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Perceptions & Opinions of Assisted Living: A Survey of AARP Members in Pennsylvania

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Perceptions & Opinions of Assisted Living: A Survey of AARP Members in Pennsylvania

**Report Prepared by Katherine Bridges and
David Cicero**

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AARP is a nonprofit, nonpartisan membership organization dedicated to making life better for people 50 and over. We provide information and resources; engage in legislative, regulatory and legal advocacy; assist members in serving their communities; and offer a wide range of unique benefits, special products, and services for our members. These include *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *AARP Segunda Juventud*, our quarterly newspaper in Spanish; *NRTA Live and Learn*, our quarterly newsletter for 50+ educators; and our Web site, www.aarp.org. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

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Background

Assisted living is the fastest growing type of senior housing in the United States with an estimated 15 to 20 percent annual growth rate over the last few years.¹ According to a recent industry estimate, assisted living accounted for 75 percent of new senior housing in 1998.² For frail older persons and adults with disabilities who need some assistance to live independently, or who no longer want to remain at home, assisted living provides an option for meeting their personal and supportive care needs.

However, the definition of an assisted living facility is somewhat unclear. For the purpose of this study, assisted living facilities are defined as facilities that “provide personal care service, including some limited health care services, like monitoring medications and physical therapy, with 24-hour supervision, in an apartment-like setting.” Federal law does not regulate assisted living programs nor does it impose minimum standards of care. Current Pennsylvania law makes no distinction between assisted living facilities and personal care homes, despite differences in the services they sometimes provide.

Consumer advocates, providers, and regulators alike are raising questions about the need for standards to preserve and enhance assisted living residents’ autonomy, maintain residents’ dignity, and create a setting where residents may age in place. AARP supports legislation designed to improve assisted living programs and to ensure a consistent quality of all non-nursing home alternatives.

This report is a section of a larger survey designed to explore the attitudes and opinions of AARP Pennsylvania members with regard to a variety of legislative issues. The report focuses on the questions concerning assisted living facilities including:

- Members’ preference for long-term care
- Importance to members of staying in assisted living rather than going to a nursing home should their needs change
- Members’ understanding/impressions of assisted living programs in comparison to other long-term care alternatives
- Support for legislation related to assisted living facilities.

¹ *The Assisted Living Sourcebook*, 1998. National Center for Assisted Living. American Health Care Association (AHCA), 1998.

² *Trends and Data: Aging Housing and Services Field*. American Association of Homes and Services for the Aging, 1999.

Methodology

This mail survey explores the opinions of Pennsylvania AARP members. The survey includes questions about state legislative issues, assisted living, long-term care, and nursing homes.

AARP conducted the *2003 AARP Pennsylvania Legislative Issues Survey* from April-June 2003. Researchers at AARP randomly selected 2,000 AARP members in Pennsylvania making sure to select the appropriate proportion from each of three age groups: 50-59, 60-74, and 75+. Each selected member received a pre-notification postcard, the survey itself, a reminder postcard, and a second survey. 1,197 members returned the survey, making the response rate 60 percent. The sample was weighted by age group to represent the actual composition of AARP members in Pennsylvania. The sampling error for this study was 2.83 percent.

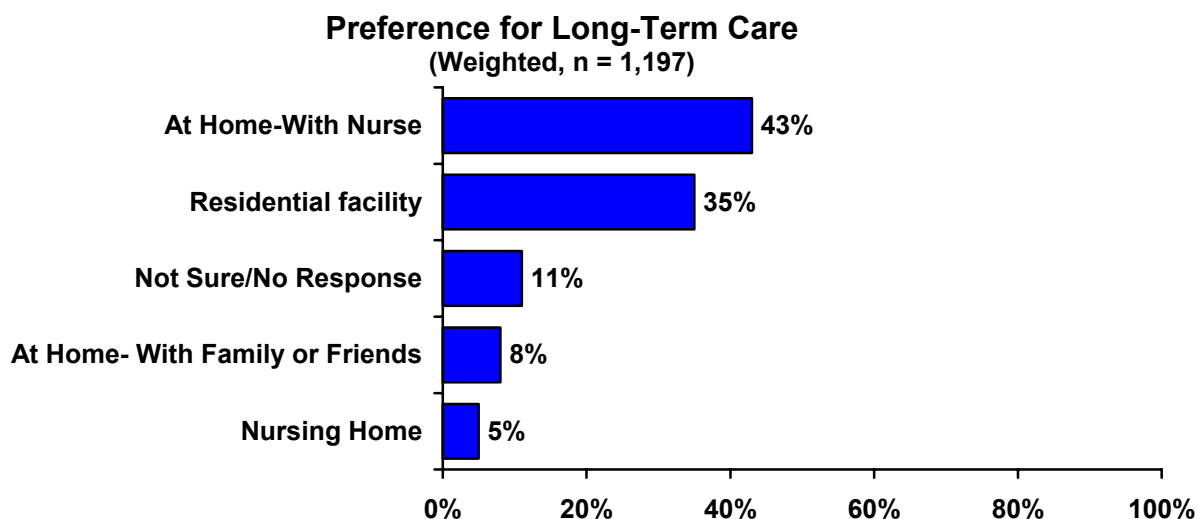
Although the survey contains questions on a variety of topics, this report focuses exclusively on those questions directly related to assisted living. There are currently 1,768,439 AARP members in Pennsylvania. Due to the large population of AARP members in Pennsylvania, a relatively small percentage of people with a particular experience or opinion can represent a large number of people in Pennsylvania.

Findings

Among out-of-home options for long-term care, members indicate residential facilities as their first choice for themselves or family.

After reading a description of long-term care and being given several options, members most often say they would prefer to receive long-term care for themselves or a family member at home with assistance from a nurse or personal care aid. However, among out-of-home options, Pennsylvania members most frequently would choose to have care provided in a residential facility, such as an apartment-like location where housing, food, and personal care such as help with bathing and dressing are provided for residents in a community setting. Over a third indicates this option to be their first choice, while only five percent would choose a nursing home.

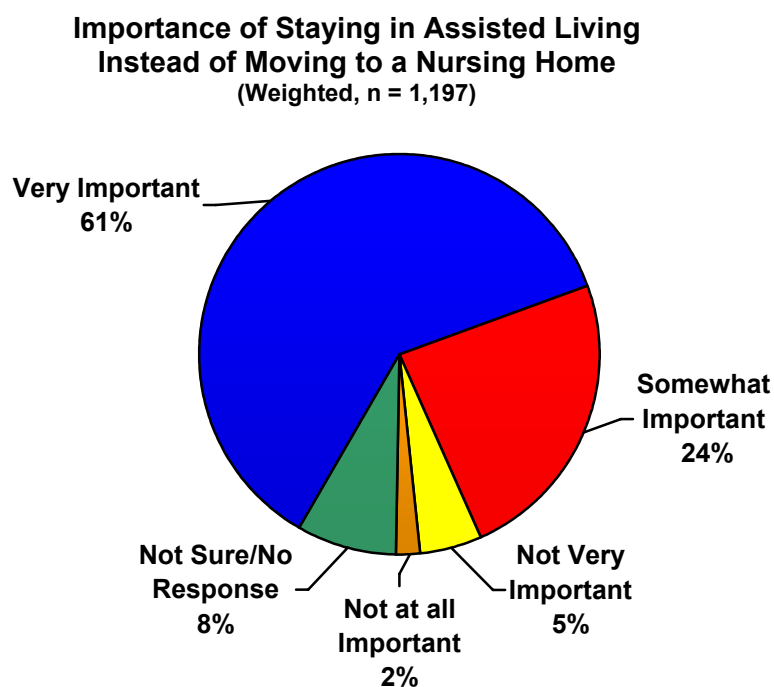
The top two choices are more often preferred by younger members (home with professional care: 49% 50-59 vs. 41% 60-74; residential care: 38% 50-59 & 37% 60-74 vs. 30% 75+. Although the least favorite of all members, older members are more likely to choose nursing home care compared to younger members (10% 75+ vs. 2% 50-59 & 4% 60-74).



The majority of members say it would be important to them to be able to stay in assisted living rather than move to a nursing home if their need for services changed.

Nearly nine in ten Pennsylvania members say if they were in an assisted living facility and their need for services changed it would be very or somewhat important for them to stay in the same facility instead of moving to a nursing home. This finding reflects their strength of preference for assisted living over nursing homes.

A larger percentage of members age 50-74 say this would be important to them compared to members age 75+ (89% 50-50 & 87% 60-74 vs. 82% 75+). Additionally, women are more likely than men to say this would be important to them (89% vs. 84%).



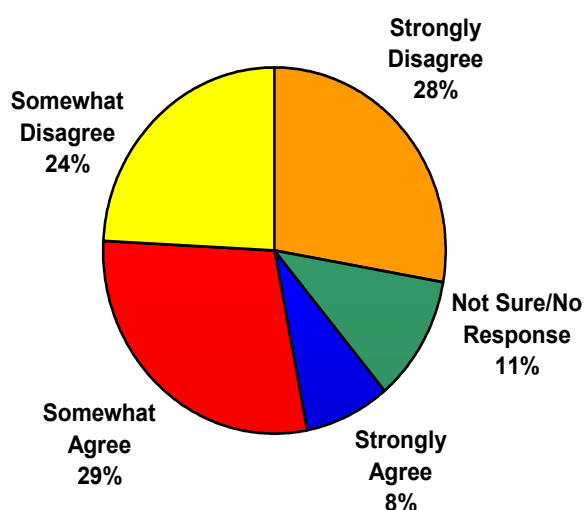
Pennsylvania members are confused about the differences in long-term care options.

In an effort to gauge what services Pennsylvania members think assisted living facilities actually provide, members were asked how similar they think assisted living facilities are to nursing homes and personal care homes.

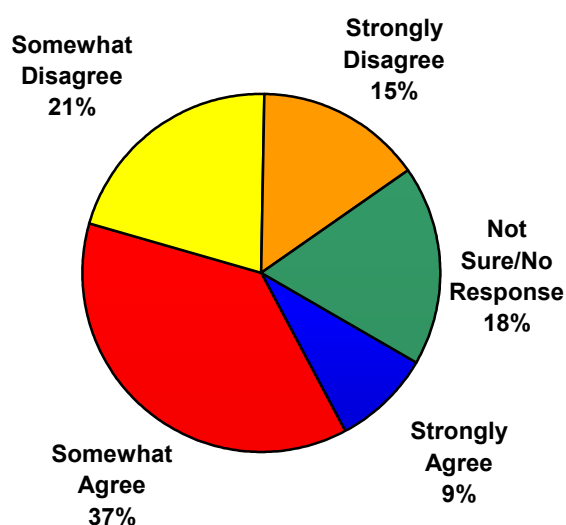
Members tend to see a greater difference between assisted living and nursing homes than they do between assisted living and personal care homes. However, there is still considerable uncertainty. Over half say there is a difference between assisted living facilities and nursing homes, while just over a third says there is a difference between assisted living facilities and personal care homes. Nearly one half thinks assisted living facilities are the same as personal care homes.

Younger members are more likely to consider assisted living facilities to be different than nursing homes (60% of members 50-59 disagree with the statement compared to 47% of those 75+). Similarly, members with incomes greater than \$20,000 a year are more likely than those with lower incomes to consider the two to be different (35% vs. 59%).

**Level of Agreement that an Assisted Living Facility is the Same as a Nursing Home
(Weighted, n = 1,197)**



**Level of Agreement that an Assisted Living Facility is the Same as a Personal Care Home
(Weighted, n = 1,197)**



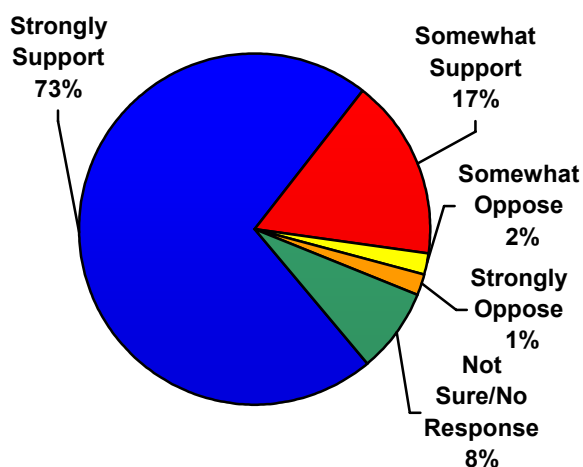
It is difficult to discern whether members are unaware of the differences among options, or if they view loss of complete autonomy as the same regardless of the setting. Regardless, there is considerable confusion among Pennsylvania AARP members about long-term care options.

At least three-quarters of Pennsylvania members support legislation to improve quality standards and residents' rights in assisted living facilities.

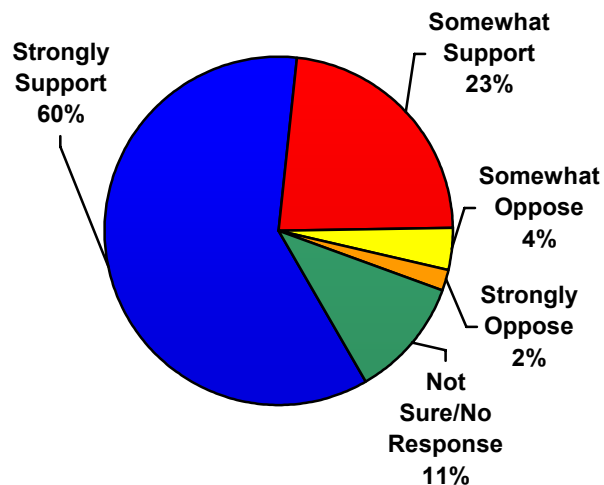
Although Pennsylvania members may not be aware of the difference between assisted living facilities and personal care homes, they overwhelmingly support legislation to improve quality standards and residents rights in assisted living facilities. The highest percentage of Pennsylvania members support legislation that would require assisted living facilities that advertise that they provide a special care environment for persons with Alzheimer's disease or other dementia to meet a specific set of standards for care and staffing levels.

Nearly nine out of ten members also support legislation that would define minimum standards for a facility to call itself assisted living. Only six percent oppose this legislation. This particular legislation would define the parameters of assisted living facilities. It would delineate what services assisted living facilities are legally permitted to provide and what services they are legally obligated to provide.

Support for Legislation to Define a Specific Set of Care Standards for Facilities that Advertise Special Care for Residents with Dementia or Alzheimer's
(Weighted, n = 1,197)

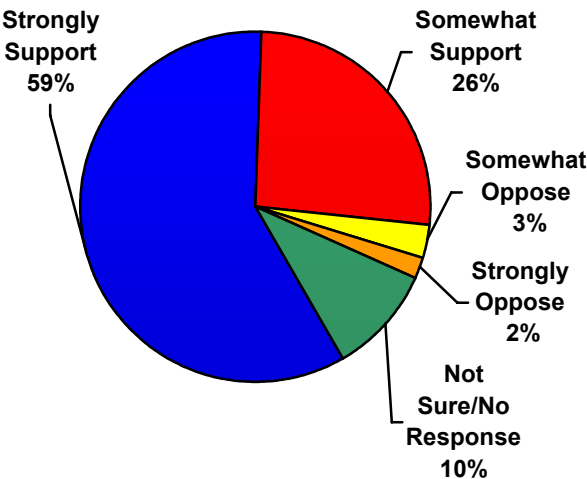


Support for Legislation for Minimum Quality Standards for Assisted Living Facilities
(Weighted, n = 1,197)

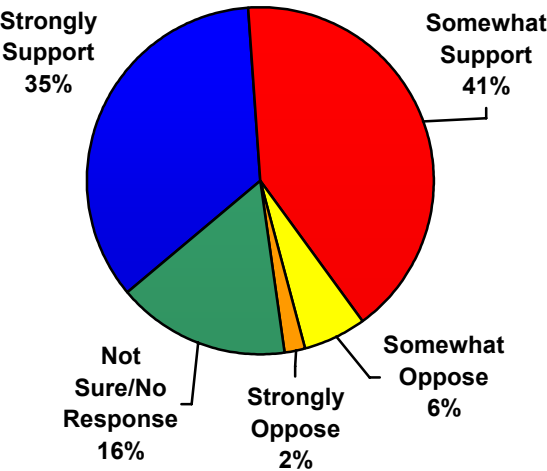


Currently, in Pennsylvania, assisted living facility residents do not have the right to appeal the facility’s decisions to a government agency or court. Eighty five percent of members support legislation that would grant residents this right, while only five percent oppose. Moreover, more than three quarters of Pennsylvania members support legislation that would require assisted living facilities to provide private accommodations for residents. Less than one in ten members opposes the legislation.

Support for Legislation to Give Assisted Living Residents the Right to Appeal Decisions Affecting Them
(Weighted, n = 1,197)



Support for Legislation to Require Assisted Living Facilities to Offer Private Accommodations
(Weighted, n = 1,197)



As shown below, younger members are more likely than older members to support each of these legislative proposals.

Percent of Members That Strongly or Somewhat Support Assisted Living Legislation by Age

Legislative Proposal	Total (N=1,197)	Member Age		
		50-59 (n=313)	60-74 (n=479)	75+ (n=325)
Specific set of care standards for facilities that advertise special care for residents with dementia or Alzheimer’s	90%	94%	92%	86%
Minimum quality standards for assisted living facilities	83	89	84	80
Give assisted living residents the right to appeal decisions affecting them	85	87	89	80
Require facilities to offer private accommodations	76	82	78	73

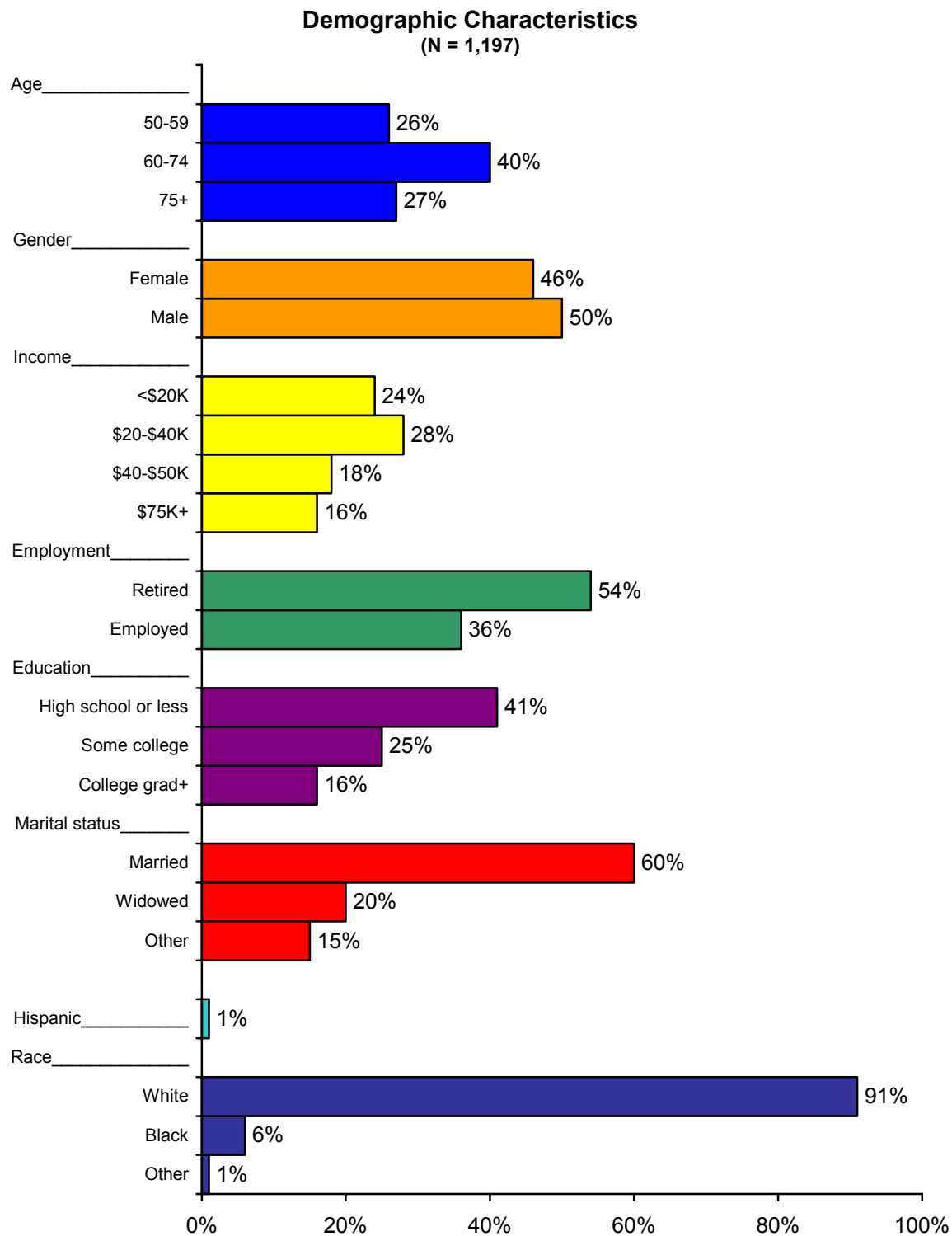
Conclusion

Generally, more Pennsylvania members believe assisted living facilities are like a personal care home than a nursing home. Members' understanding of assisted living facilities is reflected in Pennsylvania state law which subjects assisted living facilities to the same regulations as personal care homes. However, assisted living facilities tend to be designed for people in greater need of care than personal care homes and often provide services such as physical therapy and monitoring medications.

Although Pennsylvania members are uncertain about the differences in long-term care options, they clearly prefer assisted living facilities to nursing homes. Seven-times as many members would choose residential facilities than nursing homes for themselves or family members. Moreover, eighty-five percent indicate that, if they lived in an assisted living facility, it would be important for them to stay in assisted living should their need for care change.

Pennsylvania members overwhelmingly support legislation designed to define and regulate assisted living facilities. This legislation should set minimum standards for assisted living residences and define the differences between assisted living residences and nursing homes on one end of the spectrum and assisted living residences and personal care homes on the other. Older citizens and their families need to understand their long-term care alternatives as well as to be assured that they will receive satisfactory care from a competent staff should they choose assisted living.

Demographic Profile of the Members



Appendix A
2003 AARP Pennsylvania
Legislative Issues Survey
Annotated Questionnaire

2003 AARP Pennsylvania Legislative Issues Survey

WEIGHTED N = 1,197, RESPONSE RATE = 60%, SAMPLING ERROR = +/- 2.83%
 (Percentages may not add to 100% due to rounding or multiple responses. A “*” means less than 1%.)

State Legislative Issues

1. To be effective, AARP Pennsylvania wants to work on the most important issues facing Pennsylvania 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 Pennsylvania?

		Top Priority	High Priority	Medium Priority	Low Priority	Not A Priority	Not Sure	No Response
a	Availability, cost, and quality of health care	70	23	4	1	1	1	1
b	Consumer protection standards on home loans	12	26	29	14	11	5	3
c	Utility services and rates	33	36	21	5	1	1	3
d	How older persons can remain in their own homes or communities as they age	49	33	13	2	1	1	2
e	Consumer protection standards for health insurance including managed care plans	57	30	8	2	1	1	2
f	Availability, cost, and quality of long-term care services	47	35	12	2	1	1	2
g	Assistance programs for older, low-income state residents	36	35	21	3	2	1	2
h	Expanding Medicaid to help finance long-term care services for eligible individuals	39	31	19	4	2	2	3
i	Defining minimum standards for a facility calling itself assisted living	32	37	22	4	1	2	3
j	Availability of transportation systems	21	30	31	11	3	2	2
k	Access to affordable prescription drugs	73	19	5	1	1	1	1
l	Legal rights for grandparents	18	19	30	14	11	4	3
m	Protections for older workers	28	32	23	8	5	2	4
n	Access to affordable long-term care insurance	38	33	18	4	3	2	2

Assisted Living

2. How strongly do you agree or disagree with the following statement: “In my opinion, an assisted living facility is just the same as a nursing home?”

%	
8	Strongly agree
29	Somewhat agree
24	Somewhat disagree
28	Strongly disagree
8	Not sure
3	No Response

3. How strongly do you agree or disagree with the following statement: “In my opinion, an assisted living facility is just the same as a personal care home?”

%	
9	Strongly agree
37	Somewhat agree
21	Somewhat disagree
15	Strongly disagree
15	Not sure
3	No Response

Long-term care services are offered in different settings in Pennsylvania.

Nursing homes provide care 24-hours a day, 7 days a week. This includes full medical care and usually takes place in an institutional setting, in a shared room.

Personal care homes provide some personal care services such as bathing and dressing but not medical care, in a residential setting.

Assisted living facilities provide personal care services, including some limited health care services, like monitoring medications and physical therapy, with 24-hour supervision, in an apartment-like setting.

4. There has been a rapid growth of facilities that call themselves an “assisted living facility” in Pennsylvania over the last few years. The federal government does not regulate assisted living facilities. In Pennsylvania, assisted living facilities are regulated like personal care homes. There are no laws in Pennsylvania that define what an assisted living facility should be.

4. (continued) How strongly do you support or oppose legislation in Pennsylvania to define minimum quality standards for a facility to call itself assisted living? Do you...?

<u>%</u>	
60	Strongly support
23	Somewhat support
4	Somewhat oppose
2	Strongly oppose
8	Not sure
3	No Response

5. How strongly do you support or oppose legislation in Pennsylvania that requires assisted living facilities to provide private accommodations?

<u>%</u>	
35	Strongly support
41	Somewhat support
6	Somewhat oppose
2	Strongly oppose
12	Not sure
4	No Response

6. If you were in an assisted living facility in Pennsylvania and your need for services changed, how important would it be for you to stay in the same facility and get all the services you needed instead of moving to a nursing home? Would it be...?

<u>%</u>	
61	Very important
24	Somewhat important
5	Not very important
2	Not at all important
5	Not sure
3	No Response

7. How strongly do you support or oppose legislation in Pennsylvania to require assisted living facilities that advertise that they provide a special care environment for persons with Alzheimer's disease or other dementia to meet a specific set of standards for care and staffing levels?

<u>%</u>	
73	Strongly support
17	Somewhat support
2	Somewhat oppose
1	Strongly oppose
5	Not sure
3	No Response

8. Currently, in Pennsylvania, assisted living facility residents do not have the right to appeal the facility's decisions to a government agency or court. How strongly do you support or oppose legislation in Pennsylvania to give assisted living facility residents the right to appeal decisions affecting them, such as being discharged from a facility? Do you...?

<u>%</u>	
59	Strongly support
26	Somewhat support
3	Somewhat oppose
2	Strongly oppose
7	Not sure
3	No Response

Long-Term Care

Long-term care refers to care provided over an extended period of time at home, in a community setting, or in a nursing home. People of all ages who are frail, ill, or disabled who need assistance with regular daily activities, such as getting dressed, bathing, preparing meals, or eating may receive long-term care services.

9. Based on the definition above, which care option would you prefer for yourself or a family member needing long-term care?

<u>%</u>	
8	Have family and friends provide all the care at home
43	Have a nurse or a personal care aide to provide care at home
35	Have care provided in a residential facility, such as an apartment-like location where housing, food, and personal care such as help with bathing and dressing are provided for residents in a community setting
5	Have care provided in a nursing home
9	Not sure
2	No Response

10. Have you and your family discussed your preferences regarding long-term care services?

<u>%</u>	
32	Yes
63	No
3	Not sure
3	No Response

11. If you or a family member needed long-term care services, where would you be most likely to find out about these services?

Please check your **top three** choices only.

<u>%</u>		<u>%</u>	
47	Family/friend	48	Physician
3	Newspaper advertisement	9	Clergy
48	Area Agency on Aging	24	Hospital Discharge Planner
37	AARP	7	Internet
23	State Department of Aging	4	Other:_____
5	Telephone book	2	Not sure
		2	No Response

12. If you needed services in your community for you or a family member, how easy or hard do you think it would be to...

		Very Easy	Somewhat Easy	Somewhat Hard	Very Hard	Not Sure	No Response
a	Find the appropriate long-term care services <u>when</u> it was needed?	5%	35%	36%	10%	10%	4%
b	Find the appropriate long-term care services in your community or <u>within a reasonable distance from your home?</u>	8%	36%	33%	9%	8%	6%
c	Find the appropriate long-term care services <u>that you were able to afford?</u>	3%	12%	32%	36%	10%	5%

13. In the past five years, have you or a family member used any of the following long-term care services? Check ALL that apply.

<u>%</u>	
19	Lived in a nursing home
11	Lived in a residential care facility
22	Lived at home while receiving visits from skilled health professionals
13	Lived at home while receiving help with daily activities or personal care tasks from a health aide
25	Lived at home while receiving help from family or friends
2	Attended adult day care
8	Not sure
43	No Response

- 14. How strongly do you support or oppose AARP in Pennsylvania advocating for the development and expansion of long-term care services that enable people to remain in their own homes or communities, even if it meant reducing funds from other health and aging services?**

<u>%</u>	
34	Strongly support
30	Somewhat support
12	Somewhat oppose
10	Strongly oppose
12	Not sure
2	No Response

Nursing Homes

- 15. In the last five years, have you or a family member spent time in a nursing home or other residential care facility because you could not access long-term care services at home or within the community?**

<u>%</u>	
12	Yes
80	No
3	Not sure
6	No Response

- 16. If you needed to live in a nursing home, which costs about \$65,000 a year in Pennsylvania, how confident are you that you could afford the cost of care for a year?**

<u>%</u>	
14	Very confident
10	Somewhat confident
16	Not very confident
52	Not at all confident
4	Not sure
4	No Response

Long-Term Care Insurance

17. Some people 50 and older express worry about being able to afford long-term care services for themselves and their family. How worried are you about it?

%	
30	Very worried
34	Somewhat worried
17	Not very worried
11	Not at all worried
4	Not sure
4	No Response

18. Do you currently own a private long-term care insurance policy (not Medicare or Medigap) which would pay for nursing home care, assisted living, or in-home care? (Medicare and Medigap do not pay for nursing home, assisted living, or in-home care services for a long-term illness).

%	
13	Yes
80	No
3	Not sure
4	No Response

19. Would you consider buying a long-term care insurance policy? (Just for your information, the average yearly premium cost in 1999 for a comprehensive long-term care insurance plan for a person 50 years old was about \$1,080 per year and a person 65 years old was \$2,130 per year.)

%	
18	Yes [Skip to Question 21]
44	No
26	Not sure
11	No Response

20. Why would you not purchase long-term care insurance? (N=977)

%	
4	You have other resources to pay for long-term care
6	You do not think current long-term care insurance policies cover enough of the expenses
5	Your family will take care of your long-term care needs
2	Medicare will cover your long-term care costs
45	Long-term care insurance policies cost too much
2	Medicaid will cover your long-term care costs
11	It is not something you have ever thought about
5	You don't think you will need long-term care
14	You don't really understand what the insurance policy covers
20	No Response

About You

The following questions are for classification purposes.

21. Are you male or female?

<u>%</u>	
50	Male
46	Female
4	No Response

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

<u>%</u>	
26	50-59
40	60-74
27	75+
7	No Response

23. What is your current marital status?

<u>%</u>	
60	Married
1	Living with a partner
20	Widowed
7	Divorced
1	Separated
6	Never Married
5	No Response

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

<u>%</u>	
7	Less than high school
34	High school graduate or equivalent
25	Some college or technical training beyond high school
13	College graduate (4 years)
15	Post graduate or professional degree
6	No Response

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

<u>%</u>	
26	Employed or self employed <u>full-time</u>
11	Employed or self-employed <u>part-time</u>
54	Retired and not working
5	Other such as homemaker
1	Unemployed and looking for work
5	No Response

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

<u>%</u>		
57	Yes	→ If YES: Do you have access to the Internet or the ability to use online services such as America Online (AOL)? (n=685)
40	No	
3	No Response	
86% Yes 7% No 2% Don't Know 5% No Response		

27. Within the last 5 years, in which of the following activities have you participated? (Check all that apply)

<u>%</u>	
31	Phoned, written, or sent e-mail to a public official to make your views known on an issue
22	Contributed money to a candidate or political party
6	Volunteered to work on a campaign for a particular candidate or party
12	Written a letter or e-mail to a newspaper or called a radio or TV show to make your views known on an issue
20	Attended a political event or town meeting
7	Volunteered with a group working to influence local, state, or national government
48	I have done NONE of these activities in the last 5 years
3	No Response

28. What is your race?

<u>%</u>	
91	White or Caucasian
6	Black or African American
*	Asian
*	Native American or Alaskan Native
*	Hawaiian or Pacific Islander
1	Other
2	No Response

29. Are you Hispanic, Spanish, or Latino?

<u>%</u>	
1	Yes
85	No
*	Don't Know
13	No Response

30. What is your 5-digit zip code?
WRITE IN YOUR ZIP CODE ____ ____ ____ ____ ____

31. What was your annual household income before taxes in 2002?

<u>%</u>	
7	Less than 10,000
18	\$10,000 to \$19,999
16	\$20,000 to \$29,999
13	\$30,000 to \$39,999
18	\$40,000 to \$49,999
16	\$40,000 to \$49,999
14	\$75,000 or more
14	No Response

Thank you for completing this survey. Please use the postage-paid envelope and return it to State Member Research, AARP, 601 E Street, NW, Washington, DC 20049, by May 28, 2003.

AARP
Knowledge Management
For more information please contact Katherine Bridges (202)434-6329