Assisted Living and Extended Congregate Care: The Florida Experience

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CHAPTER 1

Introduction

The long-term care needs of a rapidly increasing elderly population have become increasingly apparent to the general public and policy makers alike. Long-term care services are the array of social, health, and housing services which are available to physically or cognitively impaired frail persons. Public funding of long-term care is dominated by nursing homes which consume over 80 percent of all public expenditures for long-term care. The remainder is spent to support in-home and community-based long-term care, which are commonly less expensive than nursing home care and are generally preferred by the frail elderly and other potential recipients of long-term care services (e.g., people who are dying from AIDS). We have barely begun to tap the potential of residential care, including assisted living. In fact, one of the most underdeveloped parts of the long-term care system in Florida and other states is community-residential care for publicly supported long-term care clients.

This paper provides a historical analysis of public policy to support assisted living and extended congregate care in Florida. It describes the collective efforts of advocates, providers, and public officials to address a publicly supported assisted living program for people with levels of impairment which place them at serious risk of nursing home placement. A number of additional initiatives are proposed to ensure a high quality of care in Florida=s publicly supported assisted living program. These proposals are based on recent findings (Yee et al., 1996) which highlight the potential threats to quality of care and new approaches to regulations. A second paper will address the state-of-the art of outcomes-based research on assisted living.

The six chapters describe: 1) rationale for developing publicly supported assisted living; 2) the legislative process used in Florida to establish extended congregate care; 3) the major features of the legislation; 4) the regulatory framework established for the program; 5) the major unresolved and emerging issues related to assisted living and extended congregate care; and 6) recommendations related to the further development of Florida=s assisted living program.

CHAPTER 2

The Rationale for Publicly Supported Assisted Living

By 1990, after almost two decades of largely successful efforts to expand the range of long-term care options available to the frail elderly in Florida, it was apparent that there were two major service gaps remaining for persons dependent on publicly supported long-term care services. These gaps were the absence of intensive in-home and community-residential programs for seriously impaired elderly persons. A major step was taken in 1990 to close the first gap through the implementation of the Community Care for the Elderly Nursing Home Diversion Program (CCEDP). The program enhanced the existing Community Care for the Elderly program (CCE) by providing a four-fold increase in annual funding for each service recipient, limiting case manager caseloads to no more than 40 clients, and targeting services more rigorously to seriously impaired clients who were at risk of nursing home placement. The explicit goal of CCEDP was to divert more seriously impaired clients from nursing home placement by increasing the number and types of services provided to them in their own homes. CCEDP=s implementation did not require any major changes in current statutory or regulatory requirements. It was a product of an executive branch policy initiative and a legislative appropriation.

Efforts to close the second gap in the availability of alternative residential programs did require substantial statutory and regulatory changes. Florida has a large number of congregate living facilities. In fact, the number of congregate care beds (62,000) is approaching the number of nursing home beds (69,000) in the state. The vast majority of congregate care units are rented by privately paying residents. There are fewer than 10,000 low-income citizens who receive state support for congregate housing through Supplemental Security Income (SSI) with a state supplement. On the other hand, there are over 45,000 persons receiving Medicaid assistance in Florida=s nursing homes.

There are two major reasons for the relatively small number of state-supported residents in congregate care facilities. First, the state provides a payment of only $598 a month for low-income; $470 is the SSI payment and the remainder is the Optional State Supplementation (OSS) amount. Second, any state-supported (OSS) resident requiring a substantial level of care in a number of activities of daily living (ADL) could not be admitted to or remain in a congregate care facility. This meant that moderately impaired, state-supported residents had to either enter a nursing home, at a much greater expense to the state, or find an unlicensed facility that would accept them. This Hobbesian choice prevented many congregate care residents from exercising an option available to state-supported clients of in-home care who were even more impaired than some congregate care residents.

They were not allowed to Aage-in-place@ in their residence if the residence was a congregate care facility. Furthermore, privately paying residents with significant impairments could enter and remain in congregate care facilities if they could afford to pay the monthly fees.

As a result of these regulatory and reimbursement policies, many aging policy analysts and advocates concluded that the community-residential part of Florida's long-term care system was seriously handicapped by a missing "middle ground" program. That is, the state did not have a community-residential program for state-supported citizens who needed substantial levels of personal or home health care, but did not need the level of skilled nursing care provided in nursing homes. In short, the state needed an assisted living program for low-income elderly with moderate-to-serious impairment levels.

Closing the gap in community-residential care, however, proved to be considerably more difficult than closing the gap in community in-home care. The latter required an increase in the number of services and in the intensity of the case management program. The programs existed; the additional appropriations allowed them to serve more low-income older citizens at home. The changes needed in residential care represented a qualitatively different program than had existed. Fortunately, the in-home program paved the way by providing a framework of consumer-oriented guiding principles which would also guide the residential program.

The concepts of personal autonomy, privacy, and dignity to support aging-in-place in the least restrictive environment constituted the framework for the development and operation of the in-home program. These same concepts were needed to develop a residential program designed to serve moderately to seriously impaired elderly residents, without medicalizing their care and imposing impersonal institutional constraints on daily life. This paradigm shift represented a move away from a strict Amedical model@ of care which is typical of nursing homes. The new model merged medical and social support without taking away a person=s rights to autonomy, privacy and dignity. This model of care has provided the framework for community-based care for a wide range of impaired persons since the 1970s. Florida=s CCEDP has been successful at preserving these values and providing medical and personal care in the home. The proposed changes to the community-residential program built upon these two successful models to provide appropriate care to very frail elders in assisted living through first an Extended Congregate Care (ECC) license and then later a Medicaid waiver for assisted living.

CHAPTER 3

Developing Assisted Living Legislation: Creation of the Extended Congregate Care Program

In 1990, the Florida Aging and Adult Services office of the Department of Health and Rehabilitative Services (HRS) initiated plans to develop legislation to create an assisted living program to close the gap in community-residential care for low-income, frail elderly citizens. A task force made up of advocates, service providers, legislative and agency staff, and policy experts conducted the following activities to bring about this legislation:

- studied various models of supportive housing for senior and/or disabled individuals across the country;
- conducted an in-depth study of the housing needs of older Floridians;
- initiated a process to solicit input from the owners/operators of facilities for seniors and the disabled, from senior advocates, and from senior housing consumers;
- drafted statutory language which would make it possible to extend the services which were currently allowable in congregate facilities, while simultaneously embracing consumer values (e.g., the desire to maintain autonomy and to remain in their own homes);
- supported statutory changes to the congregate care law (CS/HB 1983) in 1991;
- held public hearings on the proposed rules to solicit and incorporate consumer feedback and input into the regulations;
- negotiated with special interest groups on the proposed regulations to facilitate agreement for rules which would maximally benefit all parties involved; and
- revised, adopted, and publicized the proposed regulations.

These activities resulted in a new licensure category, Extended Congregate Care, which allowed all frail residents to age-in-place when they were living in an assisted living facility that had an ECC license. In the process of developing this new licensing category, the task force also addressed the fundamental values which were embodied in this new category. The task force recognized that the ECC license should not be a scaled down nursing home program. Rather, the new

program should be a community-residential program that embraced the same values of the in-home programs of the past 15 years: autonomy, privacy, dignity and aging-in-place in the least restrictive environment. ECC programs should maximize the opportunities for residents to exercise autonomy and minimize institutional threats to autonomy. Professional judgment should not displace resident preferences and should show tolerance for a resident=s need for privacy and dignity. One way the task force operationalized these values was to require ECC facilities to assess a resident=s abilities and her own goals and preferences and use this assessment to develop a service and activity plan that is modifiable according to the changing needs, abilities, and preferences of the individual. The assessment was standardized but the results would be individualized and based primarily on the preferences of the individual.

The legislation incorporated many of these ideas and was passed in 1991 without significant opposition. The statute is based primarily on aging-in-place and preserving autonomy. It gives the Department of Aging and Adult Services considerable latitude in admission and retention requirements. The licensing criteria and guidelines for establishing the administrative rule are listed below. Chapter 4 provides the history of the compromises achieved in developing the actual rules and regulations for implementing the ECC legislation.

A. ECC Licensing Criteria

C Demonstrate the capability to meet unscheduled resident service needs.

C Offer a physical environment which promotes a homelike setting, provides for resident privacy, promotes resident independence, and allows sufficient congregate space as defined by rule.

C Have sufficient staff available, taking into account the physical plant and fire safety features of the building, to help more infirm residents evacuate in an emergency.

C Adopt and follow policies and procedures which maximize resident independence, dignity, choice, and decision-making to permit residents to age-in-place to the extent possible, so that moves due to changes in functional status are minimized or avoided.

C Demonstrate the capacity to allow residents to make a variety of personal choices, participate in developing service plans, and share responsibility in decision-making.

C Promote the idea of managed risk.

B. Guidelines for Administrative Rules

Aging in Place. The process by which a person chooses to remain in a familiar living environment despite the physical or mental decline that may occur with the aging process. For aging-in-place to occur, needed services are added, increased, or adjusted to compensate for the physical or mental decline of the individual, while maximizing the person=s dignity and independence. Such services may be provided by facility staff, volunteers, family or friends, or through contractual arrangements with a third party . . . [ECC facilities shall provide services that] enable residents to age-in-place despite mental or physical limitations that might otherwise disqualify them from admission or continued residency in a facility licensed under this part.

Admission and Retention. The [Aging and Adult Services] Department shall establish, by rule, guidelines for admission and retention of residents which shall be based on the facility=s ability to meet resident needs as determined by resident outcomes. However, such facilities shall not serve residents who require 24-hour nursing supervision. Facilities licensed to provide extended congregate care services shall provide each resident with a written copy of facility policies governing admission and retention.

Appropriate Placement. Facilities licensed to provide extended congregate care services shall promote aging-in-place by determining appropriateness of placement based on a comprehensive review of the resident=s physical and functional status; the ability of the facility, family members, friends, or any other pertinent individuals or agencies to provide the care and services required; and documentation that a written service plan consistent with facility policy has been developed and implemented to ensure that the resident=s needs and preferences are addressed.

Managed Risk. The process by which the facility staff discuss the service plan and the needs of the resident with the resident and her representative or designee in such a way that the consequences of a decision, including any inherent risk, are understood by all parties and reviewed periodically in conjunction with the service plan, taking into account changes in the resident=s status and the ability of the facility to respond accordingly.

Shared Responsibility. Exploring options available to a resident within a facility and the risks involved with each option when making decisions pertaining to the resident=s abilities, preferences, and service needs, thereby enabling the resident, the resident=s representative or designee, the physician, the facility, and other appropriate parties to develop a service plan which best meets the resident=s needs and improves the resident=s quality of life.

Service Plan. A written plan, developed and agreed upon by the resident, facility, physician, and other appropriate parties, which addresses the unique physical and psychosocial needs, abilities, and personal preferences of each resident receiving extended congregate care services. The plan shall include a brief written description, in easily understood language, of what services shall be provided, who shall provide the services, when the services shall be rendered, and the expected outcomes.

Homelike Facilities. Encourage the development of homelike facilities which promote the dignity, individuality, personal strengths, and decision making ability of residents.

CHAPTER 4

Developing the Regulatory Framework for Extended Congregate Care: Conflict and Compromise

The legislation which established the ECC program enjoyed broad but not universal support among the aging interest groups. The degree of support was due, in part, to the involvement of most interested parties in the planning for the legislation. These groups were also involved in developing the administrative rule for implementing the legislation. In spite of this participation, some members of the nursing home industry filed a petition through the administrative hearings process to protest several provisions in the administrative rule. The protest made national headlines in an extensive report by the *Wall Street Journal* (March 4, 1992). This group was concerned that congregate care facilities with ECC licenses served potential nursing home clients at less cost than nursing homes due to the added costs incurred by current regulations of nursing homes. The group suggested also that ECC clients would receive less intensive and less professional care than their needs required. There were six main points of disagreement which were resolved through compromises between the task force and the petitioners (a group of some nursing home owners and operators). These issues and their resolutions are described below.

A. Clinical Issues

24-Hour Awake Staff. The petitioners wanted staff awake 24-hours at all extended congregate care facilities. The proposed rule would have required an appropriate emergency call device in facilities with 16 or fewer beds. The task force=s position was that additional staff should be based on the residents= needs, as identified in the assessment and documented in the service plan. Resolution: Not required. However, a question was added to the health assessment form concerning the need for night-time assistance which, if needed, must be provided by the facility.

Minimum Staffing Standards. The petitioners wanted minimum staffing standards for ECC facilities, with ratios similar to those that apply to nursing homes. The task force=s position was that staffing should be determined by the facility, based on the identified needs of the resident through the assessment and planning processes. Resolution: No minimum required for ECC license. However, more details concerning when additional staffing could be required and what must be specified in service plans were added to the ECC rule.

Definition of 24-Hour Nursing Supervision. The draft rule stipulated that any resident requiring 24-hour nursing supervision could not be placed or retained in an ECC facility. The petitioners wanted the definition of 24-hour nursing supervision removed from the rule as unnecessary

and proposed that the health assessment be used to indicate when residents are inappropriate for residence in an ECC facility. The task force took the position that the definition was critical since it established the outside parameters of services which could be offered in an ECC facility. Resolution: The definition of 24-hour nursing supervision provided in the draft rule was retained.

Allowable Nursing Services. There was some agreement on the kinds of services that could be offered in an ECC facility. The major disagreements arose in the areas of decubitus (pressure sore) care and of complex nursing services not currently allowed in the congregate care program. Regular assisted living facilities can provide care for stage one decubitus. The task force maintained that stages two and three decubitus should be allowed in ECC facilities. The petitioners wanted care only for stage one in ECC facilities. Resolution: The rule was changed from allowing any nursing services except those requiring 24-hour nursing supervision to a more detailed specification of services which could be performed in an ECC facility. Care of stage two decubitus is allowed only under limited circumstances, and stage three is not permitted.

Cognitive Impairment. The petitioners did not agree on the level of cognitive impairment that a person could have and still be maintained in a congregate care facility. They felt that people with both severe cognitive and physical impairments were not appropriate for assisted living facilities, including ECC facilities. The task force maintained that people with severe cognitive impairments and mild physical impairments could live in an assisted living or ECC facility that was properly staffed. Resolution: Persons who are incapable of making simple decisions (defined in the rule as an inability to choose a dessert or a garment) may not be admitted or retained in an ECC facility, as well as those who are a danger to themselves or to others and who are not controllable by medication.

Total Assistance with Activities of Daily Living. The petitioners maintained that only clients requiring extensive but not total assistance with activities of daily living should be allowed in an ECC facility. Persons who are totally dependent should not be allowed in any congregate facility. They proposed a scoring system based on the health assessment whereby persons who are very impaired in some activities but not impaired in others could reside in ECC facilities. The task force proposed that regular assisted living facilities continue to provide the type of ADL assistance that is allowed under the current rule and that ECC facilities should be able to provide total help with activities of daily living, provided the resident is not totally impaired cognitively or bedridden for more than 30 days. Resolution: Persons needing more than assistance with transfers, totally dependent in four of five defined activities of daily living (bathing, toileting, eating, dressing, and grooming), or bedridden for more than 14 days, are not permitted to be placed in any congregate care facility, including ECC facilities.

B. Resident Decision Making

In addition to these clinical provisions, the final ECC rule requires that facilities promote the values of autonomy, privacy, and dignity. Specifically, the rule mandates that residents= choice and decision-making be supported by providing specific opportunities in which residents are able to express their preferences. ECC facilities must allow residents to make choices in the following situations:

Remaining in the same unit, if licensed as an ECC unit, when more care is needed. As their service needs increase, residents must be allowed to stay in their units to receive the additional

services permitted in extended congregate care. Residents would need to move if they were currently residing in a part of the facility that was not licensed for ECC. This fact must be noted in the facility=s summary of ECC policies given to the resident in the admission packet.

Choosing from a variety of social and leisure activities. Residents must be provided with opportunities to participate in a variety of recreational activities. The available activities should include both planned, organized activities and the pursuit of personal interests such as reading or watching television.

Participating in all aspects of the service planning process. Residents should be actively involved in the development, implementation, and revisions of their service plans.

Participation in community activities, with transportation provided or arranged. ECC facilities should make available to residents information about community events. Residents should also be assisted in arranging transportation or, if needed, should be provided with transportation to those community activities in which they wish to participate.

Participating in the governance process of the ECC facility. Residents must be offered the opportunity to participate in the development of the facility=s operating policies and procedures related to ECC.

It took six months to resolve the above issues, but the rule was passed successfully in September 1992. Although nursing home operators initially were divided over the rule, with a substantial number either supporting it or remaining neutral, there was consensus on the final version by all interested parties. The compromises in the ECC rule were designed to allow full use of the potential of the ECC program without putting clients at undue risk. There is still concern among some assisted living providers that the compromises are too cautious and constrict their ability to operationalize Amanaged risk.@ In their view, the 24-hour nursing supervision admission restriction is a sufficient safeguard against inappropriate placement. The provisions regarding allowable nursing services, cognitive impairment, and ADL assistance excluded many individuals who could be served in an ECC facility at a higher quality of life and lower cost. These unresolved issues are described in Chapter 5.

CHAPTER 5

Debating the Future of Assisted Living

The Commission on Long-Term Care in Florida, a task force convened to make recommendations for Florida=s state-supported long-term care programs, recommended a major expansion of the ECC program in 1996; yet the future of the ECC license is ambiguous. Many observers think that assisted living, especially extended congregate care, has the potential to become an extensive and cost-effective alternative to nursing home care. Others think that assisted living is still largely untested as a nursing home alternative and may not, in practice, be qualitatively different from nursing homes, at least for severely impaired residents. At a minimum, policy makers, advocates and providers must be prepared to address a number of issues that bear directly on the capacity of the ECC program to become a cost-effective long-term care program over the next five years. These include law and rule issues, funding strategies, regulations, and implications for Florida of promising models from other states. Each of these issues is addressed in the following sections.

A. Law and Rule Issues

Current provisions of the ECC rule will receive careful attention as the provider community gains experience with the ECC program. The rule is a product of a compromise designed to allow full use of the potential of the ECC program without putting the safety of clients at undue risk. There are three areas which still require attention: nurse delegation, cognitive impairment, and admission criteria.

Nurse Delegation. The legislation did not include a Anurse delegation@ provision such as found in other states= congregate care laws. Pioneered in Oregon, nurse delegation allows registered nurses to delegate (with supervision) to certified nursing assistants the authority to give medications and shots to residents in adult foster care homes and assisted living. Facilities can hire fewer registered nurses and reduce the cost of care to the residents and, for state-supported residents, the state. This arrangement, with careful monitoring, seems to have worked well in Oregon and Indiana, but remains controversial in other states.

Cognitive Impairment. There continues to be disagreement among providers and advocates concerning the cognitive impairment provision. The ability to make a simple decision (defined in the rule as an ability to choose a dessert or garment) is not a rigorous definition of impairment and may be assessed unevenly across facilities and individuals. Moreover, cognitive impairment may not be sufficient grounds to exclude someone from an ECC facility. Many assisted living facilities in the U.S. are already effectively serving persons with Alzheimer=s Disease (Kane & Wilson, 1993). Congregate care facilities could be a major resource for persons with mild to moderate dementia.

Admission Restrictions. To meet the spirit of Aaging-in-place,@ the rule set criteria for admission to an ECC facility to be the same as for a regular ALF for at least 90 days prior to ECC admission. That is, a person could not be admitted needing ECC placement, but must meet standard assisted living facility admission criteria for 90 days (i.e., no more than three impairments in activities of daily living or inability to transfer). The A90-day rule@ reduced the potential of the ECC program to function as an alternative to nursing homes. It was viewed as necessary to prevent extended congregate care facilities from becoming under-regulated nursing homes. There were other safeguards which protected ECC clients from poor care, however. ECC legislation limited licensure to facilities with no serious licensure deficiencies, availability of a licensed nurse and additional staff when needed, and additional training for administrators and staff. Legislation also required individualized service plans which documented each resident=s progress. Because of these stringent requirements, many facilities would never qualify for an ECC license. Therefore, the additional 90-day requirement was not necessary.

The other problem with the A90-day rule@ was that it misrepresented the Aaging-in-place@ intention in the legislation. Aging-in-place is defined as the process by which a person chooses to remain in a familiar living environment despite physical or mental decline. The ECC license supports this intention by allowing a person who enters an assisted living facility with an ECC license as a relatively healthy person to remain there longer than in a standard facility without an ECC license. But another meaning of the phrase is that a person should be allowed to remain in a Afamiliar living environment@ even if it is a different location. The ECC facility is considered to be more similar to a private home environment than is a nursing home and therefore moving to an ECC facility is consistent with the philosophy of aging-in-place. Removing the 90-day restriction would extend care to:

C people who have recuperated in a nursing home who would be more appropriately placed in an ECC facility;

C people residing in Adult Family Care Homes whose conditions have deteriorated, but who are still appropriate for placement in an ECC facility;

C people living in private homes, who are the recipients of formal or informal care services and may need short-term respite care or permanent placement; and

C people residing in government subsidized housing who have increasing needs for supervision and personal care, but do not require a skilled level of care.

As a result of the A90-day rule@ debate, the 1995 legislature authorized a pilot study of the effects of allowing direct admissions to ECC facilities. This change allowed up to 35% of all ECC residents in a facility licensed for extended congregate care by July 1, 1995 to be admitted directly from a hospital, another program, or a person=s own home. The results of the study will provide more empirical data for evaluating the effects of direct admissions.

The fiscal implications of removing the 90-day restriction could be extensive. Direct admissions could fill ECC beds, many of which are empty and costly to operators. At this point, there are only 220 beds that are covered under the Medicaid waiver (see description under Funding below). As more beds are covered by the waiver, the savings could be significant as persons who meet ECC criteria are diverted from nursing homes. Current Medicaid enrollees could be discharged from a

nursing home to an ECC facility to complete their recuperation at a reduced cost to the state. Privately paying individuals who are directly admitted to an ECC facility without a Medicaid waiver also save the state money, since it takes longer for them to spend down their assets to the point where they would qualify for Medicaid and at the same time delays or precludes admission into a nursing home.

Increases in Medicaid waiver beds depends on sound evidence that ECC is a cost-effective alternative to more expensive forms of state-funded care. ECC facilities cannot add to the growing cost of institutional long-term care. As long as there is systematic downward substitution of care across the entire long-term care system (from hospitals to nursing homes to ECC facilities to standard assisted living to in-home care), there will be savings. If the system created a Awoodwork effect@ of upward substitution of care (in-home to assisted living to ECC facility, for example), the savings would not be realized. This fear was not substantiated with the experiences in the states of Oregon, Washington, and Texas. State officials found that people move to an assisted living program only when they can no longer remain in their own homes. Relaxing eligibility criteria for assisted living did not result in increases in applications beyond the states= projections (Mollica et al., 1992). Rigorous screening, client assessment, care planning, monitoring, and consolidated responsibility for long-term care policy and program management with enhanced links between acute, subacute, and long-term care providers are essential for fiscal and program success.

B. <u>Funding</u>

The long range viability of ECC for state-supported residents is dependent on the development of a funding base that will ensure the program's availability to a broad population of disabled elderly and younger adults who cannot pay for the full cost of their own care. The ECC license will allow many facilities to provide a wide range of services to private-pay residents who can afford to pay $1,600 a month and more. This will allow the state to avoid paying the cost of care under its Medicaid nursing home program for a substantial number of persons who could be served in an ECC, but who must now enter nursing homes to receive the care they require. Kane and Wilson report that assisted living rates for private-pay residents in all jurisdictions they surveyed are substantially less than nursing home rates.

The 1994 Florida Legislature took the initial step toward funding assisted living services by extending coverage under the state home and community based Medicaid waiver. The program provided additional Apersonal care and supervision services to allow persons aged 60 plus who would otherwise require nursing home placement to remain in a congregate care facility licensed for Extended Congregate Care (ECC) or Limited Nursing Services (LNS).@ The state expected to serve approximately 220 individuals in these settings with a $2.3 million appropriation, (averaging $10,454 per person a year). Florida=s Medicaid waiver covers: personal care services, homemaker services, attendant and companion services, medication administration and oversight, therapeutic social and recreational programming, physical, occupational, and speech therapy, intermittent nursing services, specialized medical supplies, specialized approaches for behavioral management for people with dementia, emergency call systems, and case management.

Eligibility for the Medicaid waiver is limited to persons who are 60 and older who are: Medicaid-eligible, disabled according to Social Security standards, appropriate for ALF placement, moving out of a nursing facility, currently a resident of an ALF but needing additional services, or at

risk of nursing home placement. In addition, they must have a case manager employed by a CCE lead agency and meet one of the following functional criteria:

- C require assistance with four or more activities of daily living or three activities plus supervision or administration of medication;
- C require total help with one or more activities of daily living;
- C have a diagnosis of Alzheimer=s Disease or another type of dementia and require assistance with two or more activities of daily living;
- C have a diagnosed degenerative or chronic medical condition requiring nursing services that cannot be provided in a standard assisted living facility but are available in an ALF licensed for limited nursing or extended congregate care; or
- C be a Medicaid-eligible recipient who meets ALF criteria, is awaiting discharge from a nursing facility placement and who cannot return to a private residence because of need for supervision, personal care, periodic nursing services, or a combination of the three.

For providers to qualify under the Florida Medicaid waiver, the facility must be licensed for extended congregate care or limited nursing services and have no record of Class I or Class II licensure violations and no uncorrected Class III violations in the past two years. Providers receive up to $750 per month per Medicaid waiver enrollee for providing a package of extra support and supervision services. There is no lifetime cap on the amount paid on behalf of each individual. If the recipient has income that exceeds $618, that additional income will be applied to the $750 maximum charge and Medicaid will pay the balance. Case management services are billed separately and recipients are not required to pay for these services.

In addition to the Medicaid waiver monies, low-income older citizens may use Supplemental Security Income (SSI) to pay for room and board charges in an assisted living facility. Taken together, these two publicly-funded sources of payments are still less than Medicaid=s reimbursement for nursing home costs (see Table 1). In fact, the state=s share for a Medicaid waiver recipient in an ECC facility is approximately one-half the cost of the state=s share of nursing home costs.

Table 1
Hypothetical Comparison of Nursing Home and Extended Congregate Care Costs

	Nursing Home ($30,000/year)	Extended Congregate Care* ($20,000/year)		
		Room & Board (SSI)	Medicaid Waiver	ECC Total
Monthly Rate	$2,500	$598	$1,080	$1,678
Federal Share	1,375	470	594	1,064
State Share	1,125	128	486	614

*Assumes 50% Medicaid matching rate and a state SSI supplement. In some states, the community standard SSI payment may be lower but still adequate to cover the room and board costs in congregate care.

The hypothetical comparison in Table 1 is typical of how states blend reimbursements from different funding sources, such as SSI and Medicaid, in order to set rates that are consistent with private rates (Mollica et al.). In some cases, combining these federal and state sources is not adequate. Mollica recommends that states add an Aassisted living supplement.@ The supplement would be paid for entirely by the state with no matching federal funds but, even so, would be less expensive than the state=s share of nursing home costs. In fact, early experience in other states indicates that 65 percent of the Medicaid nursing home rate is an adequate reimbursement level for room, board, and ECC-type services. States may adopt either flat-rate or tiered reimbursement systems. Flat-rates, according to Mollica, are Aeasier to manage but reimburse for services that may not be needed by all residents. Tiered rates require a system for measuring need and establishing the correct payment rate@(p. 15). A tiered rate approach reflects actual needs of congregate care residents and should be implemented in Florida.

As assisted living and extended congregate care become more available as long-term care options, they should be incorporated into the regular (non-waiver) Medicaid program on the same basis as nursing homes. That is, the eligibility rules should be applied to each program with reimbursement rates adjusted for the actual cost of care. Assisted living and ECC should remain substantially less expensive than nursing homes. This will be true especially if one result of this policy change is to increase the acuity level of nursing home residents. The increased levels of care may require increases in payments to nursing homes but for, hopefully, fewer residents.

C. Regulating Assisted Living: Assuring Quality in a Managed Risk Environment

Assisted living began as a congregate housing option without medical services. As such, it was regulated for safety and sanitation but not for quality of care or services. With the addition of extended congregate care and the increase in residents Aaging-in-place,@assisted living is serving a more vulnerable population. It is also receiving more public funds in the form of Supplemental Security Income with state supplementation and, in some states such as Florida, Medicaid waiver funds. Its vulnerable clientele and the use of public funds make it necessary to regulate assisted living.

Regulation of board and care homes (including assisted living) has been ad hoc and uneven across the states (Hawes, et al., 1993). Assisted living operators recognize that nursing home style regulations would defeat the spirit of assisted living (Coopers & Lybrand, 1993; Mollica et al.), yet nursing homes are assisted living=s closest sibling and, like a well-intentioned parent, state units on aging are likely to treat both industries in a similar fashion. In fact, in the state of Florida the assisted living licensing survey resembles closely the nursing home survey (FHCA, 1996). Both surveys are focused primarily on process factors. Ideally, regulations should evaluate the stated goals of assisted living: to promote autonomy, dignity, privacy, and aging-in-place in the least restrictive environment. These goals speak more to a quality of life than quality of care.

Quality of life is often a subjective outcome and is difficult to measure (Abeles, 1991; Arnold, 1991). Florida=s surveyors who license and review assisted living facilities are

expected to describe and rate the Aquality of life@ of a facility, but no guidelines are provided to evaluate this attribute (FHCA). Quality of life, according to some researchers, is associated with physical and cognitive function and economic well-being (Arnold; Wetle, 1991). Others associate quality of life with ephemeral notions of life satisfaction, autonomy, morale, and social climate (Arnold; Cohn & Sugar, 1991; Moos & Lemke, 1994). These more subjective elements have not been measured consistently across representative samples of congregate care facilities such as assisted living or extended congregate care (Kane & Wilson; Mollica et al.; Yee et al.). Yet, it is these subjective qualities that underlie the values promoted in Florida=s assisted living and ECC programs. Their presence may moderate the losses in physical and cognitive function or economic status. It may not be possible to adequately improve an elder's chronic illness or economic condition, but it is possible to not take away her autonomy and dignity as well.

Quality of care is an important outcome of highly regulated health care facilities such as hospitals or nursing homes. It is measured usually in terms of process variables such as the existence of safety procedures and nutritious meals. Outcomes such as health status are also measured. Quality of care measures, as a result, are quite specific and measurable. Currently, the assisted living facility surveyor completes several pages of forms which ask for the incidence of particular conditions and procedures (e.g., bed sores, infection control, resident rights; FHCA).

Regulations which focus primarily on health and safety outcomes may impinge on the quality of life of the people they are designed to protect. In acute care settings such as hospitals, a patient expects to give up a degree of autonomy, privacy, and dignity in favor of a short-term health intervention. In chronic care settings, such as nursing homes and congregate care, the setting is the resident=s new home and quality of life outcomes may be more important.

Quality of life and quality of care meet on the issue of Amanaged risk.@ How risk is negotiated becomes a litmus test of actual resident autonomy. It also reflects the realities of making an abstract concept like Aautonomy@ operational in the daily life of a resident who is becoming more frail. In some cases, definitions of quality of life contradict common quality of care outcomes which are measured in health care settings, such as nursing homes and hospitals. For example, quality of life may be related to a high degree of autonomy which entails a degree of risk. A resident may make an autonomous decision to forego physical therapy, although her health outcome would be improved. A quality of care model would impose sanctions on a facility that did not provide the physical therapy; a quality of life model would support the decision to honor the resident=s preference. For assisted living to succeed, both aspects of quality must be addressed.

Licensure is the primary way long-term care is regulated. Through mandatory licensing, standards of care, regular inspections, and sanctions, the state, in theory, assures the quality of long-term care (Hawes et al.). There is always the risk that regulations will also increase costs and encourage a more institutional environment as a response to the increased bureaucracy (Mollica et al.). Or quality of care may decrease as Aregulations intended to represent minimum standards become a ceiling for achievement@ (p. 17).

A new approach to quality assurance involves the use of case management to supplement existing state surveys of long-term care programs. The case manager is trained in client assessment, individualized service plans, outcome measures, and appropriate remediation. This approach includes an on-going consultation between the resident, facility operators, and case

managers. Case managers can adequately monitor up to 40 extended congregate care clients. Case management fees included in the Medicaid waiver ($100/person per month) are sufficient to ensure frequent contact as determined by the resident's needs.

In addition to enhanced case management, the ECC survey process in Florida needs to be modified. In some respects, it is more stringent than the process for regulating nursing homes. Facilities with an ECC license and residents who qualify for ECC level of care are monitored quarterly, whereas nursing homes are surveyed once a year. Assisted living facilities without ECC residents are surveyed every other year. The rule provisions for quarterly monitoring have been a major barrier to assisted living facilities becoming ECC providers. There is a substantial workload added in terms of paper documentation for an ECC provider, and the regulatory oversight by the Agency for Health Care Administration is perceived as a threat to the care provider. Some ECC providers have reported extensive survey action on the part of surveyors conducting the quarterly monitoring visits.

There needs to be a better balance between safety considerations and a resident's right to make decisions that entail risk. At a minimum, the framework should reflect the values which underly the ECC legislation and should measure how well:

- care supports autonomy, dignity, and privacy;
- care meets resident preferences within the capacity of the provider;
- activities and environment meet the level of risk acceptable to the resident; and
- residents report satisfaction with the care.

There should be evidence of ongoing negotiation between the resident, her family, the provider, and the case manager regarding each of these measures. Research has shown that negotiation of risk may never occur or occur only at the time of admission between the family caregiver and the facility operator without including the resident (Yee et al.; Clemmer, 1995; Lieberman, 1995). There needs to be adequate liability protection for providers who respect the resident's preferences while still holding the provider responsible for adequate care (Yee et al.).

The regulatory and survey process for extended congregate care could be consultive as well. Surveyors need to understand how ECC facilities differ from nursing homes and work with providers to improve the outcomes for each resident, recognizing that resident outcomes are dependent on the level of impairment and desire for care and services.

A recent study of assisted living programs found that assisted living is providing adequate levels of choice and supporting independent lifestyles, but may not be providing adequate personal care and health care or a sense of community (Yee et al.). The authors suggest that families and elders choose assisted living for its focus on independence and its decidedly non-medical model of care. Once a frail elder is living in the actual facility, her health needs may increase and personal and health care become more important. Assisted living has typically served older people with much higher levels of disability than originally anticipated (Kane & Wilson), but the industry's "narrow response to market demands may result in a service and

amenity mix that is insufficient to ensure that residents can experience what they define as adequate care and a vibrant community life." (Yee et al., p. 23).

The frequent presence of a case manager will help to negotiate additional services as changes in a resident's needs become apparent. When a resident's function improves, she may want less care and more privacy to pursue her own interests; if it should decline, she may want more personal care and increased social activities to keep her occupied. There will be a financial impact of changing service plans. One reimbursement model has been found effective in the state of Oregon. The state offers five levels of reimbursement for publicly supported assisted living residents. The levels are based on impairments in critical activities of daily living (Mollica et al.). In another model, researchers found that targeting home care services to clients who would most benefit from them delayed nursing home admission or reduced the length of nursing home stays (Greene et al., 1993).

Targeting certain residents for lower cost extended congregate care could save state funds. A recent study found that the average impairment level of Medicaid HMO members in assisted living facilities in Dade County, Florida is nearly as high as a sample of nursing home residents (Dunlop et al., 1996). It is possible to serve highly impaired residents in a less restrictive environment, such as an assisted living facility with an ECC license. Reimbursement levels will need to reflect the actual needs of the resident. In some cases the reimbursement will be at a substantial cost savings from nursing home care; in other cases the levels may approach those of nursing home care.

The future debate over regulation and financing of assisted living and specifically extended congregate care in Florida will need to address the following issues much more extensively than we have been able to address here:

- quality of life outcomes,
- quality of care processes and outcomes,
- negotiated risk processes,
- flexible responses to changes in resident needs,
- case manager roles,
- targeted placement of residents using clear criteria, and
- reimbursement based on level of care.

A forthcoming paper from FPECA will review the existing assisted living literature related to some of these issues.

D. Assisted Living in Oregon: A Comparative View

The issues involved in the debate over the future of assisted living in Florida are similar to those emerging in other states, as they attempt to develop their own version of assisted living for low- and middle-income residents. The states have a lot to learn from each other through comparative assessments of how they frame the issues and the different strategies they adopt to resolve them. An assessment of Oregon's experience with assisted living may be the most instructive because of its scope and history. Oregon's assisted living program is the most ambitious and advanced effort among the states to develop a community-residential program for seriously impaired persons.

The differences between the assisted living programs in Oregon and Florida can be traced directly to the original objectives established by each state for their assisted living programs. Oregon set the clear objective of reducing nursing home admissions by offering a more attractive (to the consumer) and lower cost (to the state) alternative to nursing homes in the form of assisted living facilities. The assisted living program was explicitly intended to be a nursing home replacement model that would address the fiscal crisis developing in relation to long-term care in Oregon and also provide the impaired elderly and disabled a more homelike and autonomy-oriented alternative to nursing homes. All strategies implemented were designed to achieve this objective.

Assisted living, in fact, was just one of several strategies designed to create a more balanced, cost-effective long-term care system. Other strategies included the consolidation of the state's programmatic functions (including the client eligibility determinations related to income and functional impairment, case management, and regulation and reimbursement of service providers) under one consumer-accessible, bureaucratically streamlined state agency ("single entry point" system) and the implementation of two 2176 Medicaid waivers (1915(c) and 1915(d)) to finance assisted living and other community programs.

Oregon used a systematic approach in developing their assisted living program. The program was piloted prior to full scale implementation and the assisted living industry was built essentially from the ground up, according to a long range strategic plan. The original objective of the program, to direct nursing home care eligible, low- and moderate-income elders into assisted living settings (at a lower cost to the state and a preferred environment for the client), has been largely achieved.

In contrast, Florida's assisted living industry was already well established prior to the implementation of the extended congregate care program. The objective established for this new assisted living licensure category was to enable congregate care residents to age-in-place; specifically, to prevent the transfer to a nursing home of established (a minimum of three-months= residency) residents who could not continue to be served in regular congregate facilities under current regulatory restrictions (for standard licensed facilities), but whose level of impairment was not severe enough to warrant 24-hour nursing care.

Although the underlying and long-range goal for the program is to prevent unnecessary institutionalization of Florida's low-income elders, the main beneficiaries of the ECC program, under its present configuration, are current assisted living residents whose mental or physical condition deteriorates during the course of residency since direct admissions into ECC beds from the surrounding community are severely restricted, due to the A90-day rule.@ And because of limited state funding (220 Medicaid waiver slots) for the provision of medically related services that are delivered directly by extended congregate care providers in Florida, this program is not yet, in practice, targeted toward low-income elders or state clients. There are not likely to be major increases in the number of Medicaid waiver supported slots until appropriations committee members and staff in the legislature are convinced that the program is a cost-effective alternative to nursing homes and not just another additional source of long-term care cost increases.

While the program principles (preserving autonomy, dignity, and privacy) are essentially identical in Oregon and Florida, the impact of the program at the macro level in each state is very different. In short, Oregon's program provides a large number of low- and moderate-income elders (up to 300 percent of SSI) but do the option to receive state subsidized care in assisted

living settings if they do not require 24-hour skilled nursing services. Florida is presently able to offer subsidized assisted living care (through OSS) only for extremely low-income individuals (income and assets standards consistent with SSI eligibility) whose care needs are, in practice, minimal enough for congregate care providers to be willing to house them for a fee of $598 per month. In effect, this does little to prevent even moderately impaired state clients from becoming Medicaid-supported nursing home residents.

CHAPTER 6

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Recommendations

Sufficient time has passed since the creation of the extended congregate care program in 1992 to justify a systematic review of the program in terms of its regulatory structure, funding, and overall role in Florida's long-term care system. The Commission on Long-Term Care in Florida has recommended major expansion of community-based alternatives to nursing home care, including assisted living. The Governor has recommended and the 1996 Legislature has appropriated several million dollars for the Medicaid home and community-based waiver which could substantially expand the ECC program. These events indicate the emerging expectation that assisted living will be used increasingly to meet the growing demand for long-term care services in Florida. Clearly, a comprehensive, systematic review of Florida=s assisted living program generally, and the ECC program in particular, is timely. One approach to conducting such a review would entail the Secretary of the Department of Elder Affairs and the Director of the Agency for Health Care Administration appointing several members each to a review task force essentially patterned after the composition of the task force that formulated the original ECC legislation. That is, the membership should include agency and provider group representatives, advocates for the elderly and legislative staff members. The task force agenda should include the following items:

1. **Assess and perhaps revise the rule-related compromises** that were reached during the original rule formulation negotiations. The assessment should focus on possible revisions to statutory language and regulations regarding:

    a. the specification of allowable nursing services in addition to the requirement that an ECC resident not need 24-hour skilled care;

    b. the extent to which persons with severe cognitive impairment can be served in the ECC environment;

    c. the 1995 compromise on direct admission to ECC licensed facilities (i.e., the 35 percent amendment to the requirement that admission to an ECC facility be restricted to those who have resided in an ALF for 90 days or longer); and

    d. living unit specifications (i.e., should the ECC license require that residents be allowed to choose a private rather than a shared room and what are the cost implications of such a provision?)

2. **Develop a long-range strategy for the evolution of the ECC program**. The strategy should be designed to envision the emerging role of ECC in relationship to other components of the long-term care system including in-home care, a range of other community-residential options (regular assisted living facilities, adult family care homes, Alzheimer's specialty units, etc.), nursing homes, and subacute care in nursing homes and hospitals. This strategy could include criteria to be used in the development of admission and service requirements for the major long-term care components.

   This strategy should also identify feasible funding mechanisms designed to support the expansion of the ECC program. Such mechanisms might include annual increases in the number of slots funded through the home and community-based Medicaid waiver program, the implementation of level-of-care based reimbursement, expanded use of resident fees and private long-term care insurance, and enhancements in the Optional State Supplementation (OSS) program.

3. **Determine the feasibility of nurse delegation legislation** that would allow nurses to supervise others who would be trained to carry out some of the duties (e.g., dispensing medications) now performed by nurses.

4. **Determine the potential to change regulatory policies and practices as they apply to all components of the long-term care system**. This shift would entail the development of program outcome measures and monitoring procedures designed to improve outcome performance. The outcome measures should be designed to feature such quality of life factors as consumer choice, privacy and the other values that guided the development of the in-home and ECC programs. The major objective of this initiative would be to create an appropriate balance between resident autonomy and safety.

5. **Develop a strategy for incorporating the ECC program into the DOEA client information system**. The ECC cannot be efficiently managed and its cost-effectiveness determined until client-specific data become routinely available.

Evaluations of ECC and the Assisted Living Medicaid Waiver programs will be completed in the next year, but they are not likely to offer a definitive assessment of the assisted living program because the state-supported assisted living program is still quite small and very much in a developmental stage. In short, the agenda items described above need to be addressed now in order to give the program sufficient opportunity to be tested as an alternative to nursing home care. The ECC program was created five years ago, but remains very small. It is not likely to grow significantly over the next five years, unless the issues described above are resolved over the next several months. Without accelerated growth, the ECC program will not become a significant part of Florida=s long-term care system.

References

Abeles, R.P. 1991. Sense of control, quality of life, and frail older people. In: J.E. Birren, et al. (Eds.). *The Concept and measurement of quality of life in the frail elderly.* San Diego: Academic Press.

Arnold, S.B. 1991. Measurement of quality of life in the frail elderly. In: J.E. Birren et al. (Eds.). *The Concept of measurement of quality of life in the frail elderly.* San Diego: Academic Press.

Clemmer, E. (1995). *Assisted living and its implications for long-term care (Issue Brief No. 20).* Washington, D.C.: Public Policy Institute, American Association of Retired Persons.

Cohn, J. & J.A. Sugar. 1991. Determinants of quality of life in institutions: perceptions of frail older residents, staff, and families. In: J.E. Birren, et al. (Eds.). *The Concept and measurement of quality of life in the frail elderly.* San Diego: Academic Press.

Coopers & Lybrand (1993). *An overview of the assisted living industry.* Fairfax, VA: The Assisted Living Facilities Association of America.

Dunlop, B.L.; Brooks, M.; Polivka, L. (1996). *The long-term care elder population profile survey: Final report to the Commission on Long-Term Care in Florida.* Tampa, FL: Florida Policy Exchange Center on Aging and Southeast Florida Center on Aging.

Florida Health Care Association. 1996. *Continuous quality improvement for assisted living facilities.* Workshop handout, January 31, 1996. Tampa, FL.

Greene, V.L.; Lovely, M.E.; and Ondrich, J.I. (1993). The cost-effectiveness of community services in a frail elderly population. *The Gerontologist, 33*, 177-189.

Hawes, C.; Wildfire, J.B.; and Lux, L.J. (1993). *The regulation of board and care homes: Results of a survey in the 50 states and the District of Columbia. National Summary.* Washington, D.C.: American Association of Retired Persons.

Kane, R.A. & K.B. Wilson, K.B. 1993. *Assisted living in the United States: A new paradigm for residential care for frail older persons?* Washington, D.C.: American Association of Retired Persons, Public Policy Institute.

Lieberman, T. (October 1995). The promise and the pitfalls of >assisted living.= *Consumer Reports.*

McCarthy, M.J. (1992). Politics & policy: Many states await results of Florida=s attempt to support >aging in place.= *Wall Street Journal* (March 4).

Mollica, R.L.; Ladd, R.C.; Dietsche, S.; Wilson, K.B.; and Ryther, B.S. (1992). *Building assisted living for the elderly into public long term care policy: A technical guide for states.* Portland, ME: Center for Vulnerable Populations, National Academy for State Health Policy.

Moos, R. H. & S. Lemke. 1994. *Group residences for older adults: physical features, policies, and social climate.* New York: Oxford University Press.

Wetle, T. 1991. Resident decision making and quality of life in the frail elderly. In: J.E. Birren, et al. (Eds.). *The Concept and measurement of quality of life in the frail elderly.* San Diego: Academic Press.

Yee, D.L.; Capitman, J.A.; Sciegaj, M.; and Leutz, W.N. (1996). *Resident centered care in assisted living: Final report on the National Survey of Assisted Living Programs and Residents.* Waltham, MA: Institute for Health Policy, Heller School, Brandeis University.

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