



Caregiving and Support for Quality Nursing Home Care: A Survey of AARP California Members

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AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice and control in ways that are beneficial and affordable to them and society as a whole. We produce *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *AARP Segunda Juventud*, our bimonthly magazine in Spanish and English; *NRTA Live & Learn*, our quarterly newsletter for 50+ educators; and our website, www.aarp.org. AARP Foundation is our affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

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About This Survey

This mail survey of AARP members in California explores their concerns, their view of state legislative priorities, and their experiences regarding prescription drugs and long-term care. This report, however, is part of the larger survey and discusses members' current experiences with care-giving and level of support for improved nursing home protections.

AARP conducted the AARP California Member Survey from July through August, 2005. A random sample of 2,000 AARP members in California, proportionally stratified by three age segments—50 to 59, 60 to 74, and 75+, was selected from AARP's membership database. Each sampled member was contacted about the survey in four ways: a pre-notification postcard, the survey itself, a reminder postcard, and a second survey. Forty-four percent of the sampled California members returned surveys by the cut-off date, providing 879 useable surveys for analysis. Thus, the survey has a sampling error of plus or minus 3.3 percent. Survey responses were weighted to reflect the distribution of the age segments in the member population of California. The weighted overall findings are discussed. Throughout the report, statistics representing member responses are reported in percentages. In some instances, percentages are small and may not seem to represent a significant proportion of members, yet when projected to the total California membership the actual number of people may be substantial. As of June 2005, the number of individual AARP members in California was 3,021,212. A full annotated questionnaire is included in Appendix A.

Highlights

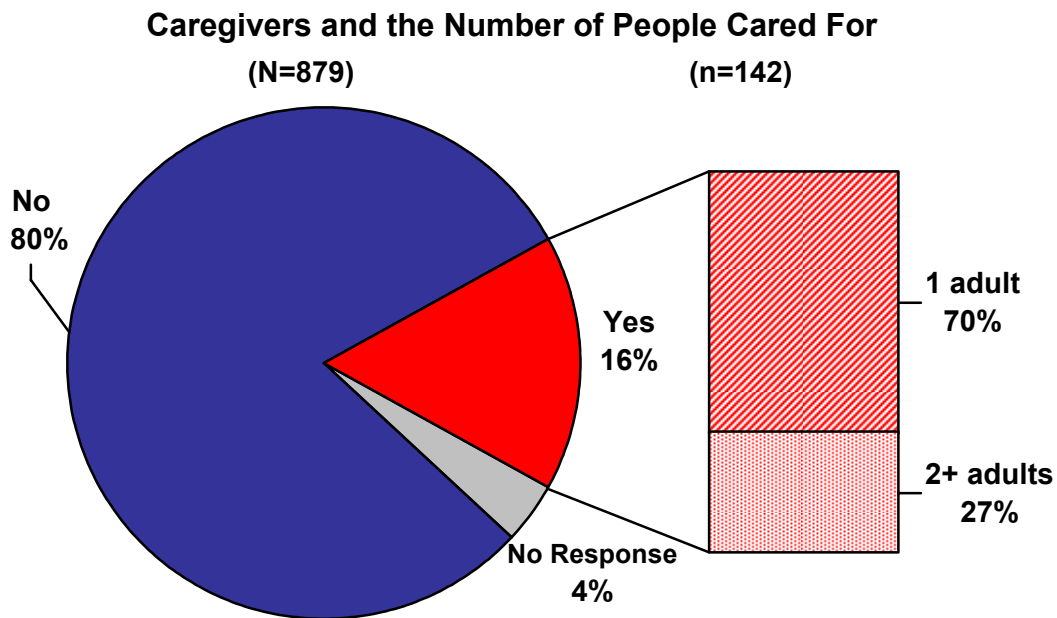
- One in six California members (16%) currently serves as a caregiver to a relative or friend. Slightly less than half provide care to their parents (43%) and live 10 miles or less from the care recipient (57%).
- Nearly eight in ten members strongly support nursing home legislation that would strengthen the enforcement of state standards to protect the health, safety, and rights of nursing home residents (79%) and would be much more or somewhat likely to vote for a candidate who supports nursing home legislation to improve the quality of nursing home care and protect residents' rights (84%).
- Members overwhelmingly support nursing home legislation that enforces nursing home safety and quality standards with citations, fines, or license revocation for nursing homes that violate those standards (93%), strengthens patient's rights (89%), and establishes a state-wide complaint response system (86%).

Findings

One in six California members currently serves as a caregiver to a relative or friend.

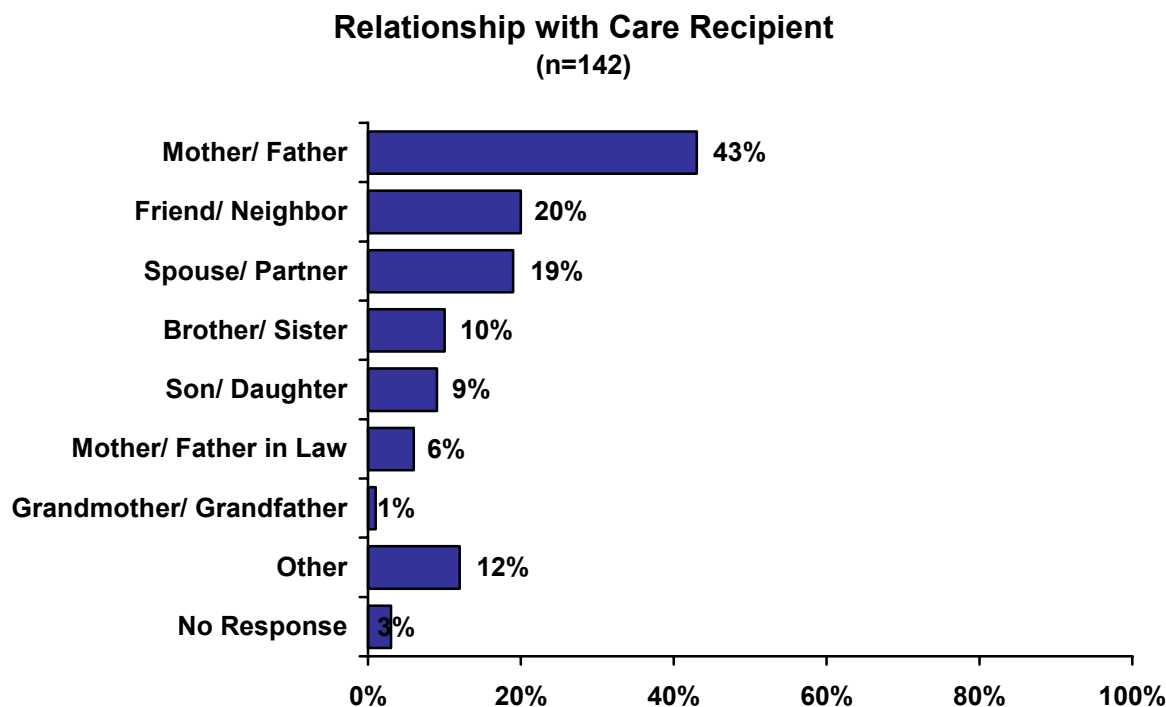
A caregiver is anyone who provides unpaid help to a relative or friend who is ill, disabled, or elderly. Sixteen percent of all members say they currently assist another person with financial assistance, running errands, doing household chores, or provide personal care and grooming help.

Seventy percent of those who do provide caregiving services provide care for one person and one in four cares for two or more people.



Over four in ten caregivers provide care to their parents and live 10 miles or less from the care recipient.

When asked about the relationship between the caregiver and the adult receiving unpaid help, parents top the list followed by friends or neighbors and then spouses.



The majority of caregivers (61%) report that the care recipient(s) do not live with them. Of those caregivers who provide care for someone who does not live with them, forty-two percent say the care recipient(s) lives within 5 miles, fifteen percent say they live between 5 and 10 miles, nine percent say between 11 and 15 miles, ten percent say between 16 and 25 miles, and nineteen percent say they live more than 25 miles away from the care recipient(s) home.

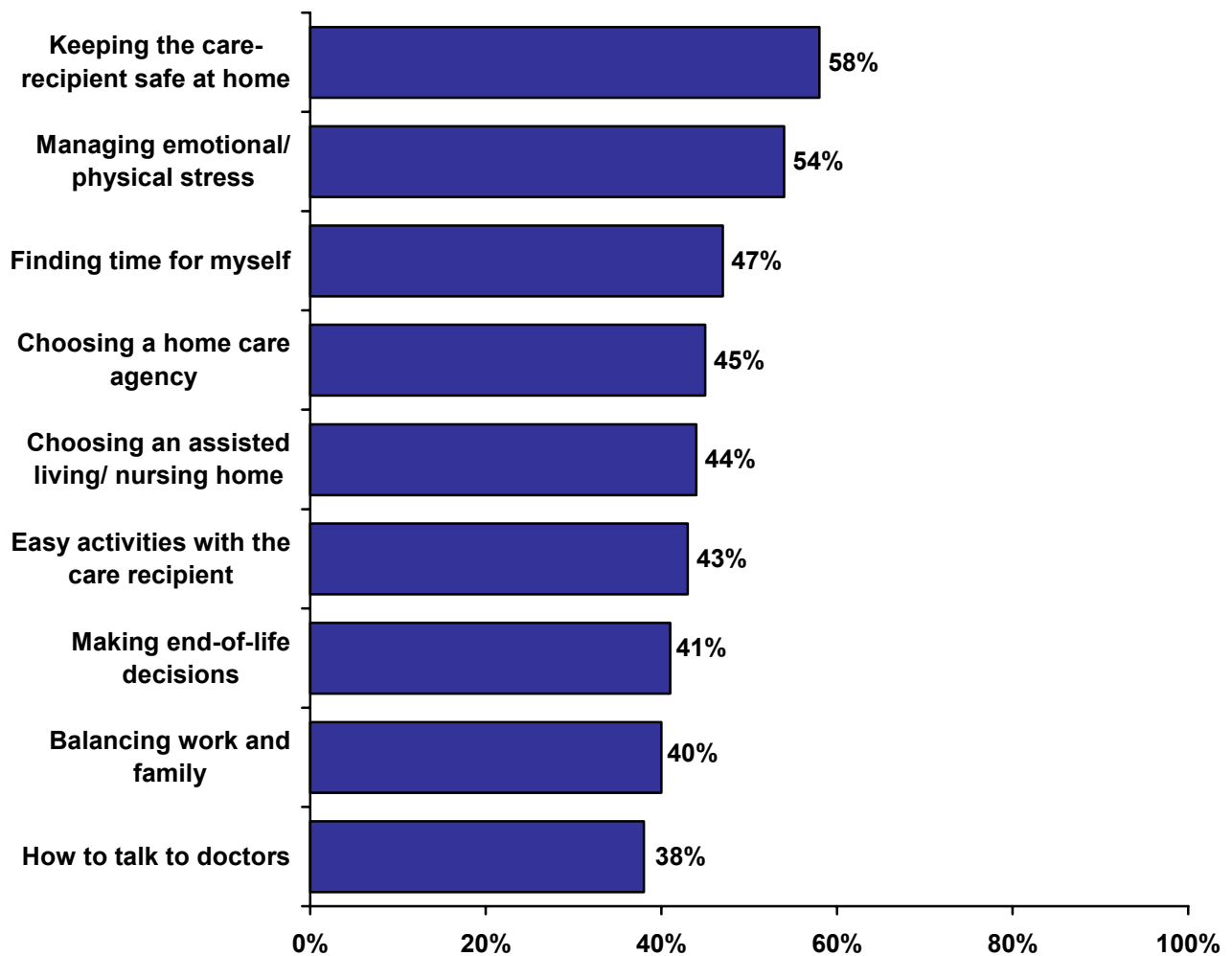
Most caregivers do not receive paid help such as an aide or nurse.

Providing care to a loved one can be a physical, emotional and financial strain on the caregiver. Of those California members who say they provide care to someone, most report that the care recipient does not receive paid help. Only about one in seven say that in addition to the care they provide, the recipient has paid help from an aide or nurse hired through an agency or service (15%) or an aide hired independently (14%). The most common type of paid help that supplements that provided by caregivers is a housekeeper to clean or cook (21%).

Safety and managing stress are the top areas where caregivers would like to receive more help or information.

Maintaining a safe environment for the care recipient is the top issue on which caregivers would like more help or information. About six in ten (58%) caregivers would like help or information on keeping the care recipient safe at home. Mental well-being is also important to caregiving members as about half or more say they would like more help or information on managing emotional and physical stress (54%) and finding time for themselves (47%).

As a Caregiver, California Members Want More Help or Information on:
(n=142)

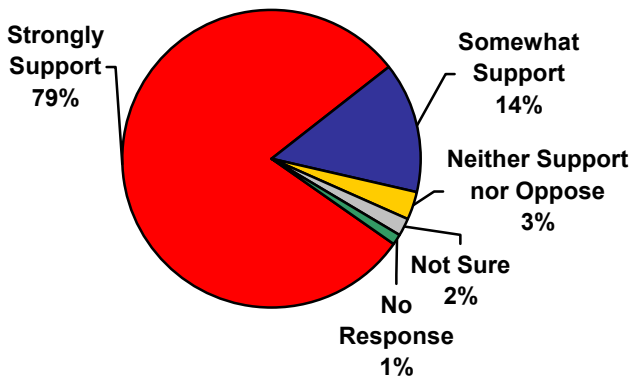


Nearly eight in ten members strongly support nursing home quality legislation.

AARP California members overwhelmingly support nursing home legislation and protections. About eight in ten members strongly support legislation in California to strengthen the enforcement of state standards to protect the health, safety, and rights of nursing home residents.

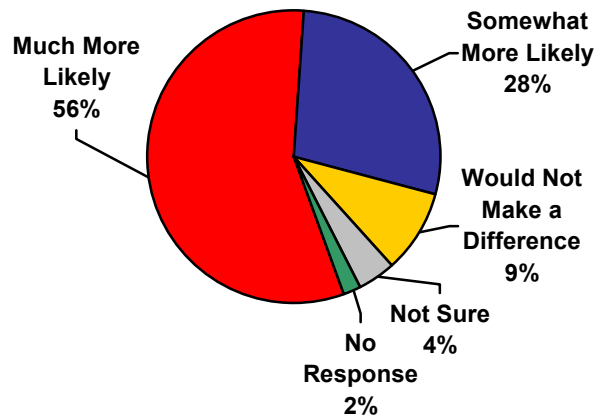
Members say they would back-up their support for nursing home legislation is by voting. More than half of all members say they would be much more likely to vote for a candidate who supports improving the quality of nursing home care and protecting residents’ rights. Fewer than one percent would be less likely to vote for a candidate who supported this type of legislation.

Support or Oppose Nursing Home Quality Legislation
(n=879)



* less than 1 percent report “Somewhat oppose” or “Strongly oppose”.

Likelihood to Vote for Candidate who Supports Nursing Home Quality Legislation
(n=879)



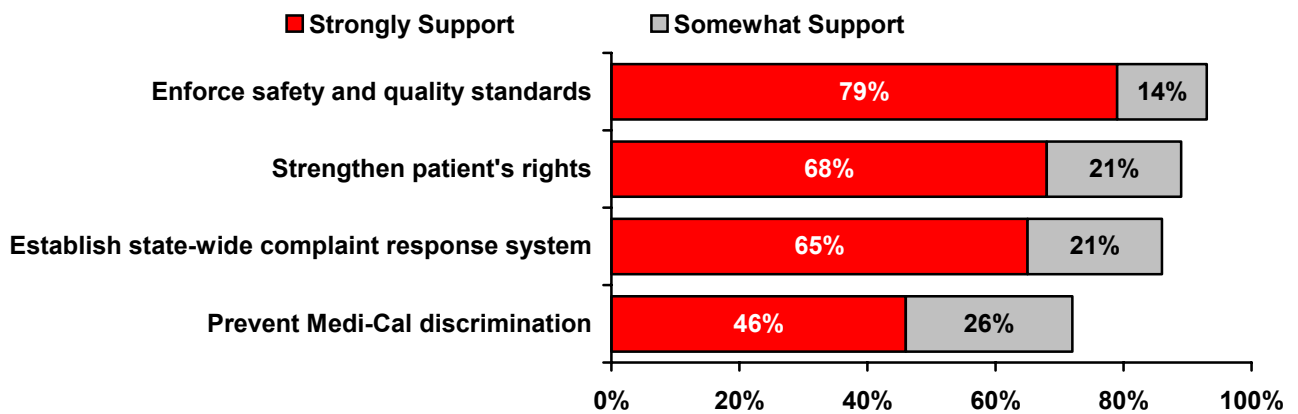
* less than 1 percent report “less likely to vote for candidate”.

About nine in ten members support nursing home legislation that enforces safety and quality standards and strengthens patient’s rights.

Members were asked to rate their support or opposition for four features of nursing home legislation being considered by the state of California. The four features intended to improve the overall quality of nursing homes are related to patient’s rights, access to care for all nursing home patients, enforcing safety and quality standards, and promoting accountability of those who not comply with the proposed standards. A majority of members support all features of nursing home legislation. Nine in ten (93%) members strongly or somewhat support enforcing safety and quality standards with citations, fines, or license revocation for nursing homes that violate those standards. More than eight in ten members support strengthening patient’s rights (89%) and establishing a state-wide complaint response system (86%). Over seven in ten (72%) members support establishing a “first come, first serve” standard to prevent discrimination against nursing home applicants on Medi-Cal.

Support or Oppose Features of Nursing Home Legislation

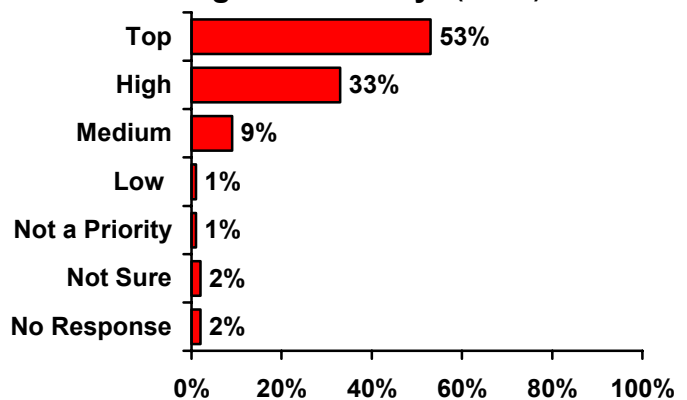
(n=879)



Nearly nine in ten members say improving the quality of nursing homes in California should be a top or high priority for AARP California.

AARP California members overwhelmingly support nursing home legislation and protections and believe the AARP California state office should do the same. When members were asked, “How much of a priority do you think it should be for AARP California to work to improve the quality of nursing homes in California?” nearly nine in ten say it should be a top or high priority.

Priority of AARP California Working to Improve Nursing Home Quality (n=879)



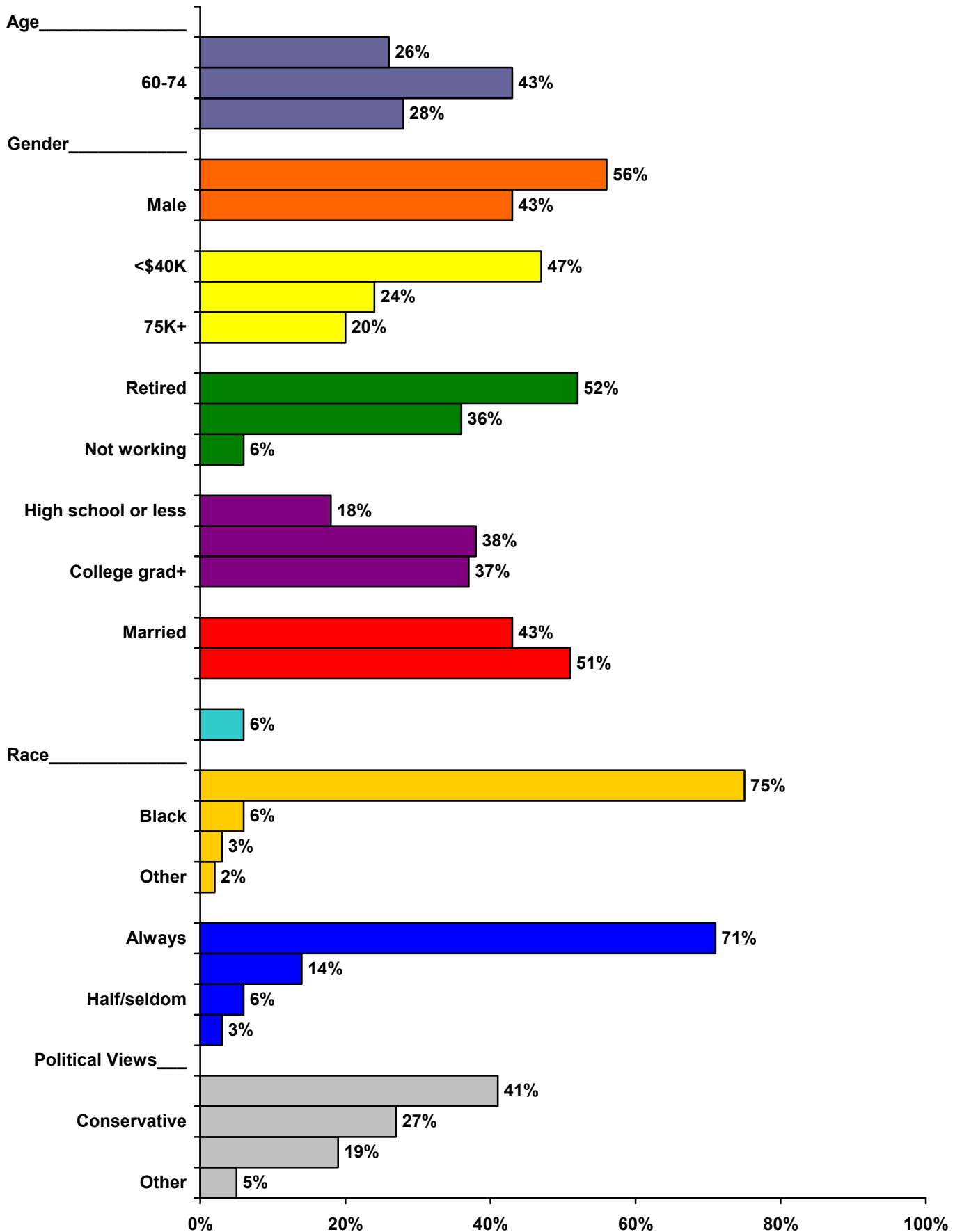
Conclusions

One in six AARP California members serves as a caregiver to a friend or loved one. In most cases, the care recipient is not receiving any paid assistance such as a nurse or aide to supplement the care provided by the caregiver. Thus, caregivers do carry the primary responsibility for assisting the care recipients. Many of these caregivers say they want more help or information on keeping care recipients safe at home. Additionally, about half say they need help in managing the emotional and physical stress of caregiving and in finding time for themselves.

AARP California members overwhelmingly support nursing home legislation that strengthens enforcement and believe the AARP state office should make improving the quality of nursing homes in California a top or high priority. As legislators look for specific actions to address quality issues, there are several that are overwhelmingly supported by California members: enforcing safety and quality standards with citations, fines, or license revocation for nursing homes that violate those standards (93%), strengthening patients' rights (89%), establishing a statewide complaint response system (86%), and establishing a "first come, first serve" standard to prevent discrimination against nursing home applicants on Medi-Cal (72%).

Respondent Demographics

Respondent Demographics



APPENDIX A
ANNOTATED QUESTIONNAIRE

2005 AARP California Member Survey

(AARP Members Weighted n = 879; Response Rate = 44%; Sampling Error = \pm 3.31%)
 (Percentages may not add to 100% due to rounding or multiple response.)

State Legislative Issues

1. To be effective, AARP California wants to work on the most important issues facing California members. Keeping in mind what is most important to you, how much of a priority should it be for AARP to work on the following legislative issues in California?

	Top Priority ▼	High Priority ▼	Medium Priority ▼	Low Priority ▼	Not a Priority ▼	Not Sure ▼	No Response ▼
a. Protecting access to promised pensions and retiree health benefits.....	60%	26%	7%	2%	3%	1%	2%
b. Maintaining access to home and community based long-term care services	38%	37%	17%	3%	2%	1%	2%
c. Expanding funding for alternative transportation services for those unable to drive	24%	31%	31%	8%	3%	2%	2%
d. Ensuring that Social Security continues to provide a guaranteed base for retirement income.....	77%	16%	4%	*	2%	*	1%
e. Expanding health insurance coverage for the uninsured	37%	30%	18%	6%	4%	2%	3%
f. Ensuring that workers age 50 and older have equal access to jobs, promotions, and employee benefits.....	40%	34%	17%	5%	2%	1%	1%
g. Maintaining Medicaid, the government program that provides health and long-term care for low income people	39%	32%	17%	6%	3%	1%	1%
h. Protecting consumers against fraudulent and deceptive business practices that can reduce their retirement savings and financial assets	56%	26%	12%	3%	2%	*	1%

1. (CONTINUED) To be effective, AARP California wants to work on the most important issues facing California members. Keeping in mind what is most important to you, how much of a priority should it be for AARP to work on the following legislative issues in California?

	Top Priority ▼	High Priority ▼	Medium Priority ▼	Low Priority ▼	Not a Priority ▼	Not Sure ▼	No Response ▼
i. Maintaining funding for housing options that allow individuals to remain in their communities as they age	31%	35%	22%	4%	3%	1%	4%
j. Maintaining the affordability of utility services ..	35%	37%	18%	4%	2%	*	4%
k. Strengthening Medicare as a base for retirement health coverage	53%	29%	11%	2%	1%	1%	4%
l. Maintaining services for older, low-income state residents	34%	35%	19%	5%	2%	1%	4%
m. Making prescription drugs more affordable	61%	24%	9%	1%	1%	*	3%
n. Enforcing quality regulations for long-term care services	43%	34%	16%	3%	1%	1%	4%

Prescription Drugs

2. Are you, yourself, now covered by any form of health insurance, such as any private or employee health insurance plan or through programs like Medicare or Medicaid?

	<u>%</u>
Yes	87
No	10
Not sure	1
No Response	3

3. Do you get any help in paying for prescription drugs from insurance or other health coverage?

	<u>%</u>
Yes	71
No	25
Not sure	2
No Response	3

4. How concerned are you about being able to afford the cost of needed prescription drugs over the next two years?

	<u>%</u>
Extremely concerned	32
Very concerned	21
Somewhat concerned	21
Not very concerned	15
Not at all concerned	7
Not sure	1
No Response	3

5. In the past 12 months, have you taken any prescription medications?

		<u>%</u>
Yes		89
No	————→ SKIP TO QUESTION 10	8
Not sure	————→ SKIP TO QUESTION 10	3

6. Are you currently taking prescription drugs on a regular basis, that is, daily, weekly, or monthly? (n=780)

	<u>%</u>
Yes	93
No	7
No Response	1

7. In the past 12 months, has paying for your prescription drugs been a major problem, a minor problem, or not a problem for you? (n=780)

	<u>%</u>
A major problem	15
A minor problem	32
Not a problem	52
No Response	1

8. In the past 12 months, approximately how much have you spent, EACH month, out of your own pocket for your prescription drugs? (n=780)

	<u>%</u>
Less than \$10 per month	8
\$10 but less than \$50 per month	31
\$50 but less than \$100 per month	23
\$100 but less than \$200 per month	15
\$200 but less than \$500 per month	12
\$500 or more per month	2
I did NOT spend money out of my own pocket for my prescription drugs	4
Not sure	2
No Response	3

9. Many people face difficult decisions when buying prescription drugs. In the past 12 months, have you done any of the following: (n=780)

	Yes ▼	No ▼	No Response ▼
a. Delayed getting a prescription filled because you didn't have enough money to pay for it?	14%	83%	3%
b. Taken less medicine than your doctor prescribed to make it last longer?	17%	80%	4%
c. Cut back on items such as food, fuel, or electricity to be able to afford a prescription drug?	10%	87%	3%
d. Decided not to fill a prescription because of the cost of the drug?.....	17%	79%	4%
e. Ordered your prescription drugs by mail or Internet from a company <u>in the U.S.</u> because they cost less?.....	19%	77%	4%
f. Ordered your prescription drugs by mail or Internet from a company in <u>another country</u> because they cost less?	6%	91%	3%
g. Traveled to Mexico, Canada, or another country to purchase prescription drugs because they cost less?.....	5%	92%	3%
h. Shopped around for the best price?.....	29%	67%	4%
i. Asked your doctor or pharmacist for generic prescription drugs instead of brand name drugs when generics are available?	62%	35%	3%

10. Even if you have not taken prescription drugs in the past 12 months, how important is it to you that the state of California work toward making prescription drug costs more affordable to residents like yourself?

	<u>%</u>
Extremely important	56
Very important	26
Somewhat important	9
Not very important	2
Not at all important	1
Not sure	1
No Response	5

11. How strongly would you support or oppose a state prescription drug discount program in California for low-income persons even if you may not be eligible to receive its benefits?

	<u>%</u>
Strongly support	60
Somewhat support	21
Neither support nor oppose	11
Somewhat oppose	2
Strongly oppose	2
Not sure	3
No Response	2

- 12. The state of California is considering ways to help make prescription drugs more affordable to residents. One option would be to ask pharmacies or drug manufacturers to enter into a rebate agreement with the state. This agreement would allow the state to buy large quantities of prescription drugs at prices below the average wholesale price, and sell them to the consumer for a discounted price. Enrollment in this program would be voluntary for individuals who earn \$32,000 or less or couples who earn \$43,000 or less each year and there would be no fee to join.**

How strongly would you support or oppose putting a state prescription drug program like this into effect?

	<u>%</u>
Strongly support	54
Somewhat support	21
Neither support nor oppose	10
Somewhat oppose	2
Strongly oppose	3
Not sure	8
No Response	3

- 13. How important is it to you that consumers like yourself have information available that would allow you to compare the safety, effectiveness, and cost of their prescription drugs?**

	<u>%</u>
Extremely important	52
Very important	32
Somewhat important	11
Not very important	2
Not at all important	1
Not sure	1
No Response	2

- 14. How strongly would you support or oppose the federal government making it easier for people to buy prescription drugs from Canada?**

	<u>%</u>
Strongly support	44
Somewhat support	23
Neither support nor oppose	19
Somewhat oppose	2
Strongly oppose	3
Not sure	7
No Response	3

15. If the federal government were to make it legal for individual citizens to buy prescription drugs from Canada at lower costs, other laws could be passed to either allow or prohibit states from purchasing prescription medications this way. If legal on a federal level, how strongly would you support or oppose the state of California being able to purchase prescription drugs from Canada?

	<u>%</u>
Strongly support	47
Somewhat support	21
Neither support nor oppose	14
Somewhat oppose	2
Strongly oppose	4
Not sure	9
No Response	3

Caregiving

16. A caregiver can be anyone who provides unpaid help to a relative or friend who is ill, disabled, or elderly. A caregiver could help that other person by providing financial assistance, running errands, doing household chores, or with personal care and grooming.

Are you currently providing this type of care to someone?

	<u>%</u>
Yes	16
No → SKIP TO QUESTION 22	80
No Response	4

17. How many adults do you provide this type of care for? (n=142)

	<u>%</u>
1	70
2	20
3 or more	7
No Response	4

18. What is/are their relationship to you? (CHECK ALL THAT APPLY) (n=142)

<u>%</u>		<u>%</u>		<u>%</u>	
17	Spouse	5	Daughter	20	Friend/Neighbor
2	Partner	4	Mother-in-law	1	Grandmother
11	Father	2	Father-in-law	0	Grandfather
32	Mother	3	Brother	12	Other (specify):
4	Son	7	Sister		_____
				3	No Response

19. Do they live in your household? (n=142)

<u>%</u>		
35	Yes	
61	No	19a. IF NO, do those you provide care for live: (n=87)
4	No Response	42% within 5 miles of your home
		15% between 5 and 10 miles of your home
		9% between 11 and 15 miles of your home
		10% between 16 and 25 miles of your home
		19% more than 25 miles from your home
		5% no response

20. Do they receive paid help from: (n=142)

	Yes ▼	No ▼	No Response ▼
An aide or nurse hired through an agency or service	15%	74%	11%
An aide or nurse hired independently or privately – <i>not</i> through an agency or service.....	14%	67%	19%
A housekeeper to clean or cook	21%	63%	17%

21. As a caregiver, would you like to have more help or information on: (N=142)

	Yes ▼	No ▼	No Response ▼
Keeping the person(s) I care for safe at home	58%	31%	12%
Easy activities I can do with the person(s) I care for.....	43%	41%	16%
Balancing my work and family responsibilities	40%	45%	15%
Finding time for myself.....	47%	38%	15%
Choosing an assisted living facility or nursing home	44%	41%	16%
Choosing a home care agency.....	45%	41%	15%
How to talk with doctors and other healthcare professionals	38%	45%	16%
Managing my emotional and physical stress	54%	35%	11%
Making end-of-life decisions	41%	44%	16%

Nursing Home Care

22. How much of a priority do you think it should be for AARP California to work to improve the quality of nursing homes in California?

	<u>%</u>
Top priority	53
High priority	33
Medium priority	9
Low priority	1
Not a priority	1
Not sure	2
No Response	2

23. How strongly would you support or oppose legislation in California to strengthen the enforcement of state standards to protect the health, safety, and rights of nursing home residents?

	<u>%</u>
Strongly support	79
Somewhat support	14
Neither support nor oppose	3
Somewhat oppose	*
Strongly oppose	*
Not sure	2
No Response	1

24. California is considering legislation to improve the overall quality of nursing home care, patients' rights, access to care, and the accountability of those who do not comply with the proposed standards. Please indicate to what extent you would support or oppose each of the following features of this bill.

	Strongly Support	Somewhat Support	Neither Support nor Oppose	Somewhat Oppose	Strongly Oppose	Not Sure	No Response
	▼	▼	▼	▼	▼	▼	▼
a. Establish a state-wide complaint response system.....	65%	21%	6%	*	1%	2%	4%
b. Establish a "first come, first serve" standard to prevent discrimination against nursing home applicants on Medi-Cal.....	46%	26%	14%	2%	2%	6%	5%
c. Strengthen patient's rights.....	68%	21%	5%	*	*	1%	5%
d. Enforce safety and quality standards with citations, fines, or license revocation for nursing homes that violate those standards.....	79%	14%	2%	1%	*	1%	3%

25. If a candidate for state office in California supported legislation that improves the quality of nursing home care and protecting residents' rights, how likely would you be to vote for that candidate?

	<u>%</u>
Much more likely	56
Somewhat more likely	28
Would not make a difference	9
Somewhat less likely	*
Much less likely	*
Not sure	4
No Response	2

Personal Concerns

26. Below is a list of concerns that have been expressed by people age 50 and older. Please check the box that most closely matches your level of concern about each item.

	Extremely concerned	Very concerned	Somewhat concerned	Not very concerned	Not at all concerned	No Response
	▼	▼	▼	▼	▼	▼
a. Having Social Security as a base for retirement income.....	58%	21%	12%	3%	3%	3%
b. Affording the cost of prescription drugs.....	47%	29%	16%	4%	1%	3%
c. Continuing to drive safely.....	39%	33%	17%	4%	3%	4%
d. Staying physically active.....	50%	31%	11%	3%	1%	4%
e. Facing age discrimination in employment.....	28%	21%	22%	13%	12%	5%
f. Affording my housing costs.....	45%	21%	17%	8%	6%	5%
g. Having high quality long-term care for myself or a family member.....	51%	26%	14%	4%	3%	3%
h. Making good financial decisions.....	46%	30%	14%	4%	2%	3%
i. Being able to get to where I need and want to go if I could not drive.....	45%	31%	15%	4%	2%	3%
j. Having Medicare as a base for retirement health insurance.....	54%	25%	12%	3%	2%	4%
k. Affording the cost of my utility services.....	40%	26%	18%	9%	4%	4%
l. Having long-term care services that would allow me or my family member to stay at home as long as possible.....	55%	25%	11%	4%	2%	3%
m. Affording health insurance.....	61%	21%	10%	3%	2%	3%
n. Assuring my pension benefits and retirement savings are safe.....	68%	17%	8%	2%	2%	3%

o.	Affording the cost of health care	63%	22%	7%	3%	1%	4%
p.	Having good employment opportunities	23%	20%	20%	14%	16%	6%
q.	Being able to stay in my own home as I get older.....	57%	23%	9%	5%	3%	3%
r.	Avoiding consumer fraud that could threaten my savings	56%	20%	12%	6%	2%	4%
s.	Affording the cost of long-term care.....	53%	24%	14%	4%	3%	3%
t.	Having enough money to meet daily living expenses	53%	20%	13%	8%	4%	3%

About You

The following questions are for classification purposes only and will be kept entirely confidential.

D1. Were you registered to vote for the last state elections?

	<u>%</u>
Yes	88
No	7
No Response	6

D2. Thinking about your state elections for California's Governor and Legislators in the last ten years, how often would you say you vote?

	<u>%</u>
Always	71
Most of the time	14
About half of the time	3
Seldom	3
Never	3
No Response	6

D3. How would you characterize your political views?

	<u>%</u>
Conservative	27
Moderate	41
Liberal	19
None of the above	5
No Response	8

D4. Do you consider yourself to be a Democrat, a Republican, an Independent, or something else?

	<u>%</u>
Democrat	46
Republican	26
Independent	11
Other	4
Not sure	5
No Response	8

D5. How interested are you in California's state government activities that affect residents age 50 and older?

	<u>%</u>
Extremely interested	49
Very interested	33
Somewhat interested	9
Not very interested	1
Not at all interested	*
Not sure	1
No Response	6

D6. Do you have access to a personal computer at home, at work, or some other place?

	<u>%</u>
Yes	68
No	25
No Response	7

D7. Have you applied for the new Medicare Prescription Discount Card?

4% Yes
 87% No
 9% No Response

D7a. If NO: Are you going to apply for this card? (n=766)

16% Yes 30% No 40% Not sure 13% No Response

D8. What is your current marital status?

	<u>%</u>
Now married	43
Not married, living with partner	4
Widowed	23
Divorced	18
Separated	2
Never married	4
No Response	6

D9. What is the highest level of education that you completed?

	<u>%</u>
Less than high school	4
High school graduate or equivalent	14
Some college or technical training beyond high school	38
College graduate (4 years)	18
Post-graduate or professional degree	19
No Response	7

D10. Which of the following best describes your current employment status?

	<u>%</u>
Employed or self-employed <u>full-time</u>	24
Employed or self-employed <u>part-time</u>	12
Retired and not working	52
Other such as homemaker	3
Unemployed and looking for work	3
No Response	7

D11. What is your race?

	<u>%</u>
White or Caucasian	75
Black or African American	6
Hispanic, Spanish, Latino	6
Asian	3
Native American or Alaskan Native	1
Other: _____	1
No Response	9

D12. What was your annual household income before taxes in 2004?

	<u>%</u>
Less than \$10,000	6
\$10,000 to \$19,999	14
\$20,000 to \$29,999	15
\$30,000 to \$39,999	12
\$40,000 to \$49,999	10
\$50,000 to \$74,999	14
\$75,000 or more	20
No Response	9

D13. What is your age as of your last birthday? _____ years

	<u>%</u>
50-59	26
60-74	43
75+	28
No Response	3

D14. Are you male or female?

	<u>%</u>
Male	43
Female	56
No Response	1

D15. What is your 5-digit zip code? WRITE IN YOUR ZIP CODE _____

D16. What county do you live in? _____

D17. Do you own or rent a home?

	<u>%</u>
Own	74
Rent	18
Neither	6
No Response	3

Thank you for completing this survey.

Please use the postage-paid envelope and return it no later than July 29, 2005 to State Member Research, AARP, 601 E Street, NW, Washington, DC 20049.

AARP
Knowledge Management
For more information please contact
Jennifer H. Sauer (202) 434-6207