

**The Role of Informal Long-Term Care and the  
Cost-Effectiveness of Community-Based Formal Care:  
A Survey of Research Findings and Their Policy  
Implications for Long-Term Care in Florida**

by

Larry Polivka, Ph.D.\*

October, 1996

**Long-Term Care Policy Series**

Prepared for the  
Commission on Long-Term Care in Florida

**Volume III**

\* Director, Florida Policy Exchange Center on Aging; Associate Professor, Department of Gerontology,  
University of South Florida

**1996**

**Florida Policy Exchange Center on Aging**

**University of South Florida, #30437**

**4202 E. Fowler Avenue**

**Tampa, FL 33620-3043**

**Phone: 813-974-3468**

**FAX: 813-974-5788**

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## **Acknowledgments**

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We would like to express our appreciation for the contributions made by Janice Blanchard and Gail Stark to the completion of this paper. We greatly appreciate the efforts of Ginny Chaplin in the preparation of this paper, from the initial draft to the final version.



## Introduction and Overview

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This is the third of ten volumes in the Florida long-term care policy series. Each of the volumes is based on work conducted by the Florida Policy Exchange Center on Aging at the University of South Florida and the Southeast Florida Center on Aging at Florida International University.

This paper (Volume III) focuses on the role of home- and community-based services in long-term care. In the first two chapters, we review the most salient findings from the research on the informal long-term care system and formal community-based services. Predictors of nursing home use are addressed in the context of how they may be used to improve the efficacy of community services. We then use the review of findings to assess Florida's current array of long-term care programs in terms of the major policy implications drawn from the literature reviews. The assessment is designed to address the following questions:

1. To what extent are Florida's long-term care policies and programs designed to support and enhance the provision of informal care? What new initiatives should be taken to strengthen informal care and enhance its efficacy as an alternative to more expensive formal care services.
2. Is the current array of long-term care programs consistent with what we know about the relative effectiveness of long-term care programs? What are the major gaps?
3. What are the implications of research findings on long-term care program effectiveness for alternative strategies to meet the projected need for long-term care services? What changes in the current array of services does the research literature suggest should be made to enhance the cost effectiveness of Florida's long-term care system over the next 5 to 15 years?

We address issues related primarily to in-home services. There are, unfortunately, relatively little research data, including evaluation findings, available on community-residential programs. More information should become rapidly available over the next few years as states move to expand their assisted living and foster home alternatives to nursing homes.

We conclude this paper with a series of policy recommendations based on the literature review and our critique of Florida's current long-term care system.

The research literature on factors associated with nursing home use, the effectiveness of community-based services in reducing nursing home use and the role of informal care as an alternative to nursing homes is now quite extensive and may be summarized as follows:

\$ The evidence is substantial that being of advanced age, Caucasian, not married, seriously impaired physically (deficiencies in three activities of daily living ADLs) or more), cognitively impaired and living alone are factors that put an individual at risk of being admitted to a nursing home. Those who are female, seriously impaired, have low incomes and few social supports are at the greatest risk of a long-term nursing home stay. Other factors have also been identified in some studies, such as availability and proximity of nursing home beds, climate and Medicaid reimbursement rates, but none seem to carry the same predictive significance as those first mentioned. It should be noted, however, that, APersons with the same characteristics will have differential rates of risk according to the community context in which they live@ (Netzer and Coward, 1996). For example, all other variables being equal, residence in a rural, rather than urban area is likely to increase substantially the risk of being placed in a nursing home.

\$ Research has clearly demonstrated that most long-term care (between 70 and 80 percent) is provided through the informal care system by spouses (mainly wives), children, other relatives, friends and neighbors and that the provision of formal services does not significantly diminish the involvement of informal care givers. On the other hand, there is not much support for the notion that formal services substantially enhance the capacity of informal caregivers to keep care recipients from entering nursing homes. Again, however, recent research indicates that targeting strategies may be designed to increase the efficacy of combining formal and informal care.

\$ Evidence of the cost effectiveness of community-based alternatives (in-home and residential care) as compared to nursing homes is mixed. Although older persons vastly prefer home- and community-based services to nursing home care, most of the several studies conducted since the early 1980s, when community-based programs began to grow rapidly, have not found that community-based programs reduce or even significantly constrain the cost of nursing home care. Many of these studies (most prominently the National Channeling Demonstration evaluation) did find, however, that community-based services helped recipients cope with chronic conditions and improved their quality of life. In short, funding for community programs is not wasteful, it just does not seem to contain the costs of nursing home care. The main reason for the absence of a cost-constraintment effect is that community programs as a whole do not seem to reduce the number of nursing home admissions; rather they expand the number of people receiving formal services in the community who are not likely to enter a nursing home whether they are receiving services or not.

More recent research, however, has found that by targeting certain services to high risk recipients in increased quantities (number of nurse visits, hours of homemaker services, etc.), community programs may reduce nursing home use. These studies are discussed in detail in this paper.

# The Role of Informal Long-Term Care

One of the most important predictors of nursing home use is availability of a caregiver. In most studies of factors associated with nursing home use, the availability of a caregiver ranks among the top three predictor variables. Clearly, informal care is an extremely important part of the long-term care equation.

The 1987-88 National Survey of Families and Households found that 10 percent of all households contain one or more family members receiving care from other household members. Forty-four percent of those receiving care were aged 60 or older. The 1991 Commonwealth Fund Productive Aging Survey of Americans aged 55 and older found that one-third of respondents reported caring for or helping a relative, friend or neighbor who was sick or disabled during the previous week. The 1990 Survey of Program Participation (SIPP) found that 83 percent of the disabled persons under age 65, and 78 percent of disabled persons over age 65, relied exclusively on informal care. The 1989 National Long-Term Care Survey (NLTC) found that over 90 percent of the chronically disabled elderly who required human assistance received care informally from family, friends or neighbors. Two-thirds relied exclusively on informal help. About 25 percent used a combination of formal (paid) and informal care. An analysis of the 1984 National Long-Term Care Survey estimated that more than 7 million spouses, adult children, other relatives, friends and neighbors were involved in providing informal long-term care to the elderly at any given point in time. Of these, 4.2 million were spouses or children. Approximately 1.5 million workers (1.9 percent of all workers) were actively involved in providing care to elderly relatives.

In the 1982 National Long-Term Care Survey, 74 percent of the disabled elderly relied exclusively on informal help. This percentage dropped to 67 percent in the 1989 NLTC. The percentage of disabled elderly who relied exclusively on formal care increased from 5.5 to 9 percent. About half of the primary caregivers of the more impaired elderly are spouses and about one-third are children. Forty-three percent of primary caregivers of the ADL-impaired elderly were caring for very severely impaired care recipients (5-6 ADL impairments). Although most primary caregivers of the elderly disabled experienced some level of difficulty associated with caregiving (personal problems, from limitations on time to illness), over 75 percent surveyed in 1982 said they experienced more satisfaction than stress in providing care (Kasper et al. 1990); and caregivers who reported higher stress also reported higher satisfaction. Caregiving can be a very difficult task, but its rewards should not be underestimated.

An issue that must be considered during this era of budget cutting activity at the federal level is the impact that cutbacks in Medicare and Medicaid funding for home care could have on families. Doty et al. (1995) describe the extent of informal care as follows:

Whatever we may believe about the status of family values in this country generally, research findings accumulated over the past twenty years underscore that family responsibility in terms of informal care provided to disabled elderly and, indeed, to disabled persons of all ages is still overwhelmingly the American norm . . . for all the growth that has occurred in public funding for home care over the past 15-20 years, we have come nowhere near the point of creating incentives for families to shift the burden of providing eldercare to publicly funded formal service providers. Data from the 1989 NLTC on hours of care received from various sources indicate that the average ADL and/or IADL disabled elder received a mean of 38.3 hours of care weekly from all sources, of which 28.7 hours were provided by primary informal caregivers, 5.6 hours by secondary informal helpers, and 4 hours by paid workers. Among primary caregivers, those who were also employed outside the home provided a mean of 18 hours of help per week; those not in the labor force provided a mean of 33.7 hours.

As care recipients become more physically and cognitively impaired, caregivers tend to supplement their caregiving with formal assistance. According to the NLTC surveys (1982 and 1984), the use of formal services by caregivers increased from 19 to 27 percent from 1982 to 1984. This trend notwithstanding, there appears to be only a very limited amount of displacement of informal care by formal care (Tennstedt, Crawford and McKinley, 1993; Greene, 1993; Wiener and Hanley, 1992). The only significant displacement seems to occur among friends and neighbors.

Edelman and Hughes (1990), in their study of extended (up to 48 months) informal care, found that:

. . . supplementation of informal services by formal community care occurred significantly more frequently than either substitution or specialization/reallocation . . . informal caregivers continue to assist homebound elderly persons 9 and 48 months after the introduction of formal services. These findings should help allay fears that community care replaces informal care with formal services. In addition, even in those cases in which substitution was found, it is not clear that this should be considered an undesirable outcome. Greene (1983) noted that if services were funded to compensate only those older individuals with an unmet need, substitution represented failure. However, if respite for informal caregivers is an appropriate outcome, then substitution may be considered appropriate.

Tennstedt, Crawford and McKinley (1993), in a study based in a representative sample of disabled adults, found that:

. . . the evidence does not support a major or persistent trend of service substitution.

They also found that the substitution of formal services for informal care was usually temporary and related to the availability of the primary caregiver. They conclude that:

There were no data to suggest that large numbers of families were voluntarily withdrawing their help in favor of formal service use. Rather, these publicly funded services appear to be doing what they are intended to do: supporting and sustaining the informal caregiving arrangement or providing care during the disruption (usually temporary) of this arrangement in order to keep the elder in the community.

More specifically, they found that:

Service substitution was more likely for certain types of care than others and was consistently associated with factors related to availability of informal care. Substitution of case management or social work for informal help with arranging services was the area with the highest rate of service substitution over time. Given the recognized fragmentation of the health and long-term care systems in the United States, a formal provider is more knowledgeable, and therefore better suited, than an informal caregiver for coordinating and arranging services for the elder.

Service substitution was more likely if there was a change in the caregiving arrangement, particularly loss or change of the primary caregiver. Data from this study reported elsewhere (Jette, Tennstedt, and Branch, 1992) indicate that the majority of elders who experienced a change/loss in caregiver had a caregiver again by the next contact. Typically, the change or loss was due to death or illness (an involuntary situation) of the caregiver rather than to competing demands or interpersonal conflict that would suggest a voluntary withdrawal from the helping role.

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In a study of relationships between caregivers and recipients, and the effect of coresidence on the quality and quantity of informal care, Tennstedt, Crawford and McKinley (1993) found that:

- C Receipt of informal care is more likely for elders coresiding with a caregiver, regardless of who that person is, as well as for elders who are more severely impaired.
- C Utilization of formal services is less likely for elders with coresident caregivers, regardless of their relationship, than for elders living alone.
- C Variance in amount of formal services used and informal care received is explained primarily by the gender and frailty level of the elder in addition to having a coresiding caregiver.

Research to date indicates that the *less* disabled elderly tend to rely on formal care; that formal care for the more disabled is largely supplemental and rarely adequate on its own to keep seriously disabled persons from being placed in a nursing home. The supplemental nature of

formal care for most seriously disabled elderly is reflected by the fact that the absence of informal help is a major predictor of nursing home use. From the perspective of research reported in the next section of this chapter, the relatively weak role played by formal care in preventing nursing home use may be substantially a function of how it is funded, organized and delivered (too little provided to ineffectively targeted recipients). Nevertheless, it is clearly the case that as persons without caregivers become more disabled and require more support and unscheduled assistance, they are more likely to require nursing home care or some form of out-of-home placement.

The energy, coping skills and commitment of caregivers are not infinite. For some, the stress and burden of caregiving eventually exceed their capacity to continue providing care. Serious cognitive impairment and behavioral problems appear to be particularly difficult for caregivers to cope with over a long period of time, as caregivers experience diminished positive feedback from the recipient and satisfaction no longer balances burden and stress.

## CHAPTER 2

# Demographic Characteristics of Florida's Elderly and Implications for Informal Care

An initial analysis by of the first wave of the Asset and Health Dynamics Among the Oldest Old (AHEAD) survey, which included a Florida oversample, has produced some findings with implications for Florida's systems of informal and formal long-term care (Henretta, 1995). These findings are shown in Table 1.

	All		Ages 70-79		Ages 80+	
	non-Florida	70+ Florida	non-Florida	Florida	non-Florida	Florida
Married, spouse present	49.4	52.5	57.4	59.3	34.7	42.08
One or more ADL Limits	30.3	27.1	22.4	18.0	44.9	41.2
One or more IADL limits	30.9	27.9	23.0	20.7	45.5	39.2
Live with children	14.7	11.4	13.9	9.4	16.1	14.5
Live less than 10 miles from a child	58.2	40.6	60.0	38.7	55.0	43.6
Has ADL or IADL limit, is not married, and doesn't live with or within 10 miles of child	4.9	5.4	2.9	3.0	8.4	9.0
<b>Income</b>						
Mean	32,255	35,916	35,684	37,743	27,037	33,566
Median	13,893	13,893	15,00	14,400	12,000	13,893
Number of People	6,484	974	4,251	644	2,233	330

A higher percentage of Florida's elderly compared to non-Florida elderly are married, particularly among those 80 and older, and they are less likely to have activities of daily living and instrumental activities of daily living (IADL) deficits. Florida's elderly are far less likely to live with a child. Florida's elderly with an ADL or IADL limitation are only slightly more likely to not be married and not living with a child or within ten miles of a child. The mean and median incomes of Florida's elderly are not substantially different from those of the non-Florida elderly, except for the mean income of those 80 and older, which is \$6,529 higher in Florida.

These findings are not surprising. The major source of growth in Florida's large elderly population is in migration from other states and to a lesser, but increasingly significant extent, from other countries, mainly Latin America. Many of these persons have incomes that allow a greater degree of mobility and are not restricted by ADL/IADL impairments. They frequently move to Florida with their spouses while their grown children and other family members remain in the original home communities. Henretta (1995) notes that:

Spouses are the most important source of help for Floridians while children are the most common helpers for non-Floridians. Thirty nine percent of Floridians receive help from spouses, compared to 22 percent of the non-Floridians. In Florida, 23 percent of the impaired receive help from children while 31.7 percent of non-Floridians do.

He also points out that:

Overall, the proportion of older Florida residents receiving no help most of the time on an ADL or any help at all on an IADL is not significantly different from non-Floridians. Forty percent of Floridians receive no help compared to 37.7 percent in the rest of the U.S. After age 80, the difference is statistically significant (34.6 percent Florida compared to 27.7 percent non-Florida). One should not expect that all impaired persons will be receiving help.

Data from future waves of the AHEAD survey may provide information that can be used to determine much more precisely what role formal services alone, and in combination with informal care, play in the lives of Florida's impaired elderly. We may conjecture from the available data, however, that the greater availability of informal care represented by the higher percentage of Florida's elderly with spouses is offset to some extent by the greater distance from children. The need for publicly supported formal services may be diminished by the lower percentage of Florida's elderly with ADL/IADL impairments and their higher incomes which can be used to purchase formal services privately. On the other hand, Florida's large and growing population of elderly includes a substantial number of seriously impaired (3+ ADL deficits). As shown in Table 2 below, there are approximately 280,000 frail elderly in 1995, and their number is projected to increase to 400,000 by 2010.

<b>TABLE 2: Estimates and Projections of the Frail<sup>1</sup> Elderly Population in Florida, by Selected Characteristics, 1995 to 2010<sup>2</sup></b>							
	<b>1995</b>	<b>2000</b>		<b>2005</b>		<b>2010</b>	
<b>TOTAL</b>	<b>281,484</b>	<b>322,883</b>	<b>100.00%</b>	<b>359,429</b>	<b>100.00%</b>	<b>400,978</b>	<b>100.0%</b>
<b>Age Distribution</b>							
65-69 years	49,624	49,232	15.4	54,673	15.3	68,246	17.2
70-74 years	48,736	50,356	15.7	49,499	13.9	54,361	13.7
75-84 years	105,320	123,494	38.6	133,537	37.5	132,813	33.4
85+ years	75,224	97,031	30.3	118,769	33.3	142,283	35.8
<b>Gender Distribution</b>							
Males	86,134	98,802	30.6	109,985	30.6	122,699	30.6
Females	195,350	224,081	69.4	249,443	69.4	278,279	69.4
<b>Household Composition Distribution</b>							
Individual	98,122	113,253	35.1	126,560	35.2	141,214	35.2
Couple	101,664	117,341	36.3	131,128	36.5	146,311	36.5
Family	35,018	40,417	12.5	45,166	12.6	50,396	12.6
Non-Family	46,681	51,872	16.1	56,574	15.7	63,057	15.7
<b>Poverty Status Distribution</b>							
at or below 100% FPL	105,901	120,858	37.4	134,106	37.3	149,588	37.3
101-150% FPL	22,299	25,657	7.9	28,616	8.0	31,927	8.0
151-200% FPL	21,070	24,243	7.5	27,039	7.5	30,167	7.5
201% or more FPL	132,214	152,125	47.1	169,668	47.2	189,297	47.2
<b>Setting of Care</b>							
Nursing Home	52,638	58,248	18.2	63,352	19.8	70,605	17.8

Adult Living Facility	6,026	6,849	2.1	7,579	2.4	8,454	2.1
At Home	220,241	255,016	79.7	285,546	79.2	318,645	80.1

Note: Percentages may not sum to 100.0% due to rounding.

<sup>1</sup>Those elderly with 3 or more deficiencies in activities of daily living.

<sup>2</sup> The frail elderly, projected needs and costs (deliverables one and two). (Mar. 1996). *Long-Term Care in Florida: A Policy Analysis*, prepared for the Commission on Long-term Care in Florida: Tallahassee, FL.



## CHAPTER 3

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### Publicly Supported Informal Care

There is growing evidence (Doty et al. 1996) that policy makers are becoming more receptive to the strategy of supporting informal caregivers by providing cash assistance or vouchers that can be used to purchase goods (assistive devices) and services (homemaker help). These programs are subject to restrictions, but 70 percent of the states do provide some form of assistance to family care providers (Keigher and Stone, 1994).

Doty et al. report that:

State officials are aware that fewer and fewer families—especially low income families—can afford for working age members not to contribute income to the household. Thus, states are increasingly willing to pay family caregivers of the severely disabled in situations where they know that the alternative is not that the family caregiver would stay at home to provide care informally but that the family member would go out to work and the state would have to pay someone else to take care of the disabled person during those hours.

Cash-based options with counseling support could theoretically be incorporated into any state or federally funded long-term or chronic-care program serving persons of all ages and many disabilities. Generally, disabled persons would have a choice of a case-managed service benefit or a monthly cash allowance of a monetary value lower than the currently available service benefit (e.g., nursing home care). To be eligible for the monthly income supplement, an individual with a disability would have to show in some predetermined way that she could effectively use the extra income to meet her long-term support needs. Consumers would be able to spend the money in ways they best see fit. They might choose to purchase services from a home care agency or referral service at current rates, pay a friend or a relative to provide personal assistance services, make needed home modifications or move to an assisted living facility or other new housing arrangement.

The counseling component would involve an assessment of need, consumer information and advice about the various service, financing and housing options available. Centers for independent living, area agencies on aging, other public or private organizations, or individuals that do not have a vested financial interest in the decisions made by the consumers would provide

the counseling service. The purpose would be to provide consumers and their families with the information and assistance they need to make their own decisions and manage their own care.

This payment option could provide disabled persons and their caregivers, as well as the state and federal government, the following benefits:

**Empowerment of consumers.** Cash and counseling options provide disabled individuals with flexibility, autonomy and decision-making power. Consumers have access to information and professional advice, but each individual and her caregiver decides how to best meet his or her needs.

**Support for families and other informal caregivers.** Many disabled persons would prefer to receive help from relatives, friends or neighbors. Cash and counseling is a simple and non-bureaucratic way to support informal caregivers.

**Lower unit costs of care.** A major barrier to the expansion of long-term care services in this country is the high unit costs of government-purchased services. Cash and counseling options could enable consumers to arrange for services of equivalent quality that are less expensive and more appropriate to their personal needs and preferences.

**Lower total costs to government.** By establishing the monthly care allowance as a percentage of the case-managed service-benefit cost, the state can ensure that the costs per client will be less than what it would otherwise pay. Additionally, administrative savings may be achieved because of lower billings and claims handling costs.

**Encourage development of consumer-directed chronic care systems.** By giving consumers the flexibility and independence to spend their money as they best see fit, cash and counseling encourages the evolution of long-term care services that are responsive to consumer needs rather than government regulations and administrative decisions.

**Create a unified model for serving frail elderly and younger persons with disabilities.** As a practical matter, it is very difficult for state administrators to define and manage in one program a set of service benefits that will truly meet the needs of Alzheimer's patients, stroke victims, young quadriplegic persons, mentally-retarded adults and severely disabled children. Because this approach would enable individuals and their families to decide for themselves what is most appropriate to meet their needs and circumstances, it may be a more efficient way to help people with very different needs through a single administrative structure.

Several different cash and counseling long-term care programs have been implemented in the U.S. and abroad. The major models are briefly described below:

**Cash Disability Allowances or Income Supplementation.** This approach provides direct cash assistance or income supplements to disabled persons to finance needed health, social and long-term care services. Cash payment is included in monthly pension or disability check and cash may be used in any way consumers believe best meet their long-term care needs.

Examples of this approach include the U.S. Department of Veterans Affairs Housebound and Aid Attendance programs that pay from \$150 to \$390 per month, and Austria's Care Money National Long-Term Care Program that pays from \$230 to \$1900 per month based on level of disability.

Eligibility criteria are relatively stringent requiring substantial levels of disability. Counseling is provided only if requested by the consumer.

**Client Budget.** This approach involves collaboration among the consumer, care coordinator/personal agent, and informal caregivers who design a plan of care and a budget to meet the plan requirements. The client and her family manage the budget and the agency conducts on-going monitoring. A program based on this model and funded by Robert Wood Johnson Foundation is now underway in New Hampshire for a group of 60 persons with developmental disabilities (New Hampshire Self Determination Project). Benefits under the program are averaging approximately 75 percent of the cost of previous service benefits.

**Cash or Service Option.** This approach requires that eligible long-term care recipients be given the choice between professionally provided services, or a cash grant that the consumer can use to meet individual needs. The leading example of this model is the German National Long-Term Care Program which was initiated in 1994 with funding from a new 1.7 percent payroll tax increase. Persons, regardless of age or income, are eligible to receive cash benefits of \$182 to \$600 a month or up to 75 visits per month by service providers if, in a doctor's opinion, they require permanent long-term care. *Early experience with the program indicates that 80 percent of those seeking assistance choose the cash benefit, which costs less than 60 percent of the service option.*

**Case Managed Cash Benefit.** This model generally takes one of the three following forms:

1) State and county funded programs that provide a monthly cash supplement to the Federal SSI payment for the purchase of in-home services to enable persons in need of long-term care to remain in their homes as long as possible. An example of this approach is the Colorado Home Care Allowance program for functionally disabled SSI recipients and others with incomes below a designated level who have been recommended for assistance by a physician. Payments range from \$100 to \$330 monthly.

2) Counties are given the option of "cashing out" benefits in which either care recipients or providers are given a check to reimburse for care provided. The Wisconsin Community Options Program (COP) exemplifies this approach. In this program the level of benefit varies by care plan. The case manager determines the level of benefit based on the care plan and the amount of money available. No cap is placed on individual care plans. The average monthly payment is \$630. Financial eligibility for on-going services is tied to whether the person is, or would become within six months, Medicaid-eligible in a nursing home. Functional criteria are also used to determine eligibility. This program is designed to ensure maximum consumer self-determination with the case manager playing the role of facilitator.

3) A dual-party check is issued to both the care recipient and the caregiver to be used to meet long-term care needs provided by the caregiver. The Michigan Home Help program is an example of the this model. In this program the consumer receives up to \$333 a month if she meets income and asset guidelines, is functionally impaired and is certified by a physician. The program is targeted to Medicaid recipients.

Florida's Home Care for the Elderly (HCE) program is similar to the Colorado and Michigan programs in terms of eligibility criteria. The HCE program, however, is designed to reimburse the caregiver for expenses incurred providing care to the client in the previous month and averages only \$100 per month, per client. Furthermore, funding for the HCE program has not been increased since 1990.

Some aging advocates think that consumer control is a priority of younger disabled adults, not the frail elderly; and some providers think that too much consumer control may undermine the government's ability to manage resources efficiently and with enough predictability to ensure solvency of the program.

The early results from Germany and Austria seem to indicate that these issues are manageable within a cash and counseling framework. The popularity of the program among the frail elderly is particularly striking. It seems to have rapidly become a very effective strategy for subsidizing informal care and integrating it with formal services.

Other concerns were expressed by participants in a recent focus group session with case managers whose clients receive in-home services through Florida's community care for the elderly programs. These concerns included the following:<sup>1</sup>

- \$ Cash vouchers may become another form of currency to be used by unscrupulous clients/caregivers in a fashion similar to food stamp abuse. An "underground economy" may develop.
- \$ This approach may actually represent more work, rather than less, for case managers because they would have to supervise and oversee the provision of services to ensure that the client was receiving proper care. Case managers would have to become teachers: they would have to counsel (often) clients/caregivers about how to hire outside help, check references, deduct taxes and complete reports. Case managers would also have to become auditors: they would have to check the accuracy of reports submitted by clients and may actually wind up doing the reports.
- \$ Workers hired by clients may not deliver the services they were hired to deliver, placing an extra burden on the case manager and the publicly funded system. Such a program, unless closely supervised, will become another "grave train" for unscrupulous private contractors and even home health agencies who will market their services to unwary elders.

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<sup>1</sup>Robinson-Anderson, Randa (June-July 1995). Focus groups conducted with Community Care for the Elderly case managers.

\$ Finally, some focus-group participants felt that economic, cultural and public policy differences between the U.S. and European countries that have implemented cash and counseling programs on a broad scale (Germany and Austria) may make this strategy impractical in the U.S. and Florida. Such a plan may work in another culture but not in the USA. Case managers asked, for instance, are women available to work as paid providers in Europe and can they better afford to live on the limited wages they would earn from a cash assistance program? Many women in this country cannot afford to give up their jobs to be low-paid caregivers because they will lose their benefits and health insurance.

In a recent speech to the National Chronic Care Consortium (Washington, D.C., June 10, 1996), Bruce Vladeck, Director of the Health Care Financing Administration (HCFA), identified changes he thinks should be made in methods of providing and paying for long-term care services, changes designed to enhance consumer control of their own care. He recommended that long-term care funds go directly to beneficiaries, not to providers. Rather than expanding the array of reimbursable services, Vladeck would prefer to decouple benefits from providers and let consumers determine the kinds of services they receive by giving them control over the dollars. This would reduce the scope and density of bureaucratic structures that have been established to reimburse care according to categories that have fractured the long-term care continuum and complicated the delivery of services. He recommended that recipient funding levels be determined by assessed levels of need (care and financial needs) and that the recipient then be left to use the money in whatever way she chooses.



## CHAPTER 4

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## The Cost-Effectiveness of Formal Home- and Community-Based Long-Term Care

Are home- and community-based programs cost-effective alternatives to nursing home care? This question has been at the heart of long-term care policy deliberations since the early 1980s. Part of the rationale for community long-term care programs from their inception in the 1970s was the perception that they would reduce the need for nursing home care as the size of the elderly population grew over the next several decades. Community Care for the Elderly (CCE) was explicitly developed in Florida, and its expansion over the years justified, as a cost-effective alternative to nursing home care. It is still true that older people overwhelmingly prefer to receive long-term care services in their own home or in as home-like an environment as possible. There is considerable debate, however, about the relative cost-effectiveness of home- and community-based care.

Evidence of the cost-effectiveness of community-based alternatives (in-home and residential care) to nursing homes is mixed. Most of the studies conducted since the early 1980s, when community-based programs began to grow rapidly, have not found that community-based programs reduce or even significantly constrain the cost of nursing home care. Many of these studies (most prominently the National Channeling Demonstration evaluation) did find, however, that community-based services helped recipients cope with chronic conditions and improved their quality of life. In short, funding for community programs is not wasteful, it just does not seem to contain the costs of nursing home care. The main reason for the absence of a cost-containment effect is that community programs as a whole do not reduce the number of nursing home admissions, rather they expand the number of people receiving formal services in the community who were not likely to enter a nursing home.

William Weissert (1991) has summarized his assessment of several studies of the cost-effectiveness of home-based versus nursing-home care for elders with long-term functional disabilities by noting that on the aggregate level, home-based services have not proven cost-effective, because 75 percent of persons who received the services would not have entered a nursing home for a substantial period of time in the absence of the services. Yet, in-home care did keep about 25 percent of those who received services out of nursing homes. These results were achieved despite the absence, in almost all the home care programs that were assessed, of features

usually associated with well-managed home-care services, i.e., targeting of services to those who need them most, accountable case management, and careful client assessment and care planning.

Jette, Tennstedt and Crawford (1995), in a recent review of the research literature on community-based long-term care, conclude that:

The hypothesized direct effects of informal and formal community care on nursing home use have received conflicting empirical support in both cohort and demonstration studies (Cohen, Tell, and Wallack, 1986, Greenberg and Ginn, 1979; Greene and Ondrich, 1990; Hanley et al. 1990; Palmore, 1976; Townsend, 1965; Wolinsky and Johnson, 1991). With respect to formal services, Colerick and George (1986), for example, reported no statistically significant difference in use of services between caregivers who institutionalized their relatives and those who did not. Others (McCoy and Edwards, 1981; Newman et al. 1990) have reported that use of formal community services was associated with increased risk of institutional placement. With respect to informal caregiving, most cohort studies have reported mixed results regarding the quality and accessibility of informal support with a reduction in institutional risk.

Demonstration studies conducted over the past decade have also addressed the question of whether community long-term care can be a cost-effective direct substitute for nursing home care (Applebaum, Harrigan, and Kemper, 1986; Kemper, Applebaum, and Harrigan, 1987). Despite strong theoretical considerations to the contrary, the overall evidence from these studies offers limited support for the hypothesis that community long-term care reduces subsequent nursing home use (Kemper, 1988).

Weissert (1988) has observed that the Channeling Demonstration project failed to cap treatment costs at a low enough level to tailor treatments to appropriate subgroups of clients and to target services effectively. In fact, the Channeling projects enrolled individuals if they had dependencies in only two or more instrumental activities of daily living (IADL<sup>2</sup>), which is a very liberal targeting strategy. Targeting has become an increasingly urgent key issue in the determination of the cost-effectiveness of home-based care (Dunlop, 1980; Weissert et al., 1991). Weissert et al. (1991) have expressed the view that:

In the past, home care has been burdened by . . . inadequate attention to the specific outcomes achievable for various subgroups and, to some extent, poor management due to a lack of understanding of the nature of its cost structure and a lack of adequate attention to cost-saving strategies born of a missionary sense that net saving would be automatic. Clearer cost and outcome objectives could lead to the use of more appropriate admission criteria and better decisions regarding care intensity and duration. These in turn could make home care more affordable, and could help convince Congress and the Congressional Budget Office that home care can be kept within affordable bounds.

Weissert (1991) has argued that the best chance of showing cost-effectiveness for home care, in terms of reducing nursing home use and long-term care expenditures, is to target services to that subpopulation needing long-term care who are likely to become *long-staying* nursing home residents under Medicaid. Based on severe impairments and to limit expenditures to a proportion

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<sup>2</sup>Instrumental activities of daily living, are activities such as grocery shopping, using the telephone, paying bills, etc.

of estimated nursing home costs, prospective budgets should be put in place to encourage cost-effective, or at least affordable, home care.

More recent research, however, has found that by targeting certain services to high risk recipients in increased quantities (number of nurse visits, hours of homemaker services, etc.), community programs may reduce nursing home use. High risk in this context is defined as relative vulnerability to being placed in a nursing home. The evidence is substantial that being older, female, low-income, childless, seriously impaired physically (deficiencies in three activities of daily living or more), cognitively impaired, and living alone are the factors that put an individual at greatest risk of a long-term nursing home stay. Other factors have also been identified in some studies, such as availability and proximity of nursing home beds and Medicaid reimbursement rates, but none seem to carry the same predictive significance as these variables.

The research findings reported in recent articles by Jette, Tennstedt and Crawford, of the New England Research Institute, and Greene, Lovely, Miller and Ondrich, of the University of Syracuse, are among the most directly relevant to the policy question of what mix(es) of client and service characteristics produce the most cost-effective results in terms of institutional avoidance. The results of their research indicate that certain mixes of clients and services may reduce nursing home use substantially.

The Jette et al. study was designed to determine the extent to which: 1) the availability of informal and formal community care provided to older persons has a direct and independent effect in reducing their risk of nursing home placement; 2) the individual's receipt of community-based services moderates (buffers) the effects of other risk factors on nursing home use; and 3) the effectiveness of informal care in delaying or preventing nursing home use is enhanced by the simultaneous use of formal services. The major findings of the study are summarized below:

Elders were more likely to be admitted to a nursing home if: their primary caregiver was male; they did not live with the caregiver; their caregiver reported personal burdens in providing care; and they used formal (purchased or publicly provided) services.

The authors suggest the following caveat:

. . . unmeasured aspects of the older person's illness or social resources could explain the observed positive association between formal service use and nursing home risk reported in this and previous research.

This finding may also indicate that the use of formal community-based services is a precursor to institutional care. In an attempt to deter nursing home admission, the family or formal service providers may recognize the increased need for care and increase the use of formal services to maintain the elder in the community. Therefore, rather than directly increasing the risk of nursing home admission, use of formal community services reflects, for many elders, an interim stage in the continuum of long-term care from primarily informal, to mixed informal/formal, to all formal (institutional) care. Among the cognitively impaired, but not the physically impaired, greater hours of formal care was associated with reduced risk of nursing home admission. The number of hours of informal care, however, was not related to nursing home admission.

The authors interpret their findings to mean that:

. . . enabling effects of formal community services may operate differently depending on the particular service/client combination. The provision of formal community services to the cognitively impaired may serve as an important respite to the primary caregivers, which enables them to continue caregiving for longer periods than those who do not receive this respite. In contrast, amount of formal service was not associated with a change in risk for those with severe physical disability. Formal community services appear to have a significant association with reduced risk of nursing home use when appropriately targeted to certain subgroups of disabled elders (Greene, Lovely, and Ondrich, 1993; Weissert and Cready, 1989). These findings need further exploration in minority elders and in subgroups with different disease profiles.

They conclude by pointing out that:

. . . the issue is what type of service under what circumstance and for what type of older person will influence subsequent risk of entering a nursing home. The direct policy implication is clear; simply expanding use of community long-term care services by all disabled older persons is unlikely to reduce nursing home use and will consequently not be cost-effective. Future targeting efforts need to take into account the particular service and client combinations.

We certainly need more research along the lines identified by Jette et al., but it is not premature to discuss the implications of at least some of their findings for the development of long-term care policy and funding strategies in Florida. First, the finding that formal care tends to reduce the risk of institutionalization for cognitively impaired elderly is encouraging, given the percentage (50 percent plus) of nursing home residents who suffer from some form of dementia. A very low percentage of the need for support services (respite, day care, personal care, chore services, etc.) among caregivers for dementia victims is currently being met.

The absence of a relationship between the provision of formal care for the physically impaired and the risk of institutionalization, which is a common finding across several previous studies, should not be interpreted to mean that formal care does not matter in terms of institutional avoidance in this population. Jette et al. point out that their findings may reflect the fact that severity of impairment will eventually overburden most combinations of informal/formal care. The authors also note that it may reflect inadequate targeting of community services to those who could benefit most from them. This has become a common concern among those responsible for the organization and delivery of long-term care services.

This finding may reflect a third factor: the relative scarcity of community-residential options for disabled elderly dependent on publicly funded services. Congregate care options including group facilities, adult foster care, public housing (HUD Sections 8 and 202) with services and assisted living facilities designed to serve the seriously impaired (cognitively and physically) are in relatively short supply for the publicly supported recipients of long-term care services. In Florida, there are only 8,800 state-supported residents in assisted living facilities and 560 in adult family (foster) care homes, compared to over 45,000 supported by Medicaid in nursing homes. Most observers report that the number of elderly who are too impaired to be cared for at home, even with extensive service packages, or who do not have adequate housing arrangements, is growing in step with the increase in the over age 85 population. This trend will cause a steady increase in

demand for the more expensive nursing home beds if initiatives are not taken to increase the availability of publicly supported community-residential care placements.

Vernon Greene and his associates have on several occasions analyzed data from the National Long-Term Care Channeling Demonstration evaluation in an effort to determine the potential for minimizing nursing home use through expanded and targeted access to community-based long-term care services. Their research has explicitly addressed the major policy research issue of what type of service for what type of older person will influence subsequent risk of entering a nursing home. In their latest reanalysis of the Channeling data, Greene et al. create a model to simulate the effect of reallocation of long-term care seniors on institutionalization.

In this way, we begin to answer some key questions regarding community-based long-term care services and nursing home use that have not yet been systematically addressed in the literature. First, by comparing nursing home use under the simulated optimum service allocation with that actually observed, we assess the technical capacity of community-based long-term care services to reduce nursing home use when optimally limited to this goal. Second, by comparing the existing allocation of budget and services in the Channeling population with that which minimizes nursing home use, we may gain insight into the nature of existing inefficiencies and into possible changes in aggregate service mixes and individual use criteria that may be broadly useful in both policy analysis and service management.

The issue we seek to isolate and address clearly is the theoretical potential of a fixed expenditure for community services to reduce nursing home use when services are unequivocally committed to this as a goal. Once this baseline potential has been established, we will then be able to understand the consequences of the constraints, inefficiencies, and multiple and competing purposes found in the real world. On the other hand, if the potential to reduce nursing home use is found to be negligible even under the conditions which theoretically maximize this effect, then this outcome can with more confidence be abandoned as a policy goal.

Using a set of cleverly designed statistical procedures including logistic regression models to measure effectiveness of community services in limiting nursing home use and a mathematical optimization procedure to identify the most cost-effective (optimum) uses of community services in limiting nursing home use compared to how they were actually used in the Channeling demonstration, Greene et al. were able to develop an optimum service allocation model. The optimum allocation of services differs dramatically from the actual pattern of services observed in the Channeling demonstration. The model found that: *If* the Channeling services had focused more on home nursing, home health aide and housekeeping services and targeted to clients with greater ADL, IADL or cognition impairments, who lived alone, had lower incomes and fewer children according to the optimum allocation model, *then* there would have been only 9.5 percent rather than 13.1 percent of total persons months spent in nursing home care without increasing total expenditures.

The following table displays differences between the actual distribution of services and nursing home risk and the distribution under the optimum service allocation model.

<p><b>Table 3. Distributions of Nursing Home Risk and Hours per Month of Services Under Observed and Optimum Service Allocations</b></p>
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	Nursing Home Risk(s)		Nursing Hours		Home Health Hours		Personal Care Hours		Housekeeping Hours	
	Observed	Optimum	Observed	Optimum	Observed	Optimum	Observed	Optimum	Observed	Optimum
Mean	13.1	.045	.95	3.36	6.31	7.59	31.9	0.00	5.52	31.51
Total hrs.			3,328	11,770	22,104	26,588	11,991	0	19,337	110,380
Percent receiving service			16	31	8	14	50	0	20	37

The table shows that by increasing the mean number of nursing hours per month from .95 to 3.36, home health aide hours from 6.31 to 7.59 and housekeeping hours from 5.52 to 31.51 per month, the mean nursing home risk for the Channeling population is reduced from 13.1 percent to .045 percent. This optimum allocation model is kept within the total actual expenditures for the Channeling demonstration by essentially eliminating the personal care component. The table also shows the percentage of clients receiving services under the optimum model increases for all the services except personal care, which goes from 50 percent of all clients receiving the service to 0 percent. Personal care is usually the most frequently used community service and the very idea of dropping it will be repugnant to most providers and advocates. It should be noted, however, that in many community-based programs there is a great deal of overlap between personal care, housekeeping and home health care. Personal care, in its many forms, is an inherent part of what many home health aides and housekeepers do routinely.

Other things being equal, the optimization favors services whose effect is large relative to their cost. That is, it favors services with a high "bang for the buck." In the optimum allocation model, 30 percent of the Channeling clients in the sample received more nursing services and 11 percent received less. Similar patterns occurred for the other services, except personal care. The authors note that:

Clearly, the optimization model finds some individuals to be highly over-served, as well as many quite under-served. Overall, 74 percent of the sample were put at reduced risk through the optimization, while 11 percent were actually put at increased risk. These latter are low-risk individuals who were among those consuming resources that the optimization determined could be better used elsewhere. About 15 percent of the sample saw their risk unaffected by the optimization.

The optimization shifts considerable additional resources to persons with the classic risk factors for nursing home use—those living alone, those without an owned home, those severely impaired in ADL, IADL, or cognition, those reporting worse health, and those with fewer children or lower income.

The authors also point out, however, that:

The dramatic reduction in nursing home use achieved by the optimization was accomplished by assuming that the entire budget for community-based services being consumed by the sample was free to be reallocated by the optimization, certainly not a situation that would be available in the real world, where at most only a fraction of these services might be systematically reallocated by public or other authorities.

These are important caveats, but it should be recognized that the "real world" may change dramatically very soon if current congressional proposals to cap the Medicaid program at 4 to 6 percent in terms of annual increases become law. Given the increasing squeeze on state general revenues, a stringent cap on Medicaid expenditures will force many states to consider major changes in their health care programs, particularly long-term care. These changes could include far more rigorous targeting of the more cost-effective programs (those that reduce nursing home use) than has ever been considered before. If this occurs, research like Greene et al. could play a major role in shaping public policy for long-term care.

It may be instructive to compare the optimum rate for housekeeping hours with the number of hours per month provided under the Florida Community Care for the Elderly Program. The Aging 2000 study (1991) found that the utilization of homemaker services by the severely impaired averaged 1.3 hours per week or 5.2 hours per month, compared to 31.5 hours in the optimum model. The Aging 2000 study also found that 50 percent of the clients who were recommended to receive homemaker services were receiving no services. There is little reason to think that these rates have changed since 1991. Per capita spending on CCE services has declined since 1991 and average annual per client expenditures were not significantly higher in 1995 than 1991. Nursing care and home health aide services are rarely provided under the CCE program, although many receive Medicare home health care.

In short, it would appear that Florida's community-based programs, except for the Medicaid 2176 Waiver Program (\$3,000 per client annually) are providing too few services on a per client basis to reduce the risk of nursing home use significantly. This issue is likely to become increasingly salient as general revenue and Medicaid funds are curtailed over the next several years. In a time of growing scarcity, however, choices will have to be made in terms of relative cost-effectiveness and the capacity to reduce nursing home use will become an increasingly important criterion in allocation of resources.

Weissert's recently more optimistic view of the cost-effectiveness of community-based care is clearly evident in the following quote from a report he prepared for the Commission on Long-Term Care in Florida:

. . . past research, and evidence from the Arizona capitated Medicaid long-term care program strongly suggest that if design and management of home care programs were improved . . . the performance and cost-effectiveness of home care can be greatly improved and may produce broader outcome benefits and improved cost savings.

To be more specific, the major features of a successful program are likely to include:

- C a patient selection instrument which strives to select patients at high risk of long-term nursing home placement;
- C assessment and selection of patients by someone other than the provider or risk contracts;
- C eligibility limited to patients whose nursing home stay would be at least three months if they do not receive home care;
- C fixed per capita payments which assume that a substantial fraction of the clients enrolled by a managed care organization will be placed in home- and community-based settings and that few will experience acute care episodes;
- C assumption of risk for nursing home, home care and the Medicare hospital deductible by the managed care organization which received the per capita payment.

These features produced favorable results in Arizona where home care appears to have been broadly and generously provided without raising overall costs (McCall et al. 1995).

The secrets of the Arizona success appear to lie in the incentives faced by the managed care plans: they had no control over whom they admitted and so were forced to accept a high risk case mix. Their payment rate assumed that many of those enrolled would be served in home care meaning that the program would lose money if it failed to provide home care services sufficient to keep enrollees at home and out of a nursing home. And the managed care plan had to pay the hospital deductible for all hospital admissions experienced by its enrollees, which gave them an incentive to prevent hospitalizations if possible.

Weissert believes that the key to making long-term care more home- and community-based oriented is to implement financial incentives designed to exploit the cost-effectiveness potential of community-based care.

Home care needs the same kinds of cost-conscious programmatic and clinical management that is coming to other aspects of the health care system. Incentives must be put in place to assure that patients are assessed for the risks they face and carefully designed protocols are followed in developing and implementing their care plan. Sorting patients into risk subgroups, design of appropriate risk-mitigation protocols, protocol training, evaluation against process as well as outcome goals, and efforts to allocated resources in relation to benefit potential should improve outcomes and lower costs. All these features should be part of any new home care initiative.

None of this is likely to happen without strong incentives in the payment system for home care, along with accompanying requirements for quality assurance including process indicators that risks have been assessed, appropriate care is being given, resources are allocated systematically and vary with risks being treated, outcomes are being achieved, complaints can be made without fear of reprisal, and costs are under control.

In summary, it would seem that the potential efficacy of home- and community-based long-term care programs is much clearer today than five years ago. It is also clear, however, that major changes are needed in the organization, management and funding of most HCBS programs in order to transform this potential into actual performance.

## CHAPTER 5

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### The Role of Prevention in Community-Based Care

Strategies designed to sustain and maintain activities of daily living, mental functioning and independence of even very frail elderly persons with chronic conditions have shown promise as some of the most cost-effective methods of containing the need for long-term care in the future and maintaining frail elderly persons in the community. The presence of chronic conditions does not diminish the potential for prevention. Appropriate prevention goals are to avoid or limit functional disability, halt or slow the advance of chronic diseases (considered incurable at this point in time), and to maintain independent living for as long as possible. The first concern in implementing preventive strategies in this population is to make the program meaningful to people already affected by chronic diseases, i.e., to project the possibility of improvement and maintenance in the absence of *Acure*® (Gorman, 1994).

**Smoking Cessation.** The past decade of research has clearly established the benefits of quitting smoking after age 50 (Office on Smoking and Health, 1989, as cited by Orleans et al. 1991). The University of Washington's Center for Health Promotion in Older Adults found that older men and women benefitted just as much from smoking cessation as did their middle-aged counterparts (Hermanson, 1988, as cited by Heine, 1992).

**Exercise.** A number of well-designed outcome studies have demonstrated that it is never too late to begin health behavior modification, especially for physical activity, nutrition, and stress reduction, in older individuals living in various settings (Schmidt et al. 1990; Muir-Brany, 1992; Mayer-Oakes, Stuck and Rubenstein, 1993, as cited by Schmidt, 1994). Physical activity has been found to increase the elders' ability to perform the activities of daily living by 67 percent, reduce the need for mental health treatment by 10 percent, increase independence by several years, and decrease the need for residential care by 67 percent (Shephard, 1978, as cited by Glazer, Snyder, and Kodner, 1985). We now know that physically active elders can build and rebuild muscle mass. Even the frail elderly can improve function by a remarkable 20 percent on a short, focused exercise regimen. No single feature of aging can more dramatically affect basal metabolism, insulin sensitivity, calorie intake, appetite, breathing, ambulation, mobility, and independence than building muscle mass (Rosenberg, 1992).

A major reason for institutionalization is the deterioration of function that prevents an individual from carrying out the essential activities of daily living unaided. For example, muscle

strength may be insufficient to move from a chair or a toilet seat, flexibility at major joints may be inadequate to allow dressing or climbing into a bath, and oxygen transport may no longer be sufficient to meet the needs of the muscles during light aerobic work. In the active (non-sedentary) individual it takes 10 to 20 years longer for oxygen transport values to drop to the threshold where independence can no longer be sustained (Shephard, 1978).

**Falls Prevention.** The most effective method for reducing injuries among the elderly is the prevention of falls, which are the number one cause of death from injury among those 75 years and older and the number two cause of injury-related death among 65- to 74-year olds (Office of Health Promotion and Wellness, 1994). Falls can be caused by a lack of physical activity resulting in poor muscle tone, decreased strength, bone mass and flexibility, gait and balance disorders, osteoporosis, use of psychoactive and multiple medications, environmental hazards, and impaired vision. Falls often result in hip fractures, which occur at a rate of more than 250,000 per year and are projected to rise to more than 800,000 per year within the next 50 years (AARP, 1992).

Hip fractures are among the most important causes of death and ill health among elderly people. Hip fractures will contribute substantially to the 2 million person-years of functional impairment and \$45 billion in direct medical costs attributable to osteoporosis in the next ten years (Chrischilles, Shireman, and Wallace, 1994, as cited by Cooper and Barker, 1995). Effective interventions to reduce falls include increased physical activity and exercise which can retard the rate of age-related bone loss from osteoporosis (Smith, Smith and Gilligan, 1988, as cited by Kutner, Ory, Baker, Schechtman, Hornbrook, and Mulrow, 1992). One research team estimated that up to 83 percent of hip fractures caused by falls could be prevented if people wore safe shoes such as athletic shoes, oxfords and walking shoes with non-slip soles (Pruitt, 1995).

In addition, the use of exogenous estrogens (balanced with progesterones) have been shown to have beneficial effects on both osteoporosis and circulatory disease (Manton and Stallard, 1994). The drug *Fosamax*, which helps increase bone strength and reduce fractures in older women, is the first non-hormonal treatment for the nation's 20 million osteoporosis patients.

**Nutrition.** Nutritional status influences the progress of many diseases and can affect the extent to which functional independence is maintained. Malnutrition among the elderly is estimated to range between 25 and 40 percent. The elderly are susceptible to malnutrition because of complex interactions of drugs, diseases, alcoholism, and socioeconomic factors. The adverse effects of nutritional deficiencies on various immune responses are well-described and recognized. The correction of nutritional deficiencies results in improved immune responses (Chandra, 1992).

The American Heart Association recommends that adults take less than 30 percent of their calories from fat and consume less than 300 milligrams of cholesterol (AARP, 1995). Choosing foods wisely and maintaining a low saturated fat diet will significantly reduce the chance of heart attack. Aggressive lipid management for a period of two years would enable 75 percent of Americans to lower their cholesterol through diet and exercise alone to a level where the risk of a heart attack is reduced to almost zero, and the risk of a second heart attack is dramatically reduced (Brody, 1994).

**Biomedical Research.** Improvements in traditional medical technology are constantly increasing our ability to improve functional status and quality of life for older individuals (National Academy on Aging, 1994). Progress in cardiac surgery has allowed common disorders such as coronary artery disease and aortic stenosis to be surgically treated in people well into their 80's and 90's. Advances in cataract surgery, and in orthopedic surgery—particularly hip replacement and knee replacement—have become more important in reducing functional impairments than used to be common in elderly people.

Between now and the aging of the baby-boom generation, we can expect major advancements in treatments, prosthetics, rehabilitative techniques and genetic research to reduce functional disability brought on by losses in vision and hearing, osteoarthritis, osteoporosis, hypothyroidism, incontinence, dementia and other conditions that cause dependence and overall decline. These advances hold the potential to substantially reduce the need for long-term care services.

**Technology.** Technological advances will allow increasing numbers of frail and disabled older people to remain in the community by enhancing their independence. Technology can create environments, such as smart houses, that actively respond to, and compensate for, physical and cognitive functional deficits. Robotic devices can assist in mobility and control. Miniature sensors can monitor physiological functions (body temperature, gait, activity levels, etc.) and make appropriate environmental adjustments. More troubling conditions can be automatically analyzed and reported to medical and other service providers for evaluation and response. By increasing the availability of relevant information, while reducing the need for direct on-site observation and assessment, increasingly scarce and expensive human resources can be conserved and allocated more efficiently (National Academy on Aging, 1994).

**Policy Implications.** Health promotion and wellness programs should be made a more integral part of Florida's community-based services for the elderly. This can be done by creating health promotion for the elderly units in county health departments, systematically training case managers in basic health prevention strategies, making health promotion information part of the training in geriatric care received by medical and nursing students and developing public service media programs designed to inform the elderly of the benefits derived from regular exercise, good dietary practices and routine medical check-ups. These services and activities are now available in some but not all parts of the state. There will be increasing pressure to reduce or eliminate these programs as fiscal resources become less available. This pressure should be resisted. Health promotion programs that focus on information sharing are not expensive to operate and their long-range benefits are potentially very substantial.



## CHAPTER 6

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## Implications for Informal Care and Home- and Community-Based Services in Florida

What are the major implications of these findings from the research literature on informal care and formal home- and community-based care for the current array and level of support for long-term care services in Florida? Unquestionably, Florida has been a leader in the development of formal home- and community-based programs designed as alternatives to nursing home care. With each of these programs, Florida played a pioneering role in the development of resources to support informal care and to create an extensive array of in-home and residential care alternatives to institutional care. Appropriations for these programs grew steadily through the 1980s. Since 1990, however, funding for all home- and community-based programs has either stagnated or declined on a per capita basis, while nursing home expenditures have continued to grow (see Table 4).

There are three major reasons for these trends in Florida's long-term care appropriations. First, as described earlier, the initial evaluation reports on the National Channeling Demonstration did not indicate that home-based care is a cost-effective alternative to nursing home care. Second, Florida's community-residential program (ALF and adult foster home programs) was not designed to be an alternative to nursing home care for seriously impaired elderly. The first community-residential program explicitly intended to serve as a nursing home alternative was the Extended Congregate Care Program, which was established by the legislature in 1992 and funded under the 2176 HCBS Medicaid waiver in 1994, with 220 reimbursable slots (see Volume II of this series). Third, Florida, like most states, began to experience a series of fiscal crises in 1989 that have greatly restricted the growth of state general revenue funded programs throughout the 1990s. Nursing homes, on the other hand, are funded as a federal entitlement under the Medicaid program and have continued to grow, as shown in Table 4, since 1990. In fact, the capacity and funding gaps between the community-based programs and nursing homes are now greater than at any time since the mid-1980s.

There were, however, four significant exceptions to the trend toward stagnation of community-based care in the 1990s, which may have major implications for the future of long-term care in Florida. The 1989 Legislature created a program in proviso called Project Diversion, which was an intensive version of the Community Care for the Elderly (CCE) program for about 1,000 clients. The average annual expenditure per client was \$5,000, or four times the per capita rate for regular CCE clients. The case load per case/manager in Project Diversion was only 30 or

40 clients per case manager as compared to a 70 or 80:1 ratio in the regular CCE program. Diversion clients were required to be seriously impaired (3 + ADL deficits) and to meet Medicaid financial eligibility criteria. Project Diversion was evaluated in 1991 and the findings indicated that the program met the cost-effectiveness criteria it had been designed to achieve. The Project Diversion design was used to reshape the 2176 HCBS Medicaid waiver in 1993 by increasing the per capita expenditures under the waiver from \$1,500 to \$3,000 by targeting services to more impaired clients.

The second exception is the rapid growth of the state's Medicaid Aged and Disabled Adults Waiver over the last six years. Funding under the waiver has grown from \$12 million in 1991 to almost \$30 million in 1996. This increase has helped offset some of the losses in per capita funding for the programs included in Table 4. Services funded under the waiver also now include a small assisted living component.

The third exception to the trend toward stagnation in community-based long-term care was the creation by the 1991 Legislature of the Extended Congregate Care Program (ECC). This program is designed to fill the gap between the regular congregate care program (ALF) and nursing home care, by permitting seriously impaired residents to be served in congregate facilities that were specially licensed to meet their needs while maximizing their opportunities to remain as autonomous as their conditions allow and preserving their privacy, while providing the broad range of services required by residents who are seriously impaired but do not need 24-hour skilled nursing care. In effect, assisted living provides residents with the same kind and level of services available to seriously impaired clients who participate in intensive home-care programs, while preserving as much of a home life environment as possible. The recent research findings described above may provide assisted living with as much of a boost among policy makers as home care is likely to receive. If increased levels of care targeted to seriously impaired recipients in their own homes substantially reduce nursing home use, then similar levels of care provided to assisted living residents may also delay or prevent nursing home placement.

<b>TABLE 4: FLORIDA LONG TERM CARE PROGRAM FUNDING 1990-1995* IN CONSTANT 1982-83 DOLLARS</b>				
	<b>Year</b>	<b>Appropriations</b>	<b>Percent of Growth in Appropriations</b>	<b>Per Capita Age 75+</b>
<b>Community Care for the Elderly</b>	90/91	32,359,340	1.00	35.34
	91/92	29,869,610	-7.70	31.82
	92/93	28,155,625	-5.70	33.30
	93/94	25,076,356	-10.90	24.40
	94/95	25,985,982	3.60	23.00
	95/96	27,173,260	4.60	22.68
<b>Home Care for the Elderly</b>	90/91	9,042,363	-0.20	8.85
	91/92	8,584,791	-5.10	8.09
	92/93	7,914,030	-7.80	7.22
	93/94	7,707,023	-2.60	6.79
	94/95	7,486,050	-2.90	6.35
	95/96	7,433,660	-0.70	6.06
<b>Alzheimer-s Program</b>	90/91	3,444,619	13.60	15.99
	91/92	3,081,979	-10.50	13.51
	92/93	2,841,173	-7.80	11.84
	93/94	2,936,949	3.40	11.63
	94/95	3,771,295	28.40	14.14
	95/96	4,277,170	13.40	15.19
<b>Older American-s Act**</b>	90/91	38,761,867	-5.70	37.92
	91/92	37,551,419	-3.10	35.40
	92/93	38,613,014	2.80	35.25
	93/94	37,364,293	-3.20	32.94
	94/95	39,419,941	5.50	33.43
	95/96	38,276,966	-2.90	31.22
<b>Adult Assistance Payments***</b>	90/91	13,860,565	14.90	13.56
	91/92	15,101,190	9.00	14.24
	92/93	13,741,064	-9.00	12.54
	93/94	13,381,640	-2.60	11.80
	94/95	13,001,468	-2.80	11.03
	95/96	12,624,493	-2.90	10.30
<b>Medicaid Nursing Home Care</b>	90/91	613,957,032	8.10	600.69
	91/92	669,482,142	9.00	631.20
	92/93	716,941,067	7.10	654.47
	93/94	713,052,683	-0.50	628.67
	94/95	861,887,797	20.90	730.99
	95/96	915,779,200	6.30	747.05

\* This table was prepared for the Commission on Long-Term Care in Florida by Kathy Okay McCharon of the Joint Legislative Management Committee, Bureau of Economic and Demographic Research and published in Volume I, *Long-Term Care for the Frail Elderly in Florida: Expanding Choices, Containing Costs*

\*\*Per capita level in 1983 was 65.58

\*\*\*This program helps cover the cost of state clients in congregate-care facilities.

Finally, the state Medicaid program, through contracts with CAC-United Health Care and PacifiCare, both large HMOs, has sponsored two Medicaid pre-paid plans for the frail elderly and a Channeling Medicaid waiver program for several years in southeast Florida.<sup>3</sup> A recent survey of long-term care program populations included samples of members of both pre-paid plans and the Channeling program. As shown in Table 5, the average physical and cognitive impairment levels of members of the pre-paid plans and clients served in the Channeling program are very close to those in the nursing home sample. In fact, cognitive impairment rates are generally higher for the pre-paid plan and Channeling samples.

**Table 5: Percentage of Medicaid Recipients with Impairments by Program**

	<b>Nursing Facilities</b>	<b>Medicaid HMOs</b>	<b>Medicaid HCBS Waiver</b>	<b>HCE<sup>1</sup></b>	<b>CCE<sup>2</sup></b>	<b>Medicaid Channeling</b>
No or mild cognitive impairment, no ADLs	1.8	4.0	14.5	5.2	25.6	3.4
1-2 ADLs	7.2	12.7	30.7	8.3	26.9	20.3
3 ADLs, or moderate cognitive impairment	9.5	15.1	20.3	18.8	21.9	16.1
4-5 ADLs, no or mild cognitive impairment	30.4	13.5	9.3	9.4	7.9	10.2
Moderate cognitive impairment and 4-5 severe ADLs or severe cognitive impairment	51.1	54.8	25.2	58.3	17.8	50.0
Severe cognitive impairment	24.5	48.8	17.8	45.9	14.5	37.8
Dementia diagnosis	53.6	34.6	14.2	31.6	11.6	37.2
Chronic incontinence	50.2	42.5	24.0	22.4	18.7	39.7

<sup>1</sup>Home Care for the Elderly

<sup>2</sup>Community Care for the Elderly

In the absence of solid program outcomes, i.e., changes in functional levels, consumer satisfaction, hospitalization rate, etc., it is not possible to assess in any definitive fashion the relative cost-effectiveness of these home- and community-based programs and nursing home care. The fact, however, that these programs are serving very impaired clients and have been operating for several years at less than half the per capita cost of nursing home care suggests that properly

<sup>3</sup>The PacifiCare program ended in August, 1996.

funded and organized HCBS services have the potential to serve substantial numbers of frail elderly persons now receiving care in nursing homes.

It may be instructive to compare these findings with a recent study by Spector et al. which used data from the institutional population component of the National Medical Expenditure Survey (NMES), which is based on a 1987 national sample of all licensed nursing homes and personal care homes with three or more beds. The study was designed to generate estimates of the percentage of nursing home residents in the sample who could be served in a less restrictive program. In this case, personal care homes and assisted living facilities.

The authors use three sets of criteria to identify the nursing-home residents who are clinically appropriate for lower levels of care. The high criteria are so labeled because they identify the highest number of nursing-home residents as clinically appropriate for lower levels of care. Conversely, the low criteria are the most restrictive and identify the lowest number of nursing-home residents as appropriate for lower levels of care. The middle criteria identify an intermediate number.

In order to approximate the high criteria using the NMES data, the authors identified:

. . . residents who had substantial medical or rehabilitation needs (as indicated by the Medicare payment of basic charges), who were comatose, who were bed- or chair fast, who hurt themselves or others, who could not communicate or understand others, or who had bedsores were deemed clinically appropriate for nursing-home care and unsuitable for lower levels of care.

The middle criteria add a single element to those in the high category: the fecally incontinent . . . We chose this additional requirement because fecal incontinence suggests a level of pathological or cognitive problems that would generally result in care demands too intensive for a personal care home. In addition to the high and middle criteria, the low criteria further restrict residents who are urinary incontinent, require help with activities of daily living (ADLs) beyond bathing and dressing, are unable to avoid dangers, wander, or have hallucinations or delusions from being designated as appropriate for lower levels of care.

The number of percentages of nursing home residents in the NMES sample meeting each of the three sets of criteria are shown in Table 6 below.

<b>Table 6: Number of Nursing-Home Residents Deemed Appropriate for Lower Levels of Care under Alternative Clinical Criteria</b>			
<b>Nursing Home Residents</b>	<b>Clinical Criteria</b>		
	<b>High</b>	<b>Middle</b>	<b>Low</b>
Current total	970,360 (70.3) <sup>1,2</sup>	655,956 (47.5)	214,042 (15.5)
With an additional criterion:			
Does not wander/avoids dangers	810,969 (58.7)	534,615 (40.5)	N/A
Has no hallucinations/delusions	736,098	493,666	N/A

	(53.3)	(35.7)	
Is fecal continent	655,956 (47.5)	N/A	N/A
Is urinary continent	593,388 (43.0)	516,786 (37.4)	N/A
Has bathing or dressing disabilities only	346,651 (25.1)	321,869 (23.3)	N/A

Data are from "Appropriate placement of nursing-home residents in lower levels of care," in *The Milbank Quarterly*, 74(1), 1996.

<sup>1</sup> Percent of total residents in parentheses: total number of residents - 1,381,075.

<sup>2</sup> For Medicaid residents, the proportions are 70.0% for the high criteria, 45.9% for the middle criteria and 14.3% for the low criteria.

The authors point out that:

The results highlight the major impact of ADL criteria on these estimates. If persons were required not to have more than bathing or dressing limitations, along with the high or middle criteria, only about one-fourth of current residents would qualify for a lower level of care. This restriction is the major reason that the low criteria include so few nursing-home residents.

The table also shows the importance of incontinence criteria, especially if ADL restrictions are not included. For example, if urinary incontinence was added to the high criteria, the number of current residents who would qualify would be reduced by about 280,000 persons (a reduction from 70 to 43 percent of nursing-home residents).

The data in Table 5 show that as many as 40 to 50 percent of the frail elderly served by the Florida Medicaid pre-paid plans and Channeling program would meet the high criteria for placement in a home- and community-based alternative to nursing home care. That is, 40 to 50 percent of those served in these programs have three or more ADL impairments, are at least urinally incontinent and are severely cognitively impaired. These findings then would indicate that the intermediate criteria used by Spector et al. would be the most appropriate level for beginning to plan a comprehensive change of long-term care policy: a change based on the objective of creating extensive alternatives to nursing home care.

## Conclusions and Recommendations

What do these long-term care trends and developments over the last 20 years indicate about the extent to which Florida's array of long-term care services support informal care and provide community-based alternatives to institutional care? The stagnant funding trends of the last several years notwithstanding, the apparatus necessary to support major initiatives in both areas is substantially in place. The CCE, HCE and ADI programs provide extensive funding to informal caregiving and help contain admissions to nursing homes.

In order, however, for these programs to reach their full potential as informal care support systems and alternatives to nursing homes, funding levels will need to be increased substantially and steadily over the next several years and qualitative changes will need to be made in kinds of clients served and in the kinds and amounts of services provided. Given the structural constraints on current and future state resources, significant increases in the community-based program will probably have to come from the same pool of resources used to fund increases in the nursing home budget. This means that state policy makers will have to be convinced that community programs are cost-effective alternatives to nursing home care for significant numbers of impaired elderly who meet nursing home eligibility criteria.

The recent research literature and experiences with Project Diversion, the Miami Channeling program and the two Dade County Medicaid HMO programs indicate that community programs can be cost-effective alternatives to nursing homes if they are systematically targeted to the seriously impaired and less affluent frail elderly, if the services they provide represent a proper mix of medical (home health care) and social services (homemaker), and if the quantities are sufficient to allow them to remain at home. Quantities that are, in fact, substantially greater than are provided in Florida's community-based programs, including the 2176 HCBS Medicaid waiver. These programs are currently meeting the needs of moderately impaired elderly with limited caregiver support and should not be altered. New funding, however, either under the 2176 HCBS Medicaid waiver or some version of a Medicaid block grant program, should be targeted to the seriously impaired elderly who are at more immediate risk of institutionalization.

### **Recommendation One: Statutory Framework**

Develop and support legislative passage of statutory language that clearly articulates the state commitment to the development of a well-organized and comprehensive long-term

care system that features the growth of home- and community-based programs and the containment of nursing home expansion. The language should clearly express the values guiding the state's long-term care policy and the goals the policy is designed to achieve.

### **Recommendation Two: Home- and Community-Based**

#### **Alternatives for the Seriously Impaired**

The state should fund programs designed to deliver home- and community-based services to those who are at greatest risk of nursing home placement (i.e., those with three or more deficiencies in activities of daily living - ADLs). The development of these programs is necessary to contain costs and to generate the funds required to expand home- and community-based alternatives by reducing the need for use of nursing homes. There are also the kinds of programs that are best designed to provide support to informal caregivers who are the major providers of long-term care. In many cases, increased availability of formal support services in the community will help caregivers provide care more effectively and for longer periods of time. In-home and community-residential programs should be expanded at a rate sufficient to reduce projected nursing home admissions by 25 percent over the next 10 to 15 years.

The expansion of community-based long-term care services through the aging network will depend increasingly on Medicaid funds available through 2176 and 1115 waivers or whatever form access to Medicaid funds may take in the future if Congress makes dramatic changes in the Medicaid program. The 1115 waiver gives the state great latitude in the development of alternative policies for the funding and delivery of health care under Medicaid, as long as expenditures do not exceed a predetermined level. Several states plan to use a 1115 waiver to expand health care coverage and contain costs through managed care initiatives. A 1115 waiver proposal could be designed to initiate a qualitative shift to a managed care approach to long-term care and to expand the use of Medicaid funds for community-based services. As these mechanisms mature, initiatives should be taken to expand the 1115 waiver to incorporate Medicare. Pooling Medicare and Medicaid funding for dually eligible clients provides incentives to better coordinate care and potential to reduce waste and fraud.

### **Recommendation Three: Nursing Home CON Freeze**

In order to enhance funding opportunities for community-based programs, the state should freeze Certificate of Need (CON) approvals for new nursing home beds for at least three-to-five years. In the absence of a freeze, a Medicaid block grant with a cost-increase cap (if passed by Congress and not vetoed) and the state-revenue cap are likely to leave little, if any, funds for community long-term care programs.

### **Recommendation Four: Consumer Control**

The state should implement a cash and counseling (or voucher program) demonstration project to determine if this strategy can serve as a cost-effective alternative to nursing home care. The demonstration should include restrictive level of disability (3+ ADL deficits), and financial eligibility criteria and a level of care-based payment structure that might range from \$200 to \$1,000 a month, depending on impairment level and availability

of informal supports. The DOEA has received Robert Wood Johnson Foundation funding to implement a consumer-control demonstration project in Florida.

The cash and counseling approach, or some voucherized version of it, is a consistent extension of the rationale used to justify community-based long-term care generally. The CCE, HCE, ADI, and ECC residential programs are all designed to maximize client autonomy, choice, dignity and privacy in settings relatively free of institutional constraints. Cash and counseling takes this emphasis on consumer control to another level within the same policy trajectory; it could also provide a major boost to the informal care system.

#### **Recommendation Five: Services Used**

Place greater priority on the expansion and integration of medical care (home health nursing and greater use of home health aides) into home- and community-based programs. If long-term care becomes part of managed care systems for the frail elderly, the medical model may overwhelm the social model unless the existing elder programs and service providers take the lead in integrating medical care with the social services. Furthermore, as community services are increasingly targeted to the seriously impaired elderly (3 + ADL deficits), there will be a greater need for medical care and for its integration with the other long-term care services.

#### **Recommendation Six: Service Quantities**

The research literature and Florida's experience with the Channeling Program and Project Diversion indicate that far more than the \$1,500 annual CCE per client expenditure is required to maintain seriously impaired persons in their own homes or in an alternative residential care setting. The annual per client expenditure should range between \$8,000 and \$20,000 for community-based programs targeted to the seriously impaired elderly.

#### **Recommendation Seven: Extended Congregate Care (Assisted Living)**

Funding for the Extended Congregate Care (ECC) program should be expanded rapidly over the next five years. The expansion should be sufficient to absorb a substantial portion of those who would otherwise be placed in nursing homes in the absence of a moratorium on certificates of need (CON) for new nursing home beds. The increase in the number of ECC beds should be determined in relationship to whatever increase is made in the capacity of the in-home programs to serve seriously impaired, nursing home eligible persons. The utility of this recommendation may depend on allowing more direct admissions from other settings to extended congregate care facilities and changing other regulatory requirements that restrict access of the seriously impaired to this program. The high impairment profile (4+ ADL impairments - see Table 5) of the HMO assisted living residents in southeast Florida suggests that intensive assisted living programs like ECC have the potential to serve a substantial percentage of the frail elderly who are currently placed in nursing homes. The expansion of the ECC program, however, should be carefully monitored in order to guard against inappropriate placements and the emergence of overly medicalized care.

#### **Recommendation Eight: Regulatory Reform**

The emphasis inherent in the ECC program on the quality of life experienced by the resident (autonomy, dignity, shared risk), constitutes the basis for a shift in regulatory strategy from a virtually exclusive focus on process and structure factors to a greater concern for client outcomes, including indicators of client autonomy and changes in functional levels. The use of outcome measures is essential to the development of regulations compatible with the ECC philosophy which gives priority to quality-of-life criteria (i.e., autonomy, privacy, dignity). Structure and process criteria are important, but they guarantee neither adequate care nor an acceptable quality of life. A facility may be safe and clean and serve nutritional meals, but still fail to provide adequate opportunities for a high quality of life because of restrictions on resident choice and limited provisions for individualized assistance. To some extent, inflexible environments produced by an exclusive emphasis on structure and process variables may be a barrier to a high quality of life for residents who wish to take a more active role in deciding how to spend their time, what activities to pursue, and what risks to take.

#### **Recommendation Nine: Adult Foster Care**

The Department of Elder Affairs should conduct a study designed to determine the potential for the Adult Family Care Home program (AFCH) to serve as an alternative to nursing home care. The study should specifically identify changes in the program that would be necessary before seriously impaired residents could be placed in them. The study should also attempt to identify the kinds of residents (impairment levels, cognitive status, etc.) who would be appropriate for placement. The study should also include an assessment of the feasibility of developing a foster care program with service components comparable in design to the ECC program. The rapid growth of the middle-income and more affluent frail elderly may substantially stimulate marketing of these services to private-pay consumers. Seventy percent of Oregon's 9,000 foster home beds for the frail elderly are occupied by private-pay residents who can afford the cost of foster home care but who could not afford the \$3,000+ monthly cost of nursing home care.

#### **Recommendation Ten: Client Assessment, Care Planning and Referral**

Expand the use of the client assessment instrument to all publicly funded, long-term care related programs and to private-pay nursing home patients on a voluntary basis.

The cost-effectiveness of home- and community-based long-term care programs is substantially dependent on the capacity to target their use to those who are seriously impaired and clearly at risk of requiring nursing home care. This capacity is, at best, partially a function of client assessment, care planning and referral procedures specifically and rigorously designed to identify high-risk clients and ensure their timely referral to home and community-based programs designed to serve high-risk clients.

- DOEA is now developing a comprehensive strategy for the systematic assessment, referral and monitoring of high-risk (seriously impaired) clients.
- This initiative includes a re-evaluation of the current client assessment instrument in terms of its capacity to identify high-risk clients accurately and reliably.

**Recommendation Eleven: Prevention and Health Promotion**

The state should develop a comprehensive strategy designed to create health promotion for the elderly units in county health departments, systematically training case managers in basic health prevention strategies, make health promotion information part of the training in geriatric care received by medical and nursing students and develop public service media programs designed to inform the elderly of the benefits derived from regular exercise, good dietary practices and routine medical check-ups. The strategy should be developed by a prevention for the elderly task force appointed by the Secretaries of the Department of Elder Affairs and the Department of Health.

**Recommendation Twelve: Managed Care and the Future of Home- and Community-Based Services**

The success of the Arizona Long-Term Care System (ALTCS) Medicaid Managed Care Program and the high impairment levels of those served in the Florida Medicaid pre-paid plans indicate that managed care strategies have the potential to create a more balanced allocation of resources between community-based and institutional care. This potential will be tested again when the Department of Elder Affairs and the Agency for Health Care Administration implement a managed long-term care demonstration in 1997. This demonstration should include a rigorous evaluation component which focuses on costs and well-defined outcomes. This same evaluation design should be applied to an assessment of the frail elderly plan operated by CAC-United Health Care.

An extensive series of policy recommendations related to managed care will be presented in Volume IV of the long-term care policy series. This paper will deal with managed care, long-term care and the aging network and will be published in January 1997.



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## Abbreviations/Acronyms

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ADI	Alzheimer's Disease Initiative Program (Florida)
ADL	Activities of daily living
AFCH	Adult Family Care Home
AHEAD	Asset and Health Dynamics Among the Oldest Old
ALF	Assisted Living Facility
ALTCS	Arizona Long-Term Care System
CARES	Comprehensive Assessment, Referral and Evaluation System (Florida)
CCE	Community Care for the Elderly
CON	Certificate of Need
COP	Community Options Program
ECC	Extended Congregate Care
HCBS	Home- and Community-Based Services
HCE	Home Care for the Elderly
HCFA	Health Care Financing Administration
HMO	Health Maintenance Organization
IADL	Instrumental Activities of Daily Living
NLTCS	National Long-Term Care Survey
NMES	National Medical Expenditure Survey
SIPP	Survey of Program Participation



