



Family Caregiver Support Program Standards

Older Americans Act

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Department of Human Services
Aging and People with Disabilities
State Unit on Aging**

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Family Caregiver Support Program Standards

I. Introduction

The National Family Caregiver Support Program (NFCSP) was established in 2000 as Title III-E under the Older Americans Act, and was officially launched in February 2001. When the Older Americans Act was reauthorized in 2006, the NFCSP broadened the populations served. The Act was reauthorized in 2016, providing further clarification as to who may receive services.

The NFCSP is a recognition that family caregivers provide the majority of care and support to their loved ones and that they are deserving of services that help them enhance their own lives as well as the person they support.

Services outlined in these Standards are meant to provide support to caregivers who care for a loved one in their home in hopes of preventing or delaying placement into a long term care setting. When family caregivers are well supported, receivers of their care are able to stay in their homes longer and can have a better quality of life.

II. Program Purpose Goals

- a. Services and resources will meet the needs of the caregiver and enhance support given to the care receiver.
- b. Services provided will help the caregiver become a better advocate and more confident in assisting the care recipient in with their physical, cognitive and behavioral needs.
- c. Services and supports will deter placement in a long-term care setting when feasible, and promote continued care within the home and/or in alternative community settings for seniors for as long as possible or desirable.
- d. Services and resources will help provide support to older relatives that are caregivers for children.

III. Program Authority

Sections 371-374 of the Older Americans Act of 1965, as Amended (P.L. 114-144), Grants for State and Community Programs on Aging and W.S. 9-2-1204.

IV. Eligibility

1. A family caregiver who is 18 years or older caring for:
 - A person age 60 years of age or older; or
 - A person with Alzheimer's disease or other dementia of any age.
2. A parent or older relative caregiver age 55 or older who lives with, and is the primary caregiver for, an individual with disabilities age 18 or older.
3. An older relative caregiver (other than a parent) age 55 or older who lives with, and is the primary caregiver for, a child age 18 or younger.

(OAA 372-373)

V. Services Provided under the Family Caregiver Support Program

The following services are allowed under the Older Americans Act Family Caregiver Support Program. Area Agencies on Aging may determine which of these services are needed and feasible in their area, and may offer some or all.

1. Information about services available in local communities. *See Service and Unit Descriptions, Group 2 Information for Caregivers.*
2. Assistance in gaining access to services and resources in local communities. *See Service and Unit Descriptions, Group 2 Caregiver Access Assistance.*
3. Individual counseling, support groups and/or evidence based training in the areas of caregiving, health, nutrition and financial literacy that assist the caregiver in making decisions and solving problems in related to their caregiving role. *See Service and Unit Descriptions, Group 1 Caregiver Counseling; Caregivers Support Groups, and Caregiver Training.*

4. Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities. Respite offers temporary substitute supports or living arrangements that afford the caregiver a brief period of relief and rest from caregiving responsibilities. Respite care is prioritized to family caregivers providing care to a frail older adult. Services can be provided in the home, adult day service program or overnight stay in a residential care setting. *See Service and Unit Descriptions, Group 1 Respite Care.*
5. Supplemental services on a limited basis to complement the care provided by caregivers. For example, assistive technology, home modifications, incontinent supplies, legal assistance, transportation. Supplemental services are prioritized to family caregivers providing care to a frail older adult. *See Service and Unit Descriptions, Group 1, Caregiver Supplemental Services and Caregiver Self-Directed Care.*

(OAA 373 (b))

VI. Priority populations to be served

The Older Americans Act prioritizes services to at-risk older adults including those who are frail and at risk for institutional placement; low-income, socially isolated, or minority individuals; Native American elders; older adults with limited English proficiency; those residing in rural areas; and Lesbian, Gay, Bisexual, or Transgender (LGBT) older adults.

The Family Caregiver Support Program also specifically calls for states and Area Agencies on Aging to prioritize services to the following populations:

1. Caregivers who are older individuals with greatest social need, and older individuals with greatest economic need. (OAA 373 (c)(2)(A))
2. Older relative caregivers of children with severe disabilities, or individuals with severe disabilities. (OAA 373 (c)(2)(B))
3. Family caregivers who support their relative that has Alzheimer's disease and related disorders with a neurological or organic brain dysfunction. (OAA 372 (b))

VII. AAA Implementation of the Family Caregiver Support Program

1. Through the development of each AAA Area Plan, identify how the core service elements stated in Section V will be provided.
2. Develop policies and procedures on how services will be provided within the AAA. Policies and procedures may include but not limited to:
 - a. When screenings and assessments are conducted and how they are used to identify the needs of the caregiver and of what services they will benefit from. AAA staff may use the assessment form provided by the DHS/State Unit on Aging or their own form(s).
 - b. How each service will be provided, either self-provided or through contract with a service provider, in partnership with another agency, or with volunteers.
 - c. Identification and providing of services for caregivers who meet the “priority” criteria as outlined in Section VI of these Standards.
 - d. Wait listing of clients for services in the event a client cannot be accommodated in a particular service at a particular time.
 - e. Identification of dollar amount limits that will be provided to each client on services such as respite or supplemental services.
 - f. Referral of individuals to other programs and services, i.e. other OAA programs, Medicaid, or local community services etc.
3. Develop partnerships with other agencies (public or private) businesses, faith based organizations or health care agencies either to provide services or information that can benefit caregivers.
4. Conduct outreach to prioritized populations of family caregivers.
5. Provide services in coordination with the local Aging and Disability Resource Connection (ADRC).
6. Develop a process for ensuring quality of services and follow-up with clients who have received services.
7. Recruit and train volunteers to expand the provision of available services.

VIII. National Aging Program Information System Reporting Requirements

1. Each AAA shall collect and report National Aging Program Information System (“NAPIS”) data as directed by DHS for all caregiver services delivered using software provided by DHS or an alternative collection and reporting method.
2. Reporting of service units shall be consistent with the “Service Units and Definitions of Older Americans Act and Oregon Project Independence Programs”, Group 1 and Group 2 Caregiver Services, please see Appendix 2 to these Standards.
3. Each AAA shall collect demographic information as required by NAPIS, and outlined in the Service and Unit Description document (Appendix 2) of these standards.
4. Each AAA will ensure that data for the Family Caregiver Support program is updated or completed at least annually and submitted in order for the State Unit on Aging to send the State Program Report (SPR).

IX. Program Income

All recipients of the Title III-E caregiver services are provided the opportunity to voluntarily contribute towards the cost of service. Any voluntary contribution will be referred to as program income and will be used for the sole purpose of expanding caregiver services.

X. Maximum Expenditures

1. No more than 10% of expended Title III-E funds may be utilized for administration of the program.
2. No more than 10% of total Federal and non-Federal share available to the State for Family Caregiver Support Program shall be used to provide support services to older relative caregivers.
(Sec. 373 (g) (2) (C))

XI. 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:

\$100 Title III E funds expended = \$100 divided by .75 = \$133.

\$133 - \$100 = \$33; therefore the required match to spend \$100 of Title III E funds is \$33.

Appendix 1 – General Terms and Definitions

Definitions that have references to the OAA or ACL Reporting Requirements for Title III and VII can be accessed by using the following links.

- **Older American’s Act (OAA)** - <https://www.acl.gov/about-acl/authorizing-statutes/older-americans-act>
- **ACL Reporting Requirements for Title III and VII (SPR Program Report)** - <https://www.acl.gov/programs/performance-older-americans-act-programs>

1. **Aging and Disability Resource Connection** means 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 person centered 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. (condensed from OAA 102 (4) (A-D))
2. **Activities of Daily Living (ADL)** means those personal functional activities required by an individual for continued well-being which are essential for health and safety. Activities include eating, dressing, grooming, bathing, personal hygiene, mobility (ambulation and transfer), elimination (toileting, bowel and bladder management), and cognition, and behavior. (OAR 411-015-0006 (1))
3. **Adult Day Services (ADS) Program** means 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 411-066-0005 (2))
4. **Alzheimer's Disease and Other Related Disorders** means a progressive and degenerative neurological disease that is characterized by dementia including the insidious onset of symptoms of short-term memory loss, confusion, behavior changes, and personality changes. It includes dementia caused from any one of the following disorders:

- a. Multi-Infarct Dementia (MID);
 - b. Normal Pressure Hydrocephalus (NPH);
 - c. Inoperable Tumors of the Brain;
 - d. Parkinson's Disease;
 - e. Creutzfeldt-Jakob Disease;
 - f. Huntington's Disease;
 - g. Multiple Sclerosis;
 - h. Uncommon dementias such as Pick's Disease, Wilson's disease, and Progressive Supranuclear Palsy; or
 - i. All other related disorders recognized by the Alzheimer's Association.
 - j. ([Alzheimer's Association – What is Dementia?](#))
5. **Area Agency on Aging (AAA)** means the agency designated by the Department as an AAA is charged with the responsibility to provide a comprehensive and coordinated system of services to older adults and individuals with physical disabilities in a planning and service area. For purposes of these standards, the term Area Agency on Aging is inclusive of both Type A and B AAAs as defined in ORS 410.040 to 410.300, 410.410)
 6. **Area Plan** means the approved plan for providing authorized and coordinated services under the Older American's Act and Oregon Project Independence. (Definition developed by SUA)
 7. **Assessment** means a collaborative process for identifying the services that will be of benefit to the caregiver. (Definition developed by SUA)
 8. **Caregiver** means an individual who has the responsibility for the care of an older individual, either voluntarily, by contract, by receipt of payment for care, or as a result of the operation of law and means a family member or other individual who provides (on behalf of such individual or of a public or private agency, organization, or institution) compensated or uncompensated care to an older individual. (OAA (102) (18) (B))
 9. **Child** means an individual who is not more than 18 years of age. (OAA 372 (a) (1))
 10. **Disability** means 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 or more of major life activity. (Condensed from OAA 102 (13))

11. **Ethnicity-** Consistent with OMB requirements ethnicity categories are Hispanic or Latino or Not Hispanic or Latino. (ACL Reporting Requirements for Title III and VII)
12. **Evidence-based training** Evidence-based programs provide interventions that have been tested and have shown to be effective. In terms of caregiving, interventions are aimed at helping the caregiver and the care recipient adopt healthy behaviors, improve health status and reduce the use of hospital services and emergency room visits.
13. **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 related disorder with neurological and organic brain dysfunction. (OAA 302 (4))
14. **Frail** means, with respect to an older individual in a State, that the older individual is determined to be functionally impaired because the individual –
 - A. (i) is unable to perform at least two activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision; or (ii) at the option of the State, is unable to perform at least three such activities without such assistance; or
 - B. 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. (OAA 102 (22))
15. **Individual With A Disability** means an individual with a disability, as defined in Section 3 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12102), who is not less than age 18 and not more than age 59. (OAA 372 (a) (2))
16. **Instrumental Activities of Daily Living or Self-Management Tasks** means a person’s ability to do housekeeping, laundry, shopping transportation, medication management and meal preparation as described in [OAR 411-015-0007](#).

- 17. Greatest economic need** means the need resulting from an income level at or below the poverty line. (OAA 102 (a) (23))
- 18. Greatest social need** means the need caused by non-economic factors which include:
- A. Physical and mental disabilities;
 - B. Language barriers; and
 - C. Cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that;
 - i. Restricts the ability of an individual to perform normal daily tasks; or
 - ii. Threatens the capacity of the individual to live independently.
- (OAA, 102 (24))
- 19. National Aging Program Information System (NAPIS) State Program Reports (SPR)** which are generated through NAPIS provides information on what services are provided through Titles III and VII (supportive services, nutrition, caregiver support, elder rights) of the OAA and who receives them and what funding is expended for these programs. ([NAPIS/SPR](#))
- 20. Older Relative Caregiver** means a caregiver who is 55 years and older; lives with, is the informal provider of in-home and community care to, and is the primary caregiver for, the child or the individual with a disability.
- In the case of a caregiver for a child, the older relative is the grandparent, step-grandparent or other relative (other than the parent) by blood, marriage, or adoption, of the child. They are the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as primary caregivers; and there is a legal relationship to the child, such as legal custody or guardianship or is raising the child informally.
 - In the case of the caregiver for an individual with a disability who is age 18-59, the older relative is the parent, grandparent or other relative by blood, marriage, or adoption of the person with a disability.
- (OAA 372 (a) (2-3))
- 21. 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. (AoA Title III/VII Reporting Requirements Appendix – Definitions)

22. **Poverty Level** means 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. [Poverty Levels – HealthCare.gov](https://www.healthcare.gov/poverty-levels/)
23. **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 grant project during the grant period. (AoA Title III/VII Reporting Requirements Appendix –Definitions)
24. **Provider** means an organization or person which provides a service to clients under a formal contractual arrangement with the AAA or SUA. (AoA Title III/VII Reporting Requirements Appendix – Definitions)
25. **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 – Definitions)
26. **Registered Client** means an individual who received one or more units of Cluster 1, Cluster 2, or Group 1 or Group 2 Caregiver services: Definition developed by DHS/APD/SUA.
27. **Rural** – Any area that is not defined as urban. Urban areas comprise (1) urbanized areas (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 –Definitions)
28. **Severe Disability** - The term “severe disability” means a severe, chronic disability attributable to mental or physical impairment, or a combination of mental and physical impairments, that

- A. Is likely to continue indefinitely; and
 - B. Results in substantial functional limitation in 3 or more of the major life activities including self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; economic self-sufficiency; cognitive functioning; and emotional adjustment. (OAA Sec. 102 (48))
- 29. Volunteer** An uncompensated individual who provides services or support on behalf of older individuals. Only staff working under the AAA, not the AAA contractors, shall be included. (AoA Title III/VII Reporting Requirements Appendix – Definitions)
- 30. Voluntary Contributions** means a non-coerced monetary sum provided toward the cost of service. (OAA 315(a) (5) (b) (1))

Appendix 2 - 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 services.

CAREGIVER SELF-DIRECTED CARE (formerly known as 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)

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 – Definitions)

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 – Definitions)

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/APD/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 for Caregivers, Savvy Caregiver, Communicating Effectively with Health Care Professionals; conferences, etc. (A session for conferences would be equal to one day's attendance at the conference). (DHS/APD/SUA definition)

Note: This does not include training to paid providers.

RESPIRE CARE

Matrices #30-4 (funded with 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 –Definitions)

Note: OAA 373 (a)(B) states priority shall be given to caregivers providing services to individuals whom meet the definition of 'frail'.

SPR Q&A #28, released in 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 are 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 – Definitions)

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 – Definitions)

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.

Appendix 3 – Family Caregiver Support Program Intake Form

FAMILY CAREGIVER INTAKE FORM

Date: _____

Caregiver Name: _____ DOB: _____ Male Female
Address: Home: _____ Mailing: _____

City/St./ZIP: _____ City/St./ZIP: _____
Phone: Home/Cell: _____ Work: _____ E-mail: _____

Race *Check all that apply*

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

Ethnicity

Client is Hispanic or Latino?

- Yes No Unknown

Referred by: _____

Relationship to Care Receiver

Husband Wife Son Son-in-Law Daughter
 Daughter-in-Law Other Fam. Member Non-Relative
When Caregiver is Grandparent Other Elderly Relative

Grandparent Status 55+: How many children under age 18 does the caregiver care for? _____

Emergency Contact

Name: _____ Home Phone: _____
Address: _____ Work Phone: _____
City/St./ZIP: _____ Cell Phone: _____
E-Mail: _____

Relationship Child Friend Grandchild Neighbor Parent Sibling
 Spouse Other Fam. Member Not Related

Care Receiver Information:

Name: _____ DOB: _____
Address: _____ Gender: Male Female
City/St./ZIP: _____ Phone: _____
Physician: _____ Phone: _____ Ext. _____

Does the care receiver have a dementia diagnosis? Yes No

Health Status/Diagnosis

Benefits/Income

What is your average monthly income? _____

Poverty Level Guidelines: <https://www.healthcare.gov/glossary/federal-poverty-level-FPL/>

Is the care receiver a veteran? Yes No

Does the care receiver currently receive services or benefits? Yes No

Does the care giver currently receive services or benefits? Yes No

If yes, what services/benefits? _____

Are services being received by any other agencies such as county, state or other organization? Yes No

If yes, what agency? _____

Living Situations Does the caregiver live with the care receiver? Yes _No

If No, then who does the care receiver live with? _____

1. Who is the primary caregiver? _____ Relation: _____
2. Is there a back-up/secondary caregiver? Who? _____
3. Are there cultural or ethnic preferences? _____
4. What does the caregiver need help with the most? _____
5. Quality of relationship? _____
6. Length of caregiving? _____ Years _____ Months
7. Is the caregiver employed? _____
8. Is quality and amount of care satisfactory? _____
9. How is the health of the caregiver? _____
10. Other support received by caregiver or care receiver? _____
11. Impact of caregiving (indicated + or -) _____ Social _____ Financial _____ Work Strain _____ Health
_____ Family Relationship

Caregiver Support Services

Please check all that apply for this caregiver

- Caregiver Access Assistance (#16/16a)
- Caregiver Respite (#30-5/30-5a)
- Caregiver Supplemental Svcs. (#30-7/30-7a)
- Caregiver Training (#70-9/70-9a)
- Support Groups for Caregivers (#30-6/30-6a)
- Information for Caregivers (#15/15a)

Caregiver Receiver Information

F=Full Assist, S=Substantial Assist, M=Minimal Assist, I=Independent

IADL No IADL Needs

F S M I

- Food Preparation
- Heavy Housework
- Housekeeping
- Managing Finances
- Medication Mgmt.
- Shopping
- Taking Medication
- Using Telephone
- Using Transportation

ADL No ADL Needs

F S M I

- Bathing
- Behavior
- Dressing
- Eating
- Eliminating
- Mobility/Walking
- Hygiene/Grooming
- Transferring

Other Needs of Care Receiver? _____

Action Plan

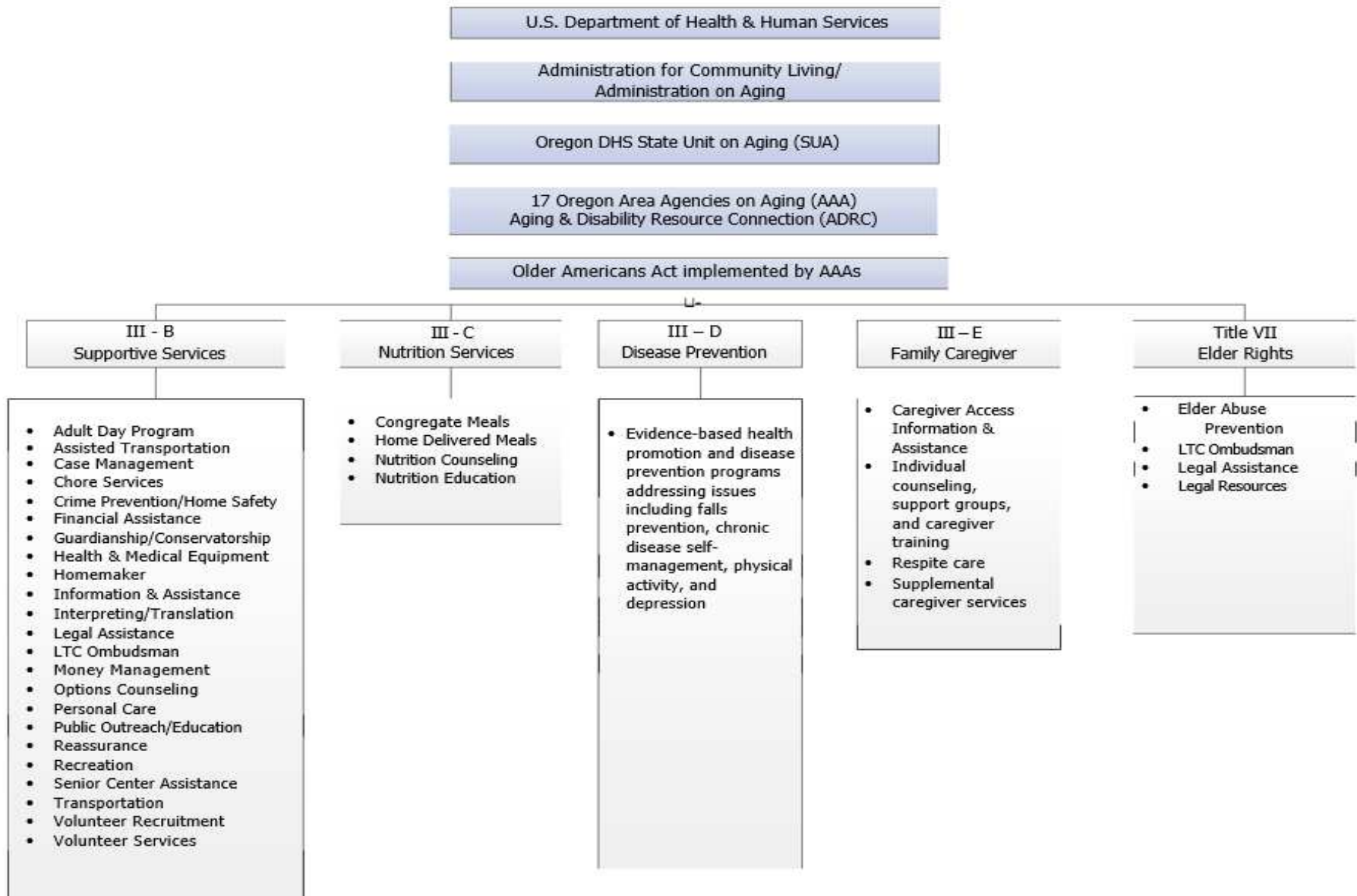
- Assist to access resources
- Respite
- Consultation
- Ed/Training
- Case Management
- Transportation
- Support Groups
- Counseling
- Other (see below)

Referred to: _____

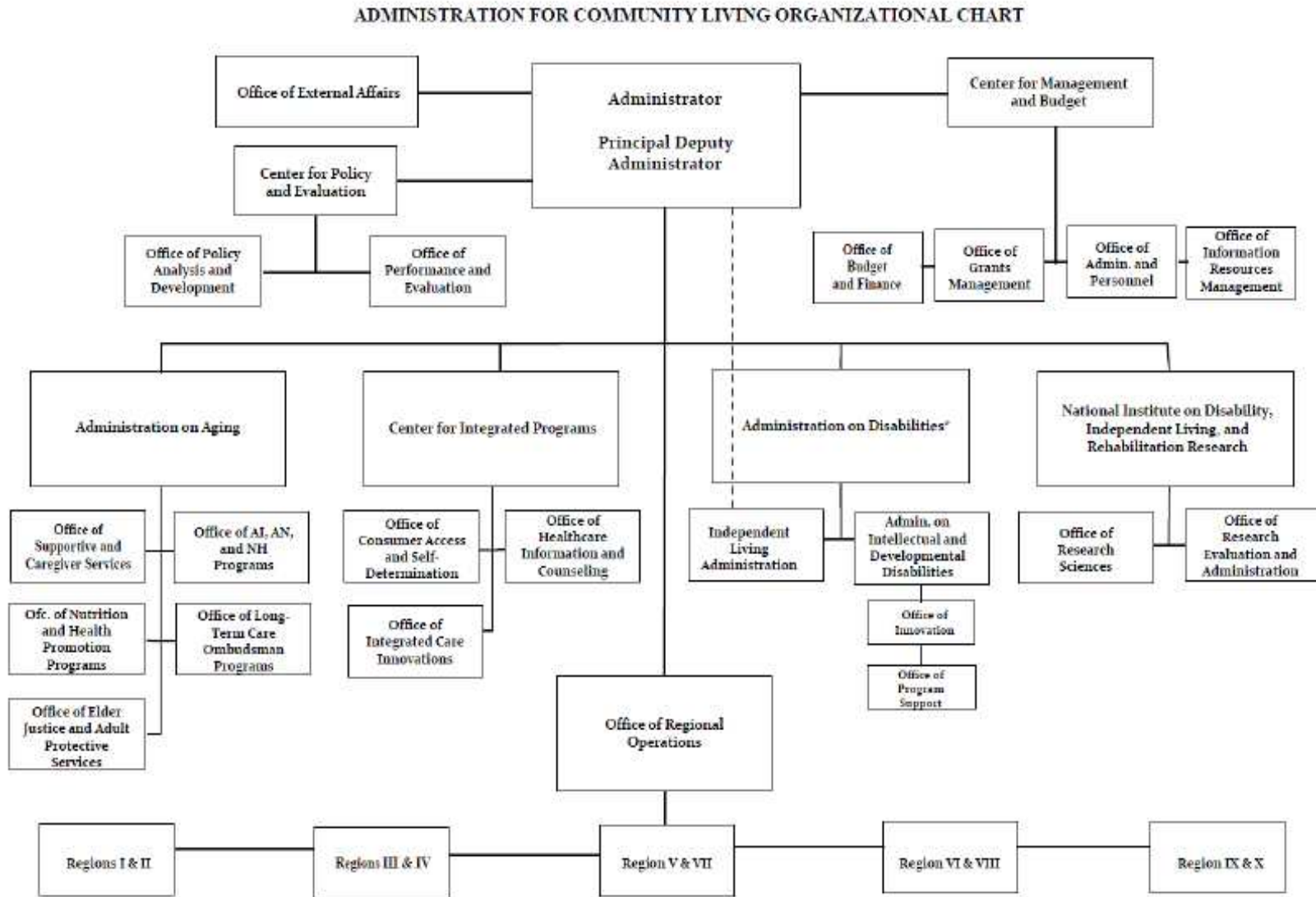
Follow-up needed:

Appendix 4 – Roles & Relationships in the Aging Network

Roles & Relationships in the Aging Network



Appendix 5 – Administration for Community Organization Chart



*The Administration on Disabilities is headed by a Commissioner, who reports directly to the Administrator, and a Deputy Commissioner/Director of Independent Living. In this dual role, the Deputy Commissioner/Director of Independent Living serves as a member of the Administrator's senior leadership and reports directly to the Administrator in carrying out the functions of the Director of Independent Living consistent with Section 701A of the Rehabilitation Act.