

The CLTC Leadership Summit

Shaping the Future

September 12 & 13, 2022
Sheraton Bloomington Hotel
Minneapolis, MN



Following the Journey of Family Caregivers: Findings from a Survey of Home-Based Caregivers

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homethrive

Research Objectives

- What challenges do family caregivers confront?
- How do caregivers decide whether or not to use paid care?
- How can we better support the needs of all caregivers?
- How does the experience of family caregivers who use paid vs home care differ?
- How does the care journey differ for family caregivers who are also working?
- Does the experience of being a caregiver raise awareness of the need to plan ahead for one's own future LTC needs?



Methodology

- Online survey, 10-15 minute interview length
- Panel and platform provided by vendor partner
- Sample specifications:
 - Family caregiver age 18+ with N=200 who used paid care at home and N=200 who did not
- Excellent results





Key take-aways – All Respondents

- **Type of help most typically provided**
 - Emotional support (80%)
 - Making care decisions (67%)
 - Help with IADLs (58%-67%)
- **Most difficult tasks for family caregivers**
 - Paying for care (58%)
 - Helping with ADLs (56%)
 - Making care decisions (46%)
- **Biggest challenges families face**
 - Getting emotional support (33%)
 - Taking time off work (32%)
 - Coordinating with MDs and other providers (32%)



Key take-aways: Home Care Users

- **Most important reason family caregivers cite for using paid home care:**
 - Lack expertise to provide needed care (18%)
 - Burnt out (18%)
 - Worried about their job/paying enough attention to work (15%)
- **Most significant challenge encountered in using paid home care:**
 - Cost (20%)
 - Worker no-show (20%)
 - Family stress having stranger in the house (15%)



Key take-aways #2 – Non-Home Care Users

- **Most important reason for NOT using paid home care:**
 - Felt it was my duty to provide care (27%)
 - Loved one didn't want stranger around (14%)
 - Couldn't afford (14%)
- **What would have been easier if you had paid home care help?**
 - Time to relax/enjoy life (48%)
 - Dealing with emotional strain of caregiving (44%)
 - Take better care of myself (35%)
- **If you had it to do over again?:**
 - YES (23%) I'd use paid home care
 - NO (43%)
 - Not sure (32%)



Key take-aways #3 – Future Planning

- **Did being a caregiver influence your future planning?**
 - Yes (47%)
 - Yes, but I was already doing future planning (26%)
 - Maybe (11%)
 - No (17%)

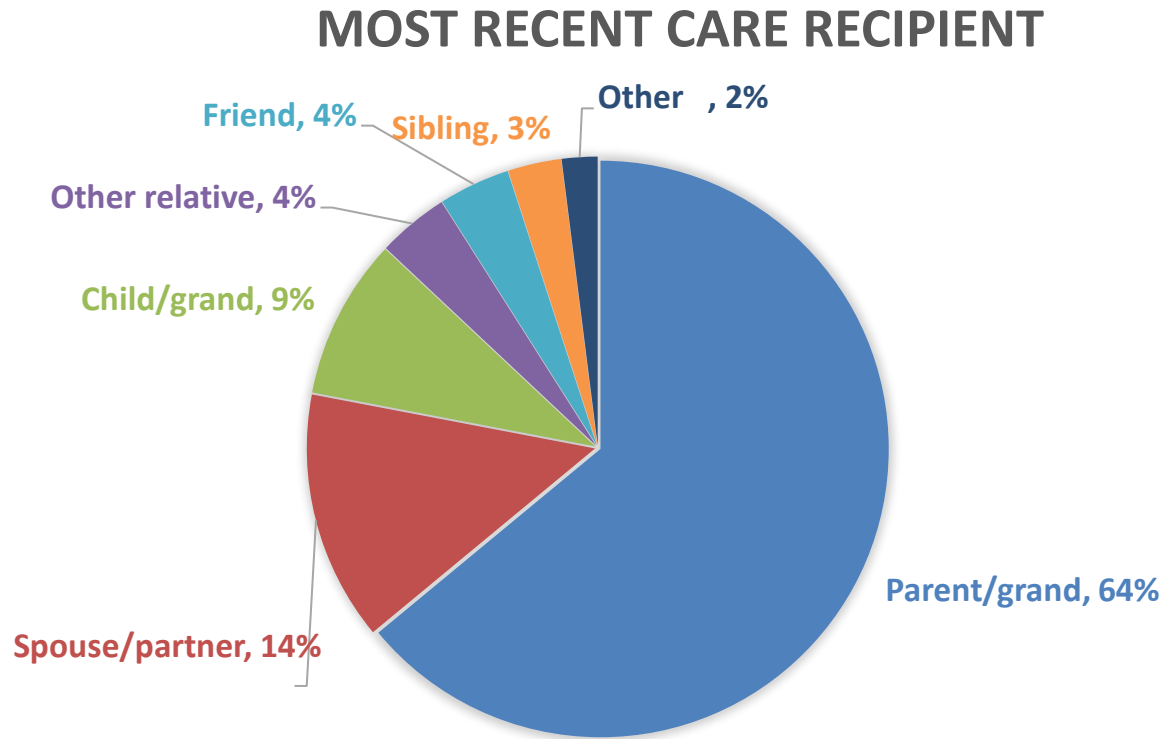
- **What retirement preparations might you do?**
 - Talk with family about preferences and needs (60%)
 - Set money aside (50%)
 - Research care options (39%)
 - Buy/bought LTC insurance (33%)



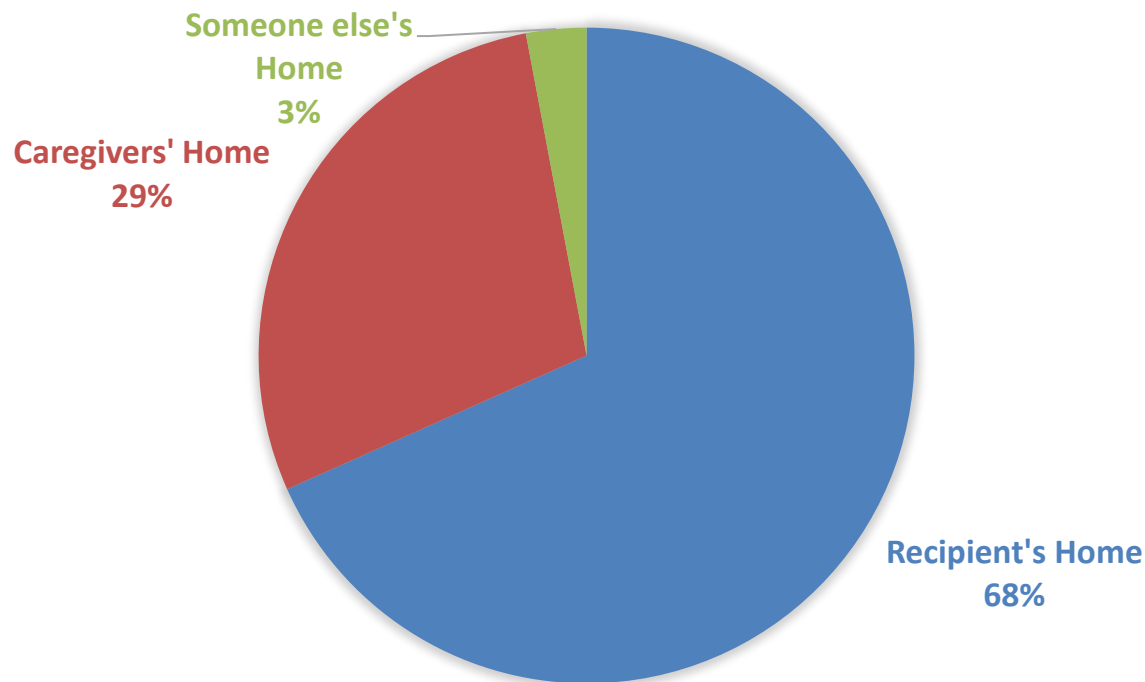
DETAILED FINDINGS



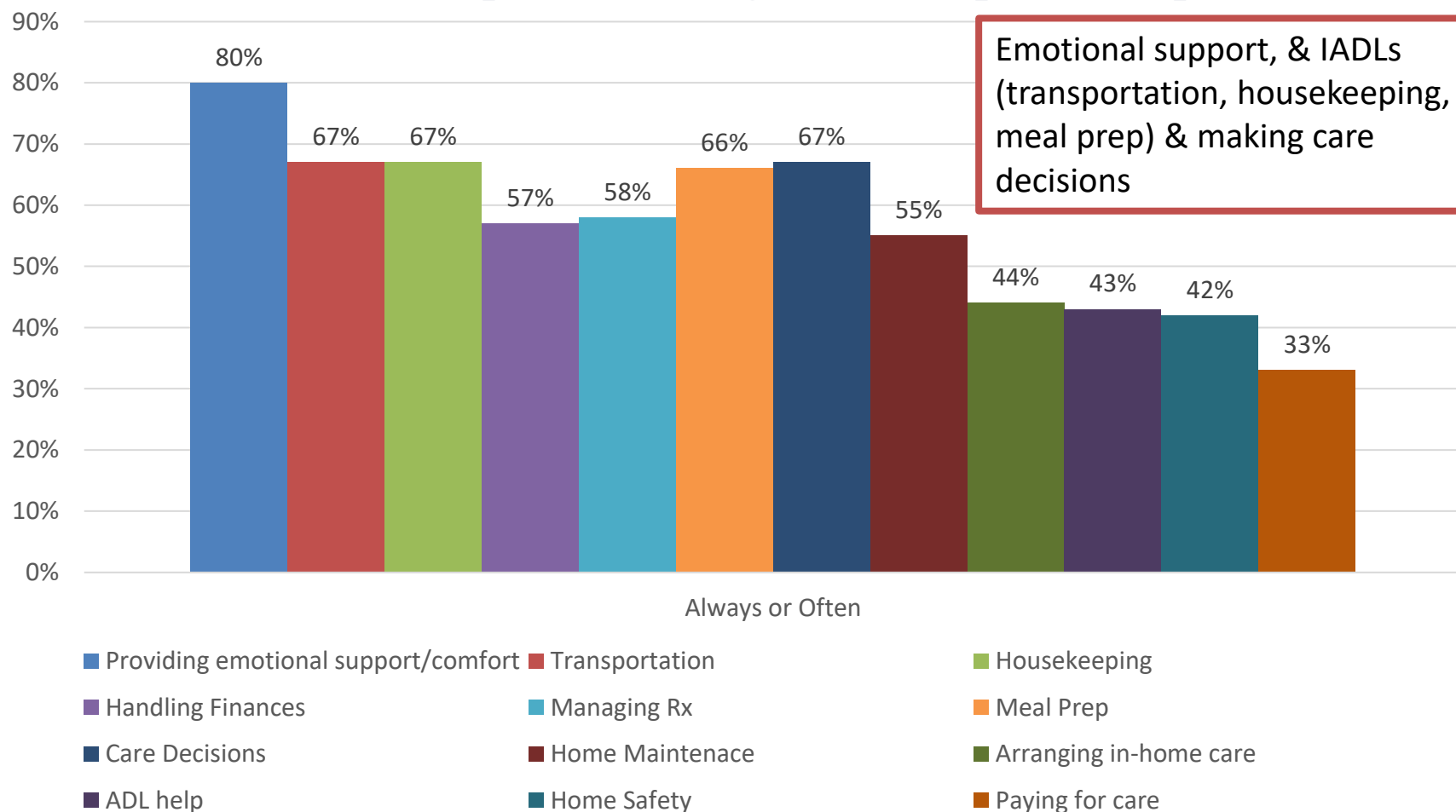
Who are they caring for?



Where is caregiving happening?

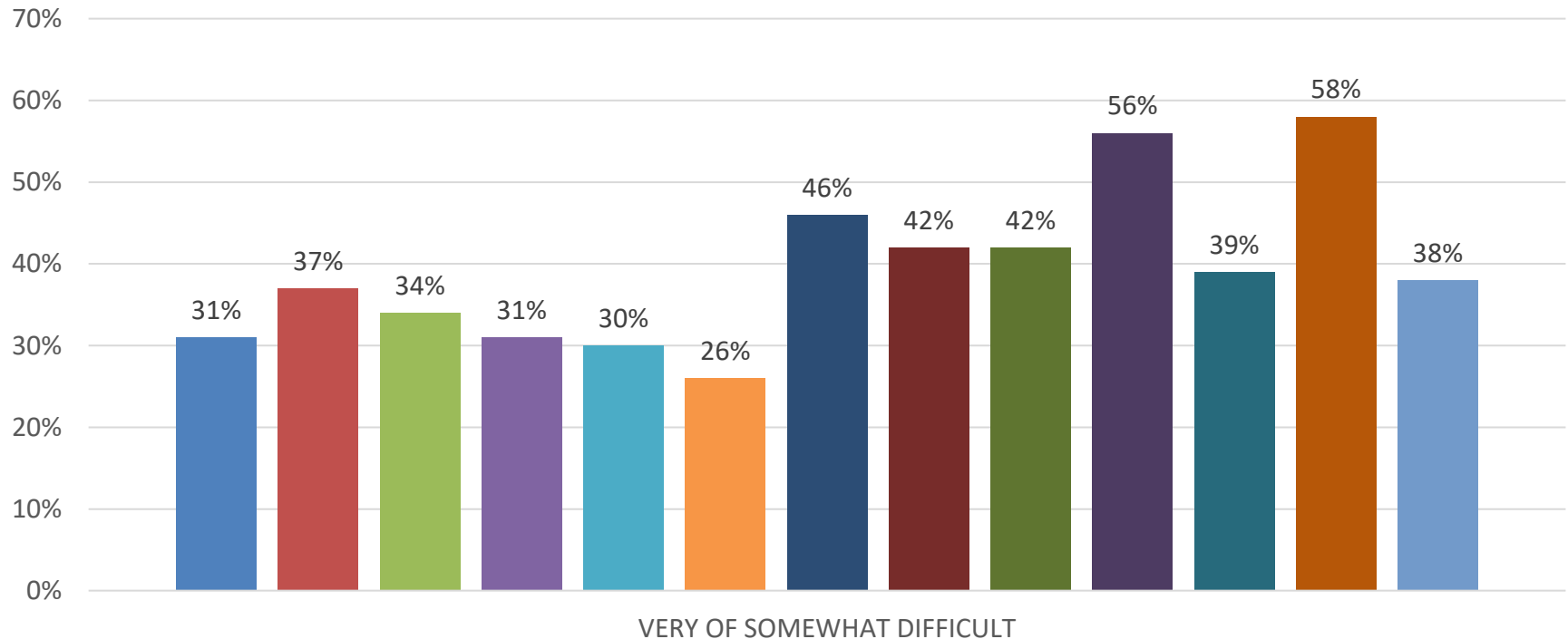


What kind of help do caregivers typically provide?



Q9. Those who need LTC may require different kinds of help. Please indicate whether and how often you are the one providing the following.

What tasks do caregivers find most difficult?



- Providing emotional support/comfort
- Housekeeping
- Managing RX
- Care Decisions
- Arranging in-home care
- Home Safety
- Buying/Renting Equipment

- Transportation
- Handling Finances
- Meal Prep
- Home Maintenance
- ADL help
- Paying for care

Paying for care, helping with ADLs, and making care decisions. Also care arrangements and home maintenance.

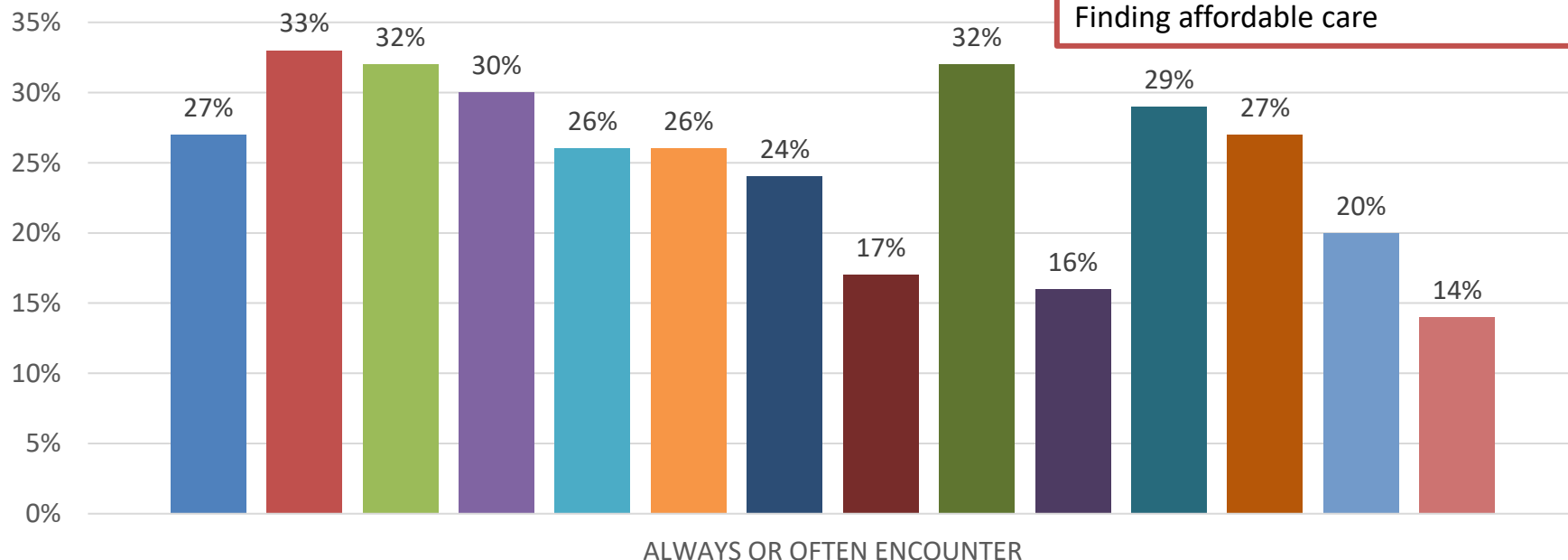


Q10. Of the caregiving tasks you perform most often, please indicate how difficult you find these tasks to be.

Caregiver challenges most frequently encountered

Caregiving Challenges

Getting emotional support; Time away from work; Coordinating with providers; Finding affordable care



■ Affording in-home care

■ Finding Affordable

■ Home safety

■ Providers not showing up

■ Lacking info to choose providers

■ Getting emotional support

■ Managing Rx

■ Affording supplies

■ How to choose providers

■ Transportation

■ Coordinating with MD and providers

■ Determining eligibility for programs

■ Time away from work

■ Deciding what care is needed

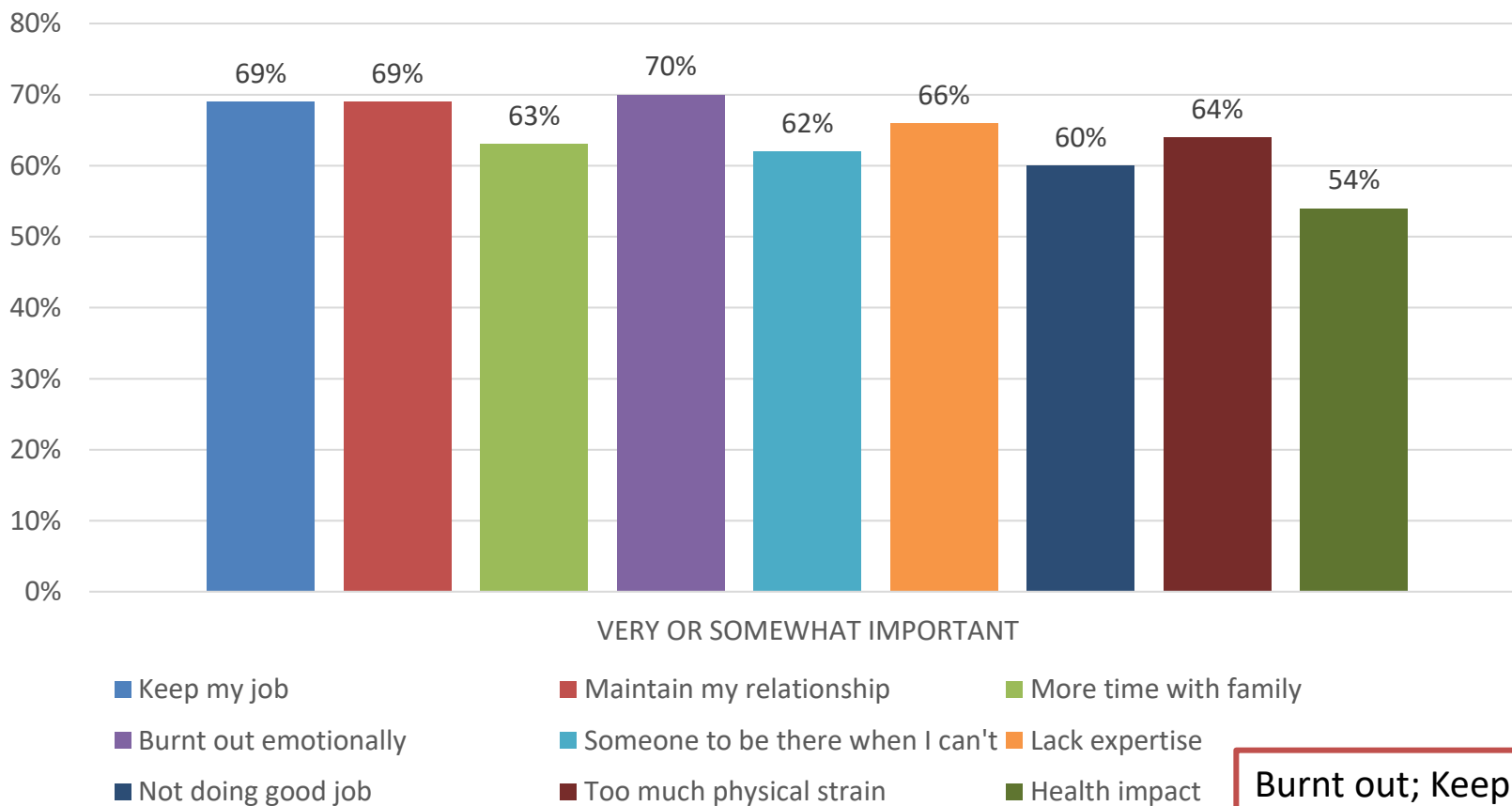


Q11. As a caregiver, how often have you encountered each of the following challenges?

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Why do family caregivers turn to paid in-home help?



**Burnt out; Keep my job;
Maintain my relationship
with care recipient; Lack
expertise**

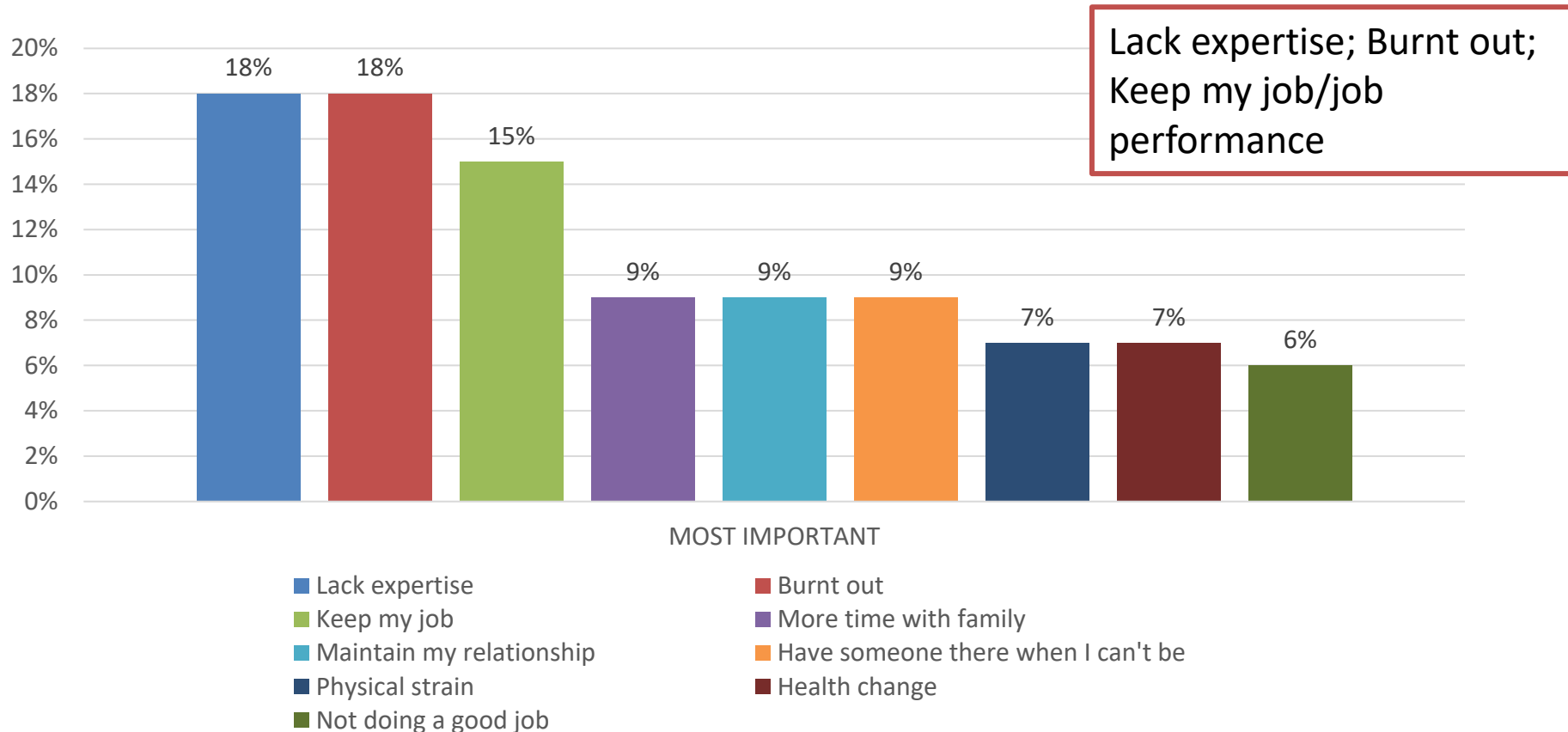


Q12. How important are each of these reasons in your decision to bring in additional paid help?

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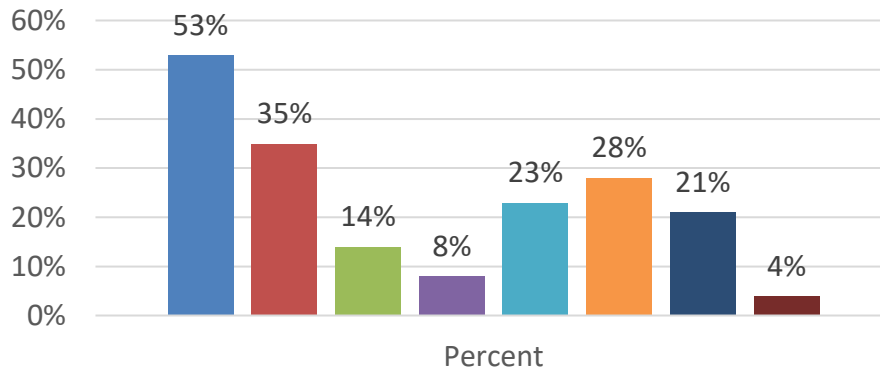
What is their most important reason for using paid in-home help?



Q13. How important are each of these reasons in your decision to bring in additional paid help?

What type of in-home care is provided?

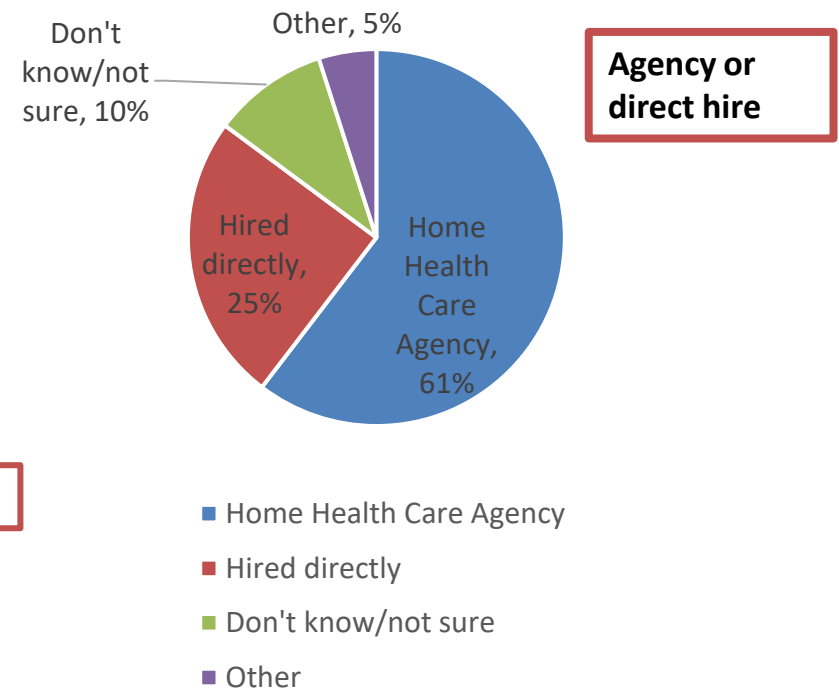
Who is the paid caregiver?



- Home Health Aide
- CNA
- Homemaker
- Adult Day Care
- LPN/RN
- Family, friend, independent paid
- Care coordinator
- Other

HHA, Independent, CNA

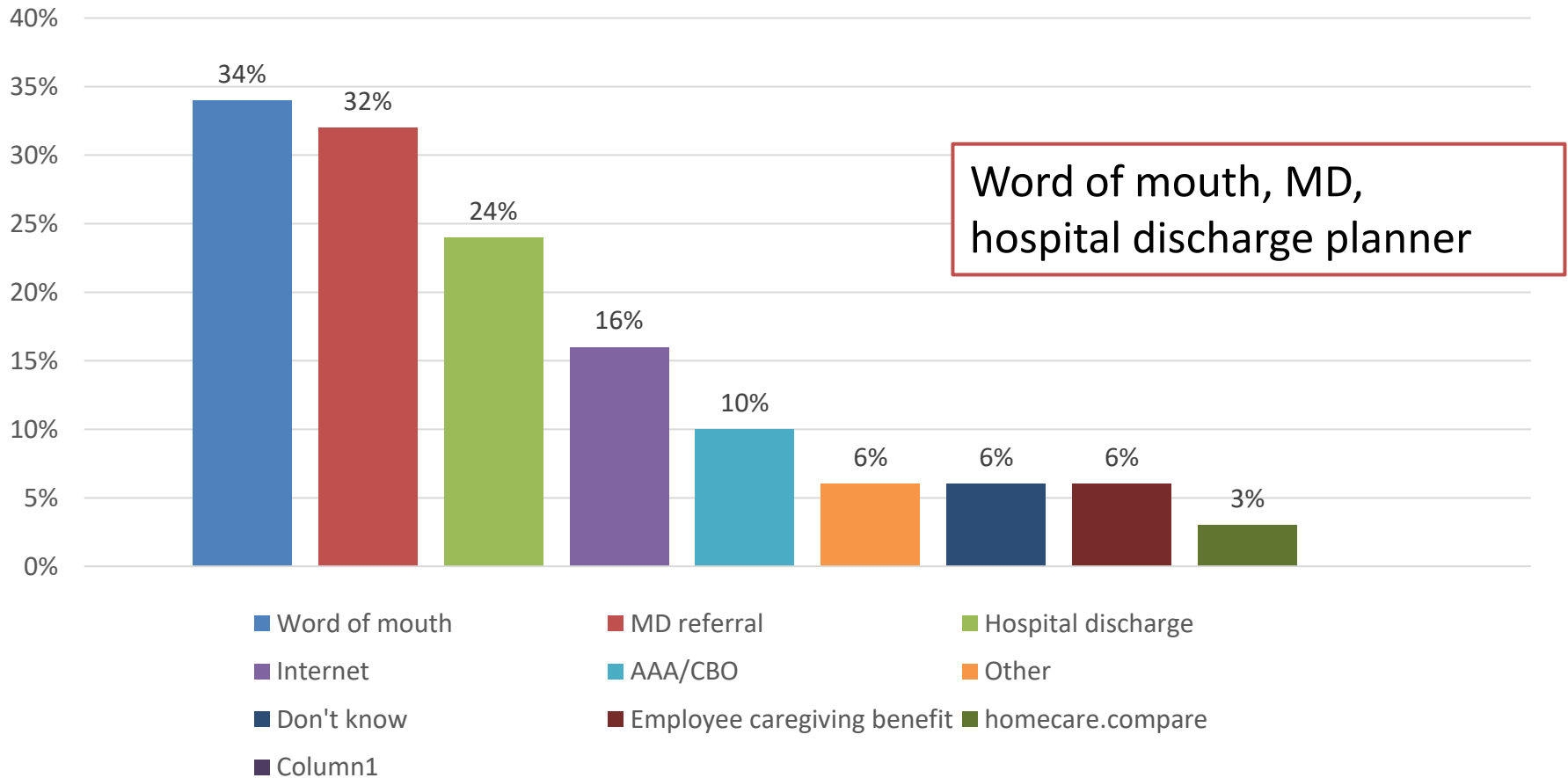
Where did you hire the caregiver from?



- Home Health Care Agency
- Hired directly
- Don't know/not sure
- Other

Q14. Which of the following paid care help did you include....Q15. Was the paid care helphired from a HHCA or someone you hired directly?

How did you find the paid in-home caregiver?

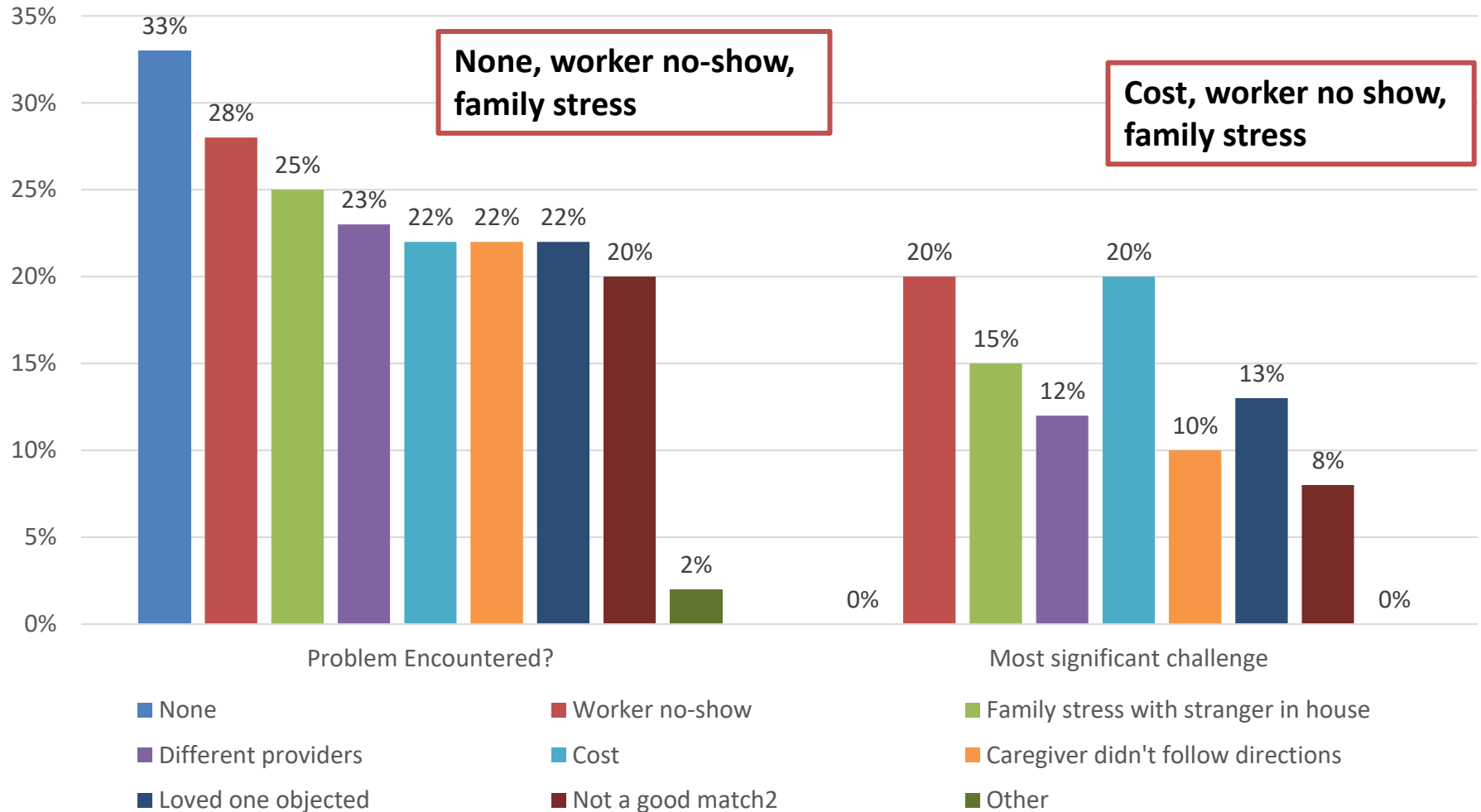


Q17. How did you identify the agency that you used?

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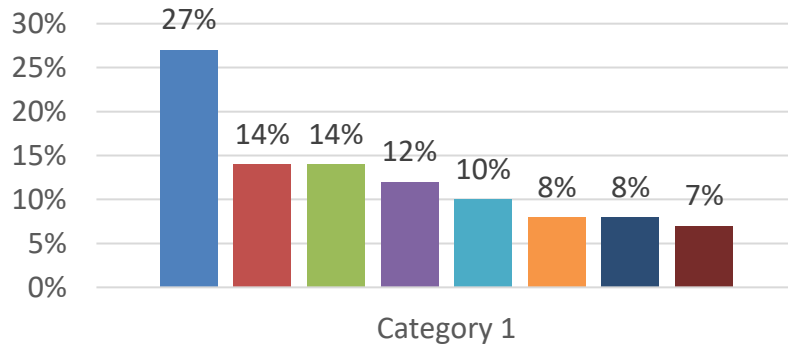
Problems and challenges with paid in-home help



Q18. Which of the following problems did you encounter? Q19. Which was the most significant challenge?

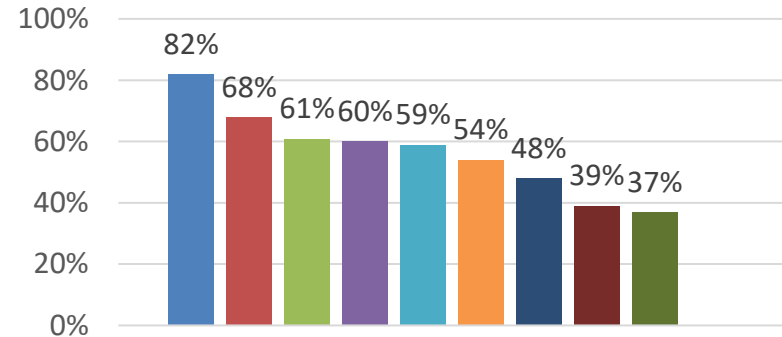
Reasons for not using paid help

Most Important Reason



- FELT IT WAS MY DUTY TO PROVIDE CARE
- LOVED ONE DIDN'T WANT STRANGER AROUND
- COULDN'T AFFORD
- Didn't trust anyone else
- Didn't feel I needed help
- Family didn't want stranger in the house
- Couldn't find/didn't know how
- Had enough help from family

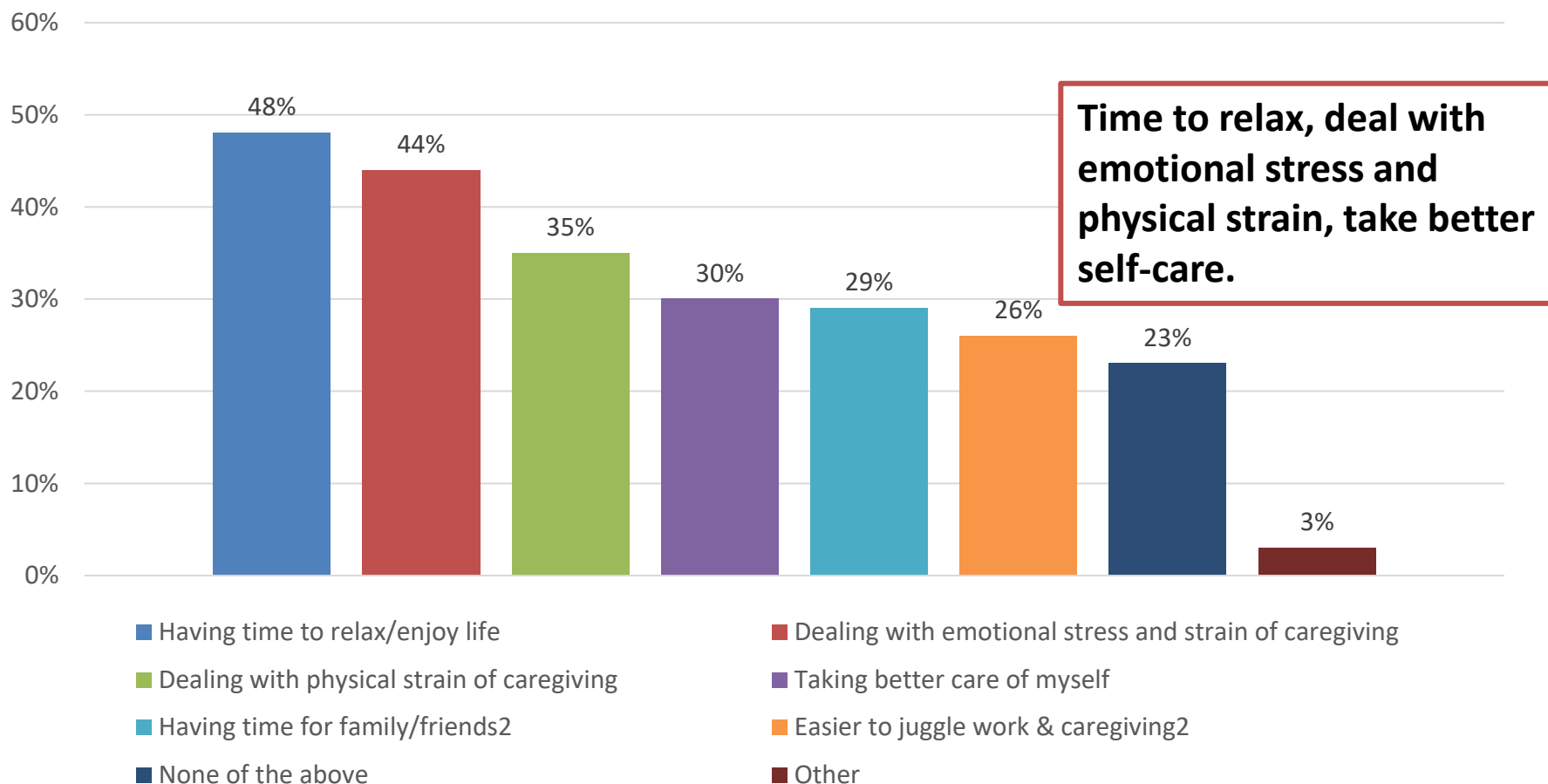
Very and Somewhat Important Reasons



- FELT IT WAS MY DUTY TO PROVIDE CARE
- LOVED ONE DIDN'T WANT STRANGER AROUND
- Family didn't want stranger around
- Didn't trust anyone else
- Couldn't afford
- Didn't feel I needed help
- Had enough help from family
- Didn't know how to find help

Q21. What considerations went into the decision to not use paid care? What was the most important reason?

What would have been easier if you had paid help?



Q23. Would any of the following been easier if you had paid help?

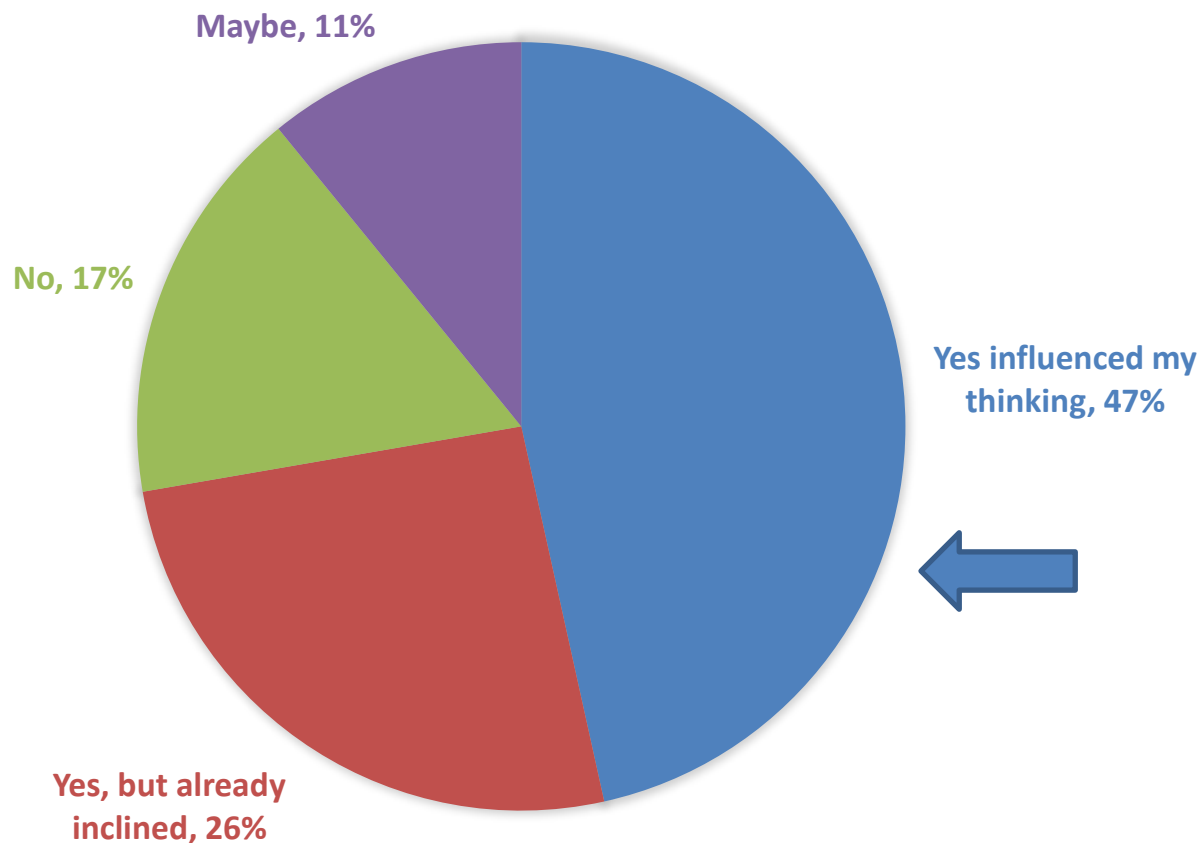
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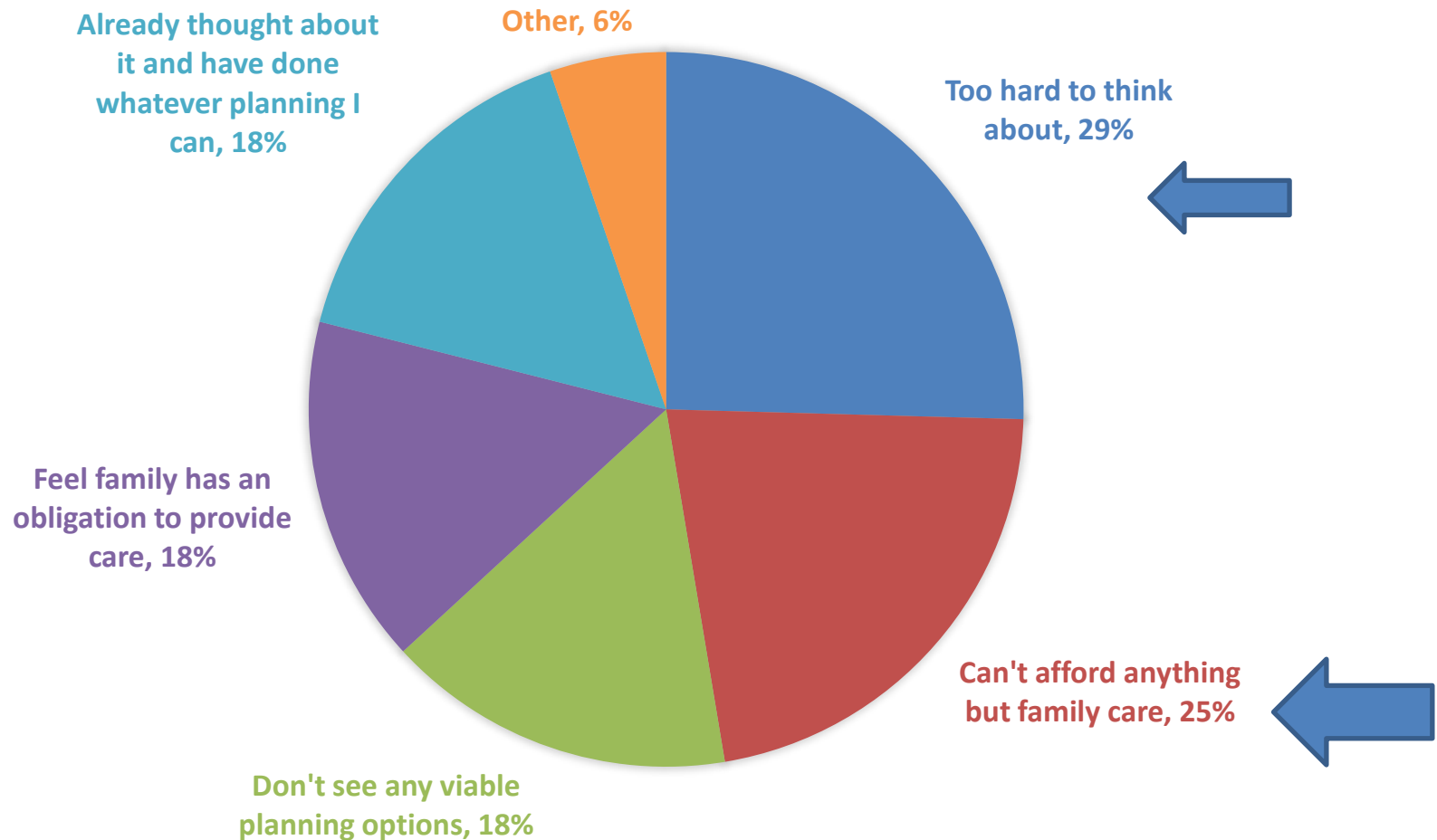
Retirement Readiness



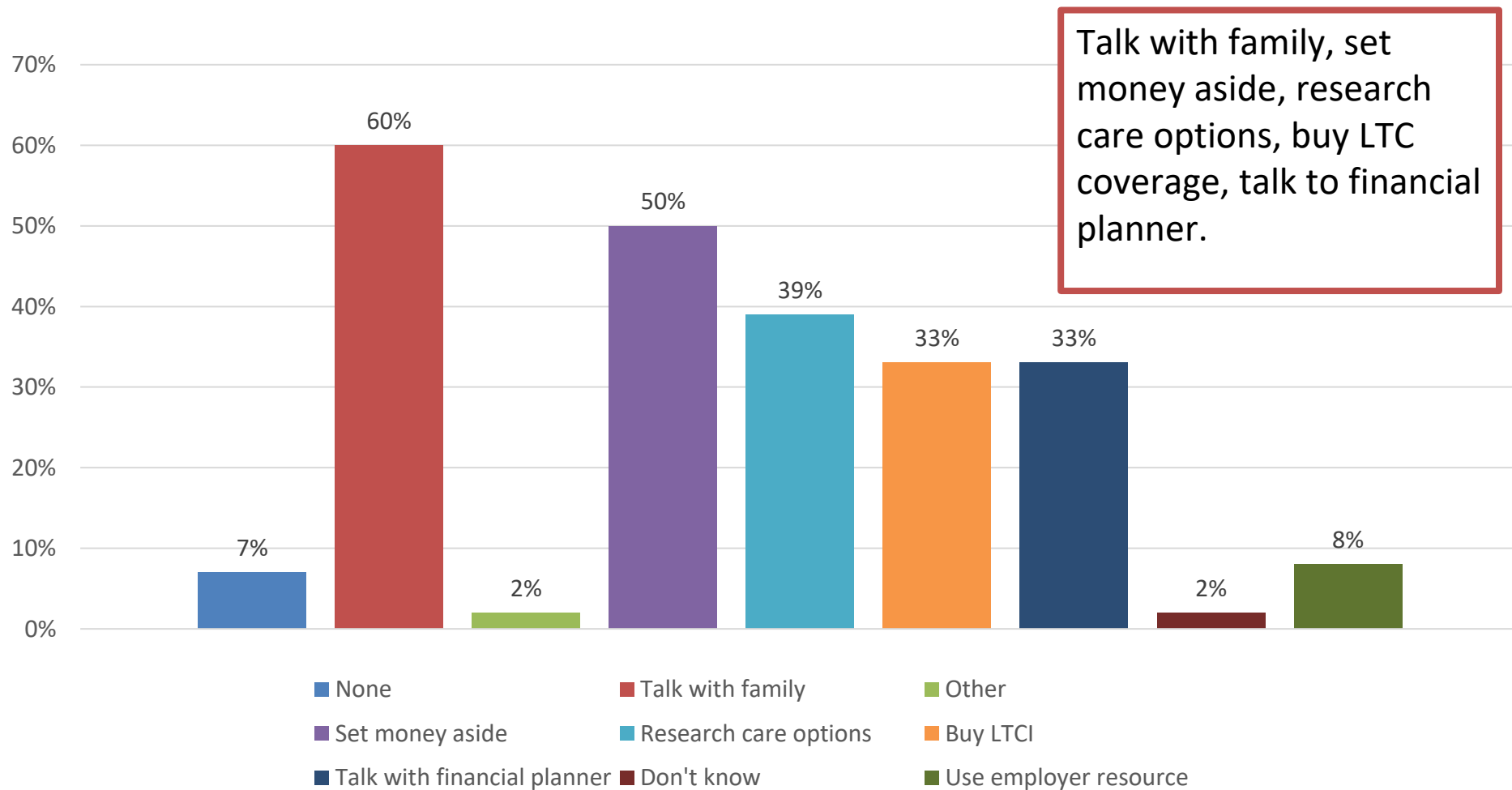
Did being a caregiver influence your thinking about planning ahead?



Why hasn't caregiving made you want to plan?



Which retirement prep might you do?



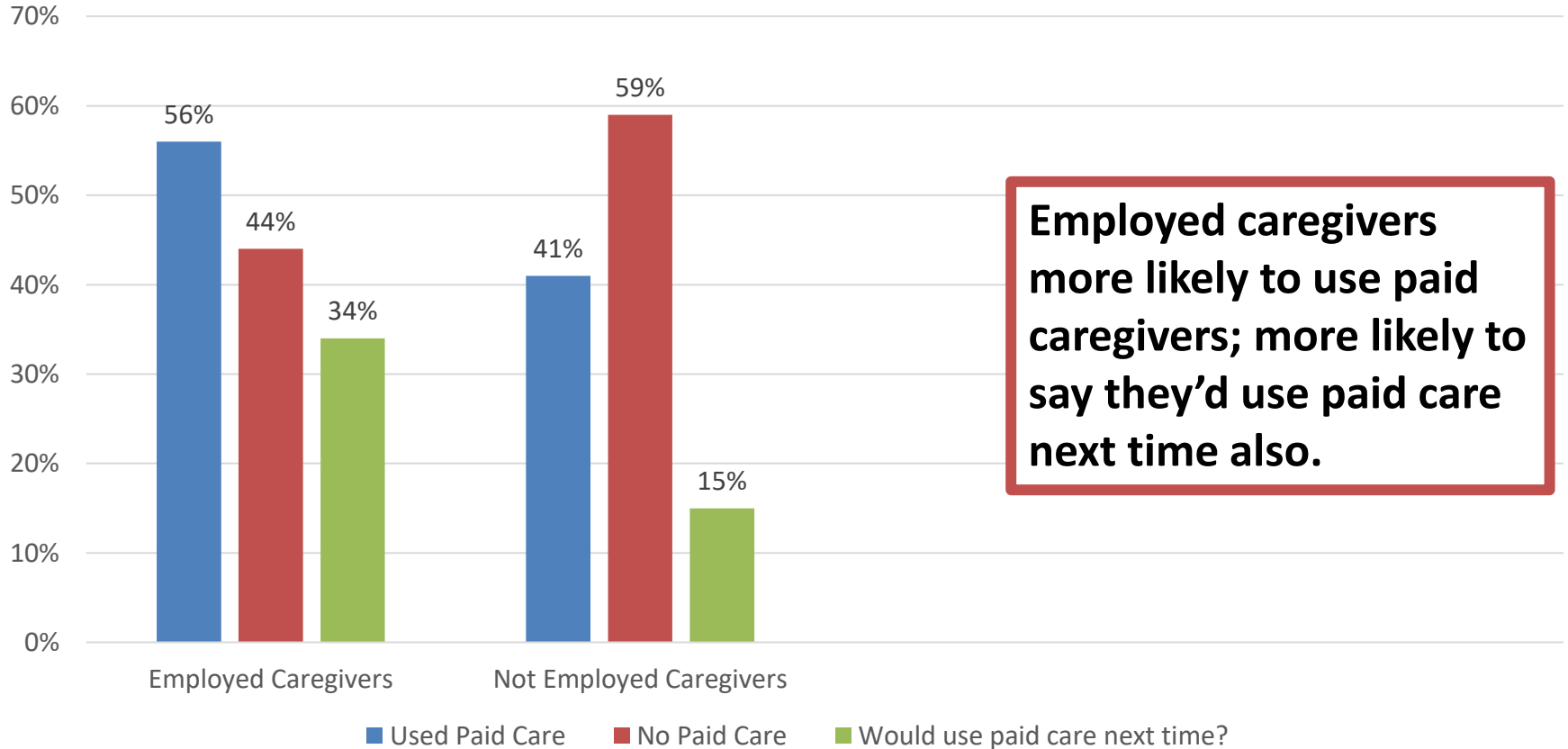


Caregivers who used paid home care
Caregivers who are also juggling employment

CLOSER LOOK

Employed Caregiver vs. Using Paid Care

Use of Paid Care by Employment Status



Closer look at family caregivers with and without paid in-home care*



*Only statistically significant differences are reported

The Headlines

- Those using paid care are more likely to have the following differences:
 - Be male
 - Be employed
 - Have greater financial resources
 - Be caring for a parent and doing so at some distance
 - Be more likely to be providing ADL help and making care arrangements
 - Had a loved one who they believe had done some preparation for retirement
 - More likely to be influenced by the caregiver experience to plan for their own retirement readiness



Closer look at family caregivers who are employed full-time vs. those who are not working*



*Only statistically significant differences are reported

The Headlines

- **Working caregivers are more likely to have the following differences:**
 - Be male
 - Have kids < 21 living at home
 - Have more education and financial resources
 - Be caring for a parent
 - Be motivated to use home care out of concern for their jobs and their families
 - More likely to use home care next time...(if didn't use it this time)
 - More likely to hire a caregiver directly – not from an agency
 - When not using home care – more likely to cite “affordability” as an issue
 - Had a loved one who they believe had done some preparation for retirement
 - More likely to be influenced by the caregiver experience to plan for their own retirement readiness



Closing credits

- Survey analysis conducted by Eileen J. Tell, CEO, ET Consulting, LLC., eileenjtell@gmail.com
- Input and guidance on survey design and financial support provided by:
 - Celeste Cobb, representing CLTC
 - Megan Hix and Bonnie Gerber, Home Instead and
 - Michael Petchenik and Bonni Kaplan DeWoskin, Homethrive



APPENDIX

SAMPLE DEMOGRAPHICS

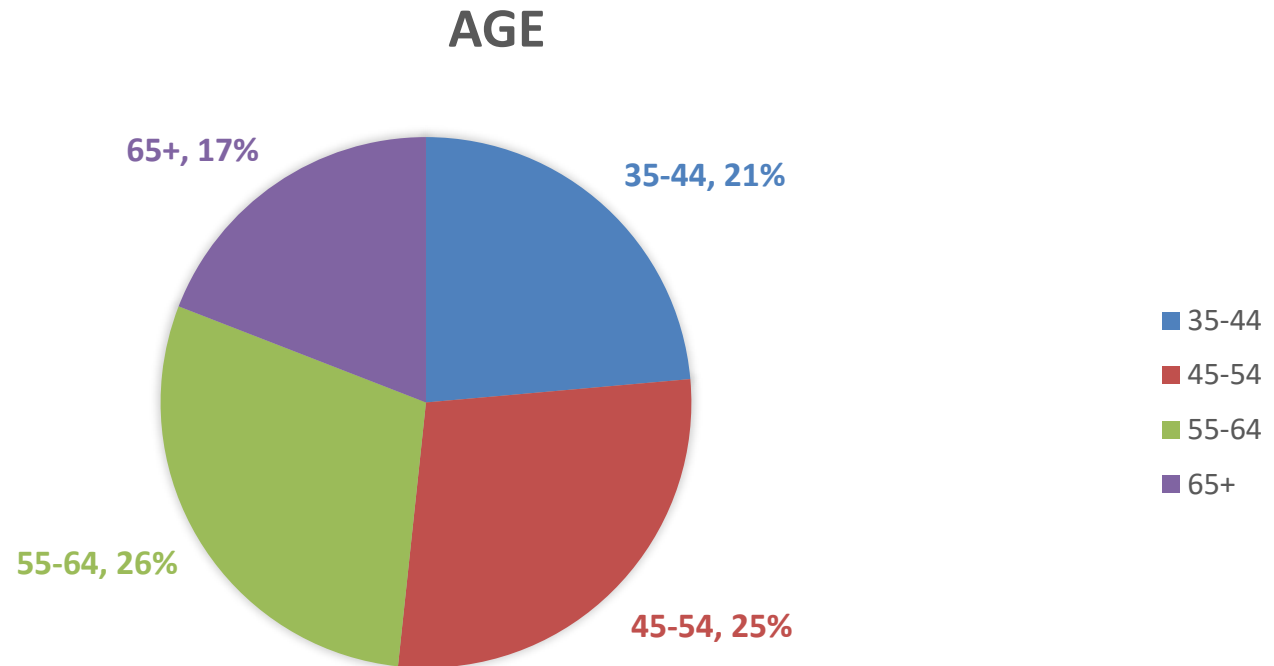


Sample Demographics

Category	Percent	Category	Percent
GENDER		HEALTH	
Female	66%	Excellent	15%
Male	34%	Good	57%
MARITAL STATUS		Fair	25%
Married	52%	Poor	3%
Single	24%	OWN HOME	
Divorced	16%	Yes	60%
Widowed/other	9%	No	40%
KIDS < 21			
Yes	36%		
No	64%		



Age Distribution

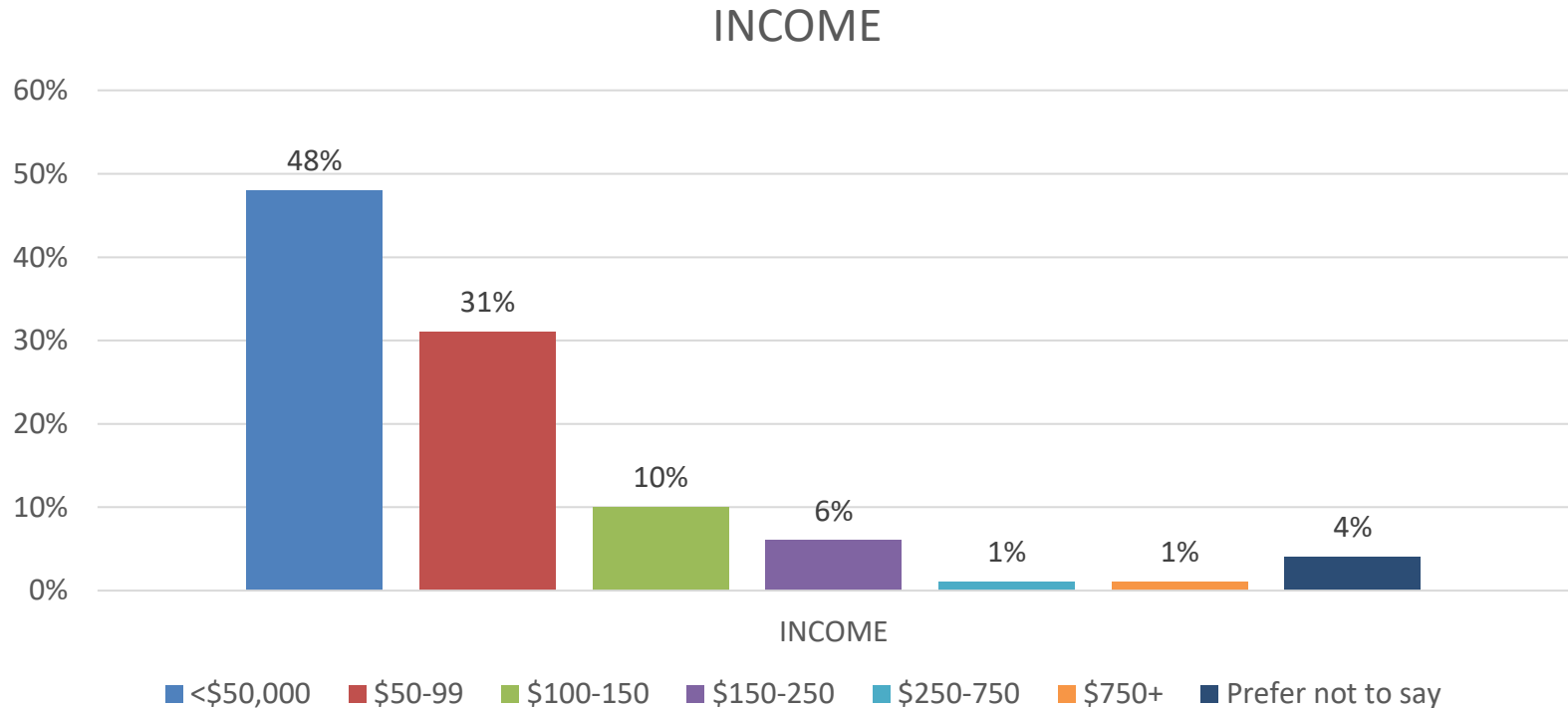


Sample Demographics

Category	Percent	Category	Percent
EMPLOYMENT		FINANCIAL/RETIREMENT PRODUCTS	
Employed	54%	Life Insurance	40%
Retired	23%	401K, 403B, etc.	35%
Homemaker/not employer	14%	None of the above	35%
Student/other	9%	IRA of some type	18%
EDUCATION		Employer pension	14%
< high school grad	2%	LTC insurance*	12%
High school grad	15%	Annuity	11%
< college grad	35%	Other	7%
College grad	37%		
Grad degree +	11%	*Known to be over-reported	

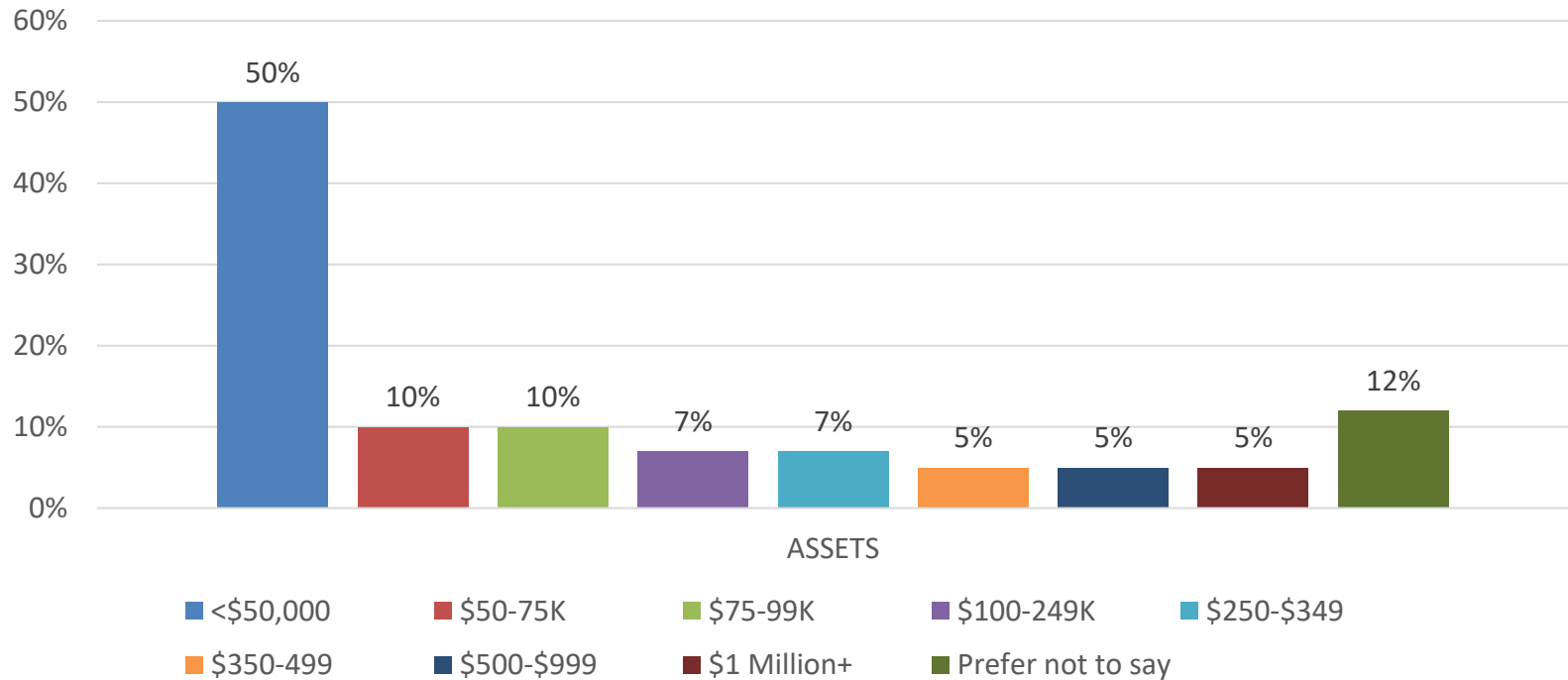


Sample Demographics



Sample Demographics

Household Assets

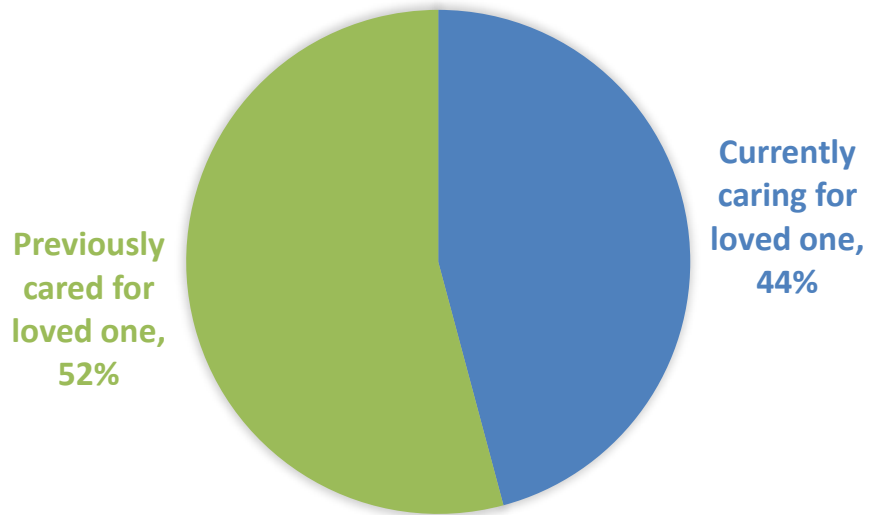


Sample Demographics

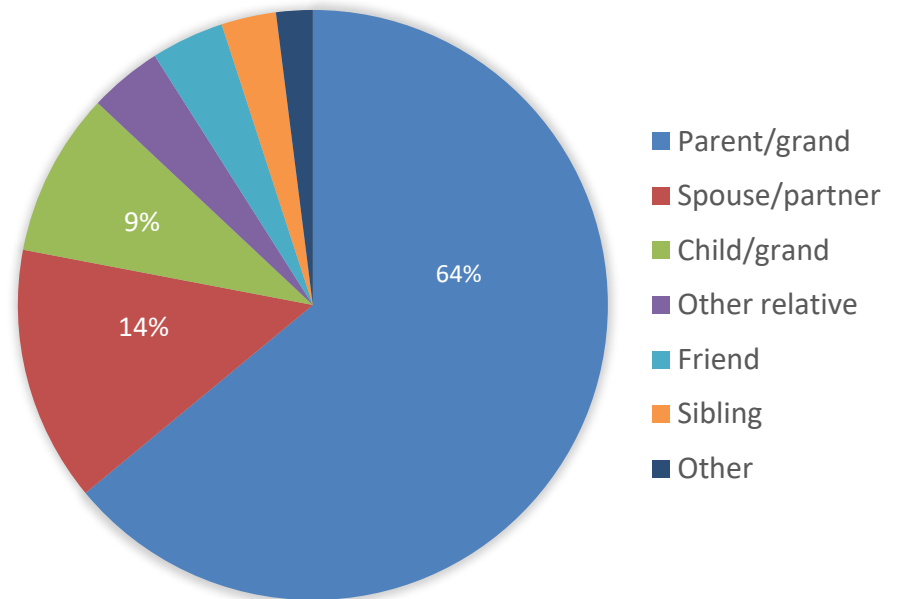
CATEGORY	PERCENT
RACE	
White/Caucasian	72%
Black/African American	18%
Asian	5%
Other	3%
American Indian/Alaska Native	2%
LATINO	
Yes	10%
No	89%
Prefer not to say	1%

About the caregivers

ARE YOU A CURRENT OR PREVIOUS CAREGIVER?



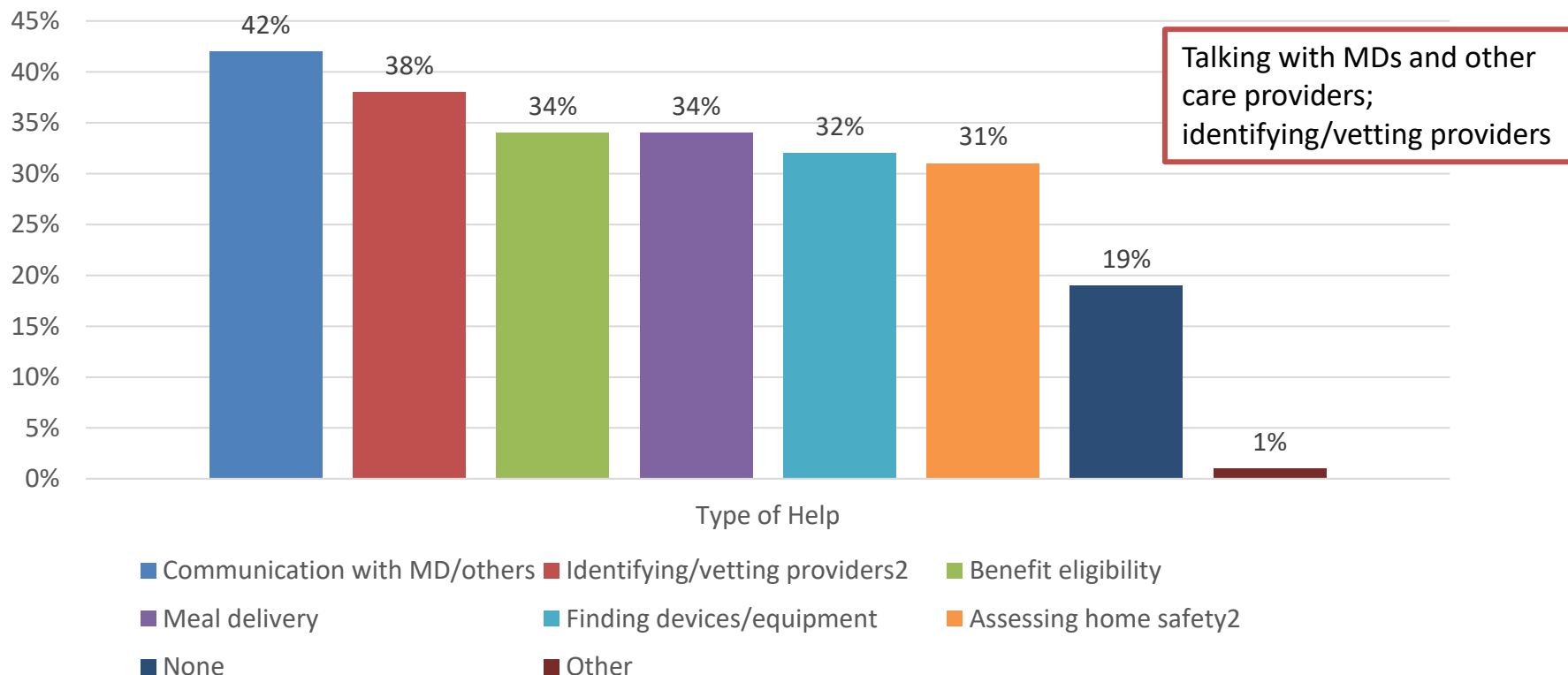
MOST RECENT CARE RECIPIENT



Q6. Which of these has been the most recent caregiving situation?

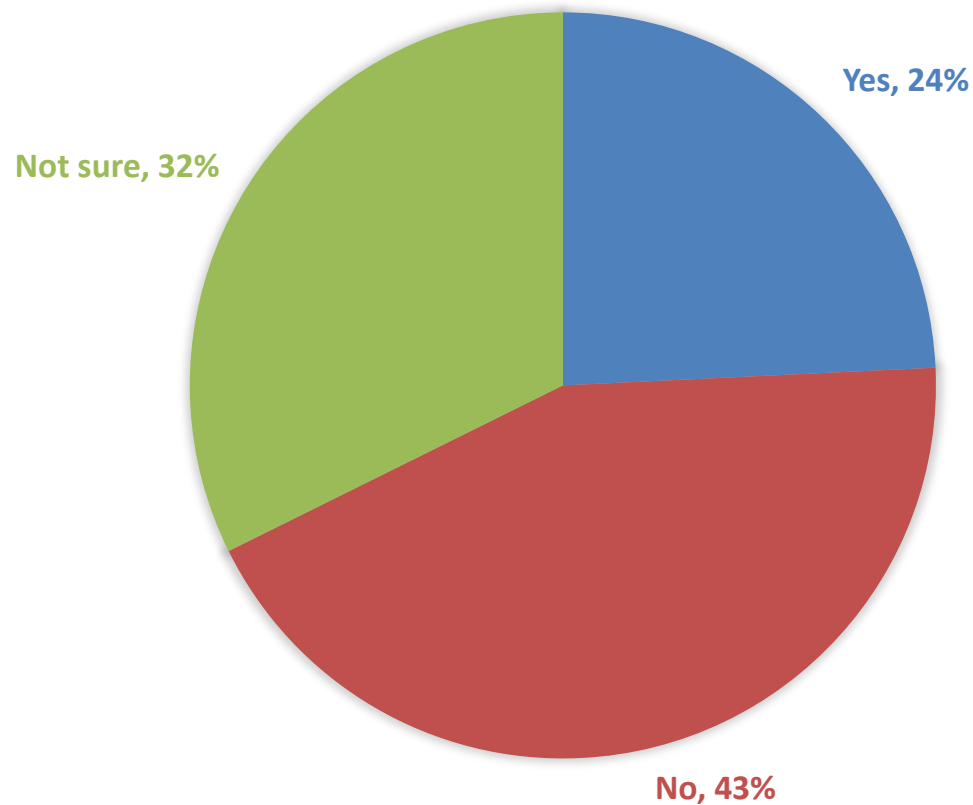
Would you have wanted help from a care coordinator?

What type of help would you have liked?



Q17a. Which of the following tasks would you have liked help with [from a care coordinator?]

Would you consider paid in-home help next time?

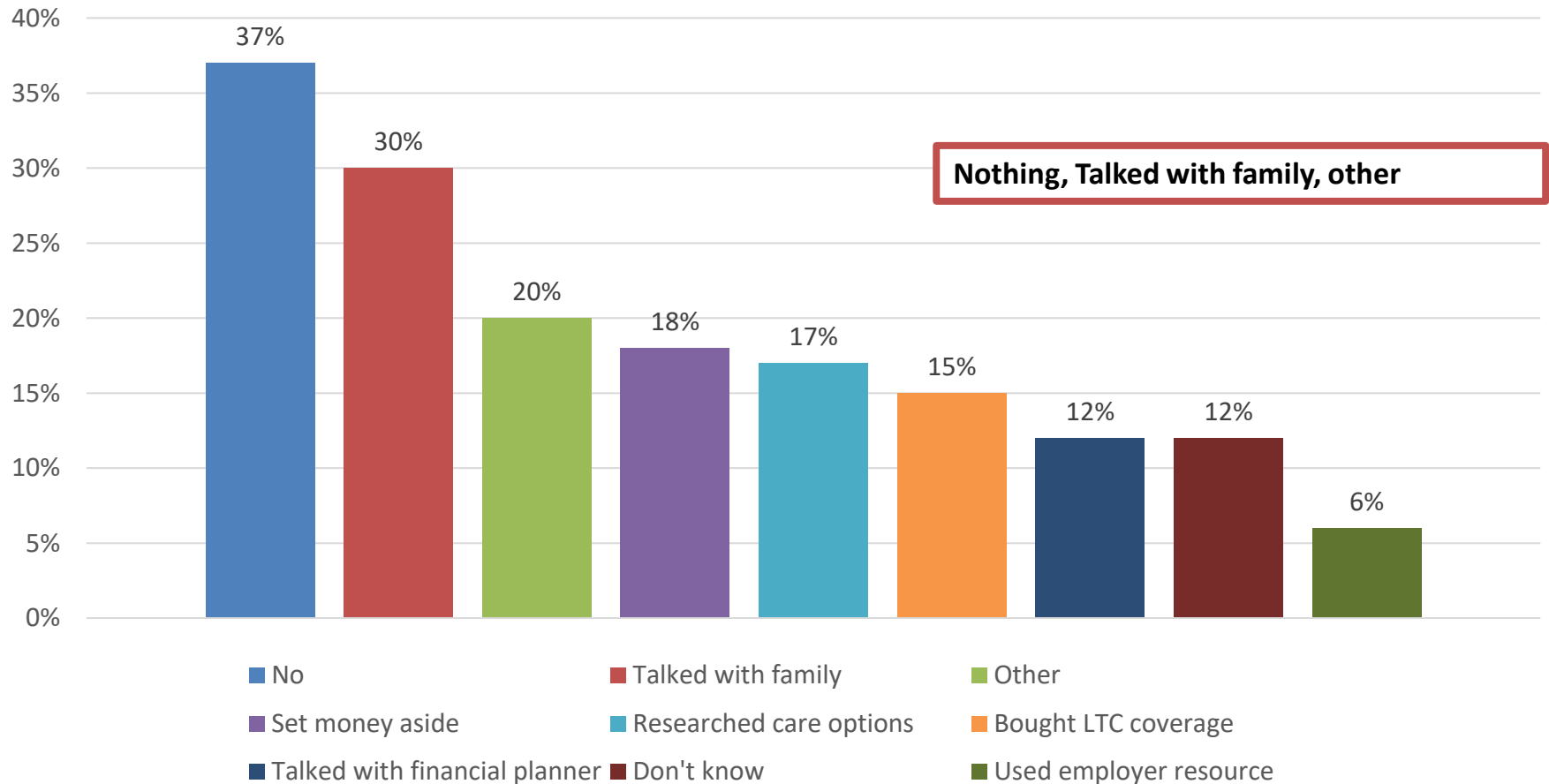


Q24. Would you re-consider having paid in-home care next time?

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Do you think care recipient planned ahead in case of future care needs?



Closer look at family caregivers with and without paid in-home care*



*Only statistically significant differences are reported

The Headlines

- **Those using paid care are more likely to have the following differences:**
 - Be male
 - Be employed
 - Have greater financial resources
 - Be caring for a parent and doing so at some distance
 - Be more likely to be providing ADL help and making care arrangements
 - Had a loved one who had done some preparation for retirement
 - More likely to be influenced by the caregiver experience to plan for their own retirement readiness

Demographic Differences: Family caregivers who used paid home care vs. those who did not

CATEGORY	PAID CARE	NONE	CATEGORY	PAID CARE	NONE
DEMOGRAPHICS			Has 401K, etc.	41%	29%
Female	61%	71%	Has annuity	15%	8%
Male	40%	29%	Has life insurance	47%	33%
Single/never married	20%	28%	Has LTC insurance	19%	6%
High School graduate	13%	18%	Income > \$100,000	25%	11%
Own home yes	68%	53%	Income < \$100,000	75%	89%
Currently employed	61%	47%	Income <\$4%	58%	70%
			Income \$250,000-\$499,999	12%	4%



Family caregivers who used paid home care vs. those who did not

CATEGORY	PAID CARE	NONE	CATEGORY	PAID CARE	NONE
Previous Caregiver	59%	46%	Often provide transportation help	32%	22%
Caring for Spouse	9%	19%	Often provide ADL help	26%	10%
Caring for parent/grand	71%	56%	Always help with coordinating/arranging in-home care	37%	15%
Caring for child/grand	5%	14%	Always help with equipment/devices	22%	13%
Local/nearby caregiving	87%	94%	Often help with home safety changes	29%	15%
Long distance caring	13%	4%	Often help with finances	23%	13%
No help from other family	18%	28%	Often help with paying for care	20%	12%



Retirement Readiness: Family caregivers who used paid home care vs. those who did not

CATEGORY	PAID CARE	NONE	CATEGORY	PAID CARE	NONE
RETIREMENT READINESS OF LOVED ONE			DID CAREGIVER INFLUENCE YOUR THOUGHTS ON PLANNING?		
Bought LTCI or Life/LTC	18%	11%	Yes	55%	38%
Talked with family	37%	24%	No	11%	22%
Researched care options	22%	11%	Maybe	8%	15%
Talked with financial planner	17%	6%	WHAT WOULD YOU DO?		
Used employer support resource	8%	3%	Set aside money	45%	46%
Don't know	7%	18%			



Caregiver Challenges

Family caregivers who used paid home care vs. those who did not

CATEGORY	PAID CARE	NONE	CATEGORY	PAID CARE	NONE
CAREGIVING CHALLENGES			Is Often challenged when providers don't show up	45%	27%
Finds managing medications somewhat difficult	27%	18%	Often challenged to get reliable transportation	12%	7%
Finds handling finances somewhat difficult	25%	16%	Sometimes challenged to afford in home care	34%	18%
Finds providing companionship and emotional support very difficult	13%	6%	Sometimes challenged about spending time away from work	36%	25%
Is often challenged by deciding about care needs	23%	14%	Often challenged about managing medications	19%	11%
If often challenged to find affordable care	23%	14%	Often challenged about coordinating with MDs	24%	17%
Is often challenged when providers don't show	13%	6%	Often challenged re. benefit eligibility	20%	14%
			Always challenged evaluating home safety	11%	5%



Closer look at family caregivers who are employed full-time vs. those who are not working*



*Only statistically significant differences are reported

The Headlines

- **Working caregivers are more likely to have the following differences:**
 - Be male
 - Have kids < 21 living at home
 - Have more education and financial resources
 - Be caring for a parent
 - Be motivated to use home care out of concern for their jobs and their families
 - More likely to hire a caregiver directly – not from an agency
 - When not using home care – more likely to cite “affordability” as an issue
 - Had a loved one who had done some preparation for retirement
 - More likely to be influenced by the caregiver experience to plan for their own retirement readiness



Demographics: Family caregivers who are employed vs. not

CATEGORY	EMPLOYED	NOT	CATEGORY	EMPLOYED	NOT
DEMOGRAPHICS			Has 401K, etc.	50%	14%
Female	62%	73%	Employer pension	18%	8%
Male	38%	28%	Has life insurance	47%	29%
Widowed	5%	12%	Has LTC insurance	16%	7%
Kids < 21	49%	19%	Income < \$100,000	78%	88%
Own home yes	68%	51%	Income > \$100,000	22%	11%
Excellent health	18%	11%	Income \$50,000 to \$74,999	35%	14%
Good health	62%	49%	Income \$75,000 to \$99,999	16%	7%
Fair health	18%	36%	Assets < \$49,999	46%	70%
College graduate	43%	29%	Assets \$50,000-\$74,999	12%	3%
Grad school +	14%	6%	Assets \$150,000-\$249,999	10%	3%



Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT	CATEGORY	EMPLOYED	NOT
Previous Caregiver	45%	63%	Often help making care decisions	26%	17%
Caring for parent/grand	68%	58%	Always help renting equipment	21%	17%
Some help from family	33%	19%	Always help making home safety changes	31%	43%
Often provide transportation help	33%	17%	Always help with meals	31%	43%
Always help with medication	31%	42%	Often help managing finances	21%	14%
Often help with ADLs	26%	10%	Sometimes help with home maintenance	28%	17%
Often help arranging for care	23%	10%	Often provide companionship	35%	26%



USING HOME CARE

Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT	CATEGORY	EMPLOYED	NOT
MOST IMPORTANT REASON TO USE PAID CARE			NOT AT ALL IMPORTANT		
To spend more time with children and meet my own needs	13%	2%	Help me concentrate/keep job	8%	43%
VERY IMPORTANT REASONS			Spend more time with children	17%	52%
To help me keep my job/concentrate	42%	21%	Under too much emotional strain	12%	27%
Spend more time with kids	40%	18%	Don't have expertise to provide care	14%	25%
SOMEWHAT IMPORTANT			So someone could be with my loved one when I can't	17%	41%
Help with job/work	42%	22%			



USING HOME CARE

Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT	CATEGORY	EMPLOYED	NOT
WHICH PROVIDER DID YOU USE			HOW DID YOU FIND PROVIDER?		
Home Health Aide	48%	63%	AAA or CBO	14%	2%
Homemaker	10%	22%	OTHER	3%	12%
Adult day care	10%	3%	WHAT KIND OF HELP WOULD YOU HAVE LIKED FROM CARE COORDINATOR?		
HOW DID YOU HIRE THEM?			Communicating with MDs and other providers	48%	31%
Directly	30%	16%	WHAT PROBLEMS DID YOU ENCOUNTER?		
			Family stress of having a stranger in the house	29%	16%



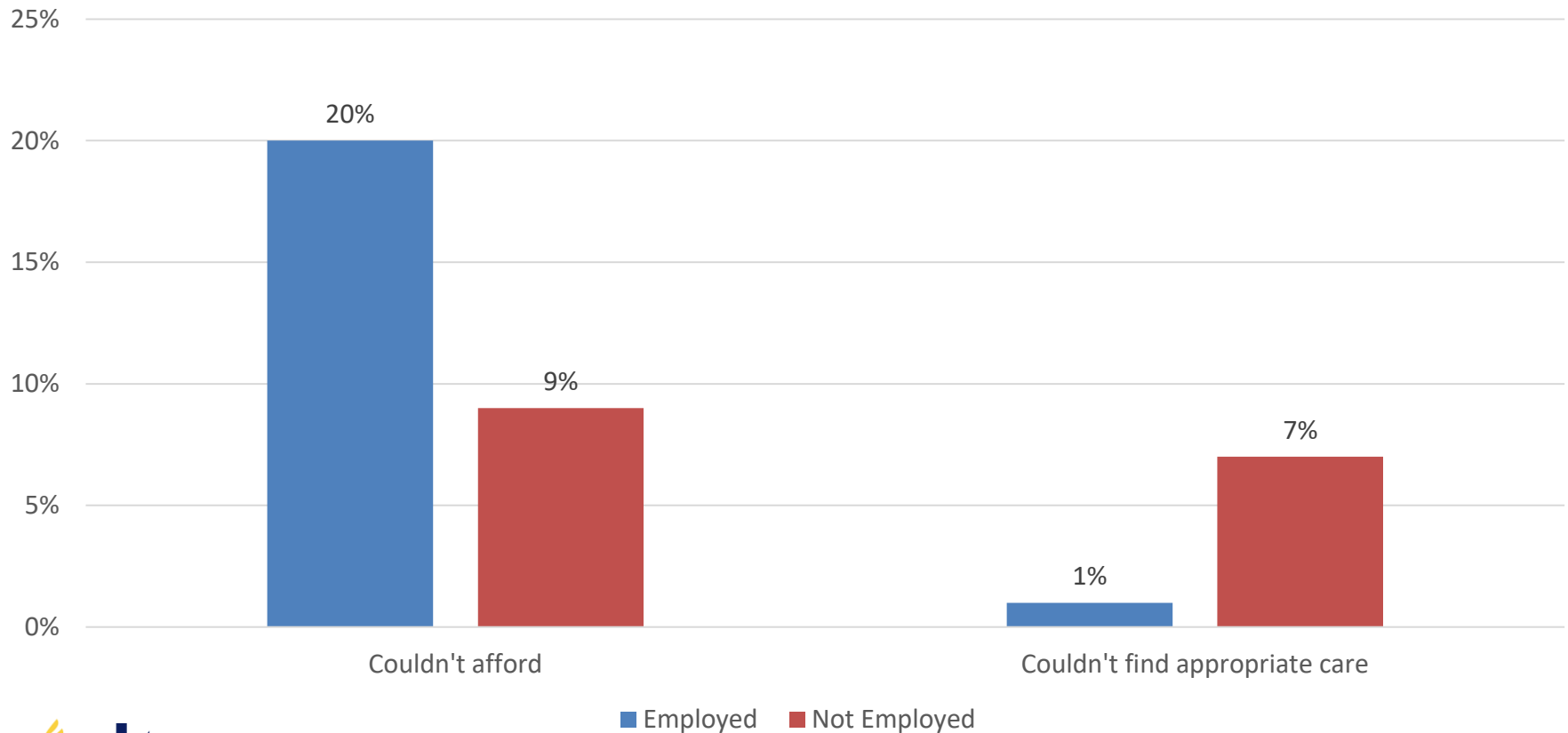
USING HOME CARE

Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT
MOST SIGNIFICANT CHALLENGE USING HOME CARE		
Workers not consistently showing up	15%	30%
Not consistently having same provider	16%	3%
Caregiver not a good match	12%	<1%

Most Relevant Reasons for Not Using Paid Help: Employed vs. Not Employed

Reasons for Not Using Home Care: Employed vs. Not Employed



DIFFICULT TASKS: Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT	CATEGORY	EMPLOYED	NOT
SOMEWHAT DIFFICULT TASKS:			VERY DIFFICULT TASKS:		
Managing medications	30%	13%	Buying/renting equipment	10%	2%
Coordinating care	30%	18%	Making home safety changes	13%	5%
Handling finances	25%	16%	Help with meals	8%	3%
Transportation	32%	20%	Providing companionship	13%	6%



CHALLENGES:

Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT	CATEGORY	EMPLOYED	NOT
CHALLENGES ALWAYS ENCOUNTERED			CHALLENGES OFTEN ENCOUNTERED		
Dealing with no-show providers	8%	2%	Deciding on care needs	22%	33%
Spending time away from work	6%	2%	Getting emotional support	24%	16%
Evaluating home safety	11%	5%	Affording paid home care	29%	15%
Transportation	32%	20%	Spending time away from work	20%	11%
			Managing medications	18%	10%
			Coordinating with MD/providers	24%	17%
			Finding benefit eligibility	20%	12%



RETIREMENT READINESS:

Family caregivers who are employed vs. not employed

CATEGORY	EMPLOYED	NOT	CATEGORY	PAID CARE	NONE
WHAT YOUR LOVED ONE DID?			YOUR RETIREMENT READINESS		
Set aside money	22%	13%	Set aside money	45%	41%
Talked with family	35%	24%	Bought LTCI	38%	23%
None	29%	49%	Talked to financial planner	38%	24%
DID CAREGIVING INFLUENCE YOUR PLANNING THOUGHTS?	17%	6%	Use employer support resource	11%	4%
Yes	52%	40%			
Maybe	7%	16%			

