

Chapter 6

Administration of the Alzheimer's Disease Initiative (ADI)

TABLE OF CONTENTS

| Section: | Topic | Page |
|-----------------|---|-------------|
| I. | Purpose of the ADI Program | 6-3 |
| II. | Legal Basis and History, Specific Legal Authority | 6-4 |
| III. | Alzheimer's Disease Characteristics | 6-6 |
| IV. | Services Provided Under the ADI Program | 6-8 |
| V. | Program Requirements | 6-15 |
| | A. Department of Elder Affairs (DOEA), Area Agencies on Aging (AAA), and Service Provider Responsibilities | 6-15 |
| | B. Coordination of Services | 6-18 |
| | C. Establishing Priorities for Service Provisions | 6-21 |
| | D. Co-Payment Assessment | 6-22 |
| VI. | Grievance Proceedings | 6-23 |

PURPOSE OF ADI PROGRAM:

- 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. **Purpose:** The purpose of the ADI is the following:
 - 1. **Special Needs:** To address the special needs of clients with Alzheimer's disease (AD) or related memory disorders, as well as their caregivers; and
 - 2. **Cure:** To find through research the cause, treatment and ultimately a cure for AD or related memory disorders.
- 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 centers;
 - 4. Specialized Alzheimer's Services Adult Day Care Centers;
 - 5. Respite care; and
 - 6. The brain bank located at the Wein Center for Alzheimer's Disease and Memory Disorders at Mt. Sinai Medical Center.

LEGAL BASIS, HISTORY AND SPECIFIC LEGAL AUTHORITY:

Legal Basis and History:

- A. Florida Statutes:** 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. Model day care programs (currently, there are 34 Specialized Alzheimer's Services Adult Day Care Centers);
 5. Four memory disorder clinics; and
 6. Through subsequent amendments:
 - a. The brain bank located at the Wein Center for Alzheimer's Disease and Memory Disorders at Mt. Sinai Medical Center; and
 - b. Additional memory disorder clinics. (Currently, there are 16 designated MDCs.)
- 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 memory disorder, or be suspected of having Alzheimer's disease or a related memory 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 period.
 - 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 day care program three days a week and 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.

Chapter 429.918, F.S.

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:** Alzheimer's disease is a type of dementia. Dementia is an umbrella term used to describe a group of diseases that may cause the brain to fail. Because Alzheimer's disease is the most common cause of dementia, the term is used to encompass the many types of dementia. Some of the more well-known types of dementia that are referenced in this document every time the term Alzheimer's disease is used include, but are not limited to, the following:
1. Multi-Infarct Dementia;
 2. Lewy Body Disease;
 3. Parkinson's disease;
 4. Huntington's disease;
 5. Creutzfeldt-Jakob disease;
 6. Pick's disease; and
 7. Normal Pressure Hydrocephalus.
- a. **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.
 - b. **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.
 - c. **Diagnosis:** A definitive diagnosis can only be made upon examination of tissue from the whole brain 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 possible placement for 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.

2. **Onset of Alzheimer's Disease:** In the early stages of the disease, the AD client often experiences confusion, 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. Becoming lost in familiar places;
 - 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. Case management is a required service for in-home and facility-based respite. Co-payment shall be assessed for all services below except Intake. **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/Specialized Alzheimer's Services Adult Day Care Center;
 9. Respite (Facility-Based);
 10. Respite (In-Home);
 11. Specialized Medical Equipment, Services and Supplies; and
 12. Transportation.
- 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. Diagnosis, evaluation, and referral services for ADI clients;

Services Provided Under the ADI Program

- 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 - providers annually to review progress relative to research efforts and exchange ideas with the providers.
- c.** 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, in-facility respite and model day care providers, which will include health professionals and caregivers.
 - ii.** AAAs, memory disorder clinics, respite, and adult day care providers 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 sixteen (16) MDCs are based regionally 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 |

DEPARTMENT OF ELDER AFFAIRS PROGRAMS AND SERVICES HANDBOOK
Chapter 6: Alzheimer's Disease Initiative (ADI) Program

Services Provided Under the ADI Program

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| 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 |
| l. | Mount Sinai Medical Center | Miami Beach |
| m. | North Broward Regional Medical Center | Pompano Beach |
| n. | Morton Plant Hospital | Clearwater |
| o. | Florida Atlantic University | Boca Raton |
| p. | Florida Hospital | Orlando |

- 2. Alzheimer's Disease Research Brain Bank:** To be accepted into the Florida Brain Bank program, there must be documentation of the diagnosis of dementia by the medical director of a state-funded MDC, or by another licensed neurologist, psychiatrist, or geriatric internist. Medical records must also include general and neurological examinations, appropriate analyses, psychiatric assessments, hematological and biochemical studies, and Computerized Tomography (CT) or a Magnetic Resonance Imaging (MRI) scan of the brain. There must be a completed donor registration form and a request for post mortem examination form.

Candidates can be identified from:

- a.** State-sponsored memory disorder clinics;
- b.** Adult day care centers and respite care providers; and
- c.** Local organizations providing services to clients with dementia and their families;
- d.** Self-referral; and

DEPARTMENT OF ELDER AFFAIRS PROGRAMS AND SERVICES HANDBOOK
Chapter 6: Alzheimer's Disease Initiative (ADI) Program

Services Provided Under the ADI Program

- e. **Brain Bank Information:** Information regarding the Brain Bank program and applications can be obtained from:

The Wien Center for Alzheimer's Disease and Memory Disorders
Mount Sinai Medical Center
4300 Alton Road
Miami Beach, Florida 33140
Phone: 305-674-2018

Services Provided Under the ADI Program

- 3. Brain Bank Activities:** The brain bank performs the following activities:
- a. Autopsies** on the brain tissue of AD clients and matching clinical data (obtained before a client's death) with the pathological findings. This is the only way to determine if the pre-morbid symptoms, responses to treatment, and other factors suggesting a diagnosis of AD were in fact the responses of a client with Alzheimer's disease.
 - b. Provision of brain tissue for approved research projects** on a national basis, with Florida projects receiving priority.
 - c. Administration of the Brain Bank:** The brain bank is administered by the Mount Sinai Medical Center in Miami. The brain bank must meet all licensure requirements mandated by the State of Florida.
 - 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 genetic counseling.
 - e. Regional Brain Bank Sites:**
Mt. Sinai Medical Center contracts annually with the State of Florida to operate the primary brain bank, and coordinate with regional brain bank sites in Orlando, Tampa, and Pensacola.

4. **Specialized Alzheimer's Day Care:** These are licensed specialized Alzheimer's services adult day care centers, licensed in accordance with Section 429.918 F.S., that are considered models because they provide specialized Alzheimer's services for AD clients. FloridaHealthFinder.gov provides an up to date listing of all Specialized Alzheimer's Services Adult Day Care Centers.
 - a. **Specialized Alzheimer's Services:** Specialized Alzheimer's services in model day care centers include, but are not limited to, those listed below:
 - i. Providing education and training on the specialized needs of persons with Alzheimer's disease or related memory disorders and caregivers;
 - ii. Providing specialized activities that promote, maintain, or enhance the ADI client's physical, cognitive, social, spiritual, or emotional health;
 - iii. Providing therapeutic, behavioral, health, safety, and security interventions; clinical care, and support services for the ADI client and caregiver; and
 - iv. 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 DOEA.
 - a. **Committee Composition:** The composition of the 10-member committee shall 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 persons diagnosed with Alzheimer's disease or related dementias; and

Services Provided Under the ADI Program

- 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 DOEA 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. The committee may enlist services, assistance, and direction from a broad representation of health care professionals, service providers, individuals affiliated with the Alzheimer's Association, and the provision of Alzheimer's Community Care, dementia-specific service providers, caregivers, and other interested or knowledgeable parties.
- e. **Frequency of Committee Meetings:** The committee shall meet quarterly or as frequently as needed.
- f. **Committee Support:** DOEA shall provide staff support to assist the committee in the performance of its duties.
- 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.

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 adult 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 Support:** Provide staff assistance to the ADI Advisory Committee; and
 - k. **Develop co-payment guidelines.**

B. Area Agency 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 adult day care services, as applicable, in accordance with Chapter 287, Florida Statutes, and the AAA board approved procurement procedures;
 - b. **Subcontracts:** Execute 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;

DEPARTMENT OF ELDER AFFAIRS PROGRAMS AND SERVICES HANDBOOK
Chapter 6: Alzheimer's Disease Initiative (ADI) Program

Program Requirements

DOEA, AAA and Service Provider Responsibilities

- 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 adult 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; and
- 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 adult day care as specified in the approved service provider application and each client's care plan.
 - a. Co-Payment:** Assess and collect co-payments; and
 - b. Client Satisfaction:** Conduct client satisfaction surveys to evaluate and improve service delivery.

COORDINATION OF SERVICES:

Coordination of services among memory disorder clinics, the AAA, and service providers is required as follows:

MEMORY DISORDER CLINICS (MDCs):

A. Coordination with Florida Silver Alert Program: Memory Disorder Clinics will collaborate with Florida Law Enforcement to facilitate a fast and safe return for persons with a permanent loss of intellectual capacity.

1. When notified that someone with possible Alzheimer's or a related dementia is missing, whether driving a vehicle or on foot, the MDC will follow the protocol established by the Silver Alert:
 - a. Call the caregiver or family to gather facts and offer services.
 - b. Send the Silver Alert Referral Form to ADRC designated contact to see if lost individual is, or has been, receiving services and if a CARES assessment is appropriate.
 - c. Offer diagnostic services of MDC and Caregiver training if appropriate.
 - d. Offer specially designed training to avoid recidivism of Silver Alert.

2. Training: MDCs will provide training in their catchment area to ADRCs, senior network personnel, formal and informal caregivers, health and social services professionals and the public.
 - a. The training will explain the Silver Alert Protocols, the part played by law enforcement, the MDCs, the senior network and the public.

It will emphasize the basic goals of the plan which are:

- i. Public safety,
- ii. Assistance to law enforcement in locating a missing senior,
- iii. Education, and
- iv. Prevention.

- B. Coordination with Respite Service Providers:** MDCs will collaborate with in-home and facility-based respite service providers at the direction of DOEA for coordination of service provision, research, and training.
1. **In-service Training:** MDCs should contact the AAA 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.
 - a. The training should be held in a central location, accessible to the providers in the PSA.
 - b. 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.
 2. **Research:** MDCs will contact each respite care provider in their service areas to establish research efforts involving respite clients and/or caregivers.
 3. **Annual Contacts:** The MDCs will initiate and maintain at least one annual contact with respite care providers to review progress with research efforts and exchange ideas.
- C. SERVICE PROVIDERS:**
1. **Referral Form:** Respite care 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:
 2. The provider will complete and send the referral form to the MDC agency on behalf of AD client/caregiver.
 3. The AD client's caregiver will contact the MDC to arrange for an appointment time.
 3. The MDC will forward the completed assessment to the respite care or model day care provider for the client's file.

While not required by statute or rule, Memory Disorder Clinics and the Area Agencies on Aging can volunteer to participate in the Dementia Care and Cure Initiative (DCCI). DCCI encourages the collaboration of MDCs, AAAs, service providers, and other community entities to engage their communities to be more dementia caring, promote better care for Floridians affected by dementia, and support research efforts to find a cure. These collaborative efforts strive to

DEPARTMENT OF ELDER AFFAIRS PROGRAMS AND SERVICES HANDBOOK
Chapter 6: Alzheimer's Disease Initiative (ADI) Program

provide an increase in the awareness of Alzheimer's disease and related dementias and the services available to those living with and affected by the disease through educational events and awareness campaigns.

ESTABLISHING PRIORITIES FOR SERVICE PROVISION:

- A. Assessment and Prioritization of Service Delivery for New Clients:** The following are the criteria to prioritize new clients in the sequence below for service delivery. It is not the Department's intent to remove current clients from any services to serve new clients being assessed and prioritized for service delivery.
- 1. Priority Criteria for Service Delivery:**
 - a.** Imminent Risk individuals: Individuals in the community whose mental or physical health condition has deteriorated to the degree that self-care is not possible, there is no capable caregiver, and nursing home placement is likely within a month or likely within three (3) months.
 - b.** Service priority for individuals not included in (a) above, regardless of referral source, will be determined through the Department's functional assessment administered to each applicant, to the extent funding is available. The Contractor shall ensure that priority is given to applicants at the higher levels of frailty and risk of nursing home placement.
 - 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.

DEPARTMENT OF ELDER AFFAIRS PROGRAMS AND SERVICES HANDBOOK
Chapter 6: Alzheimer's Disease Initiative (ADI) Program

Program Requirements

Co-Payment Assessment

CO-PAYMENT ASSESSMENT:

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

GRIEVANCE PROCEDURES:

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