

CHAPTER 6

Administration of the Alzheimer's Disease Initiative (ADI)

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ALZHEIMER'S DISEASE INITIATIVE (ADI) PROGRAM:

PURPOSE OF ADI PROGRAM:

Chapter Contents, Purpose and Program Components:

- A. Chapter Contents:** This chapter provides program policies, standards and procedures for use by the state office and all providers in the conduct of the Alzheimer's Disease Initiative (ADI) program
- B. Chapter Purpose:** The purpose of the ADI is the following:
 - 1. Special Needs:** To address the special needs of clients with Alzheimer's disease (AD) and their caregivers; and
 - 2. Cure:** To find through research the cause, treatment and ultimately a cure for AD.
- C. ADI Program Components:** The ADI is composed of the following program components:
 - 1. Alzheimer's Disease Advisory Committee;**
 - 2. Memory disorder clinics;**
 - 3. Model day care projects;**
 - 4. Respite care projects; and**
 - 5. A brain bank.**

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Legal Basis and History, Specific Legal Authority, and Alzheimer's Disease Characteristics

LEGAL BASIS AND HISTORY, SPECIFIC AUTHORITY, AND ALZHEIMER'S DISEASE CHARACTERISTICS:

Legal Basis and History:

A. Florida Statute: In 1985, the Florida Legislature enacted Sections 430.501 – 430.504, Florida Statutes. The Legislature demonstrated its recognition of the alarmingly high percentage of citizens (particularly those over age 65) affected by Alzheimer's disease and other related memory disorders by creating the following:

1. An Alzheimer's Disease Advisory Committee;
2. The Alzheimer's Disease Research Trust Fund;
3. Respite care programs;
4. Three model day care programs;
5. Four memory disorder clinics; and
6. Through subsequent amendments:
 - a. A brain bank; and
 - b. Additional memory disorder clinics. (Currently, there are 15.)

B. ADI Program Funding: The ADI is a general revenue-funded program. Each year the level of funding is determined by the legislature during its budget process. The statute revision of 1988 established population factors to be included in an allocation formula for the distribution of respite care dollars.

C. ADI Service Eligibility:

1. **Service Eligibility Requirements:** Individuals must be 18 years of age or older and have a diagnosis of Alzheimer's disease or a related disorder, or be suspected of having Alzheimer's disease or a related disorder.
2. **Caregivers:** Caregivers are also eligible to receive training, respite and related support services to assist them in caring for the ADI client.
3. **Eligibility for Multiple Services:** There is no prohibition against an ADI client receiving more than one type of ADI service during the same time period.

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Legal Basis and History, Specific Legal Authority, and Alzheimer's Disease Characteristics

- a. **Multiple ADI Services:** The use of multiple ADI services for a client should be based upon the client's assessed needs and upon the local resources available.
 - b. **Example:** A client may receive services at an ADI model day care program three days a week and also receive respite care in the home two days a week.
4. Clients MAY NOT be dually enrolled in the ADI program and a Medicaid capitated long-term care program.

Specific Legal Authority:

Chapter 430.501-504, F.S.

Chapter 58D-1, F.A.C.

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Legal Basis and History, Specific Legal Authority, and Alzheimer's Disease Characteristics

Alzheimer's Disease Characteristics:

- A. **Definition:** Alzheimer's disease (AD) affects the cells of the brain. It affects individuals from all socioeconomic levels. It produces a diminished capacity to think or understand and perform activities of daily living.

- B. **Related Disorders:** There are several other related disorders, which are included by reference every time the term Alzheimer's disease is used in this document. Some of the more well-known of these related disorders include, but are not limited to, the following:
 - 1. Multi- Infarct Dementia;
 - 2. Parkinson's disease;
 - 3. Huntington's disease;
 - 4. Creutzfeldt-Jakob disease;
 - 5. Pick's disease; and
 - 6. Normal Pressure Hydrocephalus.

Memory Loss: Memory loss, to the extent experienced by AD clients, is not a natural part of the aging process as was popularly believed in the past.

Treatment: There is no treatment available to stop or reverse the mental deterioration characteristic of AD. However, gains in research are occurring every year towards finding a cure.

Diagnosis: An absolute diagnosis can only be made upon examination of brain tissue, usually at autopsy.

- C. **Continuum of Care:** AD clients require a wide continuum of care, from basic supervision and assistance with activities of daily living (ADLs) to skilled nursing care.
 - 1. **Impact on Caregivers:** The nature of AD is such that the impact on the caregivers is as great as the impact on the person with the disease. The caregiver of the AD client plays a key role in the prevention of premature institutionalization of the AD client. Consequently, caregivers need services to assist them in the continuation of care.

Legal Basis and History, Specific Legal Authority, and Alzheimer's Disease Characteristics

2. **Onset of Alzheimer's Disease:** In the early stages of the disease, the AD client often experiences getting lost easily, short-term memory impairment and difficulty in performing familiar tasks.
3. **Impact on Caregiver at the Onset of the Disease:** The caregiver assumes certain responsibilities at the onset of the disease, ensuring the AD client receives the following:
 - a. Assistance in activities of daily living;
 - b. A safe environment;
 - c. Balanced meals;
 - d. Required medications; and
 - e. Instructions on how to complete routine functions.
4. **Disease Progression:** As the disease progresses, the AD client may also experience the following more advanced conditions:
 - a. Confusion;
 - b. Personality change;
 - c. Behavior change;
 - d. Impaired judgment;
 - e. Difficulty finding words or finishing thoughts; and
 - f. Difficulty following directions.
5. **Impact on Caregiver as Disease Progresses:** The ADI addresses the needs of the caregiver as well as those of the client. The caregiver's job becomes even more difficult and demanding as the disease progresses. When adequate services cannot be provided in the home, it may become necessary for the caregiver to consider placement outside of the home. If assisted living facility (ALF) or nursing home placement becomes necessary, the caregiver may need assistance in the selection and placement process.

SERVICES PROVIDED UNDER THE ADI PROGRAM:

ADI Services:

A. State funds appropriated for ADI services must be used for services that support and provide temporary relief from caregiving responsibilities for the ADI client's primary caregiver. These services are listed below. Refer to Appendix A, Service Descriptions and Standards, for a description of each service.

1. Caregiver Training/Support;
2. Case Aide;
3. Case Management;
4. Counseling (Gerontological);
5. Counseling (Mental Health/Screening);
6. Education/Training;
7. Intake;
8. Model Day Care;
9. Respite (Facility-Based);
10. Respite (In-Home); and
11. Specialized Medical Equipment, Services and Supplies.

B. Other ADI program components include:

1. **Memory Disorder Clinics (MDCs):** MDCs must provide research, training and services directed to persons with symptoms of Alzheimer's disease or a related dementia. MDCs provide the following service components:
 - a. Evaluation and referral services for ADI clients;
 - b. Service-related research and research on the cause, prevention and treatment of Alzheimer's disease. MDCs shall initiate at least one contact with respite and model day care providers annually to review progress relative to research efforts and exchange ideas with the providers.

- d. Training:** Develop and provide training for lay and professional caregivers.
- i. Memory disorder clinics are required to provide a minimum of 4 hours in-service training related to Alzheimer's disease annually in their designated service area for respite and model day care providers, which will include health professionals and caregivers.
 - ii. AAAs, memory disorder clinics, respite and model day care programs must collaborate in the development of training to meet staff needs.

Individuals with suspected memory loss may be evaluated at any one of the funded memory disorder clinics. Florida residents may access MDC services regardless of the ability to pay. The fifteen (15) MDCs are based at:

<u>Name of Memory Disorder Clinic:</u>	<u>Location:</u>
a. The University of Miami	Miami
b. The University of Florida	Gainesville
c. The University of South Florida	Tampa
d. Mayo Clinic	Jacksonville
e. West Florida Hospital	Pensacola
f. East Central Florida Memory Disorder Clinic	Melbourne
g. Orlando Regional Healthcare System, Inc.	Orlando
h. Tallahassee Memorial Healthcare	Tallahassee
i. St. Mary's Medical Center	Palm Beach
j. Lee Memorial Health System	Ft. Myers
k. Sarasota Memorial Health Care System	Sarasota

d. Brain Bank Minimum Service Standards:

- i. Brain bank clients should be selectively screened prior to death in accordance with established protocols.
- ii. The family should receive notification of definite diagnosis, written in clear understandable terms no later than 6 months after autopsy.
- iii. In the case of familial Alzheimer's disease, confirmation of the diagnosis in a family member carries with it an opportunity for the provision of genetic counseling.

e. Regional Brain Bank Sites: In addition to the primary brain bank site in Miami, there are coordinators at regional brain bank sites at the following locations to assist in recruiting clients and act as liaison between the brain bank and the client's family:

- i. Melbourne
- ii. Orlando
- iii. Tampa
- iv. Pensacola

f. Brain Bank Information: Information regarding the Brain Bank program and applications can be obtained from:

**The Wein Center for Alzheimer's Disease and Memory Disorders
Mount Sinai Medical Center
4300 Alton Road
Miami Beach, Florida 33140
Phone: 305-674-3543**

- 4. Model Day Care:** The day care centers are considered models because they provide specialized services for AD clients in addition to those functions provided at adult day care centers (i.e., supervision, social/therapeutic activities and personal care services).

- a. **Locations:** Model day care centers are located in the following counties:
 - i. Alachua
 - ii. Hillsborough
 - iii. Miami-Dade
 - b. **Specialized Services:** Specialized services in model day care centers include, but are not limited to, those listed below:
 - i. Providing a natural laboratory for research conducted by Memory Disorder Clinics (MDCs);
 - ii. Training in the care of ADI clients for health care and social service personnel, as well as caregivers;
 - iii. Specialized activities that take into account the ADI client's diminished level of functioning;
 - iv. Providing stimulation to the ADI client; and
 - v. Providing relief for the ADI client's primary caregiver.
5. **Alzheimer's Disease Advisory Committee:** Pursuant to Chapter 430.501(2)(3), Florida Statutes, the Governor of the State of Florida appoints a ten (10) member Alzheimer's Disease Advisory Committee to advise the Department of Elder Affairs.
- a. **Committee Composition:** The composition of the 10 member committee should include the following individuals:
 - i. At least four (4) who are licensed medical doctors in accordance with Chapters 458 or 459, Florida Statutes; or hold a Ph.D. degree and are currently involved in the research of Alzheimer's disease;
 - ii. At least four (4) who are the primary caregivers of victims of Alzheimer's disease; and

- iii. Whenever possible, the ten-member committee shall include one (1) **each** of the following professionals: gerontologist, geriatric psychiatrist, geriatrician, neurologist, social worker, and registered nurse.
- iv. **Additional Selection Criteria:** The Governor shall appoint committee members from a broad cross section of public, private and volunteer sectors.
- v. **DOEA Role:** The secretary of the Department of Elder Affairs shall forward all nominations to the Governor.
- vi. **Secretary of DOEA:** The secretary of DOEA shall serve as an ex-officio member of the committee.
- b. **Member Terms:** Members shall be appointed for four (4) year staggered terms.
- c. **Committee Chair:** The committee shall select one of its members to serve as chair for a one (1) year term.
- d. **Committee Function:** The function of the advisory committee is to advise DOEA in the performance of its duties under the ADI. As appropriate, and with the approval of DOEA, the advisory committee may establish subcommittees to carry out the functions of the committee.
- e. **Frequency of Committee Meetings:** The committee shall meet a least quarterly or as frequently as necessary. DOEA will advise MDCs, model day care providers, respite care providers and local Alzheimer's Association chapters of ADI advisory committee meetings.
- f. **Committee Support:** DOEA shall provide support staff to assist the committee in the performance of its duties. DOEA shall provide minutes and reports generated in the ADI Advisory Committee meetings to interested parties as requested. DOEA shall prepare and disseminate an annual report on the accomplishments of the ADI components to all providers.

- g. Member Reimbursement:** Members of the committee and subcommittees shall receive no salary, but are entitled to reimbursement for travel and per diem expenses, as provided in Section 112.061, F.S., while performing duties.

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Program Requirements:

DOEA, AAA and Service Provider Responsibilities

DOEA, AAA AND SERVICE PROVIDER RESPONSIBILITIES:

A. DOEA Purpose and Responsibilities:

1. **Purpose:** The purpose of DOEA in the ADI program is to plan, budget, coordinate and develop policy at the state level necessary to carry out the statutory requirements for the ADI. Where allowed by statute, DOEA may choose to directly administer a program component or may assign this function to an AAA.

2. **Responsibilities:**
 - a. **Allocation of Funds:** Allocate ADI funds to AAAs for funding of service providers of model day care and respite care programs.
 - b. **Contracting:** Contract directly with the memory disorder clinics and brain bank providers.
 - c. **Policies and Procedures:** Establish policies and procedures for AAAs and ADI providers.
 - d. **Technical Assistance:** Provide technical assistance on ADI.
 - e. **Evaluation:** Evaluate the ADI program as required.
 - f. **Monitoring:** Ensure quality of services through the monitoring process:
 - g. **Program Reports:** Develop program reports as appropriate.
 - h. **Provider Applications:** Prepare suggested format for the ADI provider applications.
 - i. **Staff Development and Training:** Ensure that ADI providers are given opportunities for staff development and training.
 - j. **Staff Liaison:** Provide staff assistance to the ADI Advisory Committee.
 - k. **Develop co-payment guidelines.**

B. Area Agencies on Aging (AAA) Purpose and Responsibilities:

1. **Purpose:** The purpose of the AAAs is to carry out policy, develop programs and monitor the ADI respite and day care programs.

2. **Responsibilities:** The AAA has the following responsibilities:

- a. **Competitive Solicitation:** Conduct competitive solicitation for agencies to provide respite and model day care services, as applicable, in accordance with Chapter 287, Florida Statutes, and the AAA board approved procurement procedures.
- b. **Subcontracts:** Enter into subcontracts with agencies to provide ADI respite and model day care services, as applicable.
- c. **Provider Application:** Review and critique the ADI service provider application to ensure completeness, accuracy and that all revisions are noted.
- d. **Administration and Monitoring:** Administer and monitor ADI program policies and procedures.
- e. **Program Reports:** Ensure that all program reports are accurately completed and submitted in a timely manner.
- f. **Technical Assistance:** Provide technical assistance to the ADI subcontracts in program planning and development and ongoing operations as needed.
- g. **Staff Development and Training:** Provide for AAA staff development and training.
- h. **Contracting Responsibilities:** Assume contracting responsibilities, including review of the applicant's subcontracts, if applicable.
- i. **Provider Fiscal Assessment:** Assess the fiscal management capabilities of the service providers.
- j. **Performance Review:** Review the performance of service providers in carrying out their service delivery responsibilities.
- k. **Processing:** Process requests for payment and reports on receipts and expenditures to DOEA.
- l. **Technical Assistance:** Provide technical assistance to providers to ensure provision of quality services.
- m. **CIRTS:** Ensure compliance with departmental Client Information and Registration Tracking System (CIRTS) policies.

- n. **Coordination:** Initiate and maintain coordination among ADI components within the planning and service area (PSA). Memory disorder clinics must provide four (4) hours of in-service training to ADI and model day care providers annually, where applicable. The AAA must collaborate and act as liaison in arranging this training.
- o. **Co-Payment:** Ensure implementation of co-payment guidelines.
- p. **Client Satisfaction:** Conduct client satisfaction surveys to evaluate and improve service delivery.

C. Service Provider Purpose and Responsibilities:

- 1. **Purpose:** The purpose of the service provider is to provide quality services to address the special needs of individuals suffering from Alzheimer's disease and related memory disorders and their caregivers.
- 2. **Responsibilities:** To provide case management, respite and/or model day care as specified in the approved service provider application and each client's care plan.
 - a. **Co-Payment:** Assess and collect co-payments.
 - b. **Client Satisfaction:** Conduct client satisfaction surveys to evaluate and improve service delivery.

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COORDINATION OF SERVICES:

Coordination of Services Responsibilities Among Memory Disorder Clinics, the Area Agency on Aging, and Service Providers:

MEMORY DISORDER CLINICS (MDCs)

- A. Coordination with Respite Service Providers:** MDCs will be assigned to respite service providers at the direction of DOEA for the purpose of coordination of service provision, research and training.
- B. In-service Training:** MDCs should contact the area agency on aging contract managers to set up four (4) hours of annual in-service training for ADI model day care and respite care providers in the respective PSAs.
 - 1. The training should be held in a central location, accessible to the providers in the PSA.
 - 2. The training should be tailored to an audience of health/social service professionals, direct service staff, and caregivers and be directly related to Alzheimer's disease.
- C. Research:** MDCs will contact each model day care and respite care providers in their service areas to establish research efforts involving respite clients and/or caregivers.
- D. Annual Contacts:** The MDCs will initiate and maintain at least one annual contact with model day care and respite care providers to review progress with research efforts and exchange ideas.

SERVICE PROVIDERS

Referral Form: Respite care and model day care center providers will be provided with a referral form for use by clients and caregivers in gaining access to MDCs. The procedure will include the following:

- A.** The provider will complete and send the referral form to the MDC agency on behalf of AD client/caregiver.
- B.** The AD client's caregiver will contact the MDC to arrange for an appointment time.
- C.** The MDC will forward the completed assessment to the respite care or model day care provider for the client's file.

ESTABLISHING PRIORITIES FOR SERVICE PROVISION:

A. Assessment and Prioritization for Service Delivery for New Clients: The following are the criteria to prioritize new clients for service delivery. It is not the department's intent to remove current clients from any services in order to serve new clients assessed and prioritized for service delivery.

1. Priority Criteria for Service Delivery:

- a. Individuals in nursing homes with Medicaid benefits who could be transferred to the community;
- b. Individuals in nursing homes whose Medicare coverage is exhausted and may be diverted to the community;
- c. Individuals in nursing homes that are closing and who can be discharged to the community;
- d. Individuals whose mental or physical condition has deteriorated to the degree that self-care is not possible, there is no capable caregiver, and institutional placement will occur within 72 hours; and
- e. When transitioning individuals receiving the Department of Children and Families' Community Care for Disabled Adults (CCDA) and Home Care for Disable Adults (HCDA) services to the department's community-based services, if services are currently not available, the AAA/lead agency case manager shall ensure that "Aging Out" individuals are prioritized for services only after Adult Protective Services High Risk and Imminent Risk individuals.

2. Priority Criteria for Service Delivery for Other Assessed Clients:

The assessment and provision of services should always consider the most cost effective means of service delivery.

- a. Functional impairment shall be determined through the department's assessment instrument administered to each applicant.
- b. The most frail clients not falling into one of the priorities cited in the above section will receive services to the extent funding is available.

B. Additional Factors:

1. **MDC and Brain Bank Prioritization:** Memory disorder clinics and the brain bank must establish written criteria to be used in prioritizing requests for their services.
2. **Denial of Services:** No one requesting a consultation from a MDC will be denied services.

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CO-PAYMENT ASSESSMENT:

Co-payment assessment information is included in Appendix B of this handbook.

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GRIEVANCE PROCEEDINGS:

Please refer to Appendix D, "Minimum Guidelines for Recipient Grievance Procedures", included in this handbook.

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