Chapter 10

Administration of the Alzheimer's Disease Initiative (ADI) Program

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Section I: Overview of the ADI Program

The purpose of the Alzheimer's Disease Initiative (ADI) program is to provide services to meet the changing needs of individuals and families living with Alzheimer's disease and related dementias (ADRD). This chapter provides program policies, standards, and procedures for use by the state office and all providers in the conduct of the ADI program.

Section II: Legal Basis and Specific Legal Authority

A. Legal Basis and History:

The ADI program was legislatively created in 1985 to provide a continuum of services to meet the changing needs of individuals and families affected by ADRD. In conjunction with the 15-member Alzheimer's Disease Advisory Committee (ADAC), of which 11 members are appointed by the Governor, the program includes the following components:

- Respite services;
- Supportive services such as case management, specialized medical equipment and supplies, and caregiver training;
- Specialized Alzheimer's Services Adult Day Care Centers;
- Memory Disorder Clinics (MDCs) to provide diagnoses, education, training, research, treatment, and referrals; and
- The Florida Brain Bank located at the Wein Center for Alzheimer's Disease and Memory Disorders at Mount Sinai Medical Center to support research.

The ADI program 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.

B. Specific Legal Authority:

- Chapter 58D-1, F.A.C.
- Chapter 429.918, F.S.
- Chapter 430.501-504, F.S.

Section III: Alzheimer's Disease Characteristics

Alzheimer's disease (AD) affects the nerve cells of the brain. It affects individuals from all socioeconomic levels. It produces a diminished capacity to think or understand, problem solve and perform activities of daily living (ADLs).

A number of other disorders can also result in irreversible, progressive symptoms of dementia with cognitive and physical decline. These include, but are not limited to, the

following:

- Multi-Infarct dementia, also known as Vascular Dementia;
- Lewy body disease;
- Parkinson's disease;
- Huntington's disease;
- Creutzfeldt-Jakob disease;
- Frontotemporal degeneration, also known as Pick's disease; and
- Normal pressure hydrocephalus.

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.

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

A definitive medical diagnosis can only be made upon examination of tissue from the whole brain at autopsy.

AD clients require a wide continuum of care, from basic supervision and assistance with ADLs to possible placement for skilled nursing care.

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 guidance for obtaining a specific, definitive diagnosis for the client's symptoms and services to assist them in the continuation of care.

In the early stages also known as onset of the disease, the AD client often experiences confusion, short-term memory impairment, and difficulty in performing familiar tasks.

The caregiver assumes certain responsibilities at the onset of the disease, ensuring the AD client receives the following:

- Assistance with ADLS;
- Assistance with obtaining a specific diagnosis;
- A safe environment;
- Balanced meals;
- Required medications; and
- Continual assistance for completing daily routine functions and activities.

As the disease progresses, the AD client may experience impaired function and conditions such as the following:

- Becoming lost going to formerly familiar places and/or leaving a supervised setting, unable to perceive risk;
- Personality change;
- Behavior change, challenging behaviors - e.g., agitation, aggression;
- Impaired judgment, inability to problem-solve, identify scams, or self-neglect;
- Difficulty finding words or finishing thoughts; and
- Difficulty following directions.

The caregiver's job becomes even more difficult and demanding as the disease progresses. The ADI program strives to address the needs and resources for the caregiver as well as those of the client.

When adequate services are not identified or cannot be provided in the home, it may become necessary for the caregiver to consider placement outside of the home. If an assisted living facility or nursing home placement becomes necessary, the caregiver may need assistance in the selection and placement process.

Section IV: Services Provided Under the ADI Program

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. Case management is a required service for in-home and facility-based respite. Refer to Appendix A, "Service Descriptions and Standards," for a description of each service once an individual has been successfully screened as eligible to receive ADI services. The services include the following categories:

- **Core Services**: Core Services include a variety of in-home services, specialized adult day care center services, and other basic services that are most needed to service ADI clients.

- **Health Maintenance Services:** Health Maintenance Services are routine health services that are necessary to help maintain the health of functionally impaired elders. The services are limited to medical therapeutic services, non-medical prevention services, personal care services, home health aide services, home nursing services, and emergency response systems.

- **Other Support Services:** Other Support Services expand the array of care options to assist functionally impaired elders and their caregivers.

A. Additional ADI Program Components:

Memory Disorder Clinics (MDCs): MDCs must provide research, training, and services directed to persons with symptoms of ADRD. MDCs provide the following components:

- MDCs provide comprehensive diagnostic and referral services for Floridians of any age who have or are suspected with ADRD;

- Services include accepting referrals from all respite and service providers and conducting subsequent diagnostic evaluations for all referred consumers and the public within the MDCs designated service area;

- Individuals with suspected memory loss may be evaluated at any one of the funded MDCs. Florida residents may access MDC services regardless of the ability to pay;

- Conduct service-related applied research that may address, but is not limited to, therapeutic interventions and support services for persons living with ADRD;

- MDCs shall initiate at least one contact with respite providers annually to review progress relative to research efforts and exchange ideas with the providers;

- The MDCs will develop training materials and educational opportunities for family professional caregivers, allied health professional caregivers, and first responders who serve individuals with ADRD and provide specialized training for caregivers, caregiver groups, and organizations in the designated service area;

- MDCs are required to provide a minimum of three (3) hours in-service training related to AD annually in their designated service area for respite, facility-based respite, and adult day and specialized adult day care providers, which will include health professionals and caregivers;

- Area Agency on Aging (AAA), MDCs, respite, adult day, and specialized adult day care centers must collaborate in the development of training to meet staff needs; and

- A staff member of the MDCs is to be designated to act as the training liaison for service providers.

Alzheimer's Disease Research Brain Bank: To be accepted into the Florida Brain Bank program, there must be documentation of the diagnosis of ADRD 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 or a magnetic resonance imaging 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:

- State-sponsored MDCs;
- Local organizations providing services to clients with dementia and their families;
- Adult day and specialized adult day care centers and respite care providers; and
- Self-referral.

The Brain Bank performs the following activities:

- 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 AD; and

- Provision of brain tissue for approved research projects on a national basis, with Florida projects receiving priority.

The Brain Bank Minimum Service Standards:

- Brain Bank clients should be selectively screened prior to death in accordance with established protocols;

- The family should receive notification of definite diagnosis, written in clear understandable terms no later than six months after autopsy; and

- In the case of familial AD, confirmation of the diagnosis in a family member carries with it an opportunity for genetic counseling.

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. Mount Sinai Medical Center contracts annually with the State of Florida to operate the primary Brain Bank, and coordinates with regional Brain Bank sites in Orlando and Miami. The Brain Bank must meet all licensure requirements mandated by the State of Florida.

Specialized Alzheimer's Adult Day Care Centers: These are specialized adult day care centers, licensed in accordance with Section 429.918 F.S.. FloridaHealthFinder.gov provides an up-to-date listing of all specialized Alzheimer's services and adult day care centers. Specialized Alzheimer's services include, but are not limited to, those listed below:

- Providing education and training on the specialized needs of persons with ADRD and their caregivers;

- Providing specialized, therapeutic activities that promote, maintain, or enhance the ADI client's physical, cognitive, social, spiritual, and emotional health;

- Providing therapeutic, behavioral, health, safety, and security interventions; clinical care, and support services for the ADI client and caregiver; and

- Providing respite for the ADI client's primary caregiver.

Section V: Program Requirements

A. General Eligibility Criteria:

- To be eligible for the ADI program individuals must be 18 years of age or older and have a diagnosis or be suspected of having ADRD where mental changes appear and interfere with the ADLs;

- To be eligible for a Specialized Alzheimer's Services Adult Day Care Center participants must have a documented diagnosis of ADRD from a licensed physician, licensed physician assistant, or a licensed Advanced Practice Registered Nurse (APRN);

- Caregivers are also eligible to receive training, respite, specialized adult day care center services, in-home services, and related support services to assist them in caring for the ADI client;

- Clients may receive services other than respite services without a 24/7 caregiver;

- The caregiver is available to assist with ADLs and instrumental activities of daily living (IADLs); however, the caregiver does not have to live with the client in order for the client to qualify for ADI; and

- Clients may not be dually enrolled in the ADI program and a Medicaid capitated long-term care program.

B. Coordination of Services:

Coordination of services among the MDCs, AAAs, and service providers is required as follows:

Florida Sliver Alert Program

- MDCs will coordinate with Florida Law Enforcement to facilitate a fast and safe return for persons with a permanent loss of intellectual capacity.

- When notified that someone with possible ADRD is missing, whether driving a vehicle or on foot, the MDCs will follow the protocol established by the Silver Alert:

    - Call the caregiver or family to gather facts and offer services;
    - Send the Silver Alert Referral Form to the AAA designated contact to see if lost individual is, or has been, receiving services and if a CARES assessment is appropriate;
    - Offer diagnostic services of MDC and caregiver training if appropriate; and
    - Offer specially designed training to avoid recidivism of Silver Alert.

MDCs will provide training in their designated service area to the AAAs, senior network personnel, formal and informal caregivers, health and social services professionals, and the public.

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:

- Public safety;
- Assistance to law enforcement in locating a missing senior;
- Education; and
- Prevention.

Respite Service Providers

- MDCs will collaborate with in-home and facility-based respite service providers at the direction of the Department for coordination of service provision, research, and training;

- MDCs should contact the AAA contract managers to set up three (3) hours of annual in-service training for ADI adult day and specialized adult day care centers and respite care providers in their designated service area;

- The training should be held in a central location, accessible to the providers in their designated service area or via virtual means;

- The training should be tailored and directly related to ADRD to an audience of health and social service professionals, direct service staff, and caregivers;

- MDCs will contact each respite care provider in their service areas to establish research efforts involving respite clients and/or caregivers;

- The MDCs will initiate and maintain at least one (1) annual contact with respite care providers to review progress with research efforts and exchange ideas;

- MDC services are available to respite clients and caregivers. If a client or potential client is in need of services through the MDC, the respite care provider will provide the client and/or caregiver with the MDC map and identify the MDC within the service area;

- Individuals with suspected memory loss may be evaluated at any one of the funded MDCs by contacting the individual clinic to arrange a new patient appointment;

- MDCs shall accept referrals from all respite, adult day, and specialized adult day

care service providers, and conduct subsequent diagnostic evaluations for referred clients, as appropriate; and

- Identify and make recommendations for treatment of other health conditions which present symptoms during the medical/clinical evaluation.

While not required by statute or rule, MDCs and the AAAs 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 provide an increase in the awareness of ADRD and the services available to those living with and affected by the disease through educational events and awareness campaigns.

C. Establishing Priorities for Service Provisions

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.

Priority Criteria for Service Delivery:

- Imminent Risk Individuals in the community whose mental and/or physical health condition has deteriorated to the degree that self-care is not possible; there is no appropriate, willing, or capable caregiver; and nursing home placement is likely within a month or likely within three (3) months.

- Service priority for individuals not included in 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, cognitive impairment, and risk of nursing home placement.

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.

- Functional cognitive impairment shall be determined through the Department's assessment instrument administered to each applicant.

- The frailest and most vulnerable clients, not falling into one of the priorities cited in the above section will receive services to the extent funding is available.

Additional Factors:

- The MDCs and the Brain Bank must establish written criteria to be used in prioritizing requests for their services.

- No one requesting a consultation from an MDC will be denied services.

D. Co-Payment Assessment:

For information about co-payment assessment with the ADI program see Appendix B, Co-Payment for Service Guidelines of this Handbook.

Section VI. Agency and Stakeholder Responsibilities

A. DOEA Responsibilities:

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

The responsibilities of DOEA are listed below:

- Develop an allocation formula for distributing ADI funds to the Planning and Service Areas (PSAs);

- Allocate ADI funds to service providers through the AAAs;

- Contract directly with the MDCs and the Brain Bank providers;

- Establish policies and procedures for AAAs, Lead Agency, and ADI subcontractors;

- Evaluate the quality and effectiveness of services and client satisfaction with the ADI program as required;

- Ensure provision of quality services through the monitoring process;

- Prepare ADI service provider application guidelines;

- Provide for staff development and training;

- Develop program reports;

- Provide and monitor program policies and procedures for the PSAs;

- Review and make recommendations for improvement on program reports;

- Develop co-payment guidelines; and

- Provide technical assistance to the AAAs in program planning, development, and ongoing operations as needed.

B. AAA Responsibilities:

The purpose of the AAAs is to carry out policy, develop programs, fund, and monitor the ADI program for the Lead Agencies and other agencies.

The responsibilities of the AAAs are listed below:

- Establish subcontracts or vendor agreements, when applicable, for ADI services. Entities providing direct services must be selected as the result of a procurement decision using competitive or non-competitive method (i.e., sole source) to provide services pursuant to a legally executed agreement. Solicitation process must be conducted as applicable, in accordance with Chapter 287, Florida Statutes, and the AAAs board approved procurement procedures;

- Review and critique the ADI service provider application to ensure completeness, accuracy, and that all revisions are noted;

- Administer and monitor ADI program policies and procedures;

- Ensure that all program reports are accurately completed and submitted in a timely manner;

- Provide technical assistance to the ADI subcontracts in program planning, development, and ongoing operations as needed;

- Provide development and training for AAAs staff;

- Assume contracting responsibilities, including review of the applicant's subcontracts, if applicable;

- Assess the fiscal management capabilities of the service providers;

- Review the performance of service providers in carrying out their service delivery responsibilities;

- Process requests for payment and reports on receipts and expenditures to DOEA;

- Provide technical assistance to providers to ensure provision of quality services;

- Ensure compliance with Departmental Enterprise Client Information and Registration Tracking System (eCIRTS) policies;
- Arrange in-service training for lead agencies at least annually;
- Initiate and maintain coordination among ADI components within the PSAs;
- Ensure implementation of co-payment guidelines; and
- Conduct client satisfaction surveys to evaluate and improve service delivery.

C. Lead Agency Responsibilities:

The purpose of the Lead Agency is to provide case management to all ADI clients to ensure service integration and coordination of service providers within ADI.

The responsibilities of the Lead Agencies are listed below:

- Assess and collect co-payments in accordance with rules adopted by the Department;
- Provide case management to applicants and ongoing recipients of ADI services;
- Conduct client satisfaction surveys to evaluate and improve service delivery;
- Provide for staff development and training related to ADRD;
- Monitor subcontracts and vendor agreements to ensure quality services and efficient use of funds. Make payments to subcontractors for ADI services;
- Demonstrate innovative approaches to program management, staff training and service delivery that impact on cost avoidance, cost effectiveness, and program efficiency;
- Establish and follow procedures for handling recipient complaints concerning such adverse actions as service termination, suspension, or reduction in services;
- Compile accurate reports; and
- Coordinate with the MDCs for the coordination of service provision, research, and training. Serve as a resource for research and statistical data by the MDCs.

NOTE: *Lead Agencies shall request and receive technical assistance from the AAA. When additional interpretation is needed, the AAA should forward the request to DOEA. DOEA will address all requests and provide a timely response.*