



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# **LONG-TERM CARE SERVICE USE:**

## **LONGITUDINAL AND PREDICTIVE MODELS**

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# **LONG-TERM CARE SERVICE USE: Longitudinal and Predictive Models**

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# AGING IN PLACE: A LONGITUDINAL EXAMPLE

"Aging in place" is a relatively new phrase that is useful in describing the changes in functional status and residential circumstances of cohorts of older people over time, and the extent to which various types of residential environments permit elders to grow old in familiar surroundings. To date, however, even simple descriptive data of this sort for cohorts of older people are scarce. The absence of such data may be an underlying factor in the presumed failure of a number of community intervention programs designed to keep frail elders from moving to nursing homes.

For a number of years, the long-term care policy concerns of federal officials have centered around the design of programs to keep frail elders from entering nursing homes. The motivation was to slow the growth of the Medicaid program, about 40 percent of which is used to pay for nursing home care of the elderly.<sup>1</sup> The most ambitious of these experimental efforts was the National Long-Term Care Channeling Demonstration<sup>2</sup> in which access to community-based services was facilitated for elders who were impaired in activities of daily living (ADL). Financial and regulatory barriers were removed, a self-selected client population was served, and services were delivered through a case-management control system. The results were disappointing. Similar findings from earlier demonstrations<sup>3</sup> underline the need to increase our knowledge of the changes over time in the functional capabilities of cohorts of elders residing in the community.

High-risk<sup>4</sup> elders have proved to be difficult to identify. Although many elders have functional and health deficiencies, in the study discussed below, we found few who had serious unmet needs, and fewer still who entered nursing homes. The majority

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<sup>1</sup> Health United States, 1987; U.S. Department of Health and Human Services, DHHS Publication No. (PHS)88-1232, Table 113.

<sup>2</sup> U.S. Department of Health and Human Services. (March, 1987). National long-term care channeling demonstration.

<sup>3</sup> Brown, T.E. Jr., Blackman, D.K., Learner, R.M., Witherspoon, M.B., & Saber, L. (1985). South Carolina Community Long-Term Care Project: A Report of Findings Under HCFA Project Grant No.11-P-97493/4 to South Carolina State Health and Human Services Finance Commission.

Capitman, J., Haskins, B. & Bernstein, J. (1985). Case management approaches in coordinated community-oriented long-term care demonstrations. *The Gerontologist*, **26**, 398-404.

Weissert, W.G. (1985). Seven reasons why it is so difficult to make community-based long-term care cost-effective. *Health Services Research*, **20**, 423-433.

General Accounting Office. (1982). The elderly should benefit from expanded home health care but increasing these services will not insure cost reductions. GAO/IPE-83-1, Gaithersburg, MD: U.S. General Accounting Office.

Hicks, B., Raisz, H., Segal, J. & Doherty, N. (1982). The triage experiment in coordinated care for the family. *American Journal of Public Health*, **71**, 991-1002.

Skellie, F.A., Mobley, G.M., & Coan, R.E. (1982). Cost-effectiveness of community-based long-term care: Current findings of Georgia's alternative health services project. *American Journal of Public Health*, **72**, 353-358.

Holahan, J. & Stassen, M. (1981). Long-term care demonstration projects: A review of recent demonstrations. Urban Institute, Washington, DC., Working Paper 1227-2.

Hammond, J. (1979). Home health care cost effectiveness: An overview of the literature. *Public Health Reports*, **94**, 305-311.

<sup>4</sup> "High risk" is the term applied to those who are most likely to require nursing home care.

of elders who actively sought care in the community were successful in their quest. When institutional placements occurred, they often were transitory. Large numbers of impaired elders continued to live in the community for long periods of time.<sup>5</sup>

This chapter discusses a study that suggests a way to develop important information about key aspects of the experiences of a cohort of elders as it ages in the community. The study examined a sample of elderly people living in the community in the state of Massachusetts.<sup>6</sup> They all were aging in place in a variety of residential settings and they drew upon whatever supportive services were available to them. The aging in place perspective was not restricted by public policy concerns with cost reductions, or by a need to justify the role of the public sector in caring for elders in the community, or by a need to study only a limited subset of highly-impaired elders.<sup>7</sup>

The data show that placements in a nursing home are rare and that informal care is available to most elders living in the community. We looked at the extent to which informal and formal care systems respond to the needs of the elderly and measured the consistency in service levels over a four year period for a representative cohort of elders.

In the study we relied on descriptive information for a representative sample of 2898 elders living in communities in the state of Massachusetts. The members of the cohort were 62 years of age and older when first interviewed in 1982, and were 66 years of age or older at the end of the four year followup period in 1986. Baseline characteristics and service use estimates regarding the first of the four followup years apply to all elders in the cohort; year two and subsequent estimates are limited to cohort members who were alive during or at the designated followup period. Our analyses thus center on the experience of a cohort of elders, tracking the cohort at distinct points in time, with period-specific estimates derived for all cohort members who were alive in those periods.

Although the findings are limited to elders from one state, they may be indicative of what is occurring in some other industrial states, particularly those that have programs that foster in-home care for frail elders.

Findings are disaggregated by type of residential setting: private homes, apartments in facilities for the elderly, and private apartments. Private homes are defined to include free-standing homes, condominiums, or mobile homes, irrespective of

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<sup>5</sup> Weissert, W.G. (1985). *op.cit.*

Morris, J.N., Sherwood, S., & Gutkin, C.E. (in press). Inst-Risk II -- An approach to forecasting relative risk of future institutional placement. *Health Services Research*.

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<sup>6</sup> Supported by grant #87ASPE183A from DHHS, Assistant Secretary for Planning and Evaluation (ASPE).

<sup>7</sup> Christinason, J.B. (1988). The effect of channeling on informal caregiving. *Health Services Research*, 23, 99-117. [<http://aspe.hhs.gov/daltcp/reports/hsres.htm>]

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the elder's ownership of the dwelling or whether the elder is considered the head of the household; private apartments are defined to include privately owned two-unit to multi-unit dwellings (as well as residential hotels) where the elder, or someone on behalf of the elder, pays rent as a condition of residency.

The issues discussed in this chapter include: the distribution of types of elders in the different residential settings; entry into a nursing home; return to the community following entry into a nursing home; change in community residence; support services received; unmet need status; and functional status. The presentation is primarily descriptive, although explanatory hypotheses are suggested.

We believe that findings of this type can be useful in laying a foundation<sup>8</sup> upon which new long-term care service paradigms can be based.

## LIVING ENVIRONMENTS

Over three-quarters (78%) of the representative sample of Massachusetts elders residing in the community lived in private homes at the time of the initial (baseline) survey. The next most prevalent housing setting was private apartments (16.2%), followed by residency in housing for the elderly (5.8%).

Socio-demographic descriptors of the sample are reported in Table 3-1. The oldest cohort is found in housing for the elderly, a quarter of whom are over 80 years old. The age profiles for the two remaining housing groups are fairly comparable. Slightly less than half were 62-69 years of age, and 20% or less were age 80 or above. Over 70% of elders in elderly housing and private apartment settings were female, but only 55.3% of those living in private homes were female. Eighty five percent of the residents in elderly housing were not married at baseline, but only 63.4% living in private apartments and 42.2% of those living in private homes were unmarried. Similarly, two-thirds of those living in elderly housing reported that they lived alone. Following the marital status pattern, the distributions of those living alone in the private apartment and private home settings were 43.8% and 23.2%, respectively.

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<sup>8</sup> Weissert, W.G. (1985), *op.cit.*

Morris, J.N., Gutkin, C.E., Ruchlin, H.S. & Sherwood, S. (in preparation). Long-term care community services: Risk groups and level of care.

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Newman, S.J. (1986). Demographic influences on the future housing demand of the elderly. In R.J. Newcomer, M.P. Lawton, T.O. Byerts (Eds.), New York: Van Nostrand Reinhold Co.

Brody, E. (1982). Service options in congregate housing. In R.D. Chellis, J.F. Seagle, and B.M. Seagle, (Eds.). *Congregate Housing for Older People*, Lexington, Mass: Lexington Books.

<b>TABLE 3-1. Socio-Demographic Characteristics</b>				
	<b>Total Cohort</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>AGE</b>				
62-69	46.0%	47.7%	26.7%	44.9%
70-74	19.4	19.9	22.9	16.0
75-79	17.4	16.4	25.3	19.3
80-84	10.2	9.8	11.7	10.9
85+	7.0	6.2	13.4	8.9
<b>SEX</b>				
Male	41.0	44.7	26.2	28.6
Female	59.0	55.3	73.8	71.4
<b>MARRIED</b>				
Yes	51.9	57.8	15.0	36.6
No	48.1	42.2	85.0	63.4
<b>LIVES ALONE</b>	29.1	23.2	66.1	43.8
<b>HOUSEHOLD INCOME</b>				
Less than \$5,000	13.6	10.4	23.8	25.5
\$5,000-\$9,999	54.4	53.3	64.8	55.8
\$10,000-\$19,999	21.2	24.1	6.2	12.7
\$20,000+	10.8	12.2	5.2	6.0
(Total Sample N=2,898)				

In addition to being older, more predominately female, less likely to be currently married, and less likely to live with someone, residents of elderly housing were poorer than their counterparts in the other two housing settings. Almost a quarter (23.8%) reported an annual household Income below \$5,000, and only 11.4% reported an income level above \$10,000. Elders living in private apartments ranked second lowest in income. While 25.5% of this group also reported an annual household income below \$5,000, 18.7% reported income in excess of \$10,000.

Those residing in private homes were the most affluent -- only 1 in 10 reported income below \$5,000, while 36.3% reported income above \$10,000.

## **PLACEMENT OVER TIME**

Two important findings emerge from the data presented in Table 3-2 which reports the residential status of the sample of elders 24 and 48 months after they were initially interviewed. First, the vast majority of elders were still alive and living in the community -- 92.9% at the two year followup, and 83.2% at the four-year followup. If we

look only at those who were alive at these periods, 98.6% were in the community at the end of 24 months, and 97.5% at the end of 48 months.

The second major finding relates to admissions to nursing homes. Only 3.4% of the original cohort were in a nursing home during the initial 24 month period; 8% during the 48 month period. Of those alive at the end of each of these periods, only 1.4% were in a nursing home at the end of 24 months, and 2.5% at the end of 48 months. Thus, for many elders, nursing home placements are either transitory or occur at the end of one's life.

<b>TABLE 3-2. Living Setting at Designated Followup Points</b>				
	<b>Total Cohort</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>STATUS AT 24 MONTHS</b>				
<b>Overview</b>				
In community	92.9%	93.4%	87.0%	92.2%
In nursing home	1.3	1.1	1.9	2.1
Dead	5.8	5.5	11.1	5.7
<b>Ever in nursing home</b>				
Total	3.4	3.0	7.0	4.6
(Now in)	(1.3)	(1.1)	(1.9)	(2.1)
(Was, now in community)	(0.9)	(0.9)	(2.6)	(0.6)
(Was, now dead)	(1.2)	(1.0)	(2.5)	(1.9)
<b>Residency for those alive at 24 months</b>				
In community	98.6	98.8	97.9	97.8
In nursing home	1.4	1.2	2.1	2.2
<b>STATUS AT 48 MONTHS</b>				
<b>Overview</b>				
In community	83.2%	84.4%	79.0%	79.6%
In nursing home	2.1	1.8	2.0	4.0
Dead	14.6	13.9	19.0	16.4
<b>Ever in nursing home</b>				
Total	8.0	7.3	10.6	11.3
(Now in)	(2.1)	(1.8)	(2.0)	(4.0)
(Was, now in community)	(2.5)	(2.4)	(2.7)	(3.2)
(Was, now dead)	(3.4)	(3.1)	(5.9)	(4.1)
<b>Residency for those alive at 48 months</b>				
In community	97.5	97.9	97.5	95.2
In nursing home	2.5	2.1	2.5	4.8
(At 24 months, 96 cases were lost to follow up due to refusal or inability to locate; at 48 months, 195 cases were lost for these reasons.)				



Among institutionalized elders who were alive at the end of 24 and 48 months, the number who returned to the community was similar to the number who remained in nursing homes: at 24 months, 1.3% of the original cohort were in a nursing home and 0.9% had been in a nursing home at some point during the 24-month period but had returned to the community by the end of the period. Two years later, at 48 months, the pattern is even stronger: 2.1% were in a nursing home at the end of month 48, while 2.5% had returned from a nursing home to the community.

Of those who died, the risk of institutional placement was considerably higher than the overall averages might suggest -- 1 in 5 over the initial two year period, and 1 in 4 over the four year period. By the end of month 24, of those who had entered a nursing home, 35% had died, 38% were still in a nursing home, and 27% had resumed community residency. In 48 months, 43% of those who had entered a nursing home had died, 26% were still in a nursing home, and 31% had returned to the community.

The use of nursing homes differs only slightly among residents living in different settings. At the end of month 24, while one percent of elders from private homes were in nursing homes, two percent of elders from the two apartment settings were in nursing homes. By the end of month 48, residents of both private homes and housing for the elderly shared a lower likelihood of nursing home placement (2.1% - 2.5%) than residents in private apartments (4.8%).

The likelihood of ever having resided in a nursing home during the four year period is highest for elders in the two apartment settings (about 11%) and lowest for those in private housing (7.3%).

Of the elders who entered a nursing home during the 48 months, and who were alive at the end of that period, those in private homes and housing for the elderly (at baseline) had a 57% chance of returning to the community. For the elders who had moved to a nursing home from a private apartment, the rate of discharge from a nursing home back to the community was somewhat lower -- 44% by the end of month 48.

Of those who died during this period, institutional placement rates were lowest for residents in the private home subgroup (22%), compared to those in private apartments (25%), and those in housing for the elderly (31%).

Cohort death rates were 5.8% in the initial 24-month period, and 9.3% in the second 24-month period for those alive in month 25. This increase is attributable both to an aging cohort and the fact that in the second period (between 24 and 48 months) a substantial number of the original sample of elders had been institutionalized. When identified (at baseline) in 1982, all sample members lived in the community. At the beginning of the second two year period, 1.4% of elders resided in nursing homes. Over four years, we can see the importance of this change in the makeup of the cohort: 42.5% of those who were ever in a nursing home had died, while only 12.2% of those who had never been in a nursing home had died.

Through 24 months, the death rate was highest for those living in elderly housing -- 11.1%. This was almost double the rate for elders in the other two settings. By the fourth followup year, the cumulative death rate was still highest for those who had resided in elderly housing at baseline (19.0%). This difference, however, was due entirely to the differential death rate in the initial 24-month period. During the period from month 25 through month 48, the elderly housing subgroup who were alive at month 25 had an 8.9% death rate, a rate identical to that of elders in private housing (8.9%) and less than that of elders in private apartments (12.0%).

Shifts in residential setting since baseline are summarized in Table 3-3, representing the baseline and followup sites of residence. Of those living in private homes at baseline, 91.5% were still living in private homes at 24 months, and 89.5% at the the 48 month followup. Only 1.2% were in a nursing home at 24 months and 2.1% at 48 months. About 6% of this cohort were in private apartments at each of the followup intervals and 1% and 2%, respectively, were in elderly housing.

<b>TABLE 3-3. Shifts in Residential Setting</b>			
<b>Residential Setting At Designated Followup Period</b>	<b>Residential Setting at Baseline</b>		
	<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>24 MONTHS (N=2615)</b>			
Private home	<b>91.5%</b>	1.4%	10.0%
Elderly housing	1.2	<b>79.7</b>	4.5
Private apartment	6.1	16.7	<b>83.3</b>
Nursing home	1.2	2.2	2.2
<b>48 MONTHS (N=2216)</b>			
Private home	<b>89.5</b>	3.1	18.3
Elderly housing	2.1	<b>63.7</b>	6.5
Private apartment	6.3	30.7	<b>70.4</b>
Nursing home	2.1	2.5	4.8

Comparable but somewhat lower levels of residential stability characterized elders in private apartments and elderly housing. Among those living in private apartments, movement was largely into private homes -- 10% through month 24 and 18.3% through month 48. Movement to a private home was most often accompanied by residency with others -- at month 48, 53% lived with a spouse, 21% lived with a child, 9% lived with some other relative, and only 17% lived alone. A much lower rate of movement to private homes is noted for those in elderly housing at baseline -- 1.4% through month 24, and 3.1% through month 48. If a tenant in elderly housing moved, the community alternative was almost always a private apartment, and the majority lived alone following the move -- at month 48, of those who entered a private apartment, 56% lived alone, 16% resided with a spouse, and 28% resided with a child.

Of those in elderly housing and private apartments, 2.2% were in nursing homes at the end of month 24. By the end of month 48, 2.5% of elderly housing tenants and 4.8% of those in private apartments were in nursing homes.

## CHANGES IN FUNCTIONAL STATUS

The functional status estimates presented in this chapter are based on an expanded version of the HRCA Vulnerability Index.<sup>9</sup> The HRCA Index differentiates elders into two groups: the functionally independent and the functionally impaired. Impairment is defined as requiring support in at least two areas -- e.g., meal preparation, housework, taking out the rubbish, dressing, and climbing stairs. As used in this chapter, those who are impaired are further disaggregated into those with activity of daily living (ADL) and instrumental activity of daily living (IADL) dependencies. ADL-dependent elders are those who require support with personal care activities, particularly dressing, and with medication management. IADL dependent elders do not have ADL deficiencies, but do have problems in independently preparing meals, removing rubbish, or completing light housework activities. Based on this expanded version of the HRCA Vulnerability Index, at baseline 77.8% of elders were functionally independent, 17.2% had IADL deficits, and 5% had ADL deficits (Table 3-4). Those living in private homes were most likely to be functionally independent, while those living in housing for the elderly were most likely to have IADL and ADL deficits.

<b>TABLE 3-4. Functional Status Distributions At Three Points in Time</b>				
	<b>Total Cohort</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>FUNCTIONAL STATUS AT BASELINE</b>				
Independent	<b>77.8%</b>	80.5%	59.4%	71.5%
IADL Problem	17.2	14.8	32.7	23.3
ADL Problem	5.0	4.7	7.9	5.2
<b>FUNCTIONAL STATUS 24 MONTHS LATER</b>				
Independent	<b>78.7</b>	80.0	71.7	74.8
IADL Problem	13.3	12.4	19.8	15.4
ADL Problem	8.0	7.6	8.5	9.8
<b>FUNCTIONAL STATUS 48 MONTHS LATER</b>				
Independent	<b>77.7</b>	79.0	67.5	75.3
IADL Problem	12.1	11.7	18.5	11.7
ADL Problem	10.2	9.3	14.0	13.0
(Total Cohort N=2898; at 24 months N=2615; at 48 months N=2216)				

<sup>9</sup> Morris, J.N., Sherwood, S. & Mor, V. (1984). An Assessment tool for use in identifying functionally vulnerable persons in the community. *The Gerontologist*, 24, 373-379.

Although some individuals changed in functional status, by and large, there was little change in the proportion of elders remaining in the cohort who were functionally independent and non-independent during the 48 month study period. At each of the three data collection points, 78% of the cohort members were found to be functionally independent.

At baseline, elders in private homes were most independent, while those in elderly housing were the most dependent. At the same time, only elderly housing tenants, in line with their higher death rate in the initial 24 month period (see Table 3-2), experienced an appreciable shift in the distribution of impaired elders over time -- resulting in a net increase in the proportion who were independent for the residual cohort at 24 months compared with the total cohort at baseline.

Aging in place over the four year period was not accompanied by a rapid loss of functional independence for surviving sample members. At the same time, concentrating only on the estimate for those with the most severe functional problems, there is a tendency in all housing settings for the proportion with ADL deficits to increase over time.

**TABLE 3-5. Relationship of Functional Status To Selected Demographic Characteristics**

Of Those with Designated Background Characteristic, The Percent with one or More IADL/ADL Deficits	Percent Who Have IADL/ADL Deficit			
	Total Cohort	Residential Setting at Baseline		
		Private Home	Elderly Housing	Private Apt
Less than 75	16.0%	13.9%	37.1%	21.0%
75-79 years of age	24.0	19.9	43.0	33.2
80+ years of age	44.1	42.9	45.6	48.1
Married	14.5	12.8	28.9	25.0
Not married	30.5	28.6	43.1	30.6
Male	16.4	13.1	23.2	37.8
Female	26.3	24.8	46.5	24.5
Live Alone	25.4	22.7	37.4	25.2
Live with Others	20.8	18.5	48.5	31.6
(Total Cohort N=2898)				

Selected socio-demographic characteristics of those with IADL/ADL deficits at baseline are reported in Table 3-5. Among those under 75, 16% had one or more deficits. This figure rises to 24% among the 75-79 age group, and to 44.1% among those 80 and over. In the first two age groups (under 75 and 75-79), a higher proportion of those living in elderly housing had one or more deficits than those living in private

homes (37.1% vs 13.9%). The same pattern holds true for those age 75-79. For both of those age categories, those living in private apartments occupy a midpoint position -- a greater proportion have IADL/ADL deficits than their counterparts living in private homes, but their rate is less than that of those living in elderly housing. However, at the 80 and above age level, the percent with IADL/ADL deficits is fairly comparable in all three housing settings.

Fourteen percent of those who were married, and 30.5% of those not married, had one or more functional deficits. Sixteen percent of males and 26.3% of females had such deficits. For both of these socio-demographic characteristics, deficit rates were generally highest for those in elderly housing and lowest for those living in private homes. Comparable patterns are noted when the elder lived alone or lived with others.

Changes in functional status over time are shown in Table 3-6. Close to 85% of elders alive at each followup period who were functionally independent at baseline remained functionally independent at followup. A large proportion of the survivors, close to half in five of the six cells in the table, display an improvement in functional status over the followup periods, while 5.5% or fewer became less functionally independent over time.

<b>TABLE 3-6. Change in Functional Status</b>				
	<b>Total Cohort</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>Proportion of Independent at Baseline Who Remain Independent</b>				
At 24 months	82.8%	87.7%	84.9%	89.0%
At 48 months	85.9	86.0	90.6	84.0
<b>Proportion Who Become More Independent (excluding the independent at baseline from denominator)</b>				
At 24 months	45.9	46.5	50.7	41.4
At 48 months	45.4	45.2	33.9	53.2
<b>Proportion Who Become More Dependent (excluding the ADL dependent at baseline from denominator)</b>				
At 24 months	13.1	13.3	13.9	12.1
At 48 months	15.4	15.2	11.9	17.4
<b>Proportion of IADL Dependent at Baseline Who Became More Dependent</b>				
At 24 months	17.6	18.9	10.7	16.5
At 48 months	23.5	24.6	16.2	24.2
<b>Proportion of ADL Dependent at Baseline Who Became Less Dependent</b>				
At 24 months	25.8	27.3	34.0	16.5
At 48 months	42.1	43.8	35.8	35.2
(At 24 months N=2615)				

Among those who were IADL dependent at baseline, less than 19% were more dependent at 24 months and less than 25% were more dependent at 48 months. Large proportions of those who were ADL dependent became less dependent, as can be seen from the last two rows of data in Table 3-6 -- 26% through 2 years and 42% through 4 years.

## **ACCESS TO SUPPORT RESOURCES**

Data on the annual amounts of supportive services received by the sample of elders was estimated for homemaking, chores, meals, personal care, medication management, shopping, and transportation. Table 3-7 shows home-based care is a pervasive feature in the lives of elders as they age in the community. Between 72% and 79% of elders in the three residential settings received informal care, levels that are considerably higher than the 22% of elders shown to have IADL and/or ADL deficits in Table 3-4. Informal supports are almost always present if elders have reduced functional capacities -- 91.2% and 95.8%, respectively, of those with IADL and ADL deficits. Even for those without functional deficits, however, informal care is the norm -- with almost three-quarters of these elders receiving some type of assistance by family and/or friends. (Reciprocal helping behaviors between functionally independent spouses was not included in the definition.)

On average, recipients of informal care were assisted with two or more activities - 2.6 for those who were functionally independent, 3.6 for those with IADL impairments, and 4.9 for those with ADL impairments. In the 12-month period following assessment of those elders who received informal care, the majority were assisted with shopping (ranging from 73% for the independent to 93% for the ADL impaired) and transportation (ranging from 55% to 76%). Among these recipients of informal care, assistance with meals and housework was received by one-quarter of functionally independent elders, a little less than half of IADL impaired elders, and about three quarters of ADL impaired elders. Informal assistance with personal care was generally limited to those who exhibited ADL impairments and was received by 4% of independent elders receiving informal care, 11% of the IADL impaired, and 64% of the ADL impaired.

Significantly fewer elders made use of formal support services in the community - about 40% overall, ranging from 35% of those who are functionally independent to 54% of those with IADL and/or ADL deficits. To some extent, the use of formal services by those who were functionally independent represents a private market or life style choice by elders and their families. At the same time, it also reflects the fact that some of those who were independent at baseline experience transitory or permanent changes in need status during the intervening time period (see Table 3-6). For example, of those who were independent at both baseline and at the two year followup, about 33% made use of formal services; of those who became IADL dependent, about 44% used formal services; and of those who moved from independent to ADL dependent, about 53% used formal services.

<b>TABLE 3-7. Distribution of Elders Receiving Care from Others (Averaged Over Four Study Years)</b>				
<b>Total Cohort or Functional Subgroup</b>	<b>Total Cohort</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>Average Annual Percent Who Received Informal Care Over a Four Year Time Period</b>				
Total Cohort	77.6	77.8	71.9	79.2
Independent	73.5	74.3	61.0	74.1
IADL Dependent	91.2	91.8	85.8	90.0
ADL Dependent	95.8	96.8	92.1	92.5
<b>Average Annual Percent Who Received Formal Care in the Community Over a Four Year Time Period</b>				
Total Cohort	40.0	37.4	66.4	43.9
Independent	35.0	31.7	59.3	41.9
IADL Dependent	54.0	54.3	78.4	43.7
ADL Dependent	52.5	47.4	75.7	68.9
<b>Average Annual Number of Areas in Which Recipients of Informal Care Were Assisted</b>				
Total Cohort	2.9	2.9	2.6	2.9
Independent	2.6	2.6	2.2	2.6
IADL Dependent	3.6	3.7	3.1	3.4
ADL Dependent	4.9	5.2	3.4	4.8
<b>Average Annual Number of Areas in Which Recipients of Formal Care in the Community Were Assisted</b>				
Total Cohort	1.8	1.7	2.4	2.1
Independent	1.6	1.5	1.8	1.7
IADL Dependent	2.3	2.1	2.7	2.9
ADL Dependent	2.9	2.6	3.3	3.3

On average, recipients of formal care in the community were assisted with 1.8 activities -- ranging from 1.6 activities for those who were functionally independent to 2.3 and 2.9 respectively for those with IADL and ADL impairments. In the 12-month period following assessment, there was no service area in which a majority of elders receiving help obtained that help from a formal source. The two most prevalent areas of support were meals and transportation in which 38% and 33% respectively of the recipients of formal care were assisted. Little difference in receipt patterns across the functional subgroups was noted. In addition to these two services, 17% of functionally independent recipients of formal care received help with housework and personal care, while less than 10% received help with shopping and medication management. For IADL and ADL impaired recipients of formal care, approximately 40% received formal help with housework and transportation, while 25% of the IADL impaired and 47% of the ADL impaired received help with personal care. Finally, formal assistance with medication management was largely localized to those who were ADL impaired: it averaged 3% of the independent, 12% of the IADL-impaired, and 35% of the ADL-impaired.

Differences exist in the usage estimates in the three housing settings. While 74% of independent elders in private homes and private apartments received informal care, only 61% of independent elders in housing for the elderly received such care. Elderly housing tenants who are functionally independent appear to be less likely to be able to rely on friends and relatives for support in the every day activities of life. This housing-associated difference in access to informal care was not observed for elders with ADL impairments; for those elders, the difference was not in the receipt of care, but rather in a reduction in the number of areas in which informal care was provided.

Inter-residential patterns of access to formal community services are more complex. Tenants residing in housing for the elderly were most likely to access formal support systems. For those who were functionally independent, 59% received formal care, while for those who were functionally impaired, slightly over 75% received formal care.

For elders in private homes and apartments, use of formal care was less than that observed in elderly housing except for those in private apartments who had ADL deficits. In the latter case, the rates were about the same. In addition, for ADL dependent elders in both apartment settings (elderly and private), although not displayed in Table 3-7, the percent using home-based formal care decreased over time going from 87.4% to 66.4% over the four-year interval for tenants in elderly housing, and from 74.8% to 63.0% for tenants in private apartments. Although we have not explored the reasons for these shifts, we note that this decreasing utilization pattern begins to bring these elders into closer proximity with the considerably lower usage experience of ADL-dependent elders residing in private homes. In addition, as indicated in Table 3-2, a higher proportion of tenants in the two apartment subgroups spent time in a nursing home (thereby reducing their need for home-based formal care).

Of those living in private homes, formal usage levels mirror the values for the total sample. In contrast to those in apartments, ADL-dependent elders living in private homes were considerably less likely to make use of formal support services in the home. Elders in private homes were shown to be much more likely to reside with a spouse (see Table 3-1), and this undoubtedly played a large part in this unique helping pattern. Such people may simply be less likely to require supports beyond those provided by family. When elderly individuals in private homes have a need for ADL support, there appears to be a greater likelihood that it can be provided informally. In addition, for the subgroups of elders in private homes who were functionally independent or had IADL deficits, the percent using home-based formal care increased over time -- rising from 19.1% in the first year to 32.4% in the fourth year for those who were functionally independent; and from 46.2% to 62.1% for those who had IADL deficits.

In assessing the use of formal services in Massachusetts it is important to consider the extent to which the State's widespread case-managed home care system is involved in the care provision process. Under the Massachusetts program, state



funds are used to provide homemaking, chore, transportation, and other home based services to approximately 4% of elders in the state. This pattern represents a relatively unique commitment by a state to the provision of community-based long-term care services. Our data suggest that significant numbers of impaired elders, particularly those in apartment settings (both in private apartments and in elderly housing), are reached by this program. Approximately 70% of ADL-dependent elders and 50% of IADL-dependent elders who received formal services were Home Care Corporation clients. For functionally-impaired elders residing in private homes, approximately 44% of ADL-dependent and 23% of IADL-dependent formal service users were Home Care clients. At the other extreme, for functionally independent (some of whom will have deteriorated over time) users of formal services, home care participation was at a much lower level -- 5% for those in private homes, 7% for those in private apartments, and 14% for those in elderly housing.

## **SERVICES USED**

Table 3-8 contains estimates of the annual hours of informal and formal care, based on average utilization values, provided to sample residents during four one-year periods. Systematic trends representing either increasing or decreasing levels of care are noted in the table. The initial, and in many ways most important finding, was the absence of significant shifts over this four-year period in informal and formal utilization levels for the total group of elders in the cohort. On average, community elders who were alive in any study year received 101 hours of informal care and 26 hours of formal care representing four hours of informal care for every hour of formal care. These findings suggest a system in equilibrium. They are consistent with our earlier finding of longitudinal stability in the estimated proportion of functionally independent elders (see Table 3-4), and fit within a model of oscillating capabilities -- some elders die and some deteriorate, but others improve, and the net effect of these changes for a given cohort is longitudinal stability in estimated risk levels and utilization profiles.

At the same time, there were inter-residential differences in informal utilization levels. Informal care was least intensive for tenants in housing for the elderly -- averaging 55 hours per year or about one-half the average for elders in private homes and private apartments. These inter-residential differences were consistent over time, and there was no indication that informal support levels were changing for the cohort as a whole, nor that elders in one setting were more or less likely to experience shifts in the intensity of informal care available to them. As would be expected, informal supports increased with disability status, with tenants in elderly housing receiving the lowest level of care at each level of disability. Highest informal care levels were found for elders with ADL deficits who lived in private apartments and private homes: they averaged 280 hours of care per-year, or a little more than three-quarters of an hour per day. In addition, for elders who were independent at baseline, we observed an increase in informal support levels over time. This occurred because of these people became slightly more functionally dependent -- increasing from an average of 73.8 hours of care in the first year to 85.6 hours in the fourth year.

<b>TABLE 3-8. Average Annual Hours of Informal and Formal Care Received (Average of Four One-Year Periods)</b>				
	<b>Total Cohort</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>AVERAGE ANNUAL HOURS OF INFORMAL CARE</b>				
<b>Total Sample Average of Four One-Year Periods</b>	<b>100.9</b>	104.1	54.7	100.1
<b>Average For Elders in Different Functional Categories at Baseline</b>				
Independent	80.4*	84.0*	41.7*	72.5
IADL Dependent	149.4	164.9	71.5	137.2
ADL Dependent	264.4*	278.3*	136.9*	280.5*
<b>AVERAGE ANNUAL HOURS OF FORMAL CARE</b>				
<b>Total Sample Average of Four One-Year Periods</b>	<b>26.1</b>	22.2*	53.1*	35.9*
<b>Average For Elders in Different Functional Categories at Baseline</b>				
Independent	19.3*	18.2*	29.3*	22.7*
IADL Dependent	48.6	37.5	74.4	73.1*
ADL Dependent	67.3*	57.7*	136.7	66.5*
* There was a steady increase in the annual hours of care from year 1 to year 4.				

For functionally independent tenants in housing for the elderly, the annual averages rose from 34.8 hours in the first year to 47.6 hours in the fourth year, while for functionally independent elders in private apartment, there was no systematic pattern of increasing informal hours of care over time.

Finally, for elders who were functionally (ADL) impaired at baseline, a different pattern of longitudinal shifts in average cohort utilization values occurred. For the high-level users who resided in private homes and private apartments, utilization went down over time from 345.5 hours to 252.3 hours in the four-year period for those in private homes; and from 313.8 hours to 223.5 hours for those in private apartments. To some extent these changes reflect the death or institutional placement of the most disabled of these cases. In addition, some experienced improvement, that is, they became more functionally independent. For ADL dependent elders in housing for the elderly at baseline, the pattern over time is much different. The average hours of care in the first followup year for this cohort was only about 40% of the level observed for ADL dependent elders in the other two settings. More importantly, their average hours of care increased over time -- rising from 134.7 hours (on average) in year one to 151.8 hours in year four. By year 4, their average hours of informal care had increased to about 63% of the level observed for ADL dependent elders in the other two settings. It appears that informal supporters are less responsive if the elder resides in an elderly housing site, although there is some indication (at least for those who are functionally independent or have ADL deficits, although not for those with IADL deficits) that the level of these supports can increase over time.

Formal care levels were also found to differ by residential setting. Unlike the preceding findings, formal care is most intensive for tenants in housing for the elderly -- averaging 53 hours per year, or about equal to the level of informal care received by these tenants. This level of care is twice that received by elders in private homes and one and one-half times the level received by elders in a private apartment. As would be expected, formal support levels increase with disability status -- averaging 19 hours per year for those who are functionally independent, 49 hours for those with IADL deficits, and 67 hours for those with ADL deficits.

Three remaining findings are worthy of special note. First, universally lower levels of formal care were observed for elders in private homes who do not have ADL deficiencies. Second, the average level of formal care for ADL-dependent adults who continue to live decreased over time (dropping from an average of 77.2 hours in the first year to 56.4 hours in the fourth year). Third, ADL-dependent elders in housing for the elderly have average utilization levels that far exceed those of ADL dependent elders in other residential settings.

## UNMET NEEDS

The unmet need estimates summarize subjective judgments of whether additional supports required with homemaking, chores, meals, personal care, medication management, shopping, and transportation. To be scored as having an unmet need, a respondent must report the need for additional support in a service area in which he/she had some level of functional restriction (no matter how minor). As indicated in Table 3-9, unmet needs for elders in Massachusetts were not a pervasive factor in the lives of most elders -- only 5% of elders reported that they had unmet needs. Although not shown in the table, the needs reported are seldom viewed by the respondents to be of major significance. In addition, very few elders required additional support in more than two areas, and most who require such supports had a need in only one area.

<b>TABLE 3-9. Percent of Elders With Unmet Needs Averaged Over Three Rounds of Interviews</b>				
<b>Average Annual Percent Who Report the Presence of Unmet Needs</b>				
<b>Total Cohort or Functional Subgroup</b>	<b>Total Group</b>	<b>Residential Setting at Baseline</b>		
		<b>Private Home</b>	<b>Elderly Housing</b>	<b>Private Apt</b>
<b>Total Cohort</b>	5.0	3.8	9.2	6.0
Independent	2.7	2.3	6.5	3.5
IADL	13.7	14.5	12.4	11.7
ADL Dependent	17.1	17.6	14.1	17.2

Unmet need levels were higher for elders with IADL and ADL deficits -- 13.7% and 17.1% respectively. But even here, approximately five out of every six impaired

elders believed that they were receiving sufficient support services. Finally, while there is some fluctuation across residential settings, the basic shape of the distributions and relative levels of unmet need were not dramatically different.

## DISCUSSION

There is very little published information on the types of changes to be expected as elders age in the community. This study provides data that suggest the importance of conducting this kind of research throughout the country. The population of elders in the community is diverse, and it is diversity that must be studied. Elders age in different types of residential settings, and although the importance of adequate housing for maintaining elders in the community has been pointed out by some researchers,<sup>10</sup> it has not received as much attention as, for example, have the large number of community-based case-management programs evaluated under Federal sponsorship. For long-term care professionals, housing has been of secondary interest, often characterized as simply the opposite of institutional residency without further differentiation. By focusing on the concept of aging in place we can begin to remedy this oversight. We therefore examined longitudinal data for subgroup cohorts of elders in three distinct types of housing, and provided descriptive information on residential mobility, death, functional status, institutional placement, and service utilization.

The data have made it possible to highlight a series of key factors that must be recognized in planning long-term care services for the frail elderly in this country. We have found that residential mobility patterns differ for elders who live in the three types of settings studied. Institutional placements were shown to be relatively rare, and many who entered a nursing home subsequently returned to the community. Informal support was found to be available to most elders. Helping patterns begin prior to functional decline, escalate with increasing disability, and achieve different levels of intensity in the three types of housing studied. Formal care also was found to be a factor in the lives of large numbers of elders living in the community. Moreover, the use of some formal care does not require that the elder first become impaired. Its spread for those in apartments

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<sup>10</sup> Sherwood, S., & Morris, J.N. (1985). The Pennsylvania domiciliary care experiment: Impact on quality of life. *American Journal of Public Health*, 73, 1983, and In, L.H. Aiken & B.H. Kehrer (Eds.), *Evaluation Studies Review Annual*, Beverly Hills, CA: Sage Publications.

Sherwood, S., Morris, J.N., Sherwood, C.C., Morris, S., Bernstein, E., & Gornstein, E.S. (February 1985). Final report of the evaluation of congregate housing services program, in connection with HUD contract #HC-5373.

Sherwood, S., Greer, D.S., Morris J.N., Mor, V., & Associates. (1981). *An alternative in long-term care: The Highland Heights Story*. Cambridge, MA: Ballinger Press.

Sherwood, S., Gutken, C.E., Lewis, T.G. Sr. & Sherwood, C.C. (1988). Housing alternatives for an aging society. In Legislative Agenda for An Aging Society: 1988 and Beyond. Proceedings of a Congressional Forum by the Select Committee on Aging, House of Representatives and the Special Committee on Aging, United States Senate, November 1987. Washington: U.S. Government Printing Office, pp.195-144.

Byerts, T.O., Howell, S.C. & Pastalan, L.A. (Eds.). (1979). *Environmental Context of Aging*. New York: Garland STPM Press.

Newcomer, R.J., Lawton, M.P. & Byerts, T.O. (Eds.). (1986). *Housing An Aging Society, Issues, Alternatives & Policy*. New York: Van Nostrand Reinhold Company.

was shown to be related to the presence of a statewide program of case-managed home care services.

In presenting these data, we hope to highlight the need for new service paradigms. There is much to be gained by finding out what is happening in the community and providing descriptive information that can be used for more effective organization of services. We recognize that, despite the fact that the data cover four years, the lessons to be learned are limited to information from a single time period (1982 to 1986) and from a single state (Massachusetts). We believe it would be useful to both states and the federal government to replicate this type of study in many other places in the country. A single national survey will not provide the information needed for realistic planning on the local or statewide level. Local issues of particular importance relate to factors such as residential density, the distribution of minority and disadvantaged populations, the rate of in- and out-migration, the extent of state or local support for community-based service systems, and local variations in the access or use of third party insurance. Because long-term care is so related to systems of informal care as well as to local variations in community and institutional service availability, we recommend that replications be completed for populations in different states with the overall effort coordinated at the national level.