Long-term Care Reform:

A Status Report

February, 1999

Angus S. King, Jr.
Governor

Kevin W. Concannon
Commissioner

Long-term Care in Maine

Goal: Reduce reliance on institutional care and expand affordable choices.

- In 1998 Maine spent $264 million on long-term care services — a reduction of $20.7 million since 1995.
- 23,646 persons received State or Medicaid-funded assistance with their long-term care needs, an increase of 19% from 1995.
- Maine ranks 9th in the nation in per capita Medicaid long-term care spending.
- 1660 new residential care "beds" were added since 1994 — 317 are dedicated for persons with dementia.
- Three assisted living programs serve 90 low-moderate income elders. A fourth project is planned for the Bangor area.
- 12,500 individuals received assessments of their long-term care needs.
- 50 licensed adult day programs serve every county — up from 12 programs in 1994.
- 10 Adult Family Care Homes each serving 5 adults in a home-like setting.
- Nursing home gross receipts tax was repealed in 1997.
- Medicaid admissions to nursing homes rose 10% from 1993 to 1997, while discharges increased 29%.

Long Term Care Reform:

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I. Faces of Long-term Care in Maine

The Bureau of Elder and Adult Services is committed to developing programs that respond to the wishes of most older people and adults with disabilities to continue to live in their own homes. When that is not feasible there are adult family care homes, residential care facilities (formerly know as boarding homes) or nursing facilities, depending on how much care is needed. For the individuals pictured on these pages, State or Medicaid funded services have made it possible for them to stay in their home, or a homelike setting.

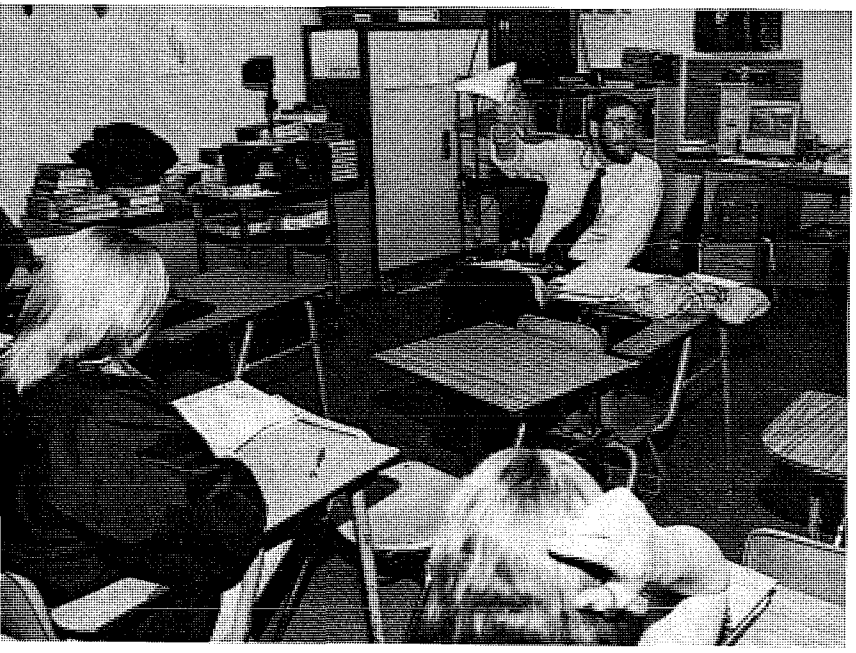
In spite of the effects of a stroke and blindness, Ms. G is able to remain in her own apartment with the aid of home care services.

Faces of Long-term Care in Maine (Cont'd)

This house in a residential neighborhood in a small town in Western Maine was renovated and brought up to state regulations with a sprinkler system and other safety features and became one of the first adult family care homes. It is owned by the sisters in the photos below who look after the five men and women who now live in this family setting. There are 10 adult family care homes, most in rural communities.

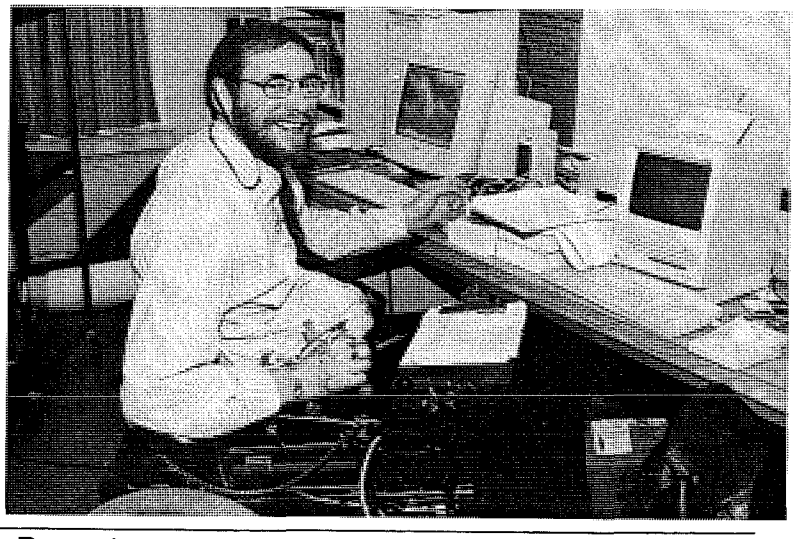
Faces of Long-term Care in Maine (Cont'd)

Without Homemaker and Personal Care Assistance services provided by the Consumer Directed-Personal Care Assistance Program, completing college and working full-time would have been impossible for Ms. L.



Mr. M teaching his college prep English III course in a high school in Southern Maine.

Mr. M was one of the first people to use the services of the Consumer Directed Home Based Care Program.



Ms. B's attendance at an adult day services program gives her older sister enough respite and time to attend to her own business, so that it is possible for her to continue as Ms. B's primary caregiver and for them to live together at home.

Six hours a week of personal care assistance make it possible for Ms. R, who is enrolled in the state Home Based Care Program, to live on her own in spite of painful arthritis and other chronic conditions.

Mr. and Ms. S consider that the services of a homemaker for four hours a week are crucial to their remaining in their own apartment where together they continue to enjoy painting and sketching. The assistance with general housekeeping, grocery shopping, laundry and errands is provided because one has limiting chronic conditions and the other Parkinsons disease.

II. Some History

Long-term care services assist persons with chronic health conditions, primarily older adults. Long-term care ranges from help with grocery shopping to intensive, high-tech nursing care. Families are the principal providers of long-term care in Maine and across the country. When family support is no longer enough, individuals often turn to Medicaid, the State-federally funded health insurance program.

♦ Yesterday – The 70's

For more than twenty years Maine relied almost exclusively on nursing homes as the way to deliver long-term care services. This model had several advantages. The federal Medicaid program reimburses the State approximately two-thirds of the cost of nursing home care. Nursing home construction and operation provided jobs and income in both urban and rural parts of the state. The quality of care in Maine nursing homes was good compared to elsewhere in the nation, and Maine established financial and medical eligibility standards that made it relatively easy to qualify for publicly funded care. So, even though most people wanted to avoid ending up in a nursing home, nursing homes became the accepted solution for those who could no longer be cared for by family.

As early as 1979, advocates for older and disabled adults came together to promote changes in public policy. Over the next 15 years there were a series of study commissions and task forces that came to the same conclusion: people preferred to remain in their homes and communities. Advocates claimed that if alternatives to nursing homes were available, people would use them and the result would be savings to the Medicaid program because home care is generally less expensive than nursing home care.

Although Maine was among the first states to offer a state-funded home care program, policy makers in the Executive and Legislative branches worried about a "woodwork effect." Would people who had been getting by with help from their families come forward to use publicly funded services? Would expenditures go even higher?

♦ The Budget Crunch – The 90's

In the early 1990's state revenues went into a sharp decline, at the same time that nursing home expenditures were rising rapidly. With only a slight increase in the number of persons served, nursing home costs had jumped by 50% over a three-year period. Governor McKernan proposed drastic changes in financial eligibility for Medicaid nursing home care that would have disqualified 6,000 nursing home residents and saved $60,000,000 in the General Fund.

Key members of the Legislature's Health and Human Services Committee, from both political parties, were sympathetic to the goal of reducing nursing home expenditures, but sought a different approach to saving the State money which could be used both for home care and for other high priority programs.

Some History (Cont'd)

♦ The Legislature Moves Toward Reform

Seeing an opportunity simultaneously to save money and to implement older and disabled people's long-standing desire for alternatives to nursing homes, the Legislature's Health and Human Services Committee fashioned a package of reforms. The goal was to reduce reliance on expensive institutional care and to offer consumers more home and community care choices. Advocates for the elderly and disabled actively supported the reforms.

In early 1994 the Department of Human Services tightened functional eligibility for Medicaid-funded nursing home care to focus on persons with greatest medical needs. Those found not eligible were to be diverted to alternative types of care. Other changes required nursing homes to increase Medicare reimbursement by certifying more beds for post-acute care. In addition, the reforms closed loopholes that allowed nursing facilities to add beds, and costs to Medicaid, without specific legislative approval. The legislation also affirmed the public policy of estate recovery and strengthened limits on transfer of assets.

Efforts to reduce nursing home admissions ran into problems early on because:

- ✓ There were not enough residential alternatives for those found ineligible for nursing home admission, but too impaired to be cared for at home. Most nursing facilities refused to convert existing space to residential care.
- ✓ There was more demand for home care than funds available, resulting in long waiting lists.
- ✓ Many individuals with Alzheimer's disease did not qualify under the new medical eligibility rules and there were few residential alternatives for them.
- ✓ Nursing homes continued to admit private pay residents without informing them of new Medicaid rules. When some of those people ran out of money, they found that Medicaid would not pay for their care.
- ✓ The Department did not do enough to educate the public about the changes.

But, there was measurable progress:

- ✓ Nursing homes responded well to a new, case mix-based payment system that rewarded them for taking residents with more impairments.
- ✓ Admissions funded by Medicare (all federal funds) increased significantly, which saved the State money.
- ✓ The number of nursing home admissions supported by Medicaid began to decline.
- ✓ As nursing home occupancy dropped, more owners agreed to convert beds to less expensive forms of residential care.
- ✓ Use of home care, adult day services, and caregiver respite programs increased.
- ✓ The legislature enacted a bill requiring pre-admission screening for all nursing facility applicants in order to give families information about medical eligibility standards and other community care options.

♦ The Governor's Initiative

In 1996, the Governor made long-term care one of his three legislative priorities. The initiative, which received strong bipartisan support from the Legislature, signaled the start of a major reprogramming of state and federal funds to support a more non-institutional service system.

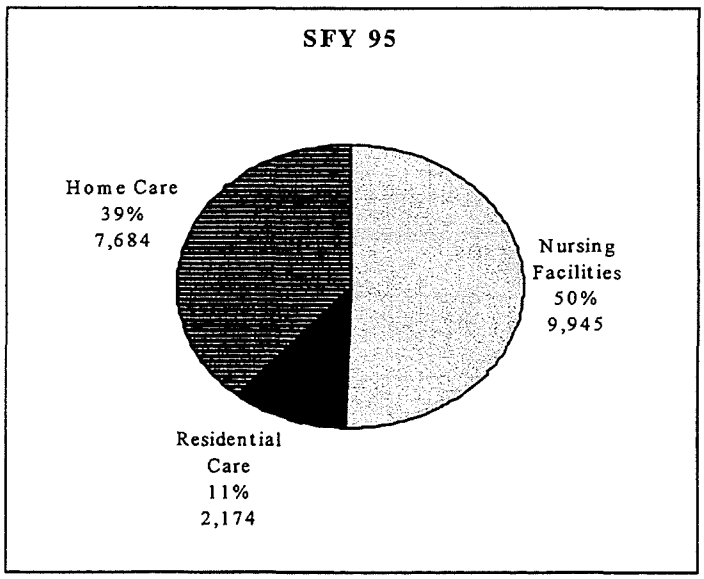
Maine has achieved unparalleled results. While most states aim, at best, to control the rate of increase in Medicaid nursing home expenditures, Maine saw a reduction in spending of 15% between 1995 and 1998. During a comparable period nursing home spending *increased* 9% nationally.

Expenditures for home and community care increased, both in total dollars and as a percentage of total long-term care spending. The increase was more than offset by savings in the nursing home account. Total Medicaid and State long-term care expenditures declined by $20,000,000 (7%) during the four-year period, 1995-1998. During the same period, the number of individuals receiving services grew from 19,000 to 23,000, a 19% increase.

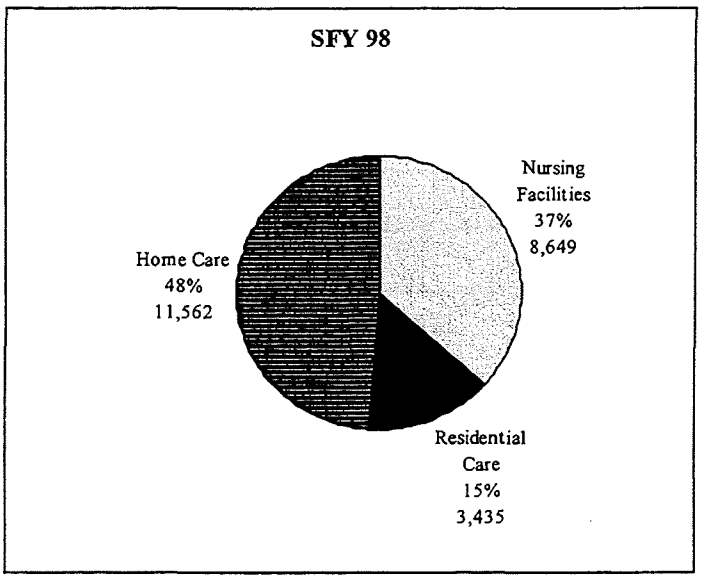
III. Long-term Care Benchmarks

The Department uses several benchmarks to measure progress in meeting the goal of reducing reliance on institutional care and expanding affordable choices for consumers and families. Those benchmarks include:

- Where consumers receive long-term care services
- Expenditures for long-term care, by setting
- Total number of persons served
- Development of home and community care programs
- Public awareness of long-term care services
- Perceptions of family caregivers

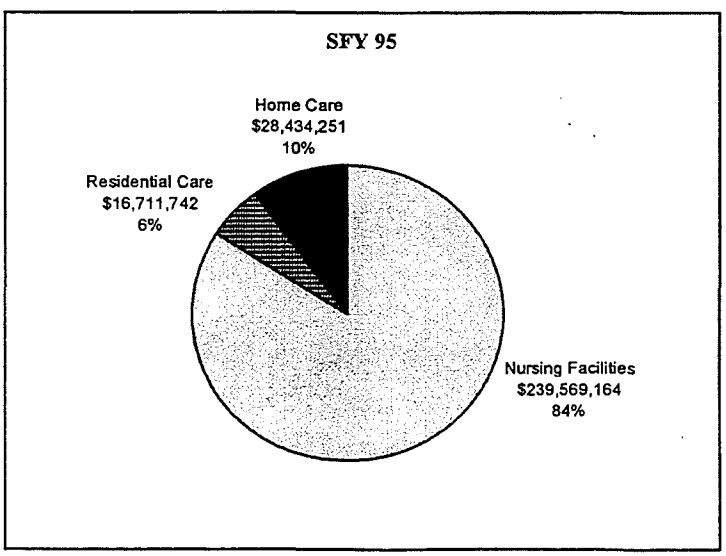


Total Consumers: 19,083

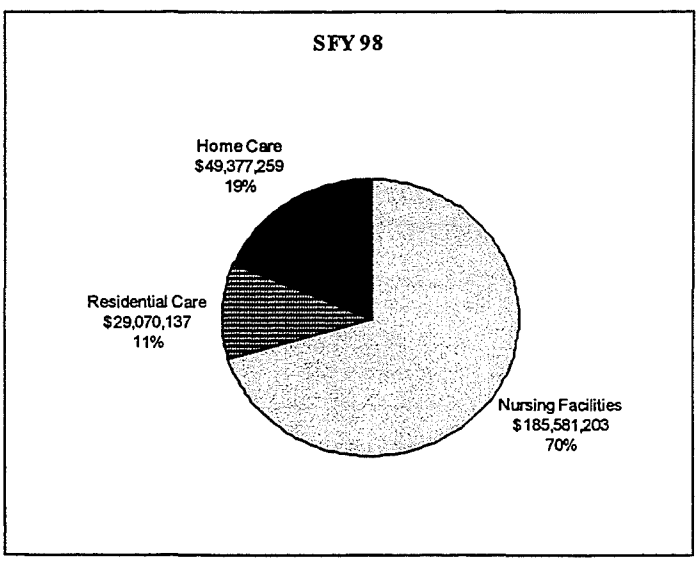


Total Consumers: 23,646

State and Medicaid Expenditures – SFY 95 and SFY 98

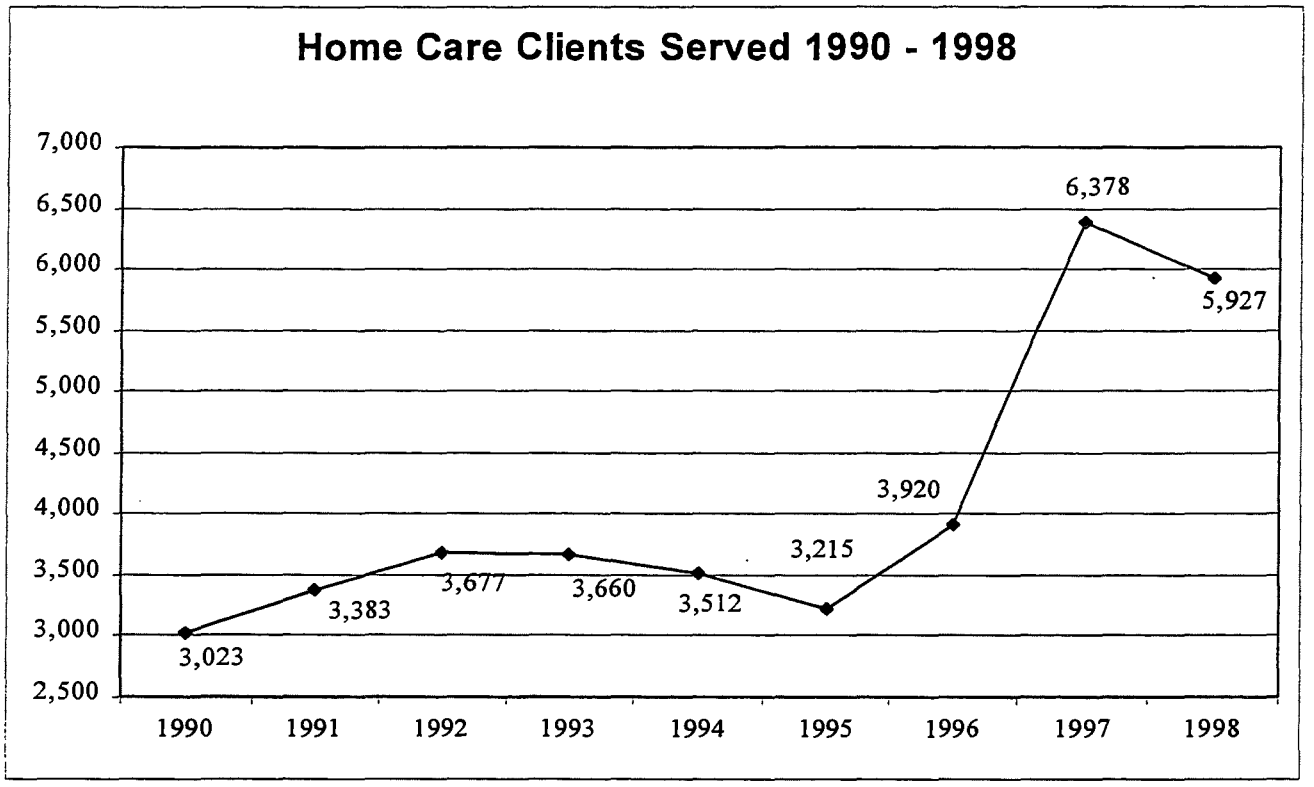


Total Expenditures: $284,715,157

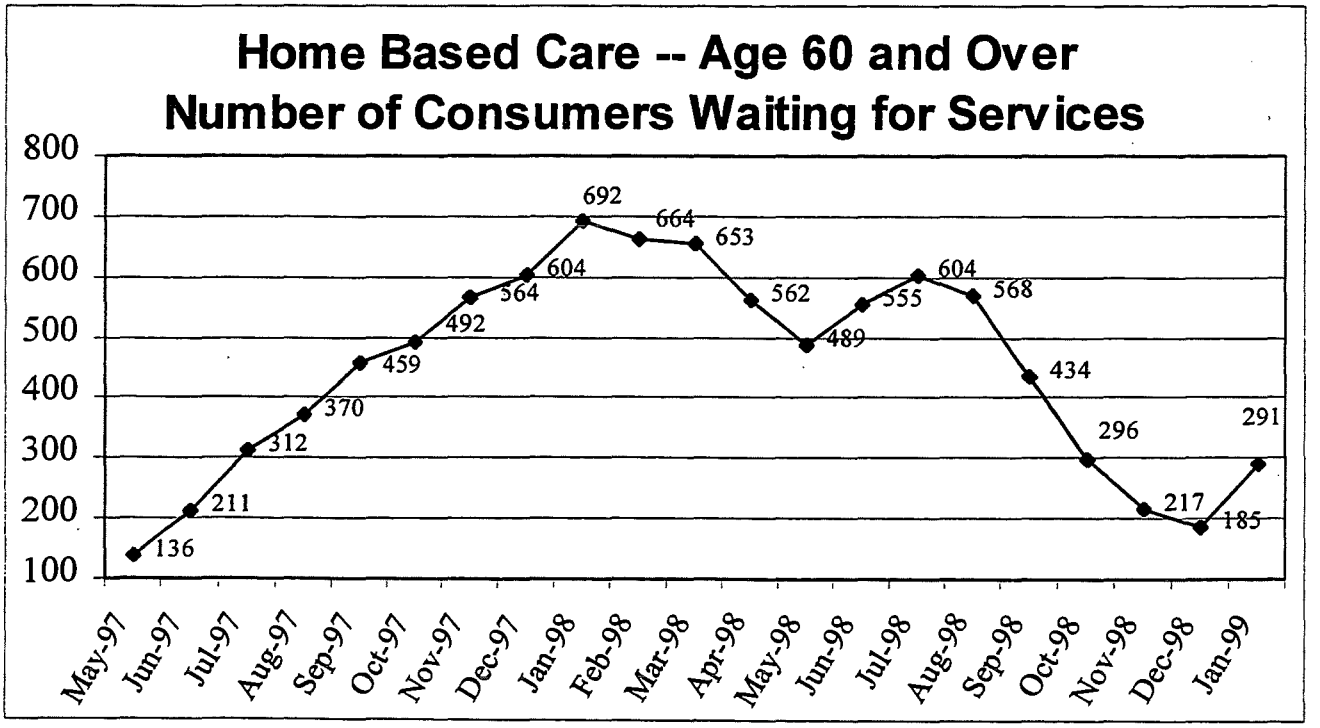


Total Expenditures: $264,028,599

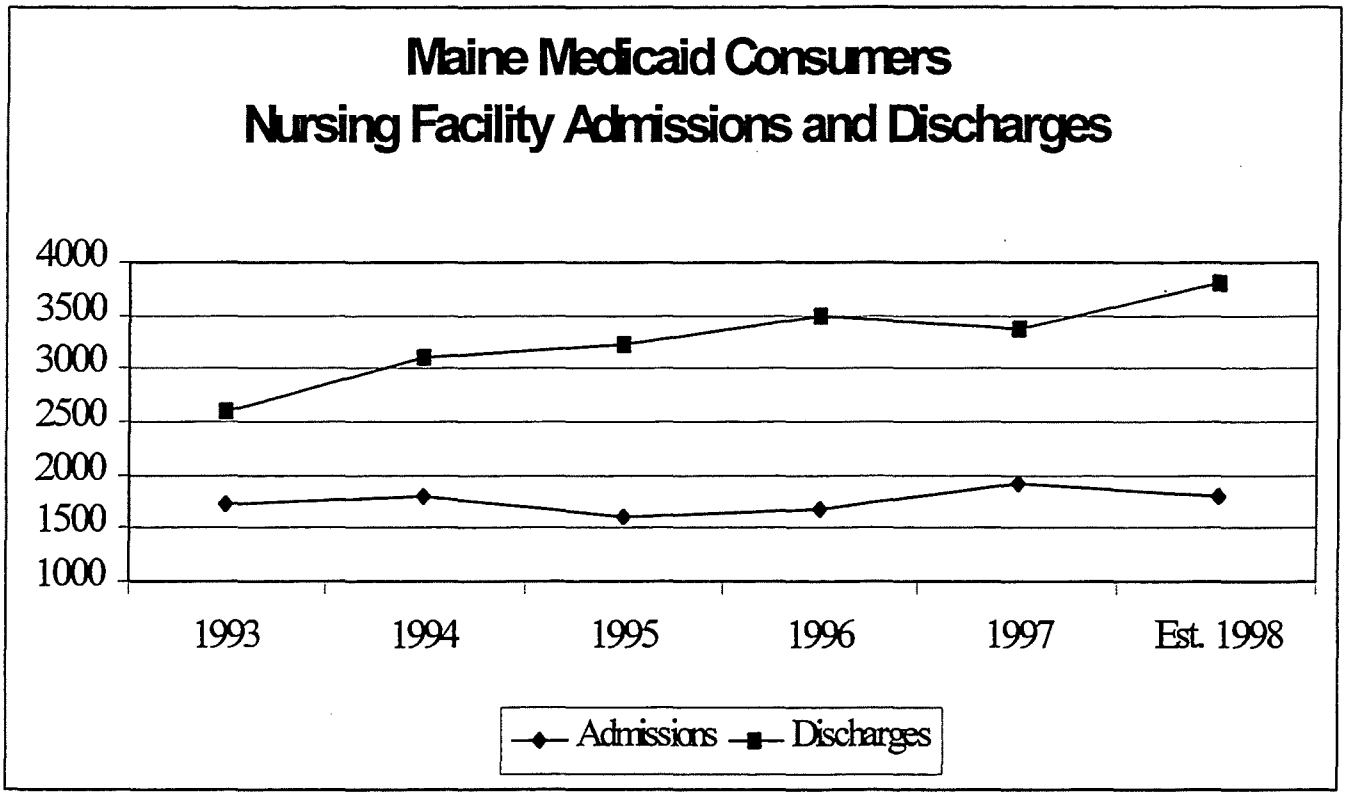
Long-term Care Benchmarks (Cont'd)

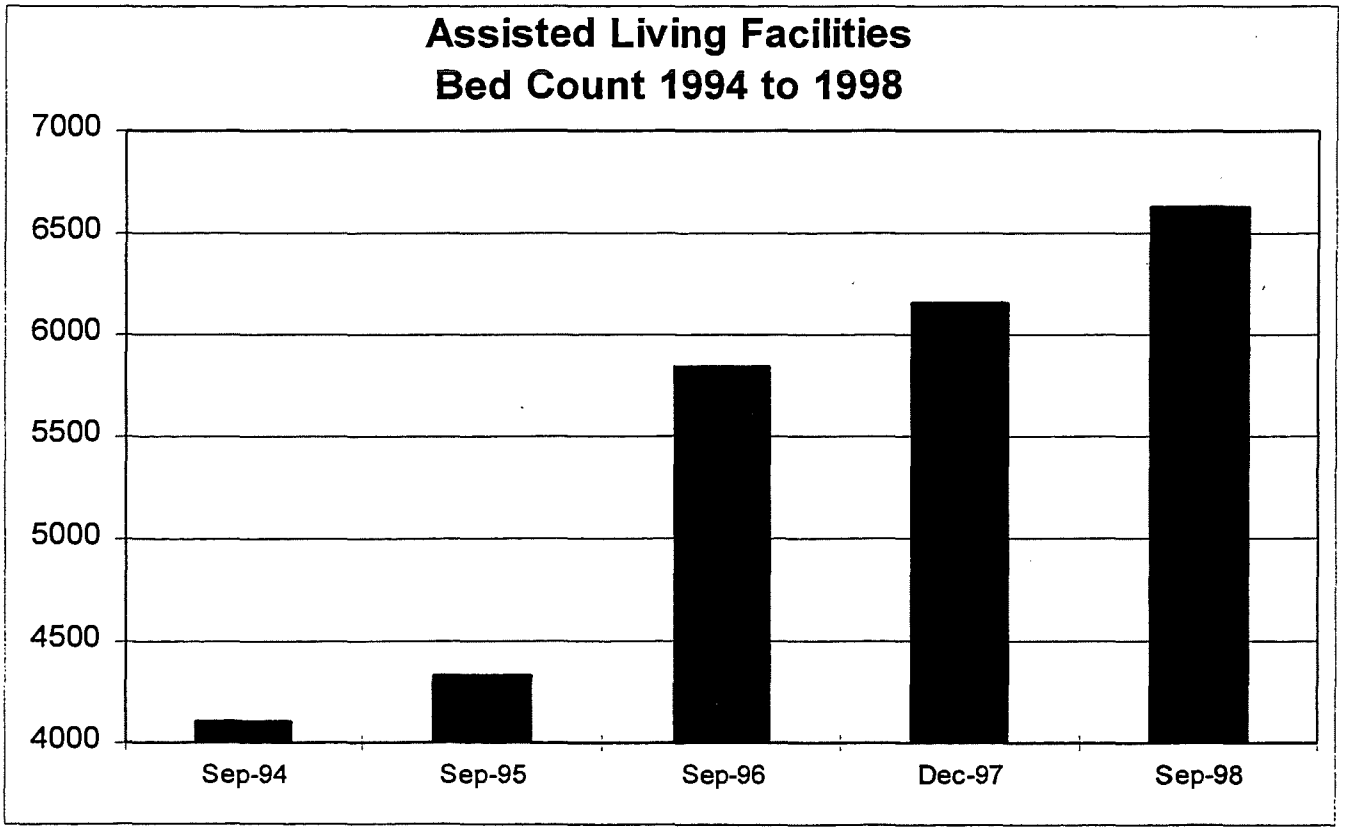


Home Care client counts include: Home Based Care; Medicaid Waivers; Medicaid Private Duty Nursing; Personal Care Services; Congregate Housing Program; and Homemaker.

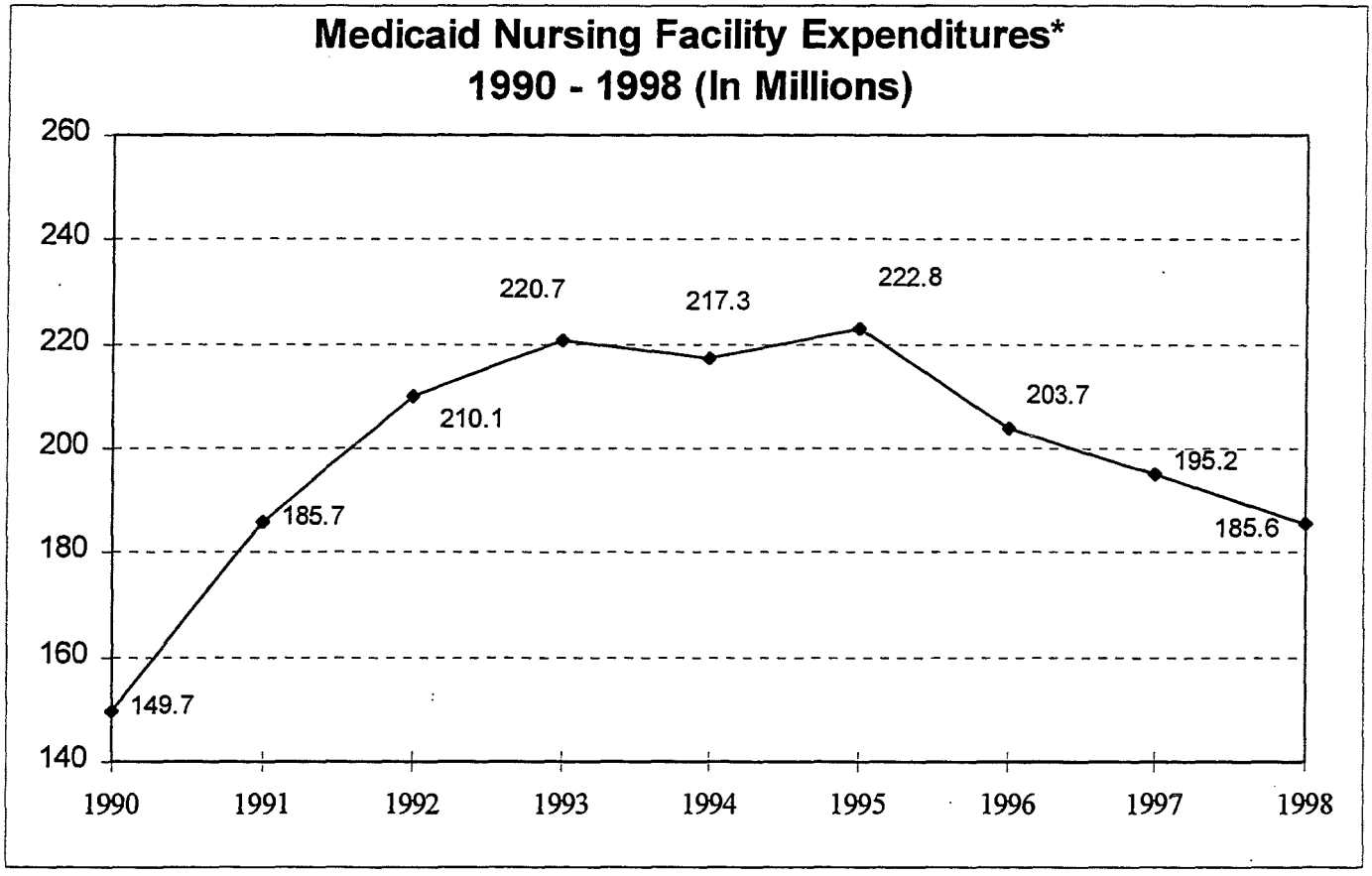


Long-term Care Benchmarks (Cont'd)





Long-term Care Benchmarks (Cont'd)

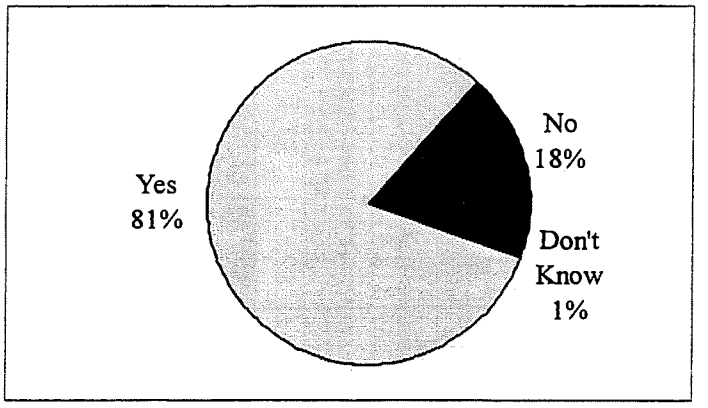


* Adjusted for Gross Receipts Tax.

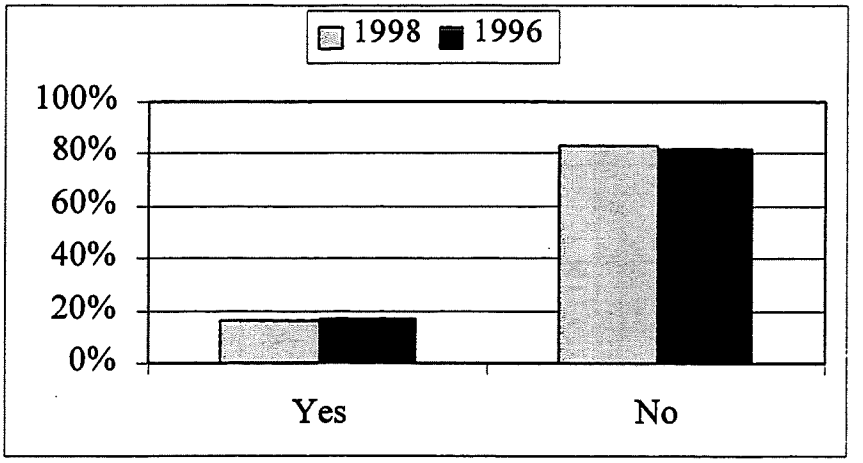
Denial of Long-term Care Eligibility: Appeals 1994-1998

	1994	1995	1996	1997	1998
Appeals Scheduled	52	250	261	247	216
Appeals Held	16	128	153	146	120
Appeals Dismissed	36	122	108	101	120
Appeals DHS Upheld	12	122	126	123	94
Appeals DHS Overturned	4	26	27	21	9
Appeals Remanded	0	0	0	2	0
Appeals Decision Pending	0	0	0	0	17

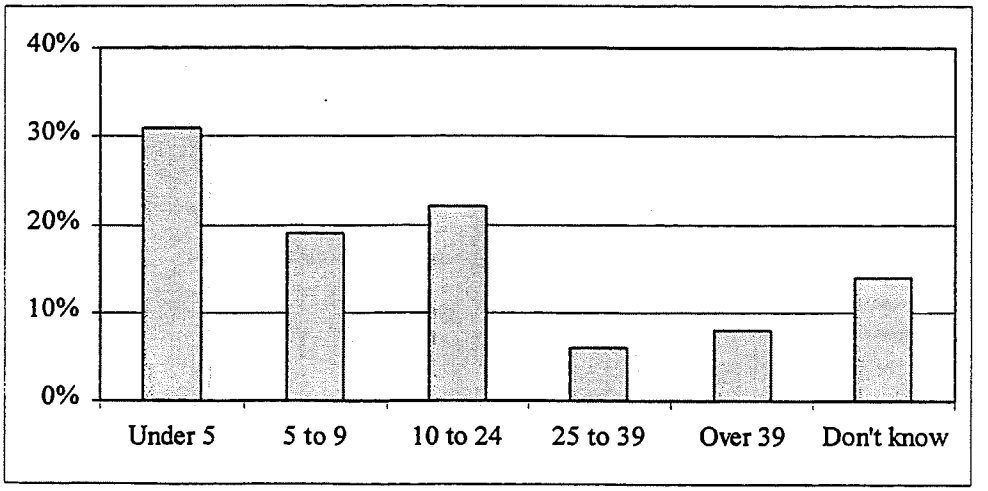
Awareness of Home Care as Alternative to Nursing Home Placement



Adults Caring for an Elderly Family Member



Hours of Caregiving Each Week



Source: Maine Development and Citizen Survey w/98.

State of Maine
State and Medicaid Long-term Care Expenditures

	SFY 95			SFY 96			SFY 97			SFY 98		
	Total Expenditure	Clients	Per Capita Cost	Total Expenditure	Clients	Per Capita Cost	Total Expenditure	Clients	Per Capita Cost	Total Expenditure	Clients	Per Capita Cost
Medicaid												
Nursing Facilities	$239,569,164	9,945	$24,089	$219,042,939	9,144	$23,955	$202,292,500	8,963	$22,570	$185,581,203	8,649	$21,457
Residential Care	$16,711,742	2,174	$7,687	$18,666,765	2,335	$7,994	$24,555,594	3,017	$8,139	$29,070,137	3,435	$8,463
Adult Day Services	$106,033	39	$2,719	$276,536	86	$3,216	$424,492	122	$3,479	$577,618	147	$3,929
Private Duty Nursing (adults only)	$939,323	61	$15,399	$789,115	35	$22,546	$1,036,028	49	$21,143	$575,833	82	$7,022
Personal Care Services (adults only)	$1,242,390	173	$7,181	$263,294	70	$3,761	$529,518	158	$3,351	$1,206,232	391	$3,085
Waiver: Consumer Directed	$1,993,971	183	$10,896	$3,440,662	218	$15,783	$5,062,143	269	$18,818	$5,552,487	283	$19,620
Waiver: Elder & Adults	$7,080,916	1,172	$6,042	$8,502,837	1,128	$7,538	$10,272,214	1,343	$7,649	$14,604,975	1,618	$9,027
Consumer-directed Personal Care	$900	7	$129	$1,175,513	140	$8,397	$2,123,423	216	$9,831	$3,068,619	288	$10,655
Home Health (adults only)	$9,849,559	4,430	$2,223	$9,550,807	4,552	$2,098	$10,084,810	4,665	$2,162	$11,072,562	4,826	$2,294
Subtotal - Medicaid	$277,493,998	18,184		$261,708,468	17,708		$256,380,722	18,802		$251,309,666	19,719	
General Fund												
Home Based Care: Elder & Adults	$4,671,076	1,296	$3,604	$4,750,920	1,386	$3,428	$6,747,308	2,899	$2,327	$7,083,230	1,772	$3,997
Home Based Care: Consumer Directed	$1,475,077	125	$11,801	$1,691,272	118	$14,333	$2,484,207	173	$14,360	$2,921,945	145	$20,151
Adult Day Care	$0	0	$0	$39,733	56	$710	$121,909	120	$1,016	$200,000	112	$1,786
Congregate Housing Program	$448,105	198	$2,263	$455,605	175	$2,603	$560,105	150	$3,734	$1,025,867	271	$3,785
Alzheimer's Respite	$0	0	$0	$150,000	125	$1,200	$400,000	332	$1,205	$400,000	550	$727
Homemaker	$626,901	NA	NA	$626,901	650	$964	$1,000,000	1,121	$892	$1,087,891	1,077	$1,010
Subtotal - General Fund	$7,221,159	1,619		$7,714,431	2,510		$11,313,529	4,795		$12,718,933	3,927	
Total Expenditure	**$284,715,157**			**$269,422,899**			**$267,694,251**			**$264,028,599**		

IV. Long-term Care Update – 1998

Maine's success in creating a long-term care system that offers consumers and their families more choices is a product of hard work by legislators, consumer advocates, families, providers, and DHS staff. No state has made such rapid progress in reducing reliance on institutional care and expanding community-based resources. At the same time, Maine has continued to look at ways to improve programs in order to assure that services continue to be responsive to consumer preferences.

Case Mix Reimbursement in Residential Care Facilities

Extends the reimbursement system in place for nursing facilities that pays based on the needs of the resident. The new system is scheduled for implementation on April 1, 1999. Specialty facilities, such as those serving persons with brain injury or AIDS, are exempt.

Certificate of Need Program Rules

Public Law 97 Chapter 689 (LD 2261) required the Department to revise Certificate of Need laws pertaining to nursing homes. These changes eliminated review of nursing home projects that were unrelated to the provision of nursing care, such as the addition of assisted living services. It also made changes to the purpose of Certificate of Need, recognizing increased competition in health care delivery, and made the review process more open to public participation. The role of the Advisory Committee was broadened. The revisions to the CON rules took effect on November 1, 1998.

"Flex" Beds in Nursing Facilities

Nursing homes would like to "flex" nursing home beds to a lower level of care in order to avoid discharging residents who lose their nursing home eligibility. Flex beds would allow nursing homes to maintain occupancy. The Department already permits this practice on a case by case basis through the "Awaiting Placement Residential Care" and "Extraordinary Circumstances," policies which reimburse facilities for residents who no longer meet eligibility. The Department also allows married couples to remain together in the nursing facility, although one of the spouses may no longer be eligible.

The Department has consistently opposed flexing beds as standard practice because residents whose condition has improved are best served in a setting more appropriate to their needs. However, the Department is considering a limited flex bed program for small nursing facilities, in rural areas where it is not feasible to create separate residential care units.

Long-term Care Steering Committee

The Legislature established several reporting requirements for the Committee, all of whose members are consumers or family members. The Committee met monthly during 1998. It studied two issues in depth: the feasibility of equalizing levels of spousal support across all long-term care programs; and reimbursement rates for personal care assistance services. The Committee submitted its findings and recommendations to DHS Commissioner Concannon; co-sponsored two well-attended

long-term care forums in Bangor and Lewiston; and surveyed more than 800 consumers and family members.

Membership of the Committee was expanded to include two new members representing consumers of independent living services under the Consumer-directed Home Based Care program.

Long-term Care Voucher Demonstration Poject

In 1997 the Legislature directed DHS to apply to the federal Health Care Financing Administration (HCFA) for permission to test the feasibility of vouchers for purchasing LTC services. The goal is to give consumers and families more control over LTC decisions by giving them more control of the money. DHS received one response, from a group representing consumers and providers in eastern Maine, to a request for proposals. HCFA responded by saying they do not have the statutory authority to waive federal prohibitions on the use of vouchers. DHS will consider a scaled-back effort to promote greater use of existing voucher options in Maine's state-funded programs.

Nursing Facility Transfer and Discharge Study

The Department contracted with the Muskie School to evaluate whether changes in nursing home medical eligibility determination standards have resulted in consumers being required to make frequent moves between various living arrangements in order to receive long-term care services.

Muskie staff looked at data from nursing home discharges during the period July, 1996 to June, 1997. Of 1,012 discharges, 204 or about 20%, were subsequently re-admitted. Of those readmitted, only 8 (4%) persons had been found ineligible for nursing home care at the time of their initial discharge. Individuals with Congestive Heart Failure or Chronic Obstructive Pulmonary Disease were more likely to be re-admitted. These residents might benefit from more careful discharge planning and follow-up once they return to the community.

Nursing Home Eligibility for Persons with Cognitive Impairment and Behavior Problems

In response to public concern that the 1994 Medical Eligibility Determination (MED) form did not adequately reflect the needs of persons with cognitive impairments, the Legislature directed the Department to revise the criteria. A "Supplemental Cognitive/Behavior Screen" was added to the MED form in June, 1996.

In 1997, 641 applicants with cognitive or behavioral problems were found eligible for nursing facility level of care based on the supplemental screen. This compares with estimates that approximately 400 individuals lost or were denied eligibility due to changes made in 1994. DHS contracted with the Muskie School at USM to evaluate the effectiveness of the new screen. Department and Muskie staff have met with interested parties to review the results of the evaluation of the cognitive screen and will do the same with the study results for the behavior screen. It appears that with

minor revisions, the current MED form could capture the same information as the "Supplemental Screen", thus eliminating the need to put consumers and families through a second set of questions. After obtaining input from consumer advocates and providers, the Department may submit legislation to amend Public Law 95 Chapter 684, the law establishing the supplemental screen.

Revise Medicaid Home Health Rules

The home health benefit serves Medicaid eligible children and adults. It is one of several home care programs under Medicaid. The Department is reviewing the home health rules in order to assure that this benefit, which is reimbursed at a higher rate than other Medicaid home care services, is targeted to consumers in need of skilled care. Proposed changes will add many of the definitions and standards now required in the Medicare home health program. More closely following Medicare guidelines may allow Maine to recover up to $1,000,000 more annually from Medicare.

Standardized Nursing Home Contract

Public Law 97 Chapter 329 (LD 991) required the Department to adopt a standardized contract for nursing facilities. A group that included provider representation, the Long-term Care Ombudsman and Legal Services for the Elderly advised the Department on the format and content of the standard contract. The Department will include the contract as part of proposed changes to the rules for licensing nursing facilities. The contract will apply to new admissions and facilities will have several months to prepare for full implementation.

Transfer of the Consumer-Directed Home Based Care Program from Department of Labor to the Department of Human Services

Public Law 97 Chapter 734 (L.D. 2060) transferred the administration of this home care program from the Office of Rehabilitation Services to the Bureau of Elder and Adult Services. Since the transfer July 1, the Bureau has continued the contract with Alpha One as the statewide administrator of the program, incorporated the existing program rules as part of the BEAS policy manual, and participated in discussions with Alpha One and the Long-term Care Steering Committee on the need to address the issue of wage increases for attendants working in this program. The Department's Part II budget request for Home Based Care includes funds for a modest increase in personal care attendant wages in the consumer directed program.

The Bureau is reviewing, in consultation with the LTC Steering Committee, consumer cost sharing in home care programs. The Alpha One administered program will be included in that review. BEAS will work with Alpha staff to make other revisions to the rules for the consumer-directed program, in order to make policy more consistent with other home care programs. One example is making the appeal procedures the same for all home care programs.

V. Maine's Medical Eligibility Determination System

What is MECARE?

MECARE is a computerized version of the Medical Eligibility Determination (MED) assessment form used to determine medical eligibility for a variety of State and Medicaid funded long-term care programs. Assessments are done for initial eligibility and to review for continued eligibility. The assessment includes an evaluation of demographic, clinical, caregiver and environmental information. The MED is used to assess eligibility for Nursing facility level of care, five Medicaid home care programs, the Home Based Care program, Congregate Housing Services program, Adult Day Services and Homemaker program.

The Department implemented MECARE in February, 1998. From March 1st through October more than 9,000 people received assessments under the new system. Maine is unique among states in developing a comprehensive database of persons needing long-term care services.

The process begins with a call to Goold Health Systems, the Department's contractor, to schedule an assessment. If the person is already known to Medicaid, any current demographic information, as well as current Medicaid enrollment status, income, and insurance information are automatically entered into the record, saving time and repetition for the consumer.

Nurse Assessors Available Statewide

Nurses who do the assessments throughout the state connect their laptops to MECARE via modem, at which point they load the most current client data onto their laptops. If a previous assessment exists, it is also loaded on to the laptop for reference. After meeting with the consumer and conducting the assessment, which may take from 1-3 hours, the nurse transmits the result electronically back to a central database. The information becomes available to others within the care delivery system who need assessment and plan of care information in order to arrange services.

There is logic internal to the system ensuring that a consistent and accurate assessment is completed. Care plan costs and co-pay calculations are automatic. The assessor is able to generate letters as well as a paper copy of the completed assessment to leave with the consumer at the time of the assessment. The software also includes a feature for tracking any appeals.

Who is receiving long-term care?

The charts on the following pages are examples of the kind of analysis and reports that can be generated from MECARE. The system provides a level of clinical detail previously unavailable. The first nine months of data show that persons in need of long-term care in Maine are overwhelmingly female, old, and low income. Many rely on adult children for informal support. Hypertension, arthritis, and congestive heart failure are their primary diagnoses and most qualify for assistance based on need for help with activities of daily living, not skilled nursing care.

Summary Statistics of 1998 MeCare Data

* The following Data was prepared by Muskie School 1998.

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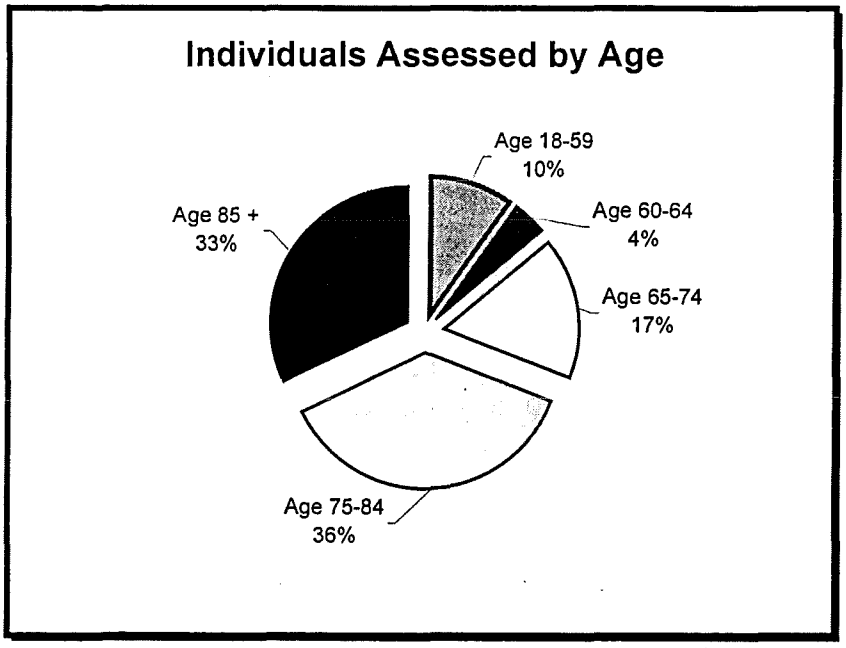
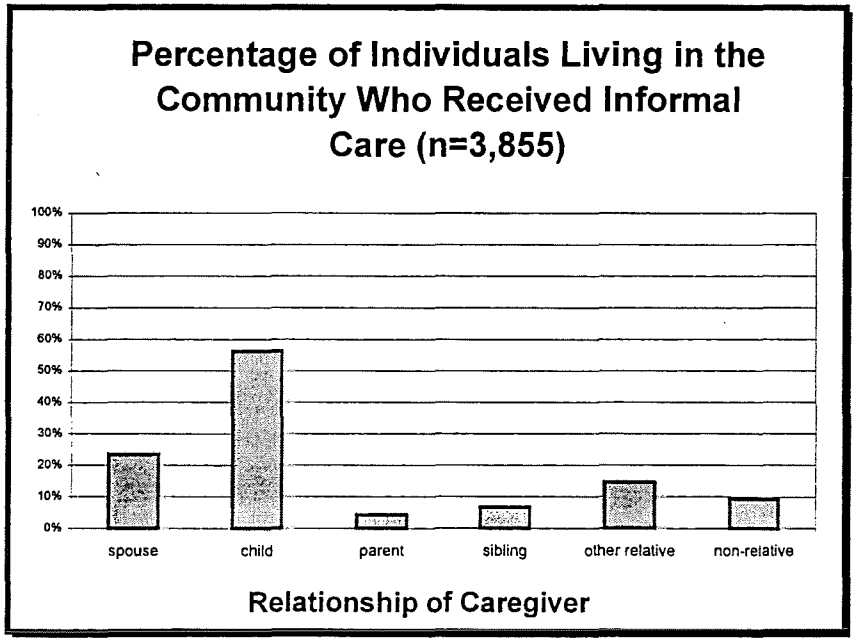


- There are twice as many women assessd as men.
- 74% of the women are 75 years or older.

2.



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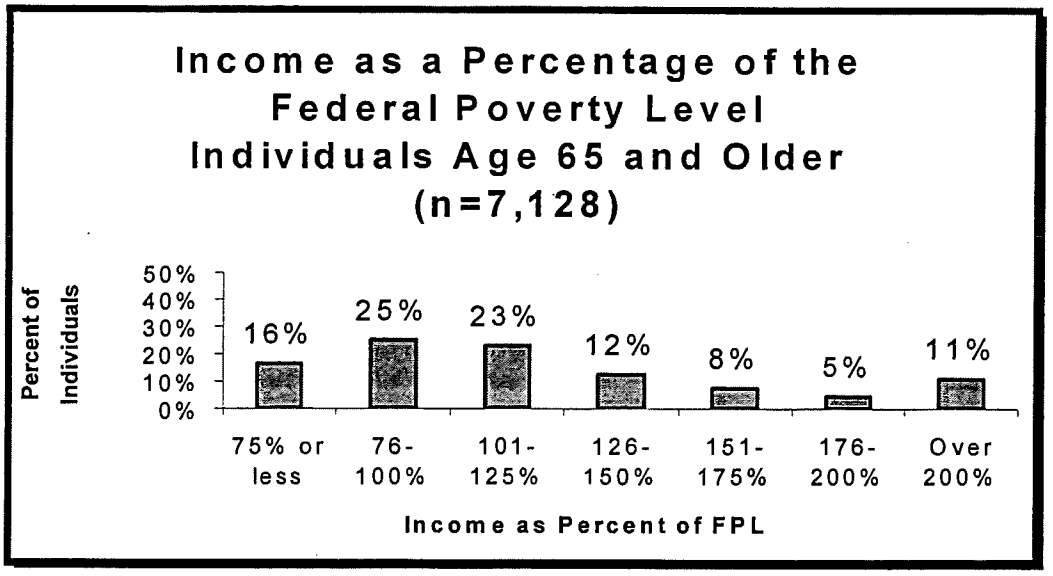

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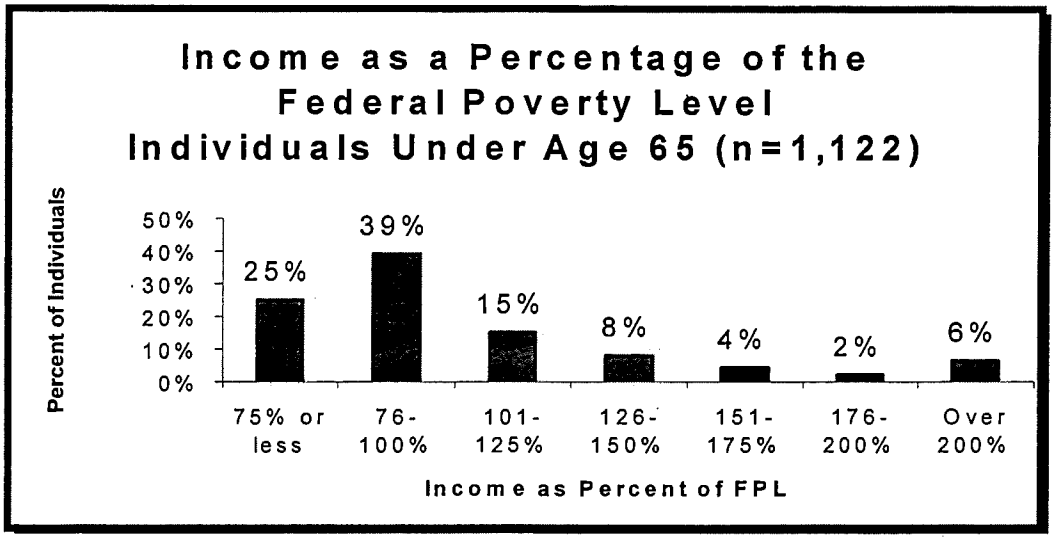


- Approximately 85% of those under 65 and 95% aged 65 and older, have few or no assets.
- Among those aged 65 and older, 41% have income below the Federal Poverty Level (FPL).
- For the younger age group, 64% have income below the FPL.

Summary Statistics (Cont'd)

4.

Top 10 Health Problems and Conditions for Individuals *Age 65 and Older* (n=7,912)			
	Health Problem/Condition	*No. of Individuals with a Diagnosis*	*Percentage of Individuals*
1	**Hypertension**	3,466	44%
2	**Arthritis**	2,755	35%
3	**Other cardiovascular disease**	2,031	26%
4	Dementia other than Alzheimers	2,005	25%
5	Congestive heart failure	1,909	24%
6	**Diabetes mellitus**	1,792	23%
7	**Allergies**	1,775	22%
8	**Depression**	1,712	22%
9	**Cerebrovascular accident**	1,635	21%
10	**Emphysema/COPD**	1,493	19%

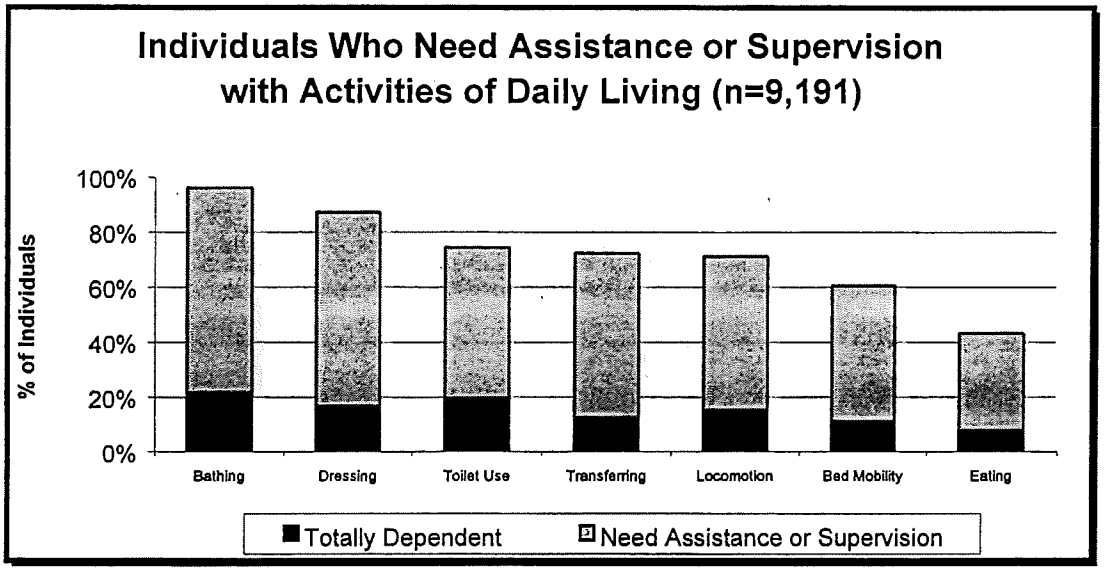
- Hypertension is the most common condition for all people assessed.
- The diagnosis in **bold** are among the top 10 diagnoses for both age groups.
- Diabetes, depression, and hypertension are chronic diseases that repond to early intervention and treatment.

4a.

Top 10 Health Problems and Conditions for Individuals *Under Age 65* (n=1,279)			
	Health Problem/Condition	*No. of Individuals with a Diagnosis*	*Percentage of Individuals*
1	**Hypertension**	368	29%
2	**Allergies**	333	26%
3	**Diabetes mellitus**	332	26%
4	**Depression**	317	25%
5	**Emphysema/COPD**	243	19%
6	**Arthritis**	223	17%
7	Seizure disorder	216	17%
8	**Cerebrovascular accident**	204	16%
9	**Other cardiovascular disease**	195	15%
10	Cancer	144	11%

Diagnoses that are bolded are common to both age groups.

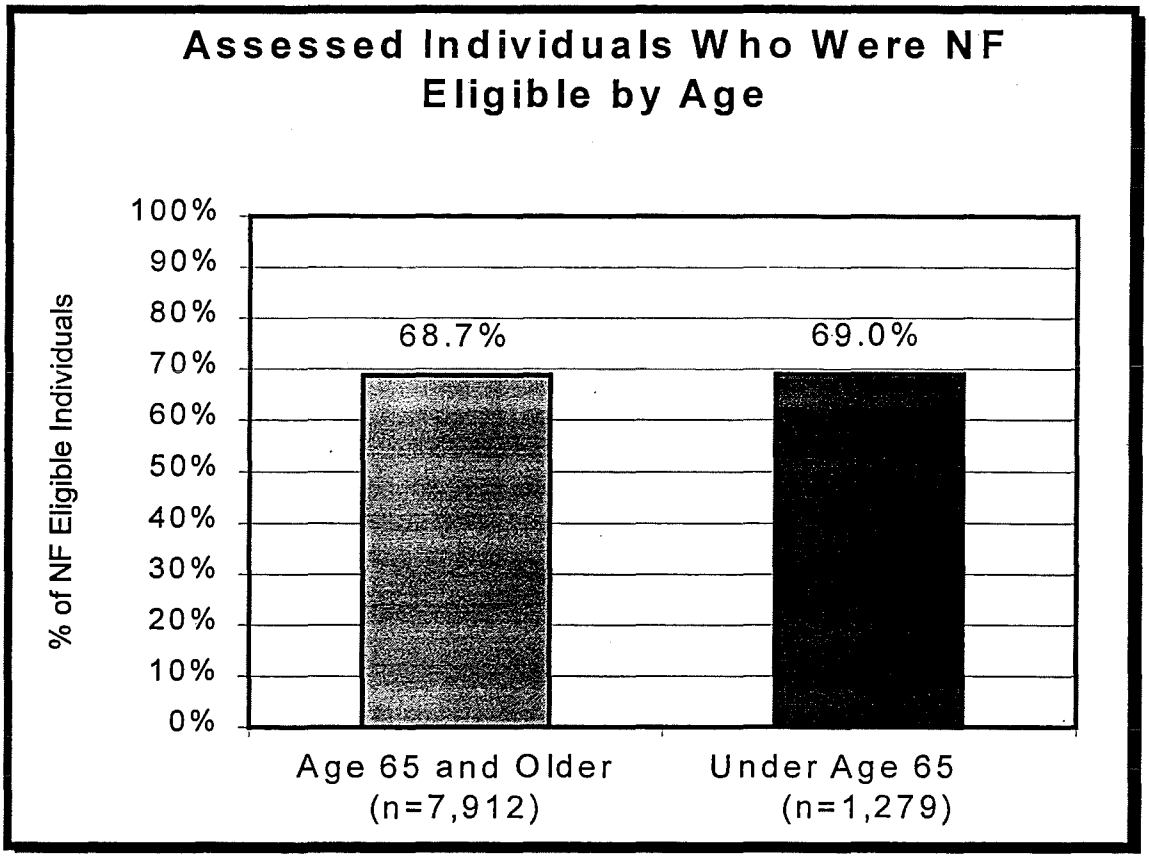
5.



- Activities of Daily Living (ADLs) and the level of assistance required to perform these tasks are a key factor driving the need for long term care services.

- More than 50% of those assessed require assistance or supervision with all tasks except eating.

6.



- The proportion found eligible for nursing facility (NF) level care is roughly the same for both age groups. This suggests that the MED assessment/reassessment process is effectively targting those with long-term care needs across age groups.

- 3,062 persons received assessments because they were seeking nursing facility level of care; others were applying for home care programs or requested an advisory assessment.

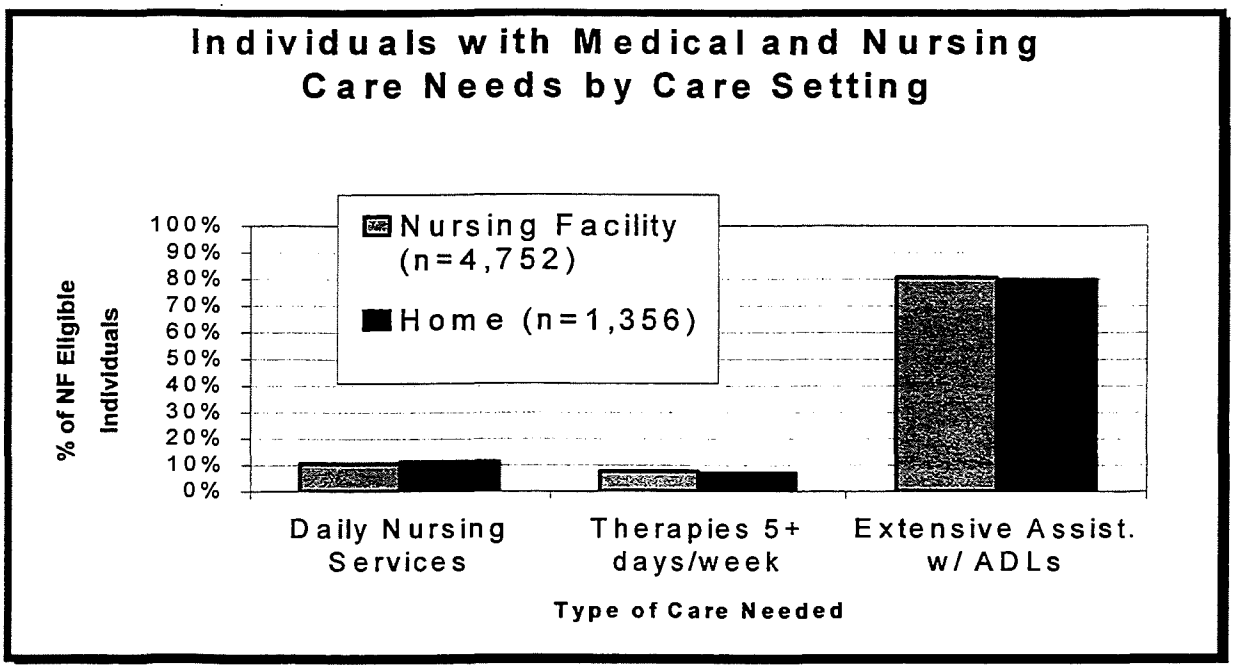
- All individuals assessed receive recommendations for community options appropriate to their level of care needs.

7.

Consumer Choice of Care Setting									
	Home		Nursing Home		Res. Care		No Choice at this Time		
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Total
NF *Eligible*	1356	22%	4752	75%	13	0.2%	200	3%	6,321
NF *Ineligible*	2221	77%	131	5%	171	6%	347	12%	2,870

- Of those found nursing facility (NF) eligible, 22% chose home as their care setting.

8.

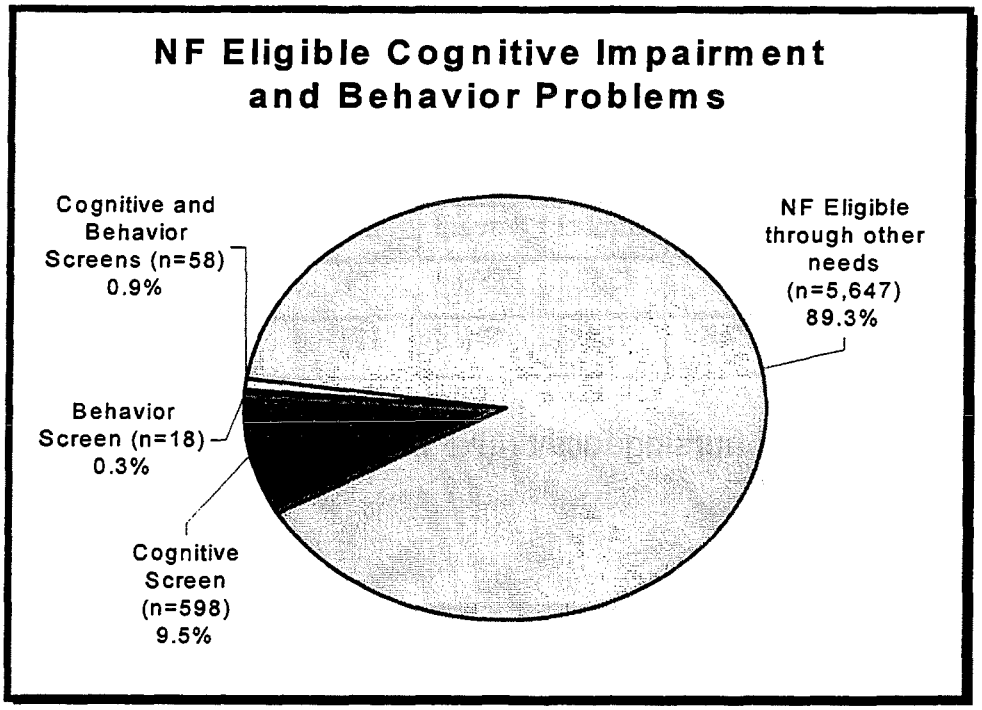


- For both those who chose home and those who chose nursing facility, the care needs are very similar.

- Among those found eligible for NF level care services, over 80% meet the eligibility criteria because they require extensive assistance with their Activities of Daily Living.

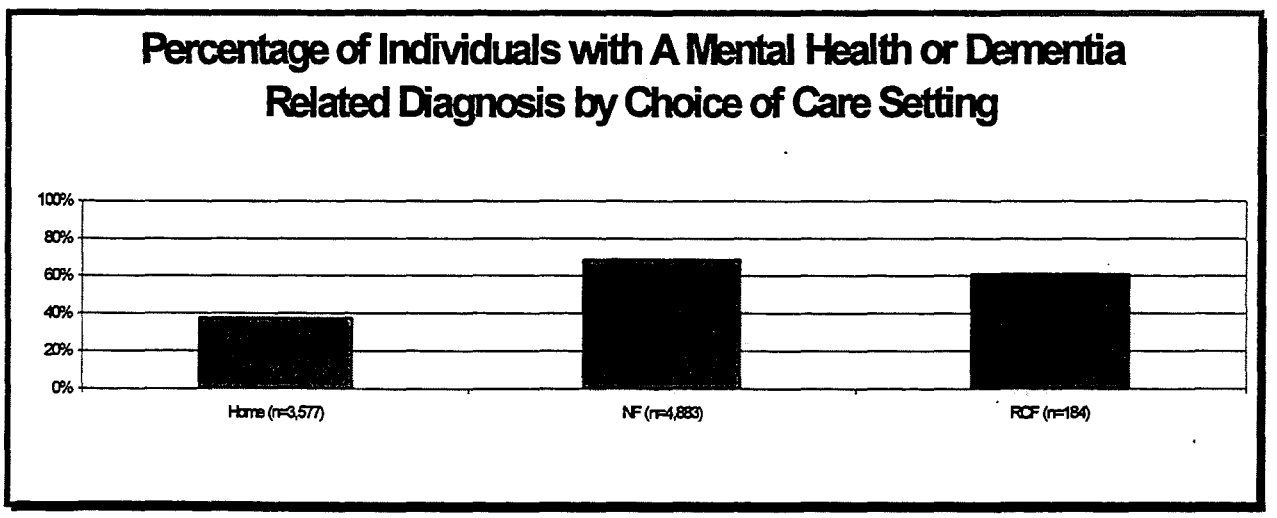
Summary Statistics (Cont'd)

9.



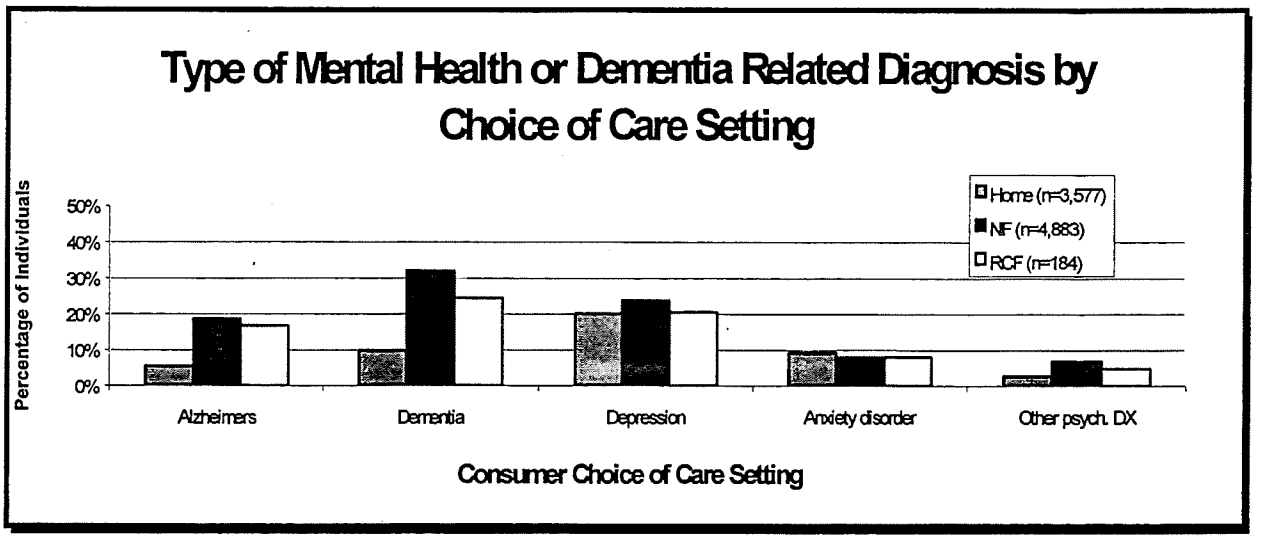
- 674 individuals were found eligible for nursing home level services as a result of the supplemental dementia screens.
- These 674 individuals represent 7.3% of all persons assessed or 10.7% of individuals found NF eligible.

10.



- Almost 70% of those who chose nursing home placement had dementia or a mental health diagnosis.

11.



- After dementia depression is the most frequent mental health problem across all care settings.

12.

Number of Program Denials by Program Type

Program	*Total Denials*	*Percentage of Total Denials*
Home Based Care	310	33.8%
Nursing Home	259	28.3%
"At Risk" Private Duty Nursing (PDN)	170	18.6%
Elderly Home Care Waiver	148	16.2%
Adults w/Disability Home Care Waiver	29	3.2%
Total	916	100%

- Approximately 10% of all assessments/reassessments have a program denied in the process. This is often due to a change in the level of care. For example, a person requesting Home Based Care could be denied that program if they are eligible for a higher level of care and can be served under Medicaid funded home care program.
- Due process is explained and a written description of hearing rights are given to all persons who are found not eligible for the program they requested.

Summary Statistics (Cont'd)

13.

Referral Source for Long-term Care Assessments		
Referral Source	*Total Referred*	*Percent of Total Referrals*
NF	4,015	43.7%
Home care agency	2,583	28.1%
BFI	931	10.1%
Hospital	537	5.8%
Family member	418	4.5%
Community agency	302	3.3%
Residential Care	134	1.5%
Other	99	1.1%
Other state agency	70	0.8%
Consumer	50	0.5%
Physician	47	0.5%
Advocacy agency	5	0.1%
Total	9,191	100%

- Nursing facilities (NF) and home care agencies are the most common source of referrals, followed by the Bureau of Family Independence (BFI).

- Consumer self referrals and physician referrals, while less frequent, indicate an increased awareness of the assessment process.

VI. Forecast

The components of a more balanced long-term care system are in place in Maine, but there are significant challenges.

Continued waiting list for state-funded home care services

The demand for services continues to outpace resources. The Department works with home care providers to assure that resources are used efficiently. In addition, DHS plans to revise the cost-sharing requirements in order to generate revenue that can be used to serve more participants.

Recruitment and retention of a qualified labor force

Staffing shortages are reaching crisis proportions in some parts of Maine. The combination of demographics and a strong economy means fewer applicants for the jobs that provide hands on care to consumers in nursing homes, residential care facilities and home care. The Maine Health Care Association, DHS, and Department of Labor jointly funded a study of the labor force issues. Low pay and lack of career advancement were the primary reasons certified nursing assistants cited for leaving the field. Personal care assistants who work in home care are paid even less, but report a higher degree of job satisfaction.

Developing assisted living that is affordable for middle-income elders

Assisted living is independent apartments where services are offered on an "as needed" basis. There are a growing number of assisted living developments at the high end, but they are not affordable for middle income seniors. Assisted living offers the privacy and autonomy of home care, and the economies of scale associated with group living. In time, it may be an important element of solving the staff shortage.

Supporting Family Caregivers with Information and Assistance

The 1998 Maine Citizen Survey showed that one out of five adults is caring for an older family member, an average of 10 hours per week. When asked what would help them, 40% reported the need for more services, and another 15% cited the need for more information. President Clinton has included funds in the proposed federal budget to support information and assistance for family caregivers. Funds, which also could also pay for respite services for caregivers, will be administered locally by area agencies on aging.

Finding alternative uses for excess nursing home capacity

Nursing home occupancy has declined in Maine from nearly 100% in 1994 to 85% today. Many facilities have converted excess capacity to residential care, but the system still has approximately 500 more beds than needed.

VII. Appendix A

Maine's Long-term Care System:
A Consumer Perspective

A Report of the
Long-term Care Steering Committee
Advisory to the Department of Human Services

Arnold Leavitt, Auburn, Chair Pro tem
Catherine Bell, Houlton
William Bridgham, Jr., Durham
Richard Farrell, Brewer
Harmon Harvey, Hallowell
Leopold Hepfner, Readfield
Cindy Leach, Falmouth
Eileen Lonsdale, Brunswick
Polina McDonnell, Cumberland
Ron Stewart, Wilton
Deborah Williams, Topsham

Staff: Betty Forsythe
Bureau of Elder and Adult Services

November, 1998

Maine's Long-term Care System: A Consumer Perspective
Long Term Care Steering Committee

The Long-term Care Steering Committee is an eleven member committee of consumers. It was established by the legislature in 1996 as part of the Governor's Long-term Care Initiative. Members are appointed by the Governor to provide input to the Commissioner of the Department of Human Services (DHS) on all policy initiatives, laws and rules concerning long-term care. The committee's mission is to ensure that a consumer perspective concerning the long-term care needs and preferences of Maine's elderly people and individuals with disabilities is reflected in policy-making, resource allocation and development and program administration decisions.

One of the most important actions of the Legislature during its 118th sesson was the passage of LD 2060, *(PL 97, Chapter 734) An Act Regarding Personal Care Assistant Services.* Among other provisions, the act transferred administrative responsibility and funding of the Consumer Directed Personal Care Assistance Program for people with disabilities from the Department of Labor to the Department of Human Services. The act thereby helped to further consolidate state home care funds and their administration. It also mandated additional representation of consumers of independent living services in the DHS policy and program development process by increasing the Long-term Care Steering Committee membership from 9 to 11. A total of four committee positions are now designated for adults with disabilities who are consumers of independent living services. Appointments have been made and the committee is now fully operational.

Charges to the Committee

Pursuant to LD 1114 (PL 97 Resolve 42), the Committee was asked to work in conjunction with DHS to prepare two reports:

- The first, due on 1/1/98, was to present recommendations about medical and financial eligibility screening for long-term care services and on the status of the availability of different long-term care options. This report was submitted to Commissioner Concannon in November, 1997.
- The second, due on 11/1/98, was to report the findings of the study comparing the levels of spousal and family support available to both married and single recipients of services under various long-term care and assisted living programs, and to submit recommendations and propose legislation to promote equity.

Pursuant to LD 2060 (PL 97, Chapter 734) the Committee was again asked to work in conjunction with DHS, to study and submit recommendations by 1/1/99, about the rates for personal care assistant (PCA) services.

Recommendations

The Committee's overarching purpose is to review the long-term care system and make recommendations which will ensure that all segments of the system have the capacity to deliver and guarantee the highest quality of care and consumer choice. All segments of the system should be more responsive to the needs of consumers and services must be

provided as expeditiously and flexibly as possible. It is in this spirit that the Committee studied the issues and arrived at its recommendations.

While the primary focus of this report is on levels of protection against impoverishment for spouses in various programs and the Medicaid reimbursement rates for personal care assistant services, related recommendations are presented within the context of a system in which the elements are interrelated and interdependent.

1. **The Committee feels that this is not the time to advocate for state legislative action that would achieve equity in spousal protections.**

While it would be desirable to address the inequity in assets and income retained among those spouses whose Medicaid eligible partners reside in Cost Reimbursed Boarding Homes or nursing homes and those receiving care in their homes, that inequity is essentially caused by federal Medicaid policies. Without a change in federal policy, this could only be remedied by the expenditure of significant state dollars. The Committee feels that using state dollars to implement recommendation #3 to increase funding for home care is a higher priority.

2. **The Committee strongly recommends that the reimbursement for consumer directed personal care attendants be increased to that of comparable agency reimbursement rates.**

(See attached chart of Reimbursement Rates for State and Medicaid Home Care Programs.) It is clear from surveys and personal testimonies that the current allowance is a major stumbling block for consumers in hiring and keeping competent employees. A number of consumers spoke of having to hire incompetent people right off the street because no one else was available at the rate they could pay. Others talked about how such PCAs didn't show up resulting in their having to spend nights in their wheel chairs.

PCAs provide a vital and sometimes life saving role for consumers and for that they are vastly underpaid. Their rate has not been increased in many years and they receive no benefits. Without PCA services people would have to enter institutional care. If the state is truly committed to providing quality consumer directed home based care, the people directing this care who want to retain control over their lives, their independence and their dignity must be given the resources to compete in the tight health care labor market and to hire and retain competent employees.

3. **The Department and the Legislature should fund home care services at a level which not only reduces the waiting lists to zero over the next biennium, but meets the projected demand without creating significant waiting lists for the foreseeable future.**

The long-term care system will only become a truly consumer responsive system when home care and related preventive services are the first option and right of a person in need of care, rather than as is the case now, as a mandated diversion from unnecessary nursing home placement.

4. **The Committee strongly supports adoption of the standard contract developed by the Department, the use of which will be proposed as a condition of nursing home licensing.**

The Committee has reviewed successive drafts of this contract which is the product of a workgroup convened by the Department. The workgroup included representatives from the Bureau of Elder and Adult Services, Division of Licensing and Certification, Long-term Care Ombudsman Program, Legal Services for the Elderly, and Maine Health Care Association as well as two nursing home administrators.

5. **The Committee recommends that staffing in nursing homes continues to be a high priority focus of Department and Legislative attention.**

Consumers are particularly concerned that facilities have enough properly trained staff around the clock to meet the needs of their residents and to ensure quality of care and quality of life for them.

Overall, there is concern that the home care industry will become much like the nursing home industry where consumers' preferences and individual needs do not play a part in how care is given. The Committee will continue to focus on the need for consumers to have influence, say and choice in the services they receive in their homes as well as on improving quality, accessibility and affordability throughout the system.

Appendix B

Long-term Care Medical Eligibility Assessment for Persons with Dementia

Maine uses the Medical Eligibility Determination (MED) form to assess functional eligibility for a range of State and Medicaid funded long-term care programs. Maine also uses a federally established form, the MDS2.0, to develop treatment plans for persons who have been admitted to a nursing facility.

To some degree, the two forms collect similar information. In those cases, the language on the MED (state form) has followed the language on the federal, MDS2.0, form. This makes it easier to compare information across time and across care settings.

In November 1997, the Department changed a definition on the MED form to conform to a change in the MDS2.0. This change involved the scale used to measure how frequently a person was exhibiting certain problem behaviors. Previously, in order to "count," a problem behavior had to occur 3 days/week. On the new scale, the behavior would have to occur 4 days/week. All parties who use the MED form were notified of the change as part of the instructions that went out with the new form.

Department staff erroneously considered this a minor change and did not submit this to the Legislature for review as a substantive rule. The change was included when the Department went out to rulemaking in November 1998. Since the change was not specifically listed on the Notice of Rulemaking concise summary, the Department then agreed to re-issue the rule and hold another public hearing. Four people attended the public hearing and spoke on this issue.

The Department compared results for two time periods, before and after the change in the criteria.

	"Old" Scale		*"New" Scale*	
	Number	***Percent***	***Number***	***Percent***
Total Assessments	*8538*		*9191*	
Received Screen Appropriately	*982*	*11%*	*1265*	*14%*
Became Eligible Because of Behavior Screen	12	< 1/2%	18	< 1/2%

It appears that this change has not adversely affected any consumers. The Department received no calls from facilities or families in the year since the change occurred. More than 60% of nursing home residents have dementia. The vast majority qualifies on a basis other than problem behavior. Also, since 1996 when the MED was modified to better address dementia issues, the resources for persons with dementia have greatly expanded.

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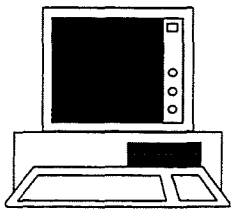

The Bureau of Elder and Adult Services Long-term Care Reform: A Status Report is also available on the Internet!

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Published by:

Bureau of Elder and Adult Services
Department of Human Services
35 Anthony Avenue
11 State House Station
Augusta, Maine 04333-0011
(207)624-5335 FAX: (207)624-5361

Toll Free: 1(800)262-2232
Local TTY: 624-5442
Toll Free TTY: 1(888)720-1925