):**

- |   |  |
|---|--|
| <input type="checkbox"/> All DHS employees                        | <input type="checkbox"/> County Mental Health Directors                  |
| <input checked="" type="checkbox"/> <b>Area Agencies on Aging</b> | <input type="checkbox"/> Health Services                                 |
| <input type="checkbox"/> Children, Adults and Families            | <input checked="" type="checkbox"/> Seniors and People with Disabilities |
| <input type="checkbox"/> County DD Program Managers               | <input type="checkbox"/> Other (please specify):                         |

**Required Action**

The Oregon State Unit on Aging along with the Family Caregiver Support Program (FCSP) Advisory Committee has completed an update to the Family Caregiver Support Program Standards. The goal of this update is to clarify and provide additional information needed to implement the program. The main updates are in eligibility, fiscal requirements, service and unit descriptions, roles of the aging network plus additional definitions and useful links.

The revised standards are effective beginning July 1<sup>st</sup>, 2012. The standards are attached and also available on the State Unit on Aging website at:  
<http://www.oregon.gov/DHS/spwpd/sua/fmly-crgvr-prgms.shtml>

**Reason for Action:** Update the Oregon’s Older Americans Act Family Caregiver Support Program Standards.

**Field/Stakeholder review:**  Yes  No

**If yes, reviewed by:** FCGSP Advisory Council with representation from Area Agencies on Aging.

*If you have any questions about this action request, contact:*

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# **Family Caregiver Support Program Standards**

## **Older Americans Act**

**Prepared by:  
Family Caregivers Support Program Advisory Committee  
In Partnership with Department of Human Services  
Seniors and People with Disabilities  
State Unit on Aging  
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**Modified: June 2012**



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## I. Background

### A. Introduction

The National Family Caregiver Support Program (NFCSP) was established in November 2000. The NFCSP, administered by the Department of Health and Human Services Administration on Aging (HHS), was officially launched by HHS Secretary Tommy Thompson in February 2001.

### B. Program Eligibility Definitions

With the Older Americans Act 2006 Reauthorization, the NFCSP has broadened the populations served. The following is a comprehensive list of unpaid caregivers that can be served through the FCSP:

- Caregivers of individuals with Alzheimer’s Disease (and related disorders with neurological and organic brain dysfunction). The care receiver and caregiver can be of any age.
- Grandparents or older relative caregivers (55 years of age or older) caring for a child related by blood, marriage, or adoption. Child is an individual 18 years or younger or of any age if the individual has a disability. Adult Child With a Disability – A child who is 18 years of age or older who has a disability and is financially dependent on an older individual. (OAA 102(a) (3)(A-C)) This includes grandparents or older relative caregivers who receive financial support payments, such as Temporary Assistance to Needy Families (TANF), Foster parent payments, Child Support, Social Security for children, etc.
- Adult family member or another individual, who is a provider of in-home and community care to older individuals (age 60 years or older).

Care Receiver	Caregiver
Person age 60 or older	Adult of any age
Child age 18 or younger	Grandparent/Relative Caregiver, age 55 and older, does not include parent
Adult or Child with disabilities of any age	Grandparent/Relative Caregiver, age 55 and older, does not include parent
Alzheimer’s (or related disorder) any age	Adult of any age
Adult Child With a Disability – A child who is 18 years of age or older who has a disability and is financially dependent on an older individual. (OAA 102(a)(3)(A-C))	Grandparent/Relative Caregiver, age 55 and older, does not include parent

**Caregiver:** A ‘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. An individual who “informally” has the responsibility for the care of an older individual or individual of any age suffering from Alzheimer’s or related disorder; or a grandparent/relative caregiver, age 55 and older who has the responsibility for the care of children or adult child with disabilities. “Informally” means the care is not provided as part of a public or private service program. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Grandparent or Other Older Relative Caregiver of a Child** – A grandparent, step grandparent or other relative of a child by blood or marriage who is 55 years of age or older and lives with the child, is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and has a legal relationship to the child, such as legal custody or guardianship or is raising the child informally. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

- lives with the child;
- is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and
- has a legal relationship to the child, as such legal custody or guardianship or is raising the child informally.

## II. Program Authority

Sections 371, 372, 373, and 374 of the Older Americans Act of 1965, as Amended (P.L.106-501), Grants for State and Community Programs on Aging, and W.S. 9-2-1204.

## III. Program Overview

### A. Program Purpose

- To assist family caregivers in their expanding roles by providing program components that will ease family caregiver stress and increase coping.

### B. Program Goals

- Assist family caregivers to successfully meet the challenges of their caregiving role, while being supported in that role.
- To deter institutionalization, when feasible, and promote continued care within the home and in alternative community settings for seniors for as long as possible or desirable by family caregivers.
- Provide highest service levels possible.

## IV. Federal Requirements and Reporting

### PROGRAM REPORTING

AAA shall collect and report National Aging Program Information System (“NAPIS”) data as directed by DHS for all caregiver services provided, using DHS provided software or a DHS approved alternative collection and reporting method. For full details on reporting criteria see Group 1 and Group 2 Caregiver Services detail published in DHS SPD AR-11-047 (<http://www.oregon.gov/DHS/spwpd/sua/docs/oaa-opi-serv-def.pdf>)

### Program Income

All recipients of Title III-E caregiver services will be provided an opportunity to voluntarily contribute towards cost of service. Said contribution, hereby referred to as program income shall be used for the sole purpose of expanding caregiver services.

### Maximum Expenditures

- a) Administration - No more than 10% of expended Title III-E funds may be utilized for administration purposes.
- b) Caregivers serving children - No more than 10% of expended Title III-E funds may be utilized to support services to caregivers serving children (under age 18).

### Matching Funds

Federal funds may not pay for more than 75% of total caregiver expenditures. The required match is calculated as shown in the following example for \$100 of Title III-E funds expended equals \$100 divided by .75 equals \$133; \$133 minus \$100 equals \$33; the required match to spend \$100 of Title III-E is \$33.

## V. Service and Unit Descriptions

### GROUP 1 CAREGIVER SERVICES

**Requires reporting caregiver's age, gender, rural, race, ethnicity, relationship to service recipient, unduplicated caregiver count, and units of service.**

**EXCEPTIONS: CG Cash & Counseling requires unduplicated client count only – units of service optional.**

#### **CAREGIVER CASH & COUNSELING**

**Matrices #73 (serving elderly) 73a (serving children) (1 unit = 1 client served)**

Services provided or paid for through allowance, vouchers, or cash which is provided to the client so that the client can obtain the supportive services which are needed. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

#### **CAREGIVER COUNSELING**

**Matrices #70-2a (serving elderly) 70-2b (serving children) (1 unit = 1 session per participant)**

Counseling to caregivers to assist them in making decisions and solving problems relating to their caregiver roles. This includes counseling to individuals, support groups, and caregiver training (of individual caregivers and families). (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

#### **CAREGIVER SUPPLEMENTAL SERVICES**

**Matrices #30-7 (serving elderly) 30-7a (serving children) (1 unit = 1 payment)**

Services provided on a limited basis that complement the care provided by family and other informal caregivers. Examples of supplemental services include, but are not limited to, legal assistance, home modifications, transportation, assistive technologies, emergency response systems and incontinence supplies. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Note:** Home-delivered meals and transportation to caregivers serving elderly or caregivers serving children are to be reported under this matrix. Refer to Caregiver Standards for expanded list of examples.

No ADL/IADL is required for supplemental services to caregivers serving children. For caregivers serving elderly, service priority should always be given to caregivers providing services to individuals meeting the definition of 'frail'. (See General Terms and Definitions)

## **CAREGIVER SUPPORT GROUPS**

**Matrices #30-6 (serving elderly) 30-6a (serving children) (1 unit = 1 session per participant)**

Peer groups that provide opportunity to discuss caregiver roles and experiences and which offers assistance to families in making decisions and solving problems related to their caregiving roles. (DHS/SPD/SUA definition)

## **CAREGIVER TRAINING**

**Matrices #70-9 (serving elderly) 70-9a (serving children) (1 unit = 1 session per participant)**

Training provided to caregivers and their families that supports and enhances the care giving role. For example: Powerful Tools training; Communicating Effectively with Health Care Professionals; conferences, etc. (A session for conferences would be equal to one day's attendance at the conference). (DHS/SPD/SUA definition)

**Note:** This does not include training to paid providers.

## **RESPIRE CARE**

**Matrices #30-4 (OPI) #30-5 (serving elderly) 30-5a (serving children) (1 unit = 1 hour see notes)**

Services which offer temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for caregivers. Respite Care includes: (1) In-home respite (personal care, homemaker, and other in-home respite); (2) respite at a senior center or other nonresidential program; (3) respite provided by placing the care recipient in an institutional setting such as a nursing home for a short period of time; (4) and for grandparents/relatives caring for children – day or overnight summer camps. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov) & SPR Q&A #28, 2008)

**Note:** OAA 373 (a)(2)(A & B) states priority shall be given to caregivers providing services to individuals whom meet the definition of 'frail'. (See General Terms and Definitions).

SPR Q&A #28, 2008 states units of service for overnight institutional respite and overnight summer camps are more appropriately reported by days than hours. Example: Two days of institutional respite is 2 units (not 48 units) and six days at camp equal 6 units instead of 144.

## GROUP 2 CAREGIVER SERVICES

**Requires reporting service units and estimated unduplicated caregiver count or when applicable, an estimated number of caregivers and service units. No demographics required.**

### **CAREGIVER ACCESS ASSISTANCE**

#### **Matrices #16 (serving elderly) 16a (serving children) (1 unit = 1 contact)**

A service that assists caregivers in obtaining access to the available services and resources within their communities. To the maximum extent practicable, it ensures that the individuals receive the services needed by establishing adequate follow-up procedures. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Note:** Case management and information and assistance to caregivers is an access service.

### **INFORMATION FOR CAREGIVERS**

#### **Matrices #15 (serving elderly) and 15a (serving children) (1 activity)**

A service for caregivers that provides the public and individuals with information on resources and services available to the individuals within their communities. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Note:** Service units for information services are for activities directed to large audiences of current or potential caregivers such as disseminating publications, conducting media campaigns, and other similar activities.

## A. General Terms and Definitions

The following terms and definitions are related to Oregon's Older Americans Act (OAA) and Oregon Project Independence (OPI) service programs. The source follows each definition.

**Act:** National Family Caregiver Support Program (NFCSP)

**ADL (Activities of Daily Living)** – Personal functional activities required by an individual for continued well being, which are essential for health and safety. For the purposes of these rules, ADLs consist of eating, dressing/grooming, bathing/personal hygiene, mobility (ambulation and transfer), elimination (toileting, bowel, and bladder management), and cognition/ behavior as described in Oregon Administrative Rule (OAR) 411-015-0007. (OAR 411-032-0000). For more information on ADL's, you can visit: [www.dhs.state.or.us/policy/spd/home.htm](http://www.dhs.state.or.us/policy/spd/home.htm) or find information on OAR 411-015-0006 (1).

**Adult Child With a Disability** – A child who is 18 years of age or older who has a disability and is financially dependent on an older individual. (OAA 102(a)(3)(A-C)).

**Adult Day Services** – A community-based group program designed to meet the needs of adults with functional impairments through service plans. These structured, comprehensive, non-residential programs provide health, social and related support services in a protective setting during part of a day, but for less than 24 hours per day. (OAR 411-066)

**Aging and Disability Resource Center** – A point of entry to comprehensive information on the full range of available public and private long-term care services, service providers, and resources within a community and options counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances. (OAA 102(a)(4)(A-C))

**Alzheimer's Disease and Other Related Disorders** – A progressive and degenerative neurological disease characterized by symptoms of short-term memory loss, confusion and behavior and personality changes. It includes all other related disorders recognized by the National Alzheimer's Association including dementia caused from Multi-Infarct Dementia (MID), Normal Pressure Hydrocephalus (NPH); Inoperable Tumors of the Brain; Parkinson's Disease; Creutzfeldt-Jakob Disease; Huntington's Disease; Multiple Sclerosis; Uncommon Dementia such as Pick's Disease, Wilson's Disease, and Progressive Supranuclear Palsy. (OAR 411-032-000)

**Caregiver** – An individual who “informally” has the responsibility for the care of an older individual or individual of any age suffering from Alzheimer’s or related disorder; or a grandparent/relative caregiver, age 55 and older who has the responsibility for the care of children or adult child with disabilities. “Informally” means the care is not provided as part of a public or private service program. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov) )

**Child** – An individual who is not more than 18 years of age or an individual 19 to 59 years of age who has a severe disability. This definition relates to the caregiver services. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Civic Engagement** – Individual or collective action designed to address a public concern or an unmet human, educational, health care, environmental, or public safety need. (OAA 102(a)(12))

**Disability** – Except when such term is used in the phrase “severe disability”, “developmental disability”, “physical or mental disability”, “physical and mental disabilities”, or “physical disabilities” - a disability is attributable to mental or physical impairment, or a combination of mental and physical impairments, that results in substantial functional limitations in one (1) or more of major life activity. (OAA 102(a)(13)(A-I))

**Disease Prevention & Health Promotion Services** – Individual or group programs based on best practices and/or evidence-based research, that identify health risks and needs, prevent health problems, and/or help older adults manage their health conditions. Programs should address identified health needs of older adults in the community, and where possible, should use evidence-based approaches and evaluated outcomes to address needs. These may include health risk assessments and screening linked to referrals and/or follow-up education; health promotion programs that help participants prevent and/or manage chronic conditions, alcohol and substance abuse, health risks such as smoking cessation, weight loss; physical activity programs to promote activity and prevent falls; educational programs on health risks and conditions or use of preventive health services and medication management. (Condensed from OAA 102 (a)(14)(A-L))

**Elderly Client** – A service recipient who is 60 years of age or older or who is less than 60 and has a diagnosis of Alzheimer’s or a related disorder. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Ethnicity** – Consistent with OMB requirements ethnicity categories are *Hispanic or Latino* or *Not Hispanic or Latino*. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Evidence-based Program** – Evidence-based programs are interventions that have been tested through randomized control trials and have been shown to be effective at helping participants adopt healthy behaviors, improve their health status, and reduce their use of hospital services and emergency room visits. (DHHS FFY2011 AoA *Justification of Estimates for Appropriations Committees*)

**Focal Point** – A community center, senior center, or multi-purpose center/facility established to encourage the maximum co-location and coordination of services for older individuals. (OAA 102(a)(21) and 306(a)(3)(A))

**Frail** – 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; or due to 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. (OAA 102(a)(22)(A)(i) & (B))

**Grandparent or Other Older Relative Caregiver of a Child** – A grandparent, step grandparent or other relative of a child by blood or marriage who is 55 years of age or older and lives with the child, is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and has a legal relationship to the child, such as legal custody or guardianship or is raising the child informally. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Greatest Economic Need** – A need resulting from an income level at or below the poverty line. (OAA 102(a)(23))

**Greatest Social Need** – A need caused by non-economic factors, which include physical and mental disabilities; language barriers; and cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that restricts the ability of an individual to perform normal daily tasks; or threatens the capacity of the individual to live independently. (OAA 102(a)(24)(A-C))

**HCW (Homecare Worker)** – A provider, as described in OAR 411-030-0020 and 411-031-0040, who is directly employed by the eligible individual via the Client Employed Provider Program, and who provides hourly services to eligible individuals. Homecare Workers also include providers in the Spousal Pay Program. (OAR 411-032-0000 (31))

**Note:** Homecare worker and Client Employed Provider (CEP) are synonymous and depending upon age of the document or data collection means – either term may be present or appear in DHS publications and DHS-owned software applications.

**High Nutritional Risk** – A score of six (6) or higher on the Determine Your Nutritional Risk checklist published by the Nutrition Screening Initiative.

See <http://edis.ifas.ufl.edu/he944> for the checklist and risk summaries. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov) )

**Note:** Nutritional Risk Assessment is on the DHS/SPD NAPIS Registration and OACCESS under the Nutrition tab (accessed by selecting the Service Icon).

**IADL (Instrumental Activities of Daily Living) aka "Self Management Tasks"** – Housekeeping, including laundry, shopping, transportation, medication management and meal preparation as described in OAR 411-015-0007. (OAR 411-032-0000)

**In-Home Care Agency** – A licensed agency (by DHS Public Health Division) that provides in-home care services for compensation to an individual in that individual's place of residence. "In-home care agency" does not include an agency providing home health services as defined in ORS 443.005. (OAR 333-536)

To request list of licensed agencies serving Oregon send e-mail to: [mailbox.hclc@state.or.us](mailto:mailbox.hclc@state.or.us)

**Living Alone** – A one person household. Household as defined by the U.S. Census Bureau - living quarters in which the occupant(s) live and eat separately from any other persons in the building and which have direct access from the outside of the building or through a common hall. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov)); Household is defined and found at [www.census.gov](http://www.census.gov).

**NAPIS: (National Aging Program Information System)** – Information describes the services provided under Older Americans Act funding titles in collaboration with an aging network that includes 56 State Units on Aging, 655 Area Agencies on Aging, 244 Tribal organizations, and over 29,000 local community service organizations., expenditures, client demographics and staffing profiles for each state and U.S. territory. (Definition crafted by SUA from information available at [www.aoa.gov](http://www.aoa.gov).)

**NSIP (Nutritional Services Incentive Program) Meal** – A congregate or home-delivered meal prepared in compliance with nutritional requirements as outlined in the Older Americans Act (OAA) and served to an eligible individual as defined in the OAA. (Definition based on OAA and condensed by SUA)

**Note:** Eligible NSIP meals include those served to the under 60 spouse in the company of the 60 years of age or older spouse; any age adult with disability who resides with or is in the company of an individual 60 years of age or older; caregivers and care recipients aged 60 or older; caregivers who are the spouse of the care recipient - regardless of age; and any age volunteer assisting with meal site or delivery of meals.

**Poverty** – Persons considered to be in poverty are those whose income is below the official poverty guideline (as defined each year by the Office of Management and Budget) in accordance with subsection 673 (2) of the Community Services Block Grant Act (42 U.S.C. 9902 (2)). The annual HHS Poverty Guidelines provide dollar thresholds representing poverty levels for households of various sizes and is typically released each February. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Poverty Level:** The income level indicated in the Federal Poverty Income Guidelines developed and annually updated and published in the Federal Register by the United State Department of Health and Human Services.

**Program Income** – Gross income received by the grantee (AAA) or sub-grantee (AAA contractor) such as voluntary contributions or income earned as a result of a program supported by the OAA grant. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov); condensed by SUA)

**Provider** – An organization or person which provides a service to clients under a formal contractual arrangement with the AAA. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Race** – Consistent with OMB requirements, race categories are *American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander*, and *White*. Respondents should ideally be given the opportunity for self-identification, and are to be allowed to designate all categories that apply to them. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Registered Client** – An individual who received one or more units of Cluster 1, Cluster 2, or Group 1 or Group 2 Caregiver services: (Definition developed by SUA)

**Rural** – Any area that is not defined as urban. Urban areas comprise (1) a central place and its adjacent densely settled territories with a combined minimum population of 50,000; (2) an incorporated place or census designation with 20,000 or more inhabitants. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov))

**Target Population** – Older individuals, with particular attention to low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, older individuals at risk for institutional placement and older individuals residing in rural areas. (OAA 305(a)(2)(E))

**Note:** 45 CFR 1321.69(a) states the following shall be given priority in the delivery of services: Persons age 60 or over who are frail, homebound by reason of illness or incapacitating disability, or otherwise isolated.

**Unduplicated Client Count**– Counting a recipient of a service only once during the reporting period. (Definition crafted by SUA)

**Unit Count** – The number of units of service received by an unduplicated client during the reporting period. (Definition developed by SUA)

**Volunteer** – An uncompensated individual who provides services or support to AAA and/or AAA service providers. (AoA Title III/VII Reporting Requirements Appendix – [www.aoa.gov](http://www.aoa.gov); enhanced by SUA)

**Voluntary Contributions** – A non-coerced monetary sum provided toward the cost of service. (OAA 315(a)(5)(b)(1))

## B. Target Priorities

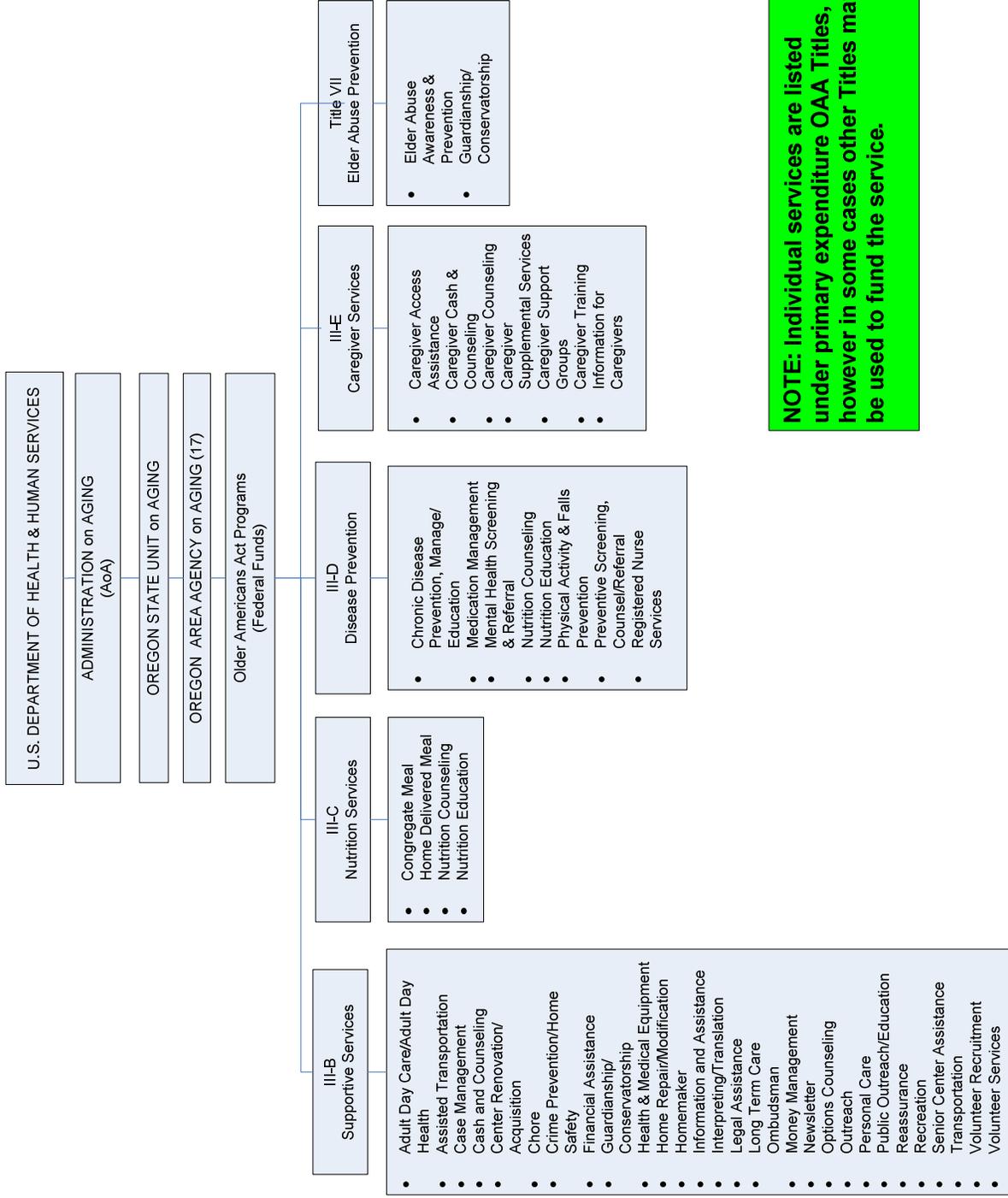
Priorities were also established with the NFCSP:

- Caregivers who are older individuals with greatest social need and/or greatest economic need with particular attention to low-income older individuals and to low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural areas;
- For family caregivers who provide care for individuals with Alzheimer's Disease and related disorders with neurological and organic brain dysfunction, the Area Agency on Aging (AAA) or State involved shall give priority to caregivers who provide care for older individuals with such disease or disorder; and
- For grandparents or older individuals who are relative caregivers, the AAA/State involved shall give priority to caregivers who provide care for children with severe disabilities.

**Priority:** In providing services under this subpart, the State, in addition to giving the priority described in [Section 372\(b\)](#) shall give priority to:

- Caregivers who are older individuals with greatest social need, and older individuals with greatest economic need (with particular attention to low-income older individuals); and
- Older individuals providing care to individuals with severe disabilities, including children with severe disabilities.

# VI. Roles of the Aging Network



## A. Administration on Aging (AoA)

Under the authority of the Older Americans Act (OAA), the Administration on Aging (AoA) works closely with other partners in the national aging network to plan, coordinate, and provide home and community-based services to meet the unique needs of older persons and their Agencies on Aging (AAA) and Indian Tribal Organizations (ITO).

Under the NFCSP, AoA, through its central office staff and nine regional offices, performs a number of tasks, including policy development, technical assistance, research and demonstrations, and systems development.

AoA has provided technical assistance through a number of activities, including:

- Establishing a technical advisory group (TAG) comprising researchers and aging network representatives who informed the content of the 2001 Resource Guide and advised on other AoA technical assistance activities;
- Created a web page devoted to the NFCSP;
- Commissioned more than 20 issue briefs from prominent researchers and staff of the aging network and posting them to the NFCSP web site;
- Sponsoring the September 2001 National Family Caregiver Support Program: from Enactment to Action conference at which more than 700 participants exchanged information and generated new ideas;
- Organized a structured listserv to disseminate research-based information and to generate the exchange of information among network staff; and
- Commissioned the Resource Guide, which brings together information gained from all of the above activities in a practical, easy-to use format.

AoA also is administering the National Innovation Program under the NFCSP and is engaged in systems development work related to caregivers with other federal agencies. For example: Centers for Medicare and Medicaid Services [CMS] and the Office of the Assistant Secretary for Planning and Evaluation [ASPE] and national organizations.

## B. State Unit on Aging (SUA)

A state's governor designates a state government agency as the SUA to serve as the focal point for all matters relating to older persons within the state. SUA's are located within a multipurpose state agency and in Oregon this agency is the Department of Human Services, Seniors & People with Disabilities. SUA's are responsible for ensuring effective implementation of the NFCSP broad policy objectives. SUA functions include:

- **Management and Administration:** With input from the AAA's local plans, advisory bodies, and consumers of services, SUA's develop a state

plan inclusive of the NFCSP. SUA's also assume the primary role for the development of an Intrastate Funding Formula (IFF), approving the AAA area plans, and monitoring the activities and expenditures under the approved area plans.

- **Service System Development:** SUA's develop a state-level multi-faceted service system in keeping with the NFCSP and integrate this system into the social and health services system for older persons.
- **Services Development:** SUA's set policies on quality assurance, provide guidance, and facilitate information exchange between AAA's to make resources available that help shape services development in the state.
- **Advocacy:** SUA's identify areas in which caregiver support programs might need legislative support and might advocate greater state funding. SUA's also advocated for programs with other public agencies and private organizations and promote caregiver support programs with the public at large.

### C. Area Agencies on Aging (AAA)

AAA's are public or private nonprofit agencies designated by SUA's to carry out the OAA at the sub-state level. AAA's assume many of the same broad responsibilities as the SUA management and administration, service system development, services development, and advocacy but focus more on the local area and on direct involvement in services development and delivery. AAA's can be public agencies located within county governments, a regional planning council, a unit of city government, an office within an educational institution or an independent nonprofit organization.

How AAA's carry out their role in implementing the NFCSP likely will be heavily influenced by their role relative to other OAA functions. For example: needs assessment, contract development, and monitoring will be foremost for AAA's that primarily fund providers to deliver services. For AAA's more active in service delivery, e.g., provision of information and referral and care management by in-house staff, issues regarding staff development, assessments, and service coordination might be of primary concern. AAA's at both ends of the spectrum will benefit from improved understanding of caregiver needs and strategies for meeting their needs.

### D. Service Providers (SP)

All local SP's concerned with older persons should consider their role in NFCSP implementation. AAA's will fund some SP's directly. These and other SP's and community organizations might consider serving as a potential referral source as they identify a caregiver in need, raising public awareness of caregivers, offering support groups, training caregivers or generating funds to supplement caregiver programs. AAA's can foster this type of service development through small service development grants, training providers, regular information exchange meetings or co-location of services.

## VII. Resources and Useful Links

### **ADRC – Aging and Disability Resource Connection**

The Aging and Disability Resource Connection of Oregon (ADRC) is the first call to make to get information on all aspects of aging or living with a disability. By contacting the ADRC you will reach trained professionals who will be able to provide you with the information you are seeking or help you determine what services might work best for you.

#### **Eldercare Locator**

<http://eldercare.gov/Eldercare.NET/Public/Index.aspx>

Are you a family caregiver in need of information or assistance? Are you interested in learning more about the programs and services that may be of assistance to you or your loved one? The Eldercare Locator, a public service of the U.S. Administration on Aging, is the first step to finding resources for older adults in any U.S. community. Just one phone call or Website visit provides an instant connection to resources that enable older persons to live independently in their communities. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.

#### **Family Caregiver Alliance - National Center on Caregiving**

[http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=368](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=368)

Established in 2001 as a program of the Family Caregiver Alliance, the National Center on Caregiving (NCC) works to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Uniting research, public policy and services, the NCC serves as a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders and family caregivers throughout the country.

#### **National Alliance for Caregiving**

<http://www.caregiving.org/>

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

The Alliance was created to conduct research, do policy analysis, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions, and represent the US caregiving community internationally. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of

those they care for, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients.

### **The National Family Caregivers Association**

<http://www.thefamilycaregiver.org/index.cfm>

The National Family Caregivers Association educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.

### **Generations United**

<http://www.gu.org/OURWORK.aspx>

Generations United is the national membership organization dedicated to improving the lives of children, youth, and older people through intergenerational strategies, programs, and public policies. Generations United represents more than 100 national, state, and local organizations representing more than 70 million Americans. With its emphasis on public policy, advocacy and programming, Generations United has served as a resource for policymakers and the public on the economic, social, and personal imperatives of intergenerational cooperation.

### **The Brookdale Foundation Group – Relatives as Parents Program (RAPP)**

<http://www.brookdalefoundation.org/RAPP/rapp.html>

Established in 1996 in response to a growing understanding of the need for enhanced services and supports for grandparents raising grandchildren, The Brookdale Foundation Group established the Relatives as Parents Program (RAPP) to encourage and promote the creation or expansion of services for grandparents and other relatives who have taken on the responsibility of surrogate parenting due to the absence of the parents. Currently RAPP provides supportive services, primarily to relative caregivers caring for children outside the foster care system, through an extensive network of support groups across the country.

### **Extension**

[http://www.extension.org/family\\_caregiving](http://www.extension.org/family_caregiving)

This website was created by the United States Department of Agriculture (USDA), Cooperative Extension System. Here, caregivers and advocates can access a wide range of information and materials designed to help them learn about and provide supportive services to family and relative caregivers. Topics include disaster preparedness, military families, and grandparents raising grandchildren, housing, and nutrition.