

Disability and Aging Collaborative Webinar

Changing Nature of Family Caregiving: New Research and Policy implications

Tuesday, June 30, 2015



National Council on Aging

Disability and Aging Collaborative

- American Association on Health and Disability
- American Association of People with Disabilities
- AARP
- ADAPT
- Alliance for Retired Americans
- Altarum institute
- AFSCME
- ANCOR
- The Arc of the United States
- Association of University Centers on Disabilities
- Alzheimer's Association
- Bazelon Center for Mental Health Law
- Caring Across Generations
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- Community Catalyst
- Dana & Christopher Reeve Foundation
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- Disability Rights Education & Defense Fund
- Easter Seals
- Families USA
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- Leading Age
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- National Association for Home Care and Hospice
- National Committee to Preserve Social Security and Medicare
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- National Disability Rights Network
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- National Senior Citizens Law Center
- Paralyzed Veterans of America
- Paraprofessional Healthcare Institute
- SEIU
- United Cerebral Palsy
- United Spinal Association
- VNAA –Visiting Nurse Associations of America



Support From

Community Living Policy Center
University of California, San Francisco
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Family Support Research and Training Center
University of Illinois at Chicago
(Grant Number #90RT50320)

Funded by the Administration on Community Living, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).



Power Point

- Can I get a copy of the Power Point?
- Will an Archive of the webinar be available?

YES! YES! YES!

- You will receive copies in a follow up e-mail early next week. Please share with others!
- Or visit www.ncoa.org

Questions and Comments



**All Lines Will Be Muted During the Call
To Ask A Question Use the Chat Function**

Webinar Overview

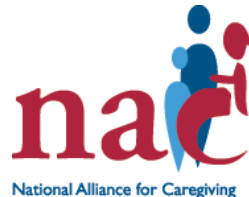
- Introduction
 - Joe Caldwell and Kripa Sreepada (National Council on Aging)
- Speakers:
 - Gail Hunt (National Alliance for Caregiving)
 - Steve Kaye (Community Living Policy Center, UCSF)
 - Jed Johnson (Easter Seals)
- Questions and Answers (20 – 30 minutes)



Caregiving in the U.S.

2015 REPORT

CONDUCTED BY:



Research Sponsors



About the Report

- Family caregiver is defined as an individual, age 18 or older, who provides unpaid care to family member or friend who needs assistance with everyday activities
- The research study is based on qualitative, online interviews of 1,248 family caregivers age 18 and older
 - Includes a random sample of 1,015 caregivers, with oversample for African American, Hispanic/Latino, and Asian American Pacific Islander caregivers*
- Special focus on family caregivers who support a loved one for at least 21 hours each week (“higher-hour”), medical/nursing tasks, caregivers in the workplace, and caregivers age 75 or older

The Changing Nature of Family Caregiving

Caregiving today affects everyone. Either you are a caregiver, know someone who is, or you expect to be one.

Today's Family Caregiver

Caregivers reflect the diversity of the United States: they come from every age, gender, race/ethnicity and socioeconomic status.

Performs at least 2 Activities of Daily Living (ADLs); 4 Instrumental Activities of Daily Living (IADLs) and a number of Medical/Nursing (M/N) Tasks



Responsibilities Include:

- ADL- Bathing, Dressing & Feeding
- IADL- Housework, Cooking & Managing Finances
- M/N Tasks- Injections, Tube Feedings & Colostomy Care

Who are They?

The typical caregiver is a 49 year-old female caring for a 69 year-old relative due to a long-term physical condition.

22% of caregivers are caring for someone with Alzheimer's or dementia.

More are considered “higher-hour”-- providing increased hours of care each week.

<u>SNAPSHOT</u>	
60%	Women
40%	Men
13%	African American/ Black
6%	Asian American Pacific Islander
17%	Hispanic/Latino
62%	White

Higher-Hour Caregivers

Higher-hour caregivers provide at least 21 hours each week caregiving.

The average amount of time for higher-hour caregivers is **62 hours per week** and they have a high burden of care (4 out of 5 in a 5 point scale).

They are typically the sole, unpaid care provider and nearly four times as likely to be caring for a spouse or partner.

These caregivers often report that they had “no choice” in taking on the caregiving role.



Overall:

32% of caregivers are higher-hour

Breakout by Ethnicity:

White: 28%, Asian American Pacific Islander: 37%, African American/Black: 39%, Hispanic/Latino: 40%

Caregivers Age 75 and Older

Caregivers age 75 or older are typically caring for a close relative (spouse, adult child, or sibling). They are the sole provider of care, and usually live with the care recipient.

These caregivers, on average, have provided care for 5 ½ years, spending about 34 hours per week performing multiple caregiving responsibilities:

- 2 Activities of Daily Living (ADL);
- 5 Instrumental Activities of Daily Living (IADL); and
- Medical/Nursing Tasks (M/N Tasks).



Responsibilities Include:

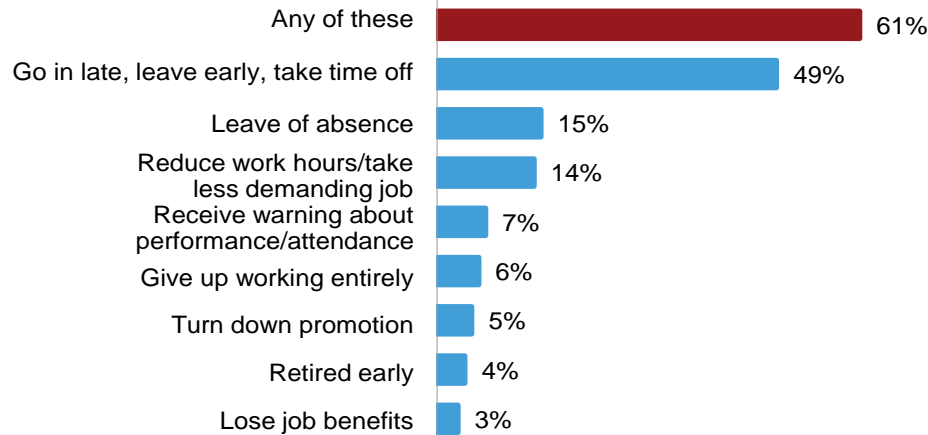
ADL- Bathing, Dressing & Feeding

IADL- Housework, Cooking & Managing Finances

M/N Tasks- Injections, Tube Feedings & Colostomy Care

Balancing Caregiving & Work

Base: Working Caregivers of Recipient Age 18+ (n=724)



Hours Caregiving per Week	
0-20 (n=527)	21+ (n=194)
58%	69%*
47%	53%
12%	23%*
10%	25%*
5%	11%*
4%	12%*
3%	11%*
3%	8%*
2%	5%

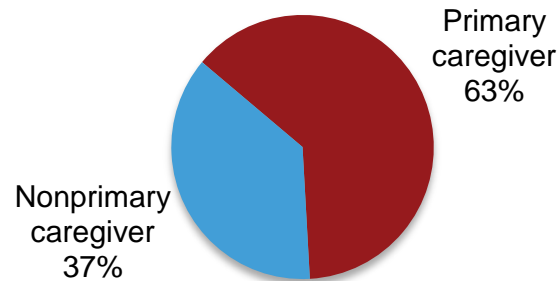
60% of caregivers were employed at some point in the past year while also caregiving. Higher-hour caregivers are more likely to report experiencing nearly all of these work impacts.

Other Impacts on Work/Caregiving Balance

- Primary caregivers are more likely to report that caregiving impacted their work, as are caregivers who felt they had “no choice” in taking on the role
- 70% of caregivers who perform medical/nursing tasks reported that caregiving impacted their job
- Employees working 30 hours a week or more were more likely to report workday interruptions as a result of caregiving
- 39% of caregivers left their job to have more time to provide care
- 34% of caregiver left their job due to lack of flexibility

Most Respondents are Primary Caregivers

Base: Caregivers of Recipient
Age 18+ (n=1,248)



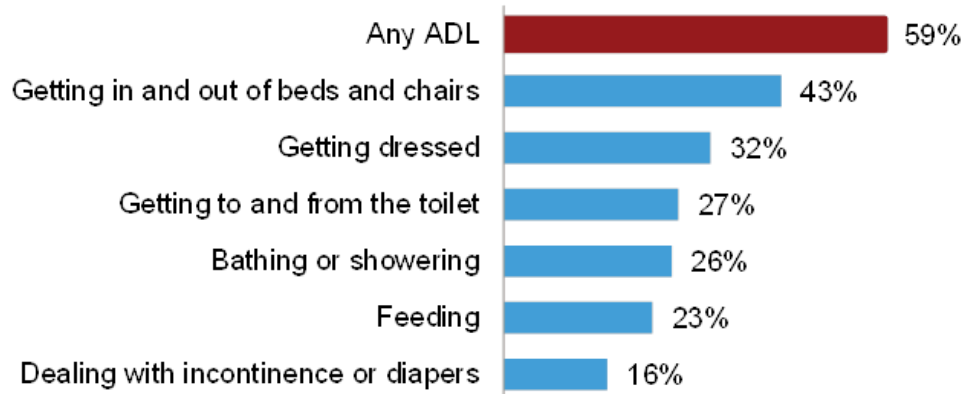
% Primary Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
56%	77%*

Caring for Whom?

	Caregivers of Recipient Ages 18+ (n=1,248)	Hours of Care	
		0–20 (n=826) A	21 or more (n=416) B
Relative	85%	81%	93%^A
Parent	42	42	43
Spouse or partner	12	7	24 ^A
Parent-in-law	7	8	5
Grandparent or grandparent-in-law	7	8 ^B	4
Adult child	5	5	6
Uncle or aunt	4	4	3
Sibling	3	3	3
Other relatives	3	3	3
Sibling-in-law	2	3	1
Grandchild	*	*	--
Nonrelative	15	19^B	7
Friend	10	13 ^B	4
Neighbor	3	3	2
Other nonrelative	2	3	2

Help with Activities of Daily Living (ADLs)

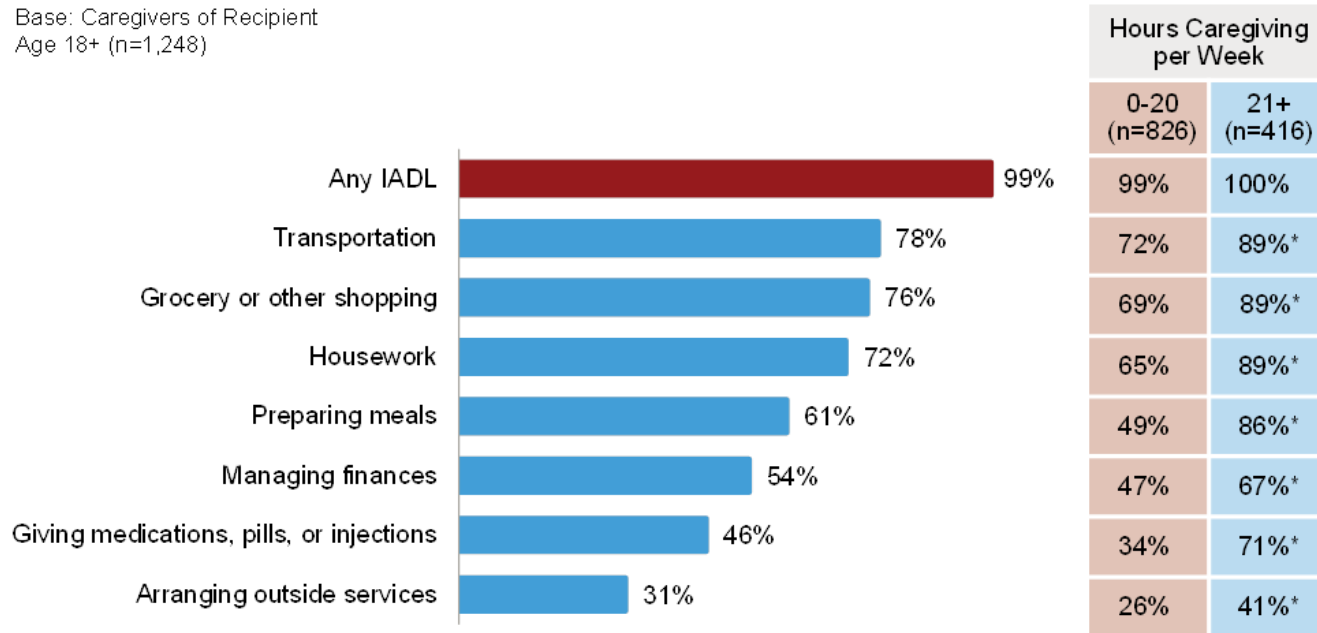
Base: Caregivers of Recipient
Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
51%	75%*
36%	59%*
22%	51%*
21%	40%*
17%	45%*
18%	36%*
9%	31%*

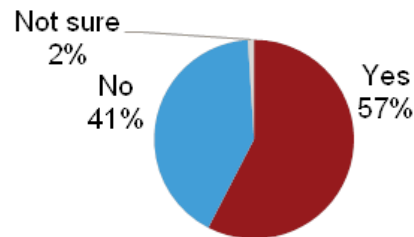
Help with Instrumental Activities of Daily Living (IADLs)

Base: Caregivers of Recipient
Age 18+ (n=1,248)



Medical/Nursing Tasks

Base: Caregivers of Recipient
Age 18+ (n=1,248)



% Yes	
Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
45%	83%*

In addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform. Known now as medical/nursing tasks, these skilled activities include:

- giving injections,
- providing tube feedings,
- managing catheter and colostomy care, and
- many other complex care responsibilities.

Medical/Nursing Tasks continued...

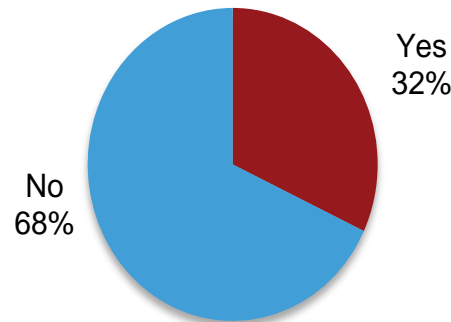
More than 8 in 10 higher-hour caregivers are performing medical/nursing tasks without any prior preparation.

Caregivers in the most complex care situations are the ones most likely to be performing medical/nursing tasks without any preparation.

62% of high-burden caregivers are performing medical/nursing tasks without prior preparation.

Most Caregivers Have No Paid Help

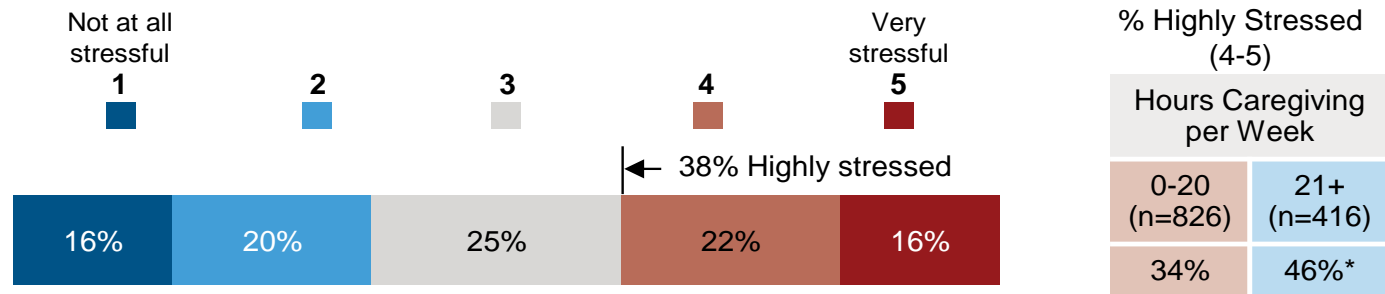
Base: Caregivers of Recipient Age 18+ not in nursing home or assisted living (n=1,147)



% Yes	
Hours Caregiving per Week	
0-20 (n=740)	21+ (n=401)
30%	34%

Many Caregivers are “Highly Stressed”

Base: Caregivers of Recipient
Age 18+ (n=1,248)

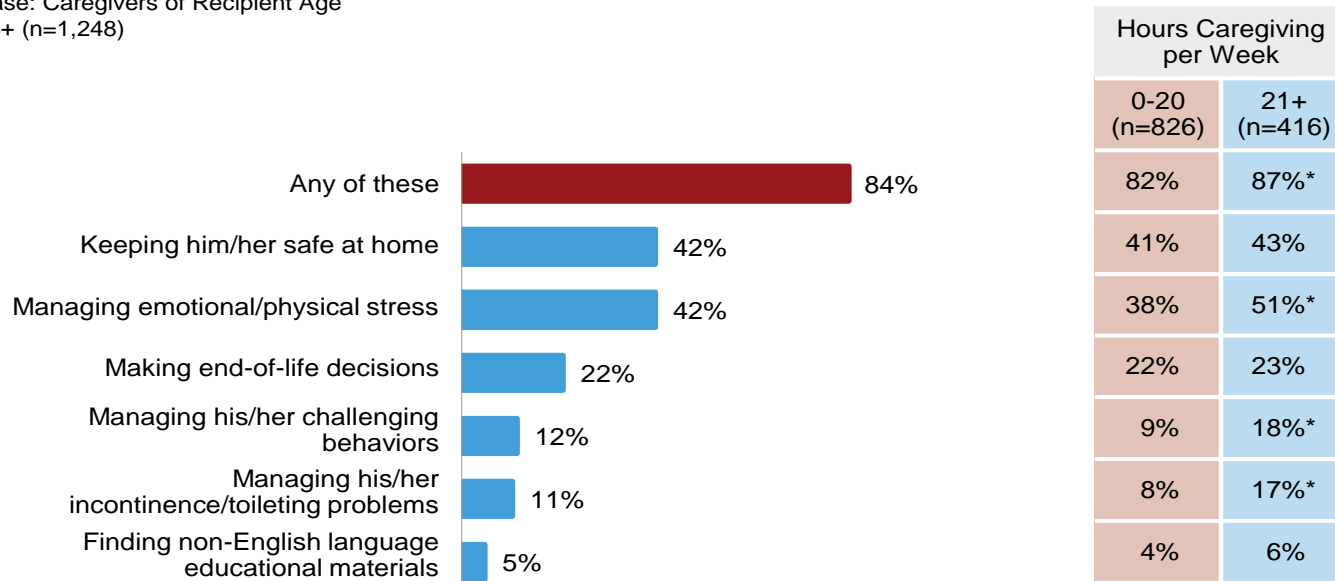


Experiencing emotional stress is more common among higher-hour caregivers. Over half of those who feel they had no choice in taking on their caregiving role report high levels of emotional stress (53%).

Supporting Caregivers

Information Needs

Base: Caregivers of Recipient Age 18+ (n=1,248)



Higher-hour caregivers are more likely to want information overall. Those higher-hour caregivers are especially interested in managing stress, managing their loved one’s challenging behaviors, and dealing with incontinence.

Recommendations

1. Identify high-risk caregivers.
2. Support caregivers in the workplace.
3. Provide resources to new caregivers.
4. Offer training.
5. Encourage advance planning for when caregivers can no longer provide care.

More Information

Gail Hunt

President & CEO

National Alliance for Caregiving

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www.caregiving.org

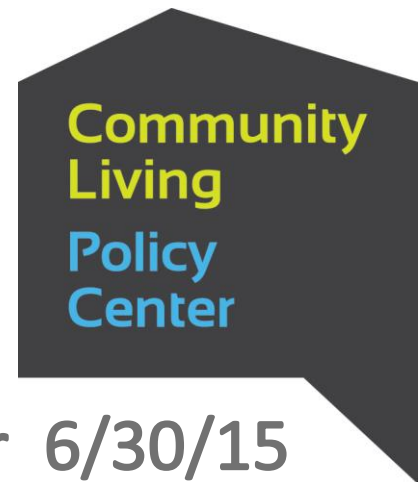
@NA4Caregiving

Changing Patterns of Family Caregiving

Steve Kaye

Community Living Policy Center

University of California San Francisco

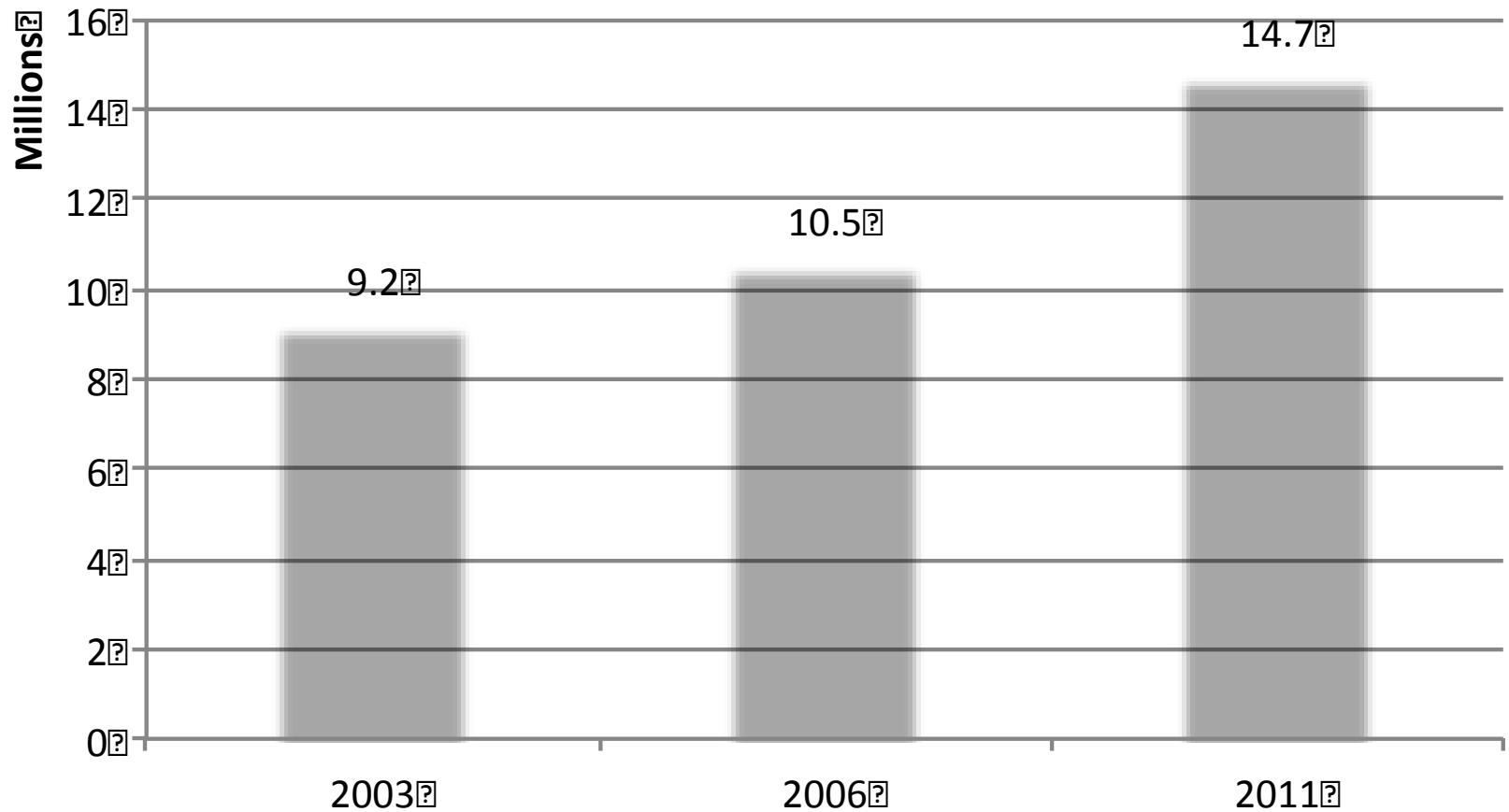


Disability & Aging Collaborative Webinar 6/30/15

Research funded by National Institute on Disability, Independent Living, and Rehabilitation Research and the Administration for Community Living (NIDILRR grant number 90RT5026)

Big increase in unpaid caregiving

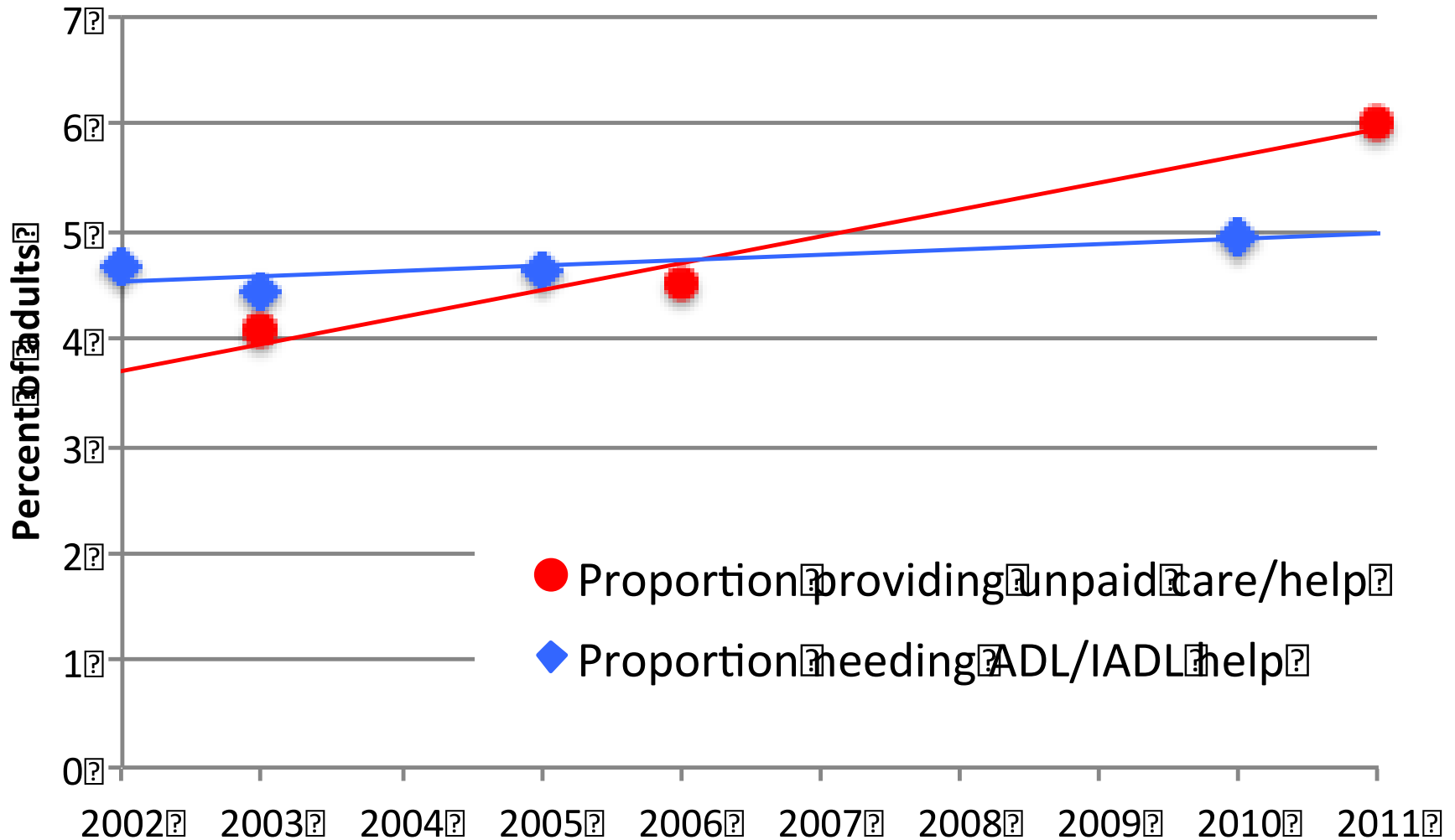
Adult Caregivers, 2003–2011



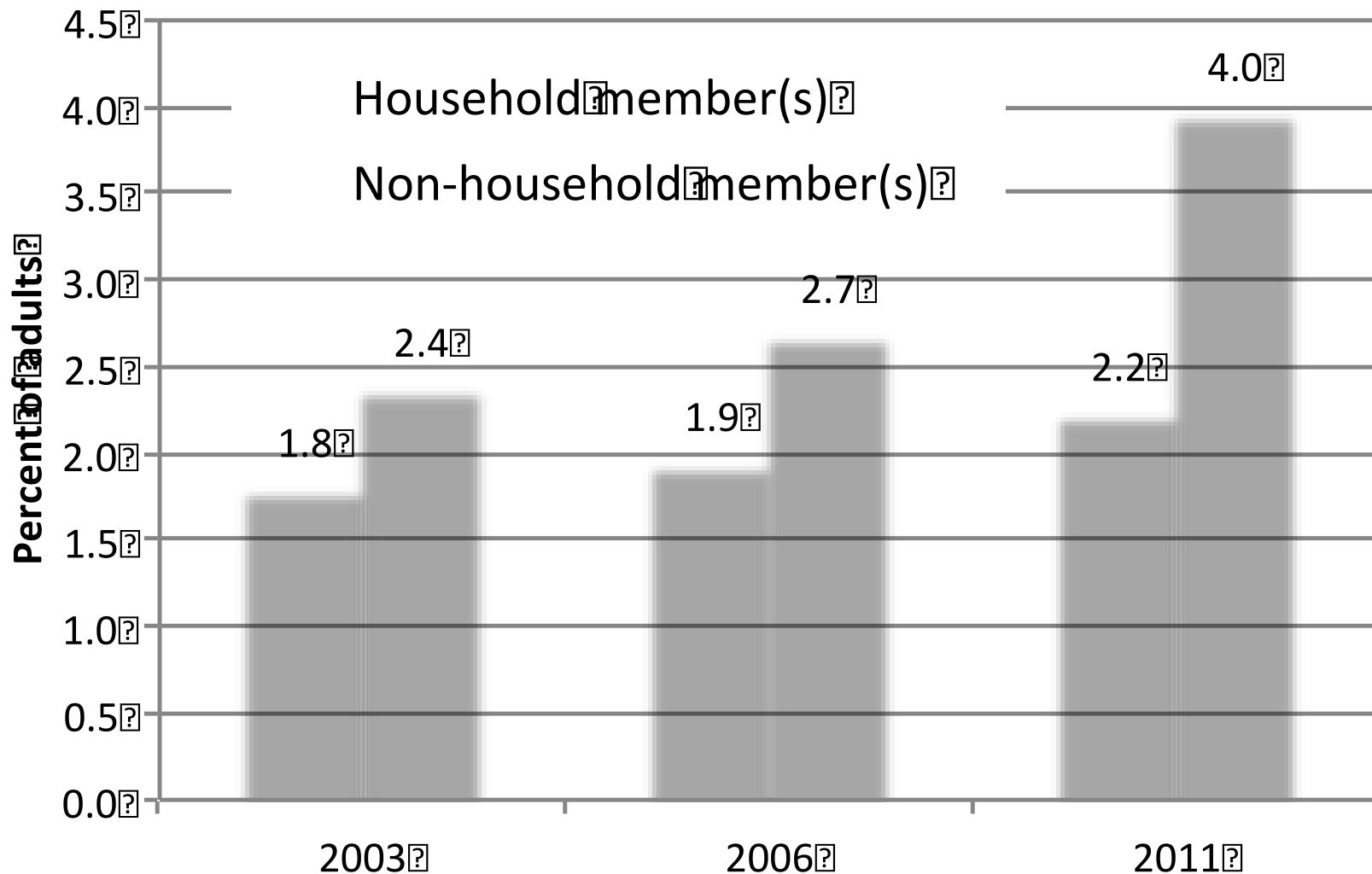
Data Source

- Survey of Income & Program Participation
 - Nationally representative survey conducted by the Census Bureau
 - Longitudinal: New panel sampled every few years
 - Interviewed every 4 months over ~3 years
 - Supplemental modules on “informal caregiving” once per panel: 2003, 2006, 2011
 - **Unpaid** family members & friends only
 - Supplemental module on disability/ADL/IADL once or twice per panel

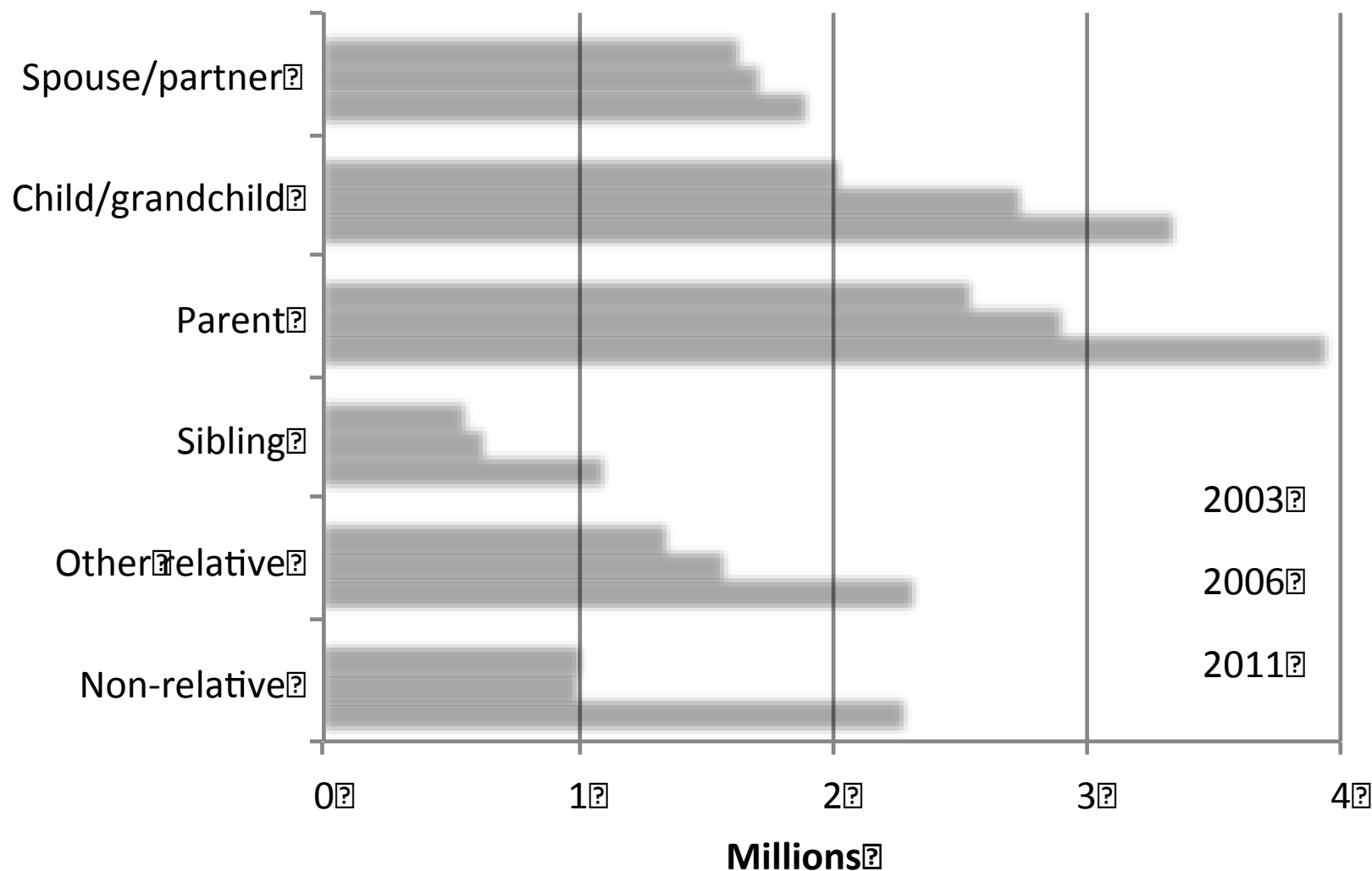
Caregiving increasing faster than reported need for help



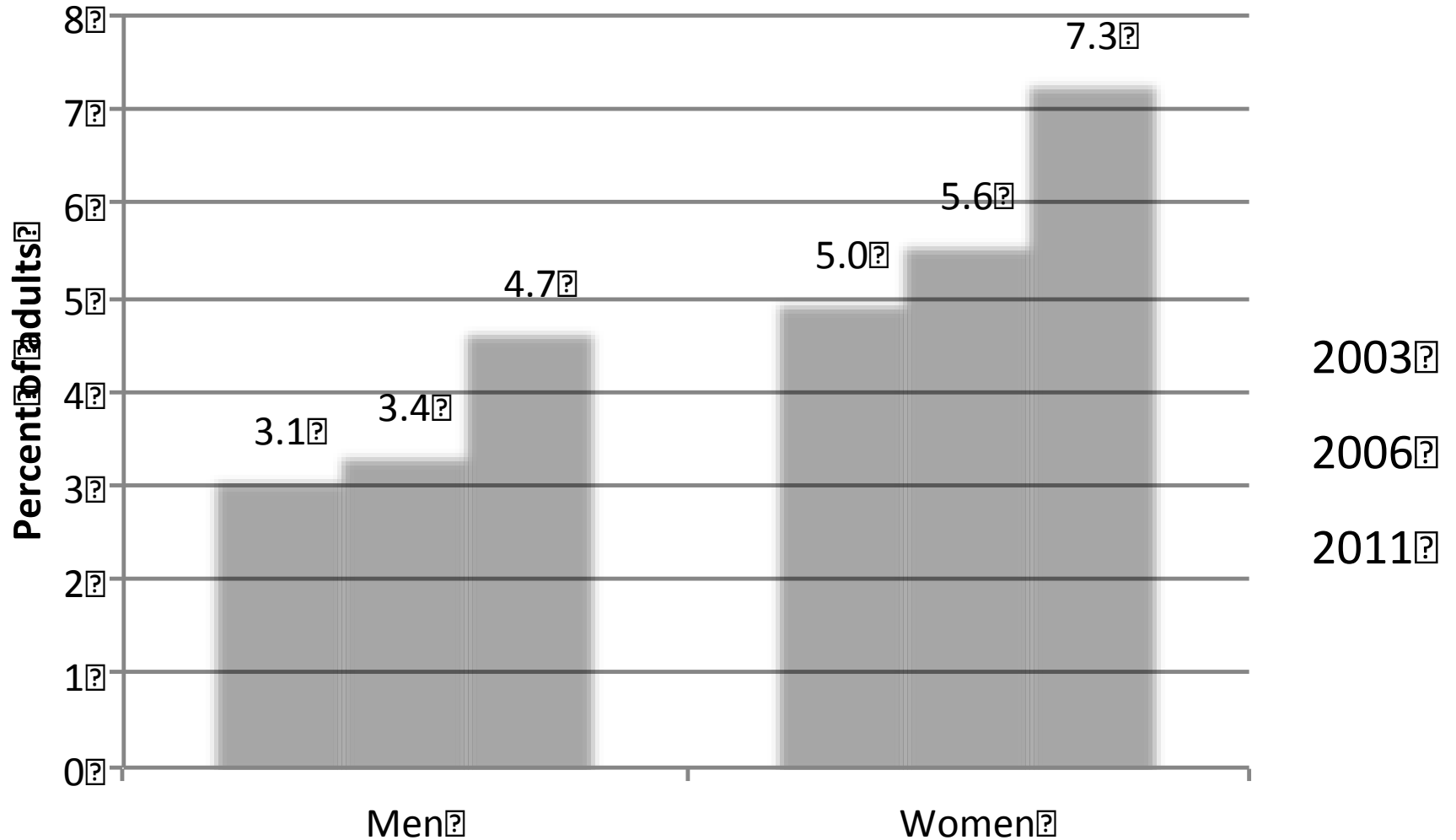
Big increase for care of non-household members



Recipients of unpaid caregiving

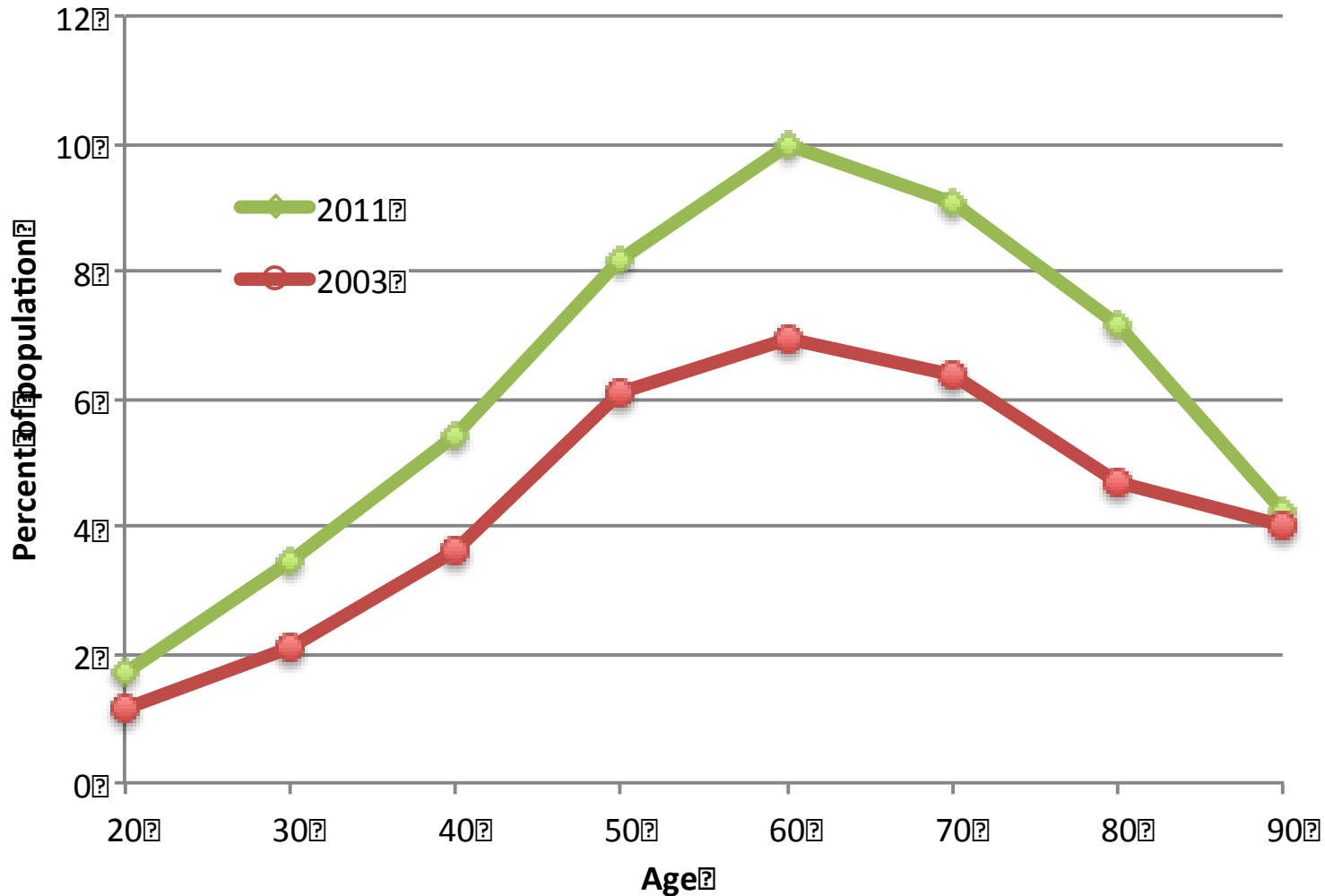


Who provides care?



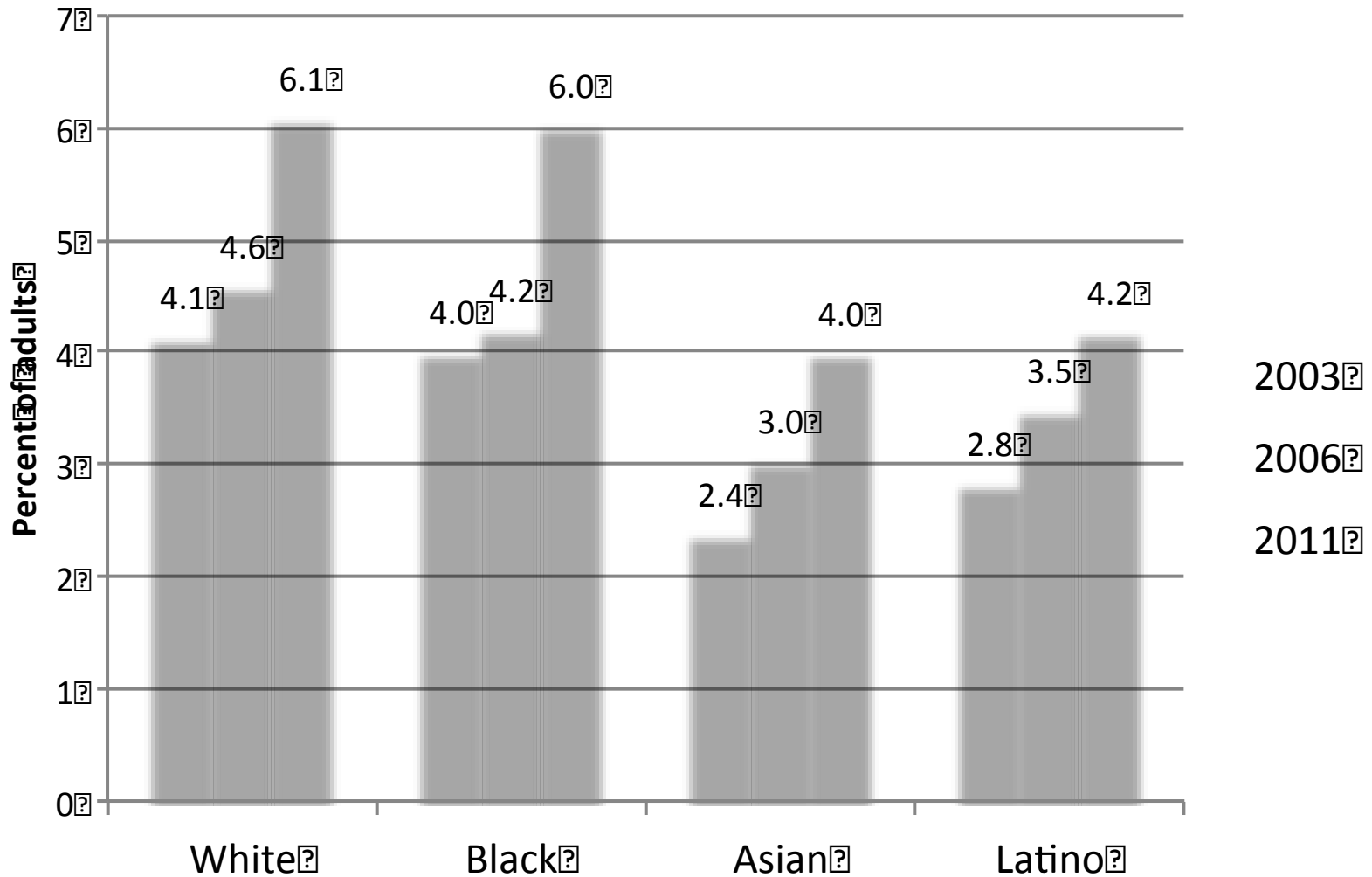
Who provides care?

Caregiving by Age, 2003 & 2011



Who provides care?

Caregiving by Race/Ethnicity, 2003–2011

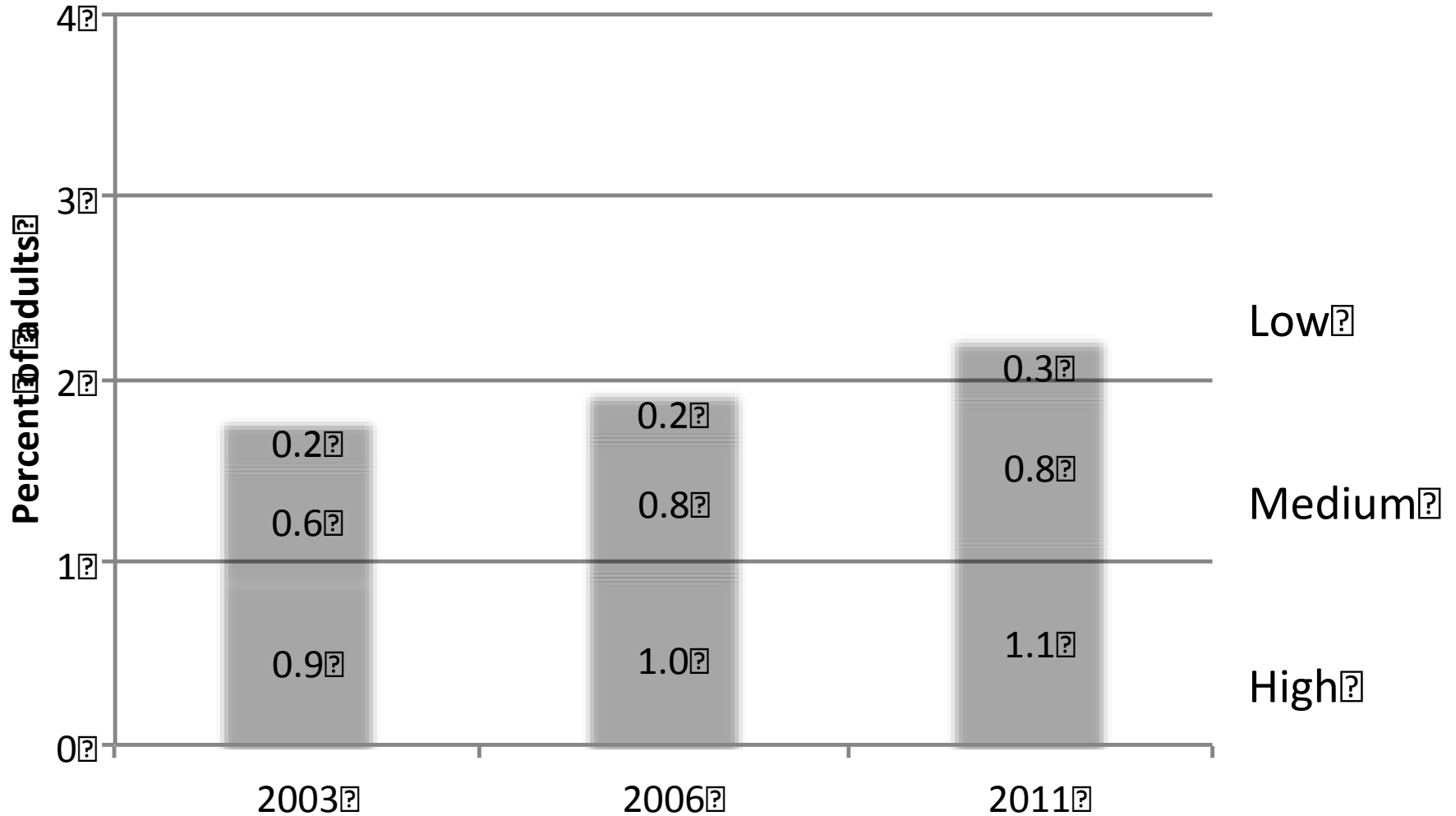


Tasks & amount of help

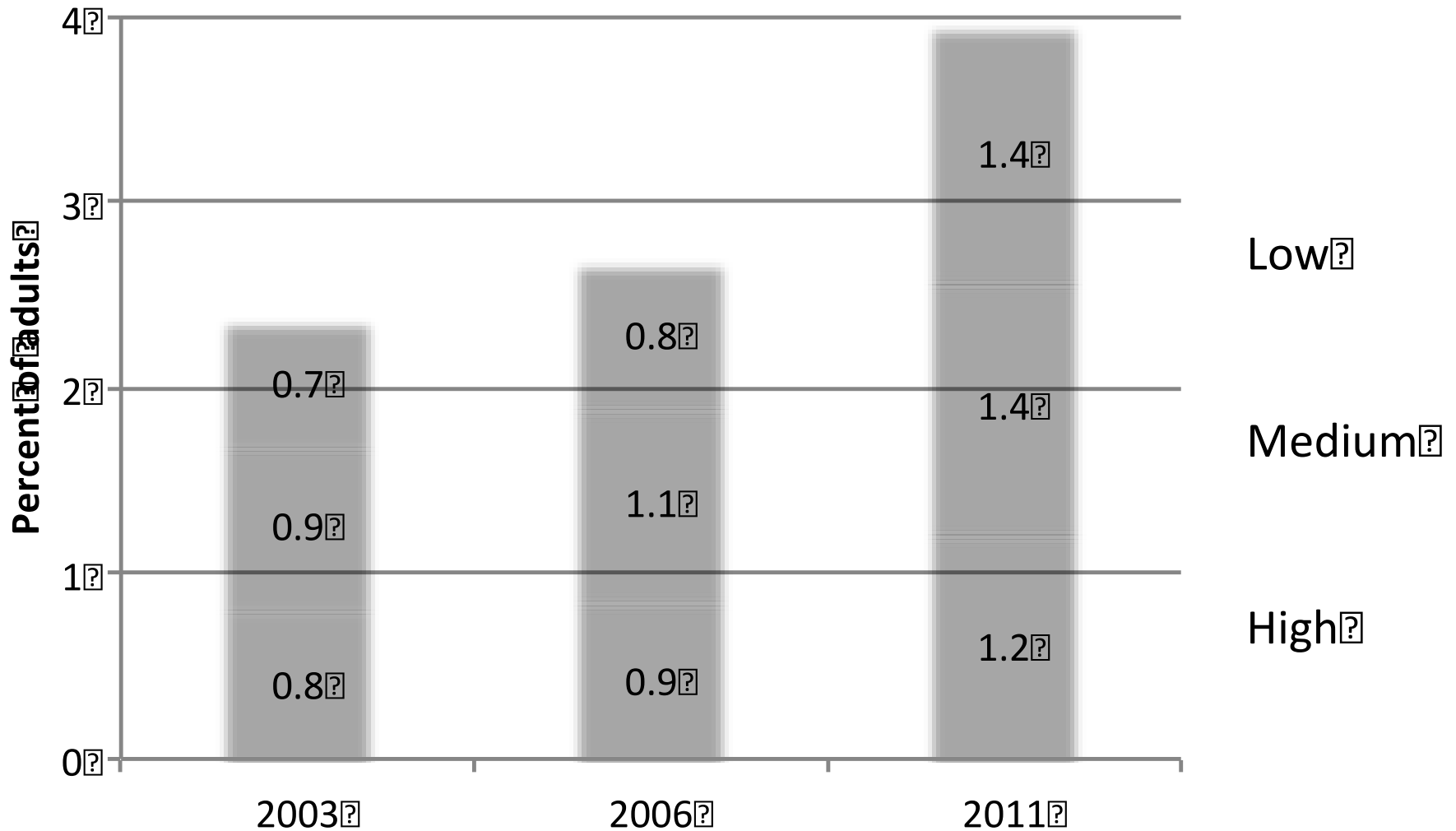
- ADL:
 - “dress, eat, bathe, or get to the bathroom”
- IADL/health:
 - “medical needs such as taking medicines or changing bandages”
 - “keep track of bills, checks, or other financial matters”
- Other:
 - “taking him/her shopping or to the doctor's office”
 - “any other”

Care category (mutually exclusive)	Median hours per week (Household)	Median hours per week (Non- household)
High (Helps with ADLs)	40	13
Medium (IADL/health, no ADLs)	20	6.5
Low (No ADLs or IADL/health)	10	4

Care given within the household



Care given outside the household



How can we explain this rapid change in patterns of caregiving?



- Hypotheses:
 - De-institutionalization
 - Family structure
 - Economy
 - Baby Boomers
 - ?

What's going on?

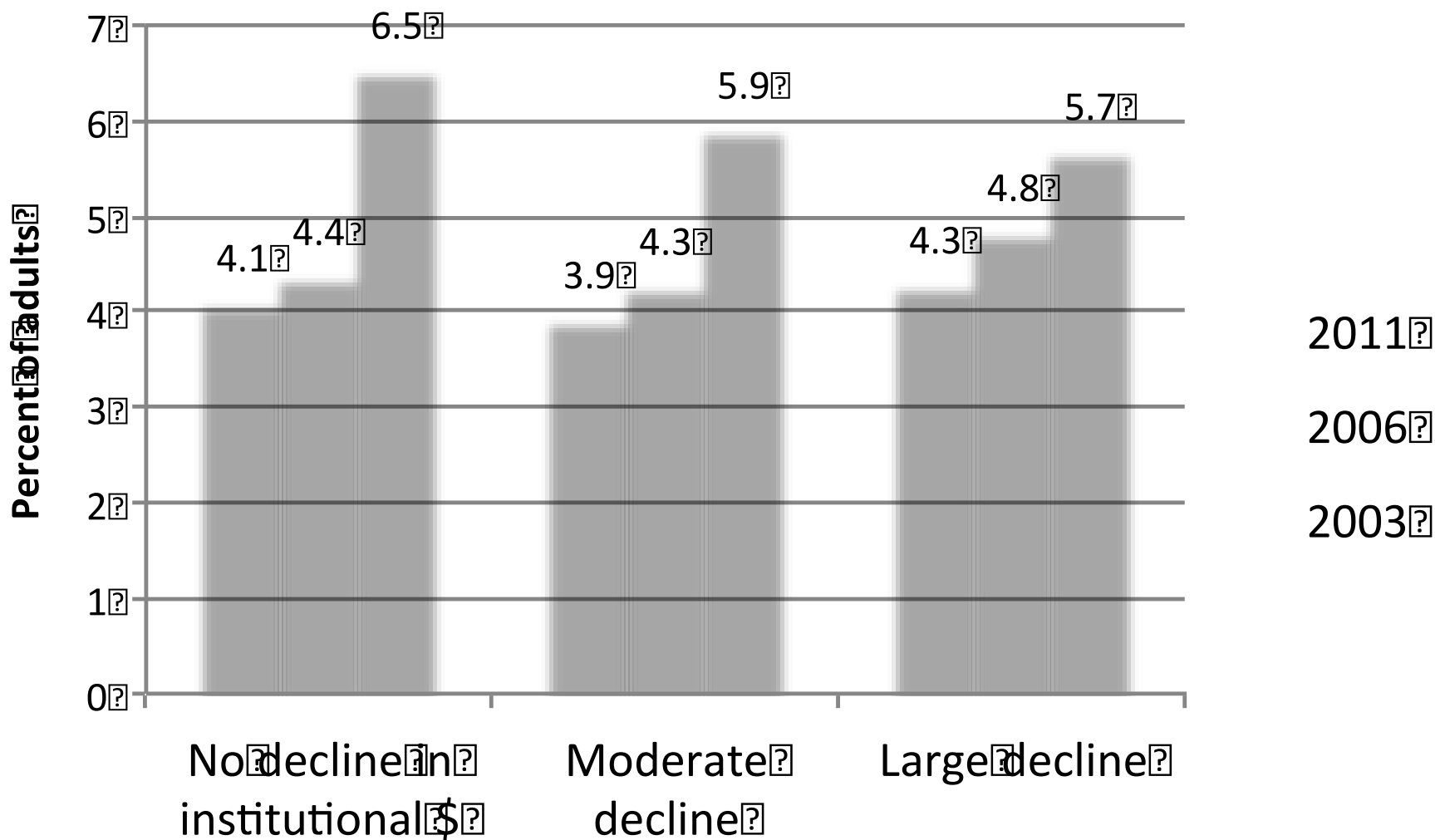


Hypothesis:

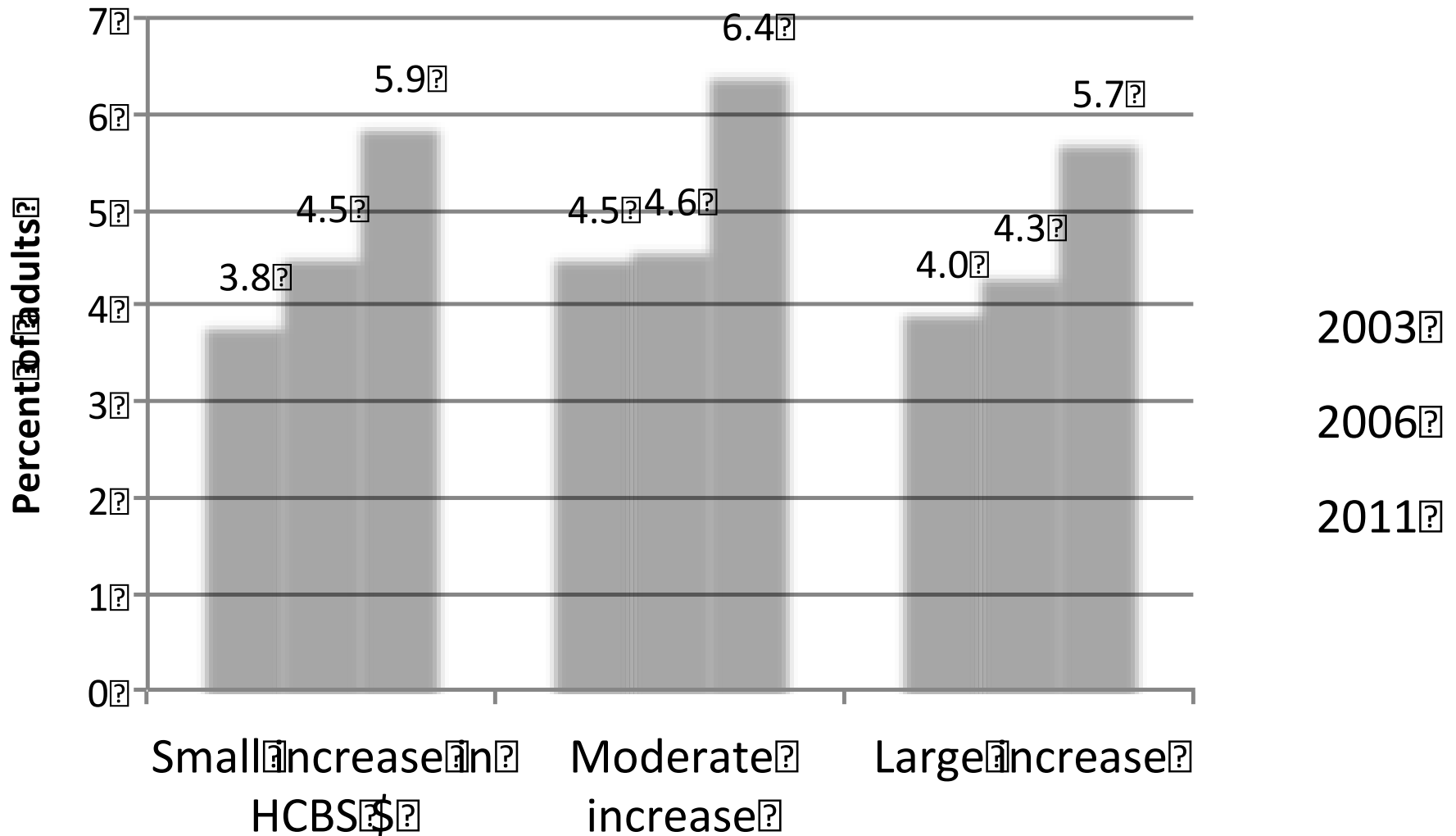
People who would've been institutionalized in the past are now living in the community →

More family caregiving

Does caregiving vary with institutional spending?



Does caregiving vary with HCBS spending?



What's going on?



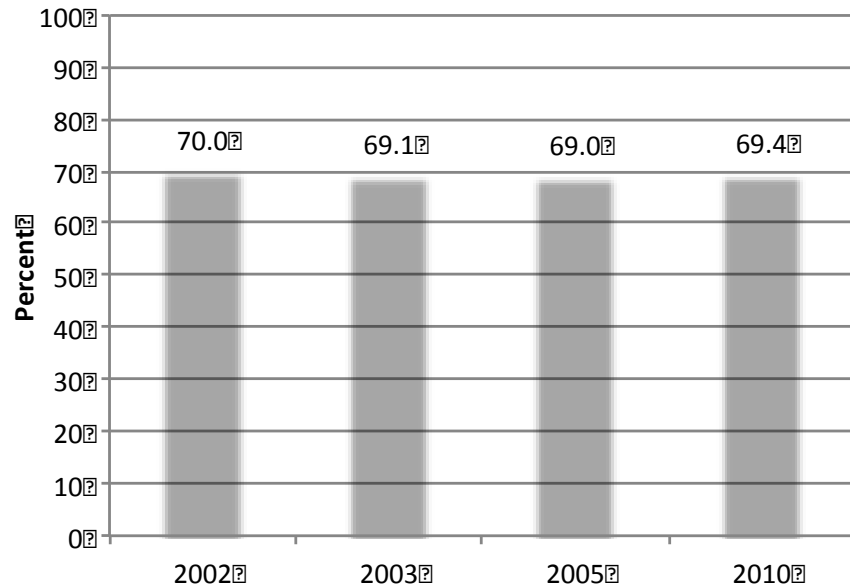
Hypothesis:

Families have dispersed, so more people needing help live alone or with fewer caregivers →

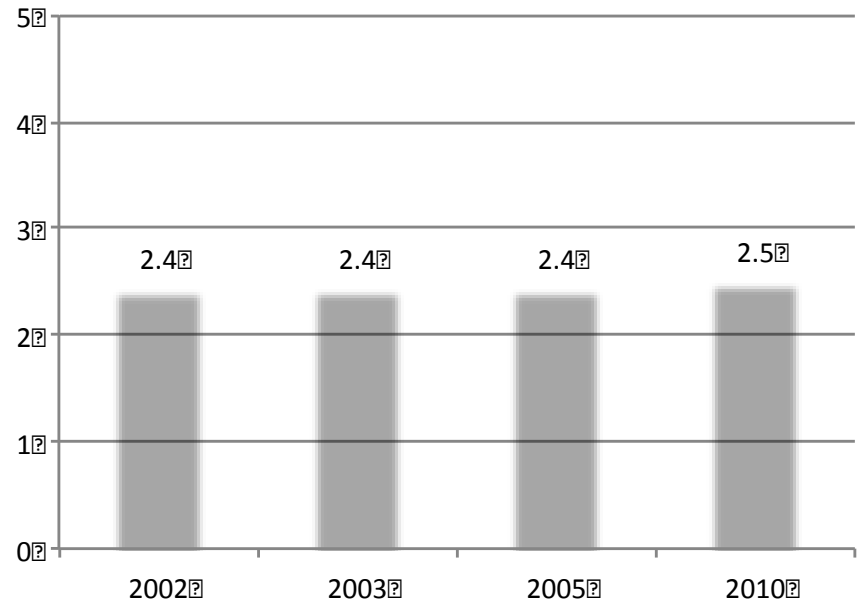
More outside-the-home caregiving

No change in living arrangement

Proportion of ADL/IADL Population Living with Family



Household Size Among ADL/IADL Population



What's going on?

Hypothesis:

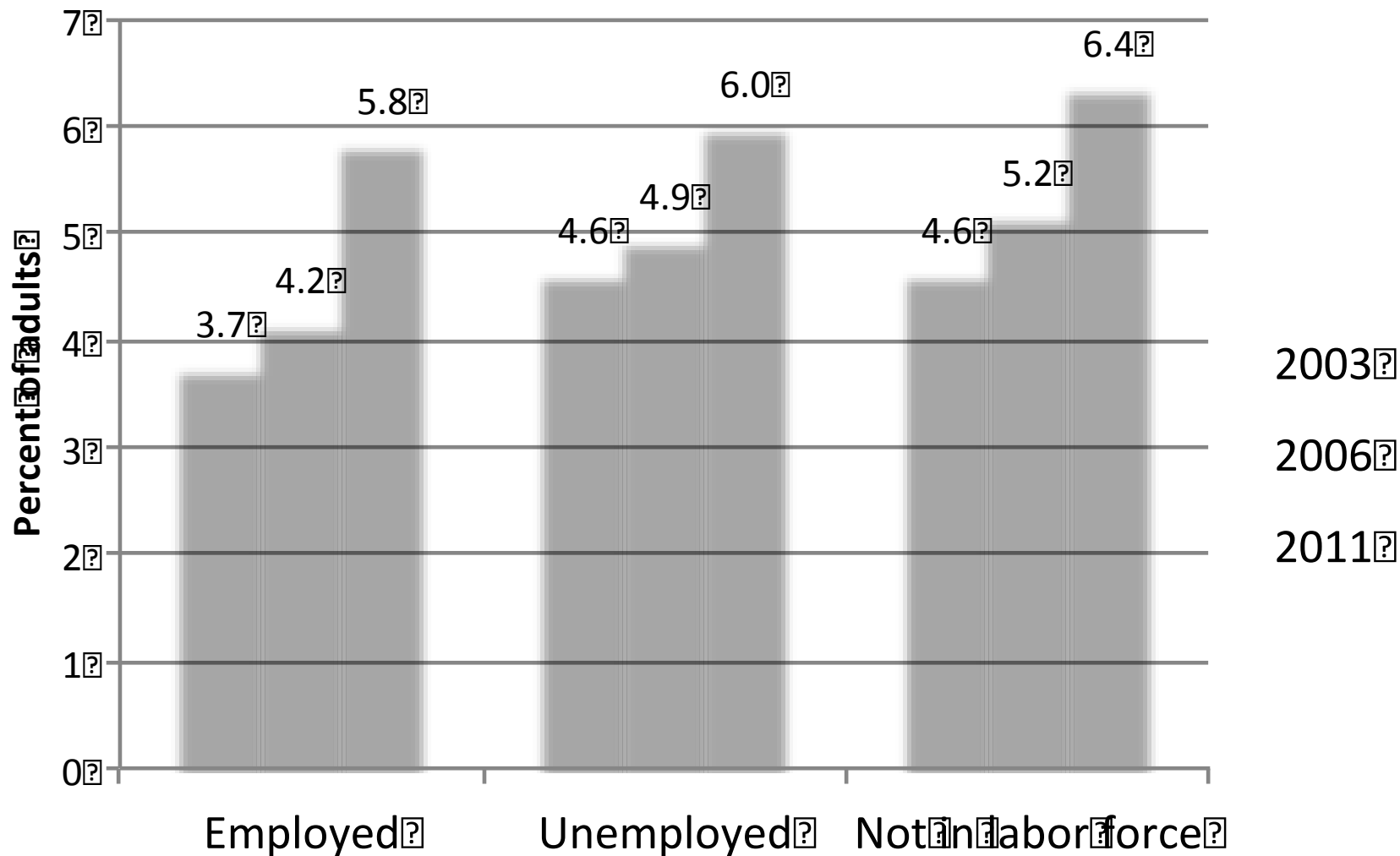
Recession →

Unemployment →

More availability for caregiving

Is it the newly unemployed?

Caregiving by labor force status



What's going on?

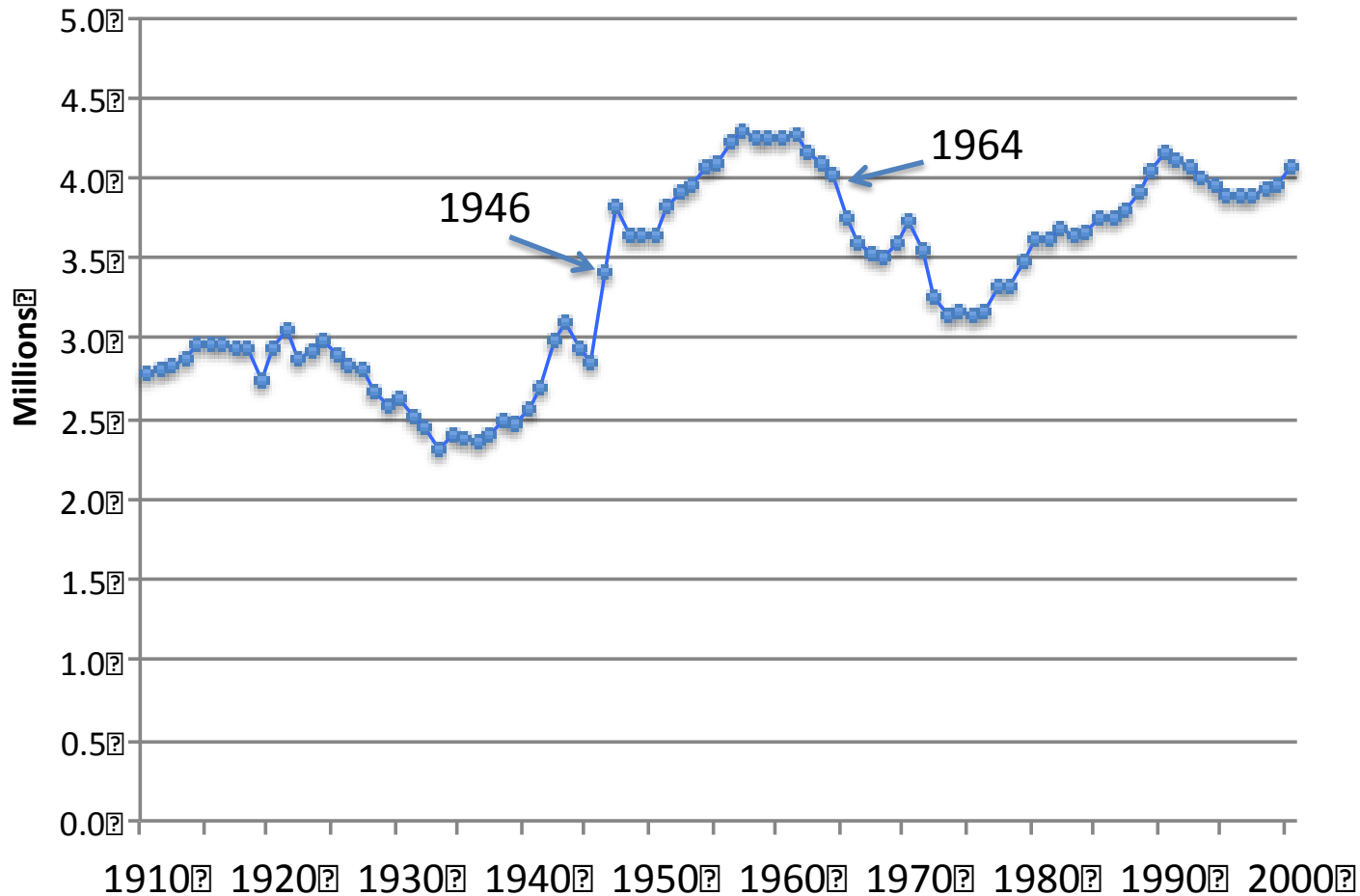
Hypothesis:

Either as caregivers or recipients, Baby Boomers have different expectations of or attitudes toward caregiving →

More diffuse pattern of caregiving

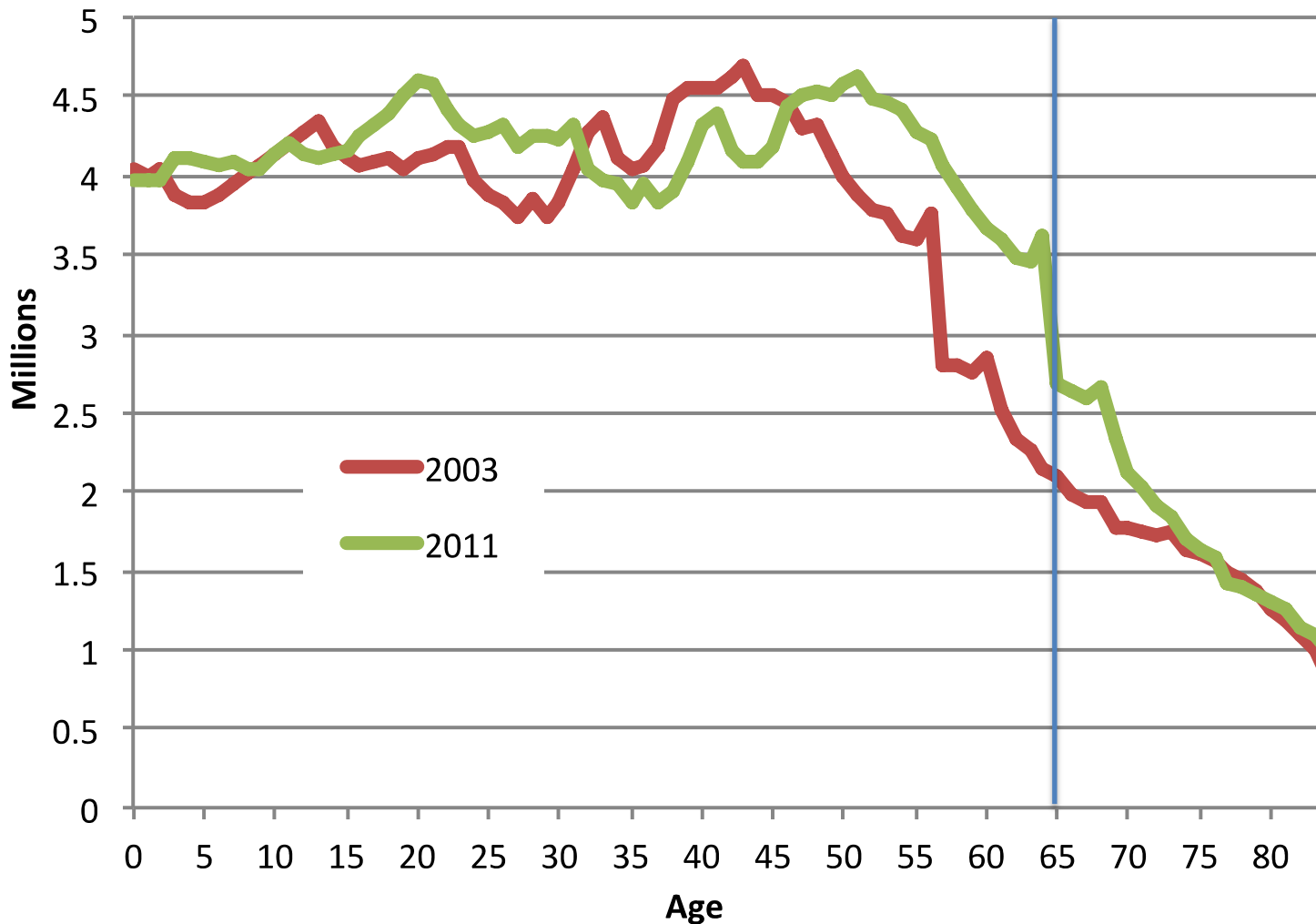
The Baby Boom

Live Births by Year, United States



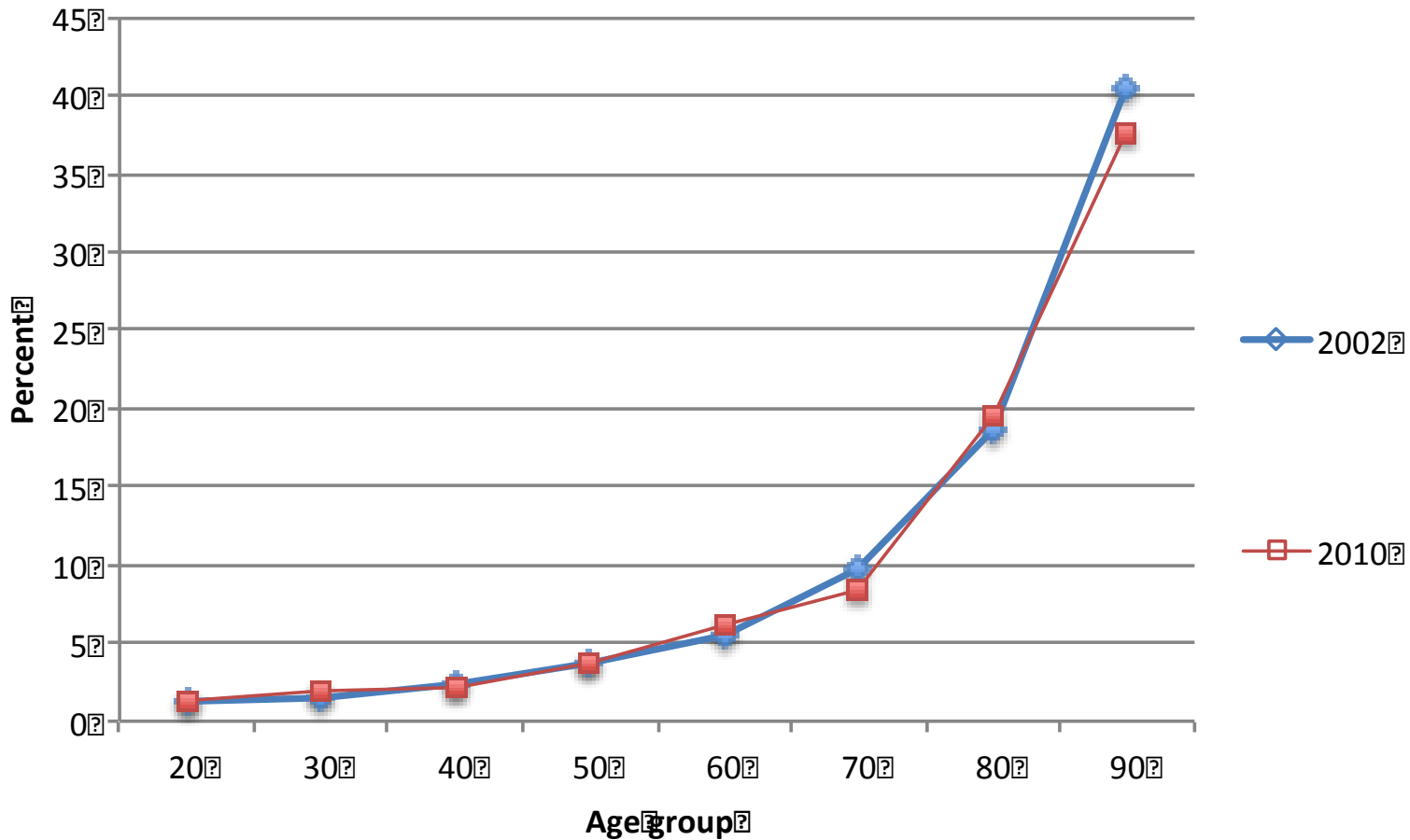
The oldest Boomers reached retirement age in 2011

U.S. Population by Age, 2003 & 2011



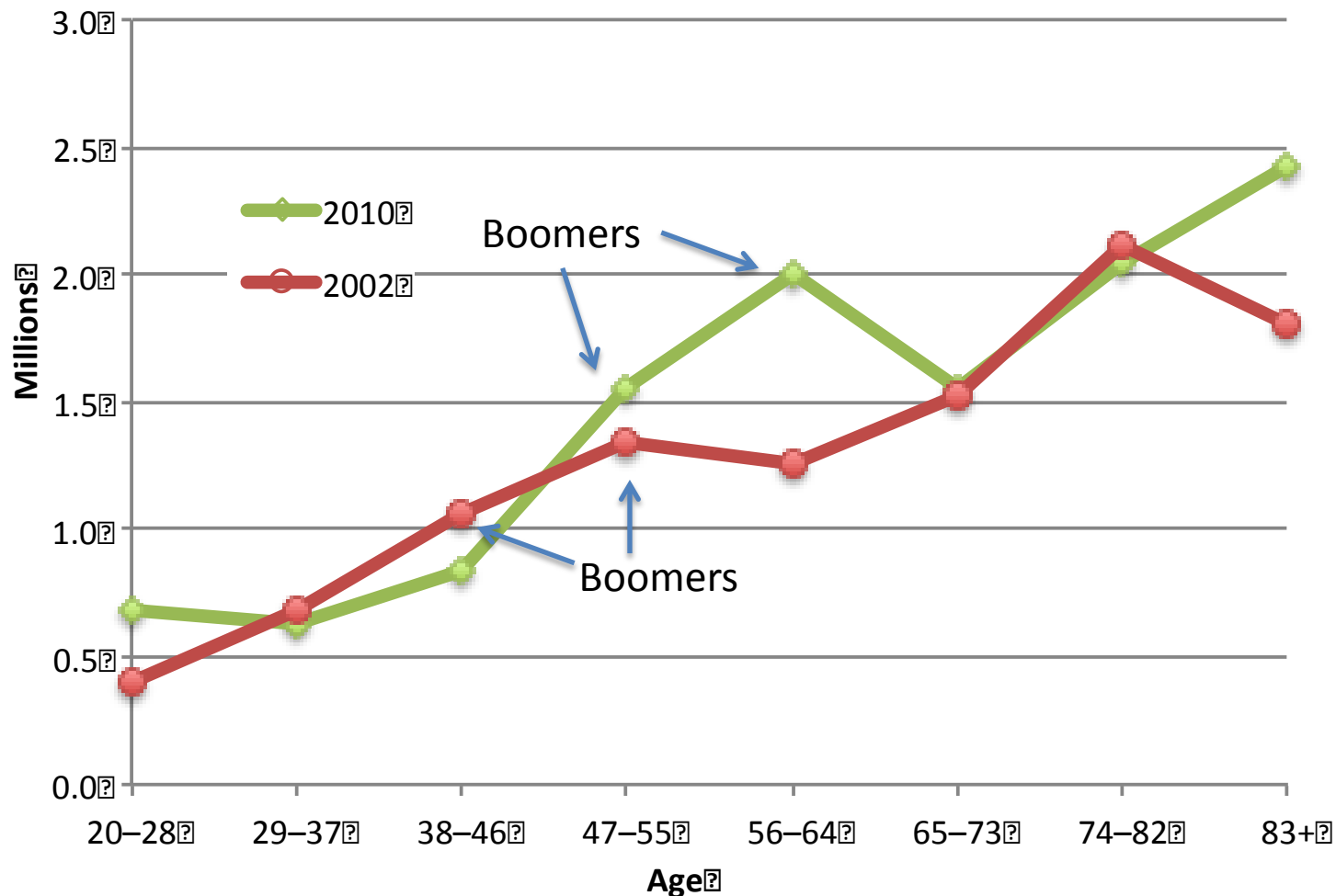
No change in prevalence of need for ADL/IADL help by age

Proportion Needing PAS, by Age



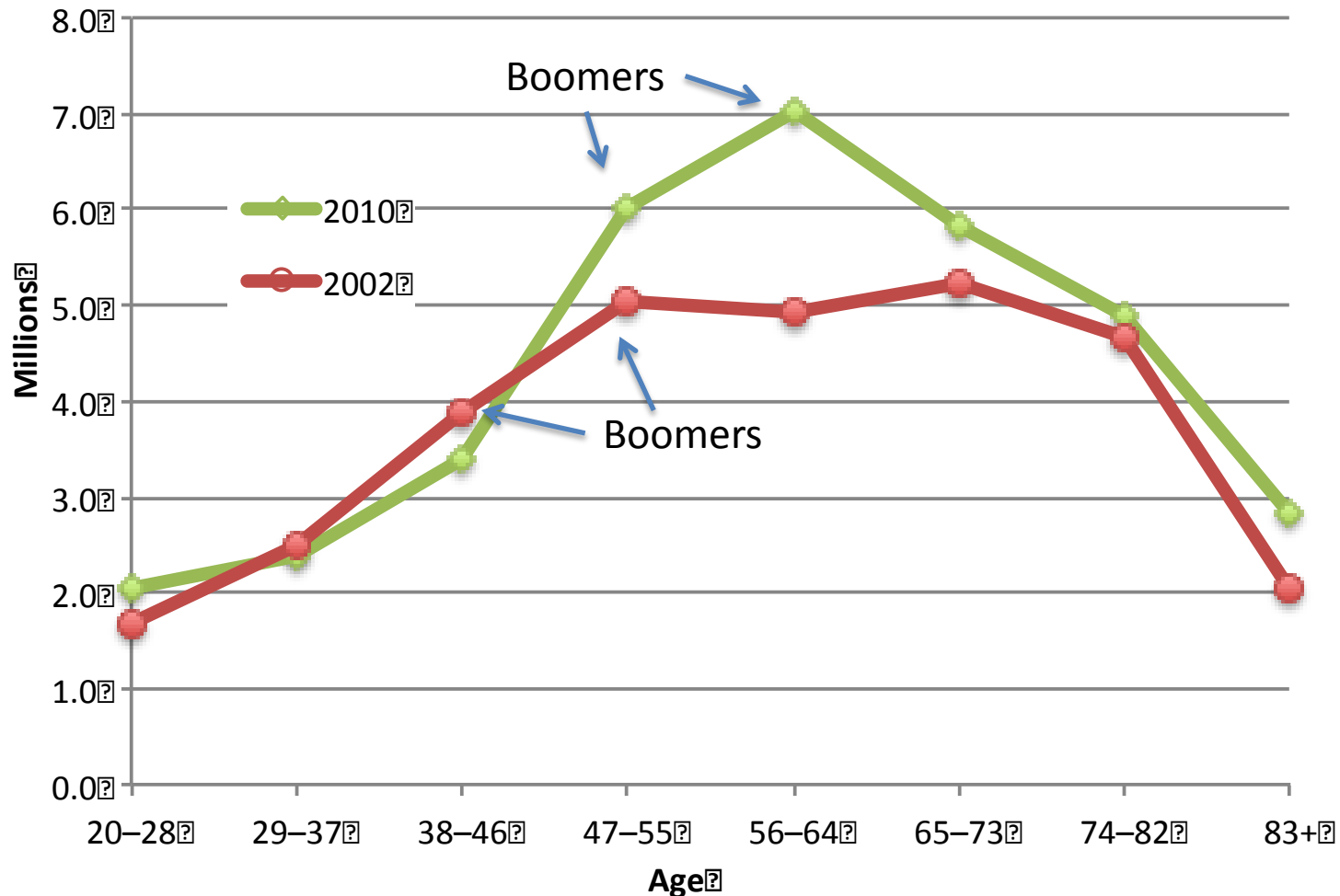
But age distribution of ADL/IADL pop. now has a boomer bump

Adults Needing PAS by Age



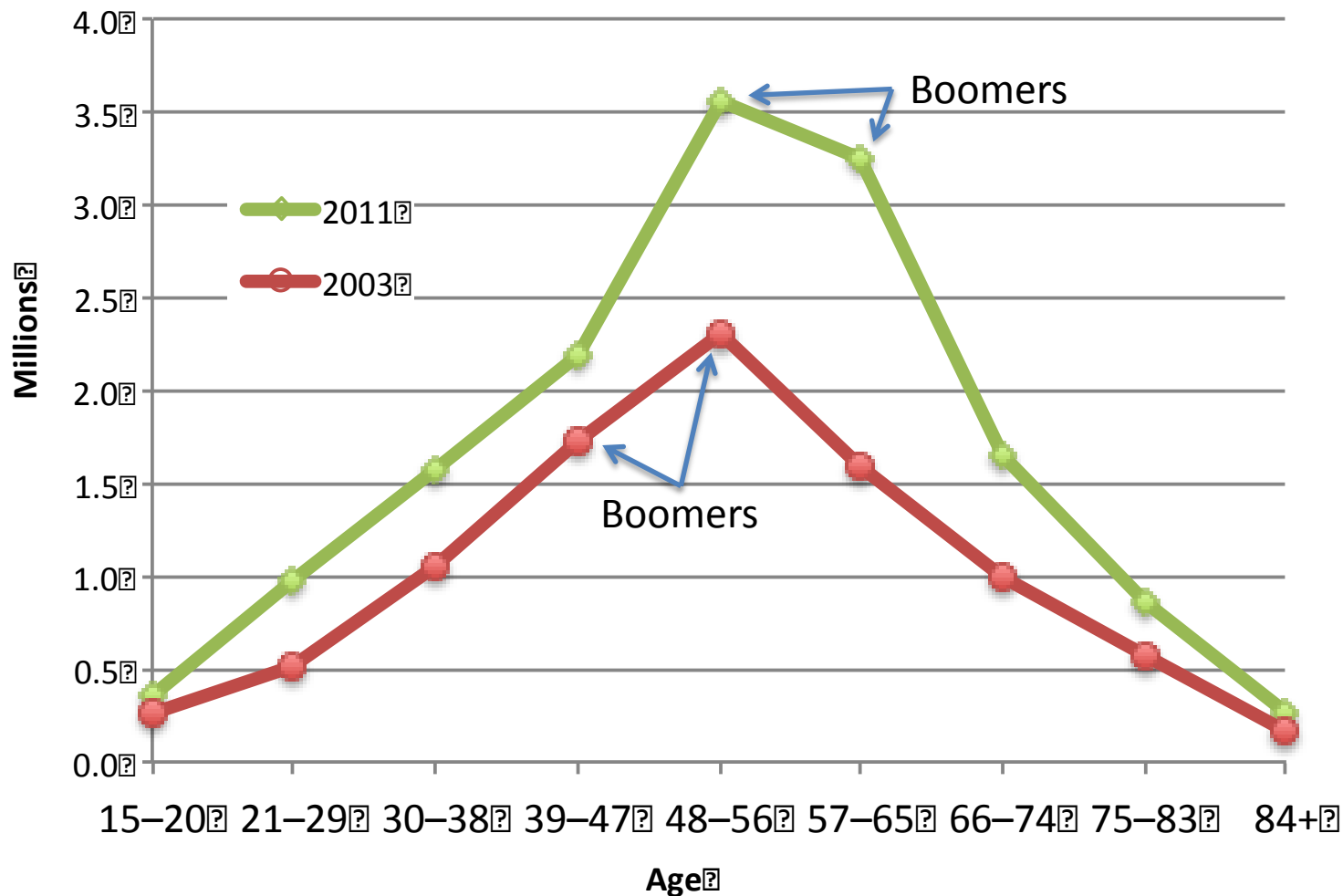
Caregiving recipients don't always "need help" in ADL/IADL

Has disability, not reported ADL/IADL

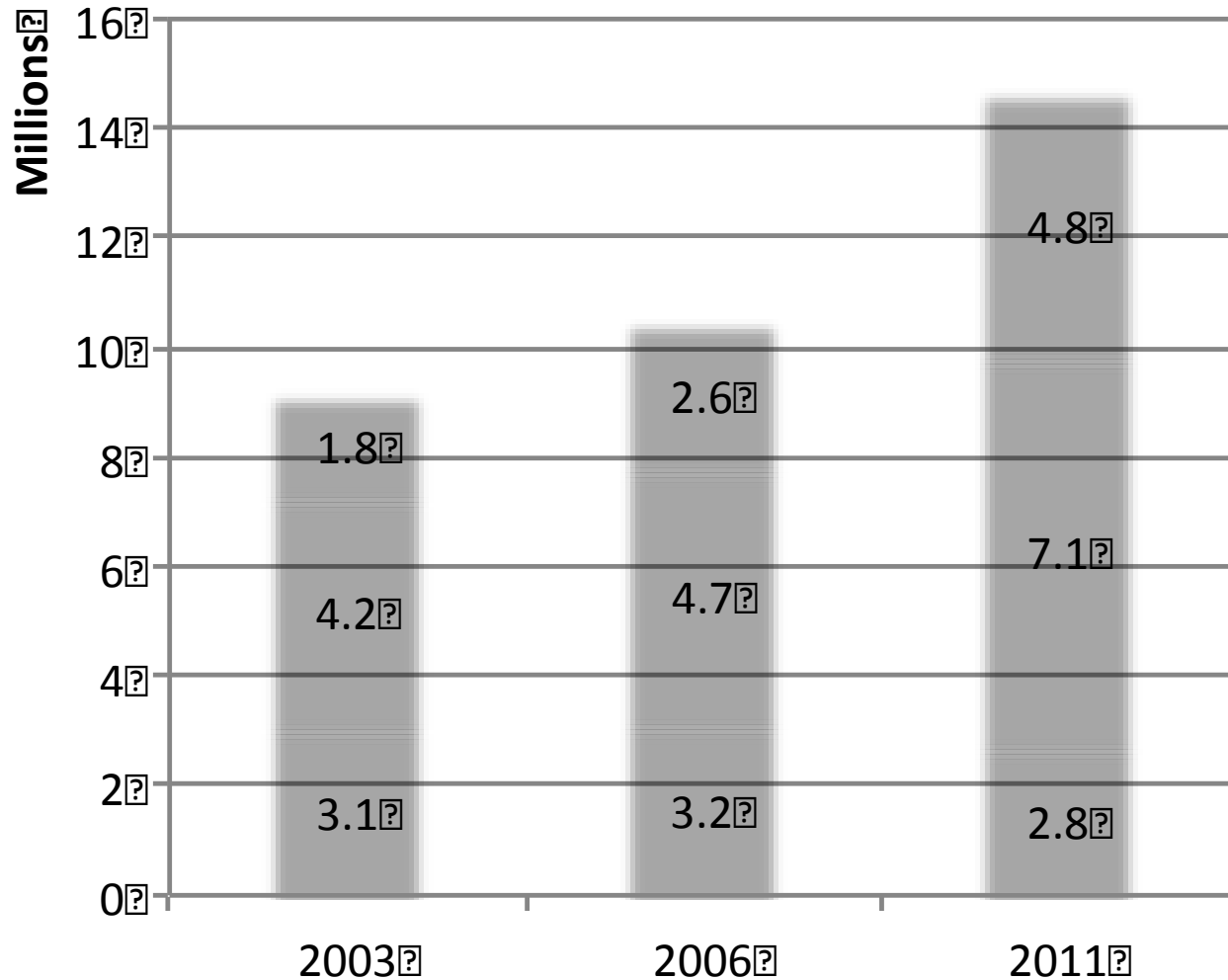


Boomers have emerged as the principal caregivers

Caregivers by Age, 2003 & 2011



4/5 of caregivers are Boomers or post-Boomers



Post-Boom
(Gen X/
Millennial)

Baby
Boomers

Pre-Boom
(Greatest/
Silent)

Research on Boomer caregivers

From Guberman, et al., Baby Boom caregivers: care in the age of individualization. *Gerontologist*, 52(2), 210-218, 2002.

- “Caregiver identity as among one of many social identities.” They “won’t leave a job to take care of a family member.”
- “Care is more and more conditional, limited, and circumscribed.”
- Role as “guaranteeing quality of life for the disabled person and as managing services.”

Conclusions

- From 2003–2011, large, broad-based increase in unpaid caregiving
 - Not explained by increase in reported need for help
 - Especially for recipients outside the household
 - Especially for low levels of care: few hours/week
- Paid family caregiving not addressed
- No evidence it's related to rebalancing, recession, family structure changes
- Related to shifts in expectations & attitudes as Baby Boomers become principal caregivers and recipients?
- Increased need for paid services for recipients & caregivers



Many Faces of Caregiving Study

made possible by MassMutual Financial Group



CHANGING THE CONVERSATION ABOUT CAREGIVING - EASTERSEALS.COM



Many Faces of Caregiving Study



Easter Seals and Caregiving

Thanks to MassMutual Financial Group, Easter Seals conducted the *Many Faces of Caregiving Study* to learn more Millennial and Generation X caregivers as well as individuals from those generations who have yet to take on that role



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Many Faces of Caregiving Study



Easter Seals Caregiving Footprint

- Military/Veteran Caregiver webinar series (supported by Newman's Own Foundation) in partnership with the Elizabeth Dole Foundation
- Nation's leading non-profit provider of Adult Day Services
- At the forefront in government relations/policy arena at federal, state, and local level
- Dept. of Veterans Affairs contract providing education/training for nearly 30,000 Caregivers supporting those who have served our country
- Leader in lifespan respite care supporting Caregivers across the generations



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Many Faces of Caregiving Study



Easter Seals & Caregiving cont.

- Smoking Cessation & Caregivers initiative (supported by CVS Health Foundation)
- National Center on Senior Transportation (Transportation Solutions for Caregivers)
- TA & Dissemination Partner – UIC Family Support Research & Training Center
- Prior MassMutual “Sibling Study” 2012
- Support Groups
- www.easterseals.com/caregiving





Many Faces of Caregiving Study



METHODOLOGY

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Many Faces of Caregiving Study



- Impulse Research conducted an online survey with a random sample of 1043 Millennials and Gen Xers, men and women ages 25-49.
- The respondents are representative of American men and women 25-49.
- The overall sampling error rate for this survey is +/-3% at the 95% level of confidence.
- Conducted in January 2015.





Many Faces of Caregiving Study



DEMOGRAPHICS

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Demographic Information

Demographics	Caregivers (n=341)	Non-Caregivers (n=701)
Male	46%	43%
Female	54%	57%
25-35	48%	44%
36-49	52%	56%
African American	14%	9%
Asian	8%	8%
Latino/Hispanic	11%	8%
Caucasian	64%	71%
Under \$45k	41%	46%
\$50k to \$100k	39%	36%
Over \$100k	16%	11%
High School	23%	24%
Some College	25%	28%
College Graduate	39%	35%
Graduate School	12%	12%



Many Faces of Caregiving Study



Caregiving Relationships

- 40% - Parent
- 22% - Child
- 16% - Grandparent
- 14% - Spouse
- 14% - Friend
- 9% - Sibling
- 6% - Aunt/Uncle
- 4% - Other
- 56% - Provide unpaid care
- 35 % - Provide both unpaid care & financial support
- 9% - Provide only financial support





Many Faces of Caregiving Study



- [Andrea Simone](#): supporting her husband Tony who received a severe brain injury while serving in Afghanistan. (Hallmark Channel's Home & Family/Sen. Durbin campaign ad)
- [Danielle C. Dallo](#): Mother to, Daniel, who has Autism Spectrum Disorder. (Her story on easterseals.com)
- [Ashley Campbell](#): story of caring for her father, the iconic country western singer - Glen Campbell, has been captured in the Oscar-nominated film, "I'll Be Me" (CNN in last weekend & again in Nov)





Many Faces of Caregiving Study



KEY FINDINGS

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Many Faces of Caregiving Study



Younger than we think? Gender?

One-third of Millennial and Gen X respondents identify themselves as caregivers – many individuals between the ages of 25 and 49 are already serving in this role.

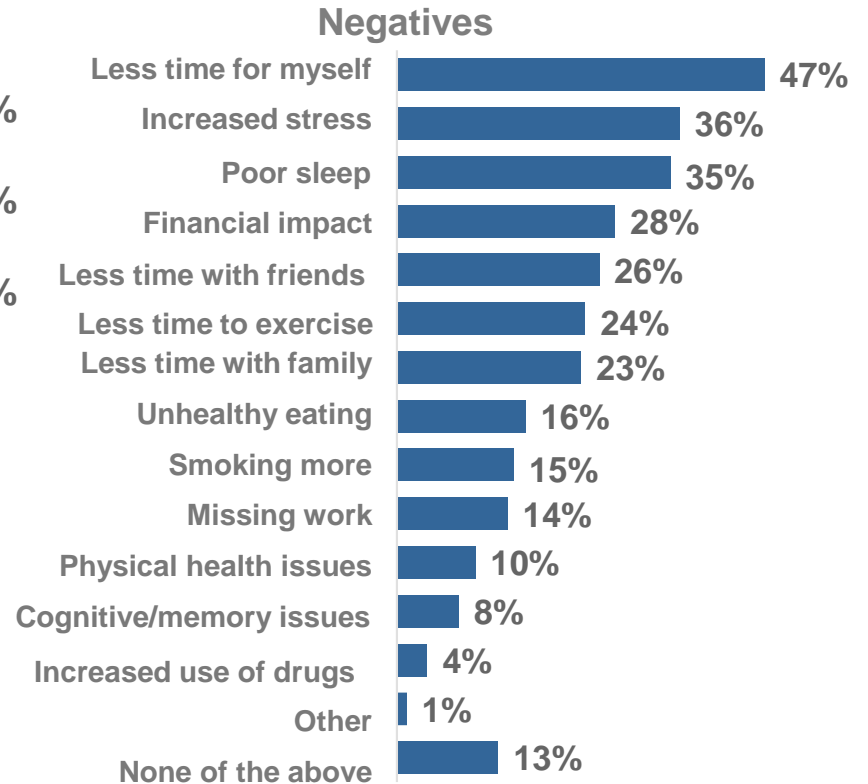
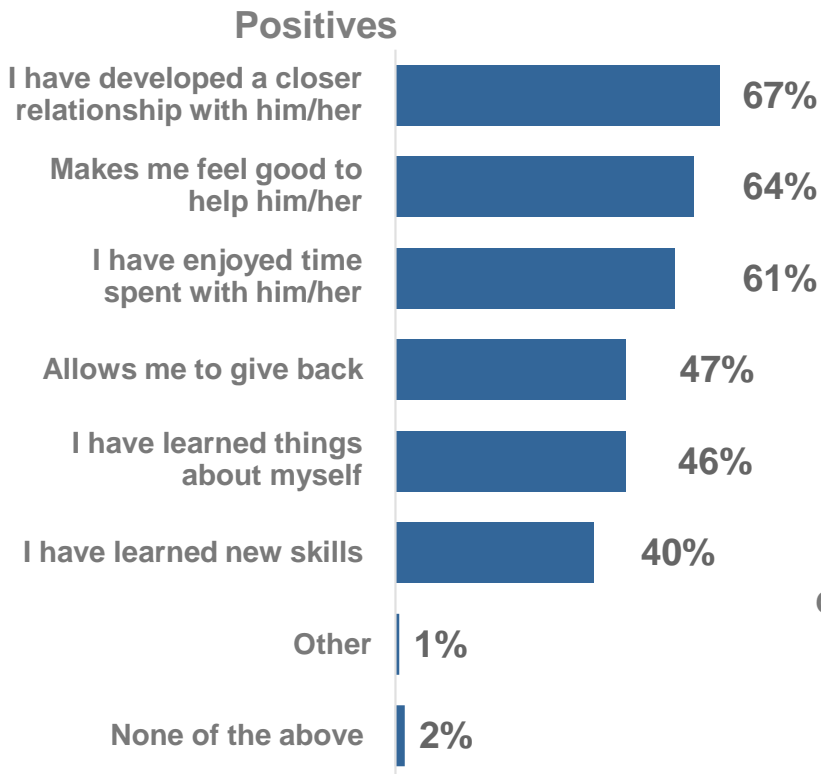
Nearly equal number of men and women identify themselves as caregivers

(13% Male caregivers provide only financial support vs. 6% of Female caregivers)



Caregiving Opportunities & Challenges

Men are more likely to smoke (21% vs 10%) while women are more likely to report feeling increased anxiety and stress (43% vs 26%) and unhealthy eating (21% vs 11%)





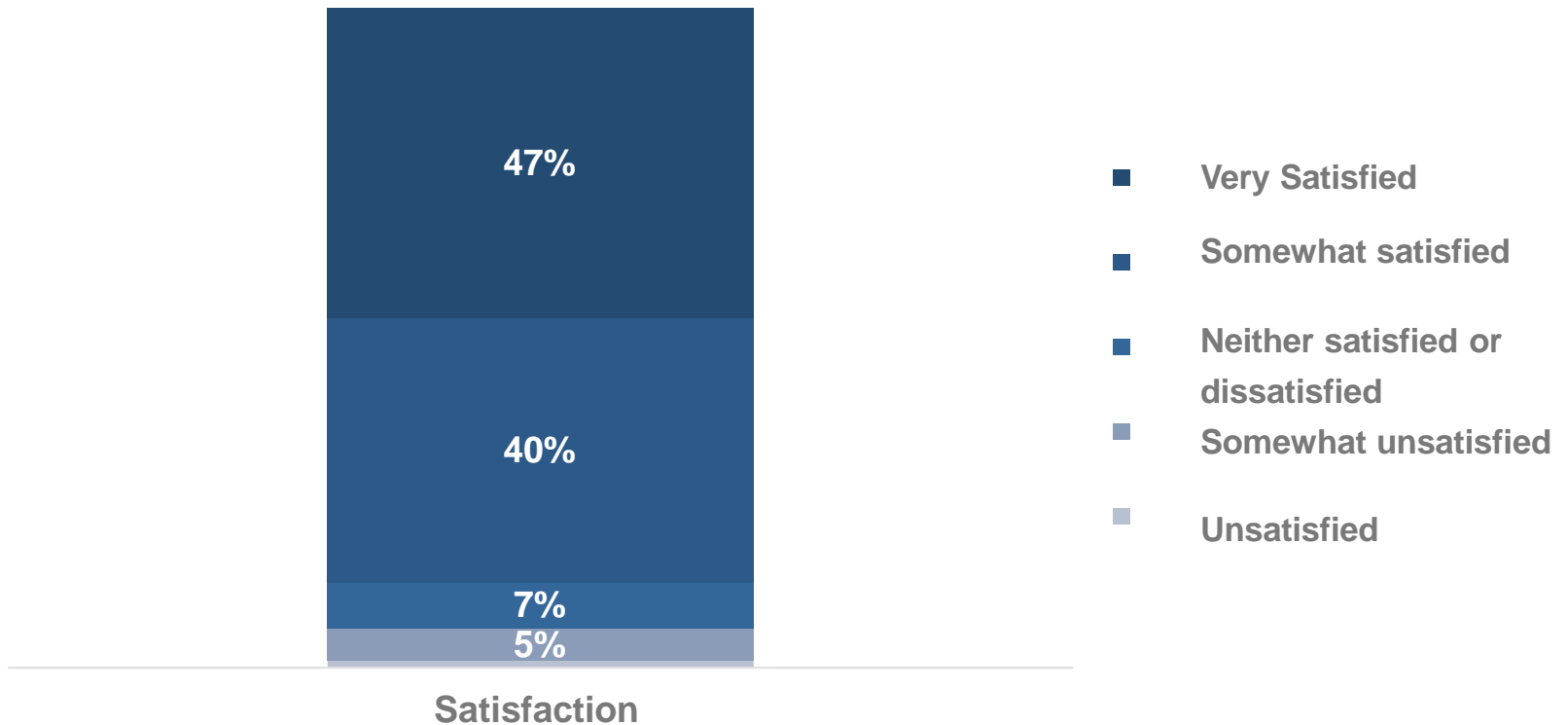
Many Faces of Caregiving Study



- 67% of **Millennials** and 55% of **GenX** caregiver respondents report **providing care on a daily basis**.
- Measuring Caregiving trajectory in decades vs. years?
- Millennial and Gen X caregivers
 - 5% Less than 6 months
 - 15% Six months to 1 year
 - 22% 1 to 2 years
 - 17% 2 to 3 years
 - 12% 3 to 5 years
 - 17% More than 5 years
 - 5% Occasionally, off and on
 - 7% All their life



Satisfaction with the level of care you are providing?





Many Faces of Caregiving Study



Perceptions vs. Realities of Care

For those already providing care: 42% supporting someone with emotional/mental health condition; 35% memory problem/dementia; 27% with a primarily a physical condition

For those who expect to provide care: 70% envision support needed for physical condition; 30% for emotional/mental health condition; 28% for memory problem/dementia





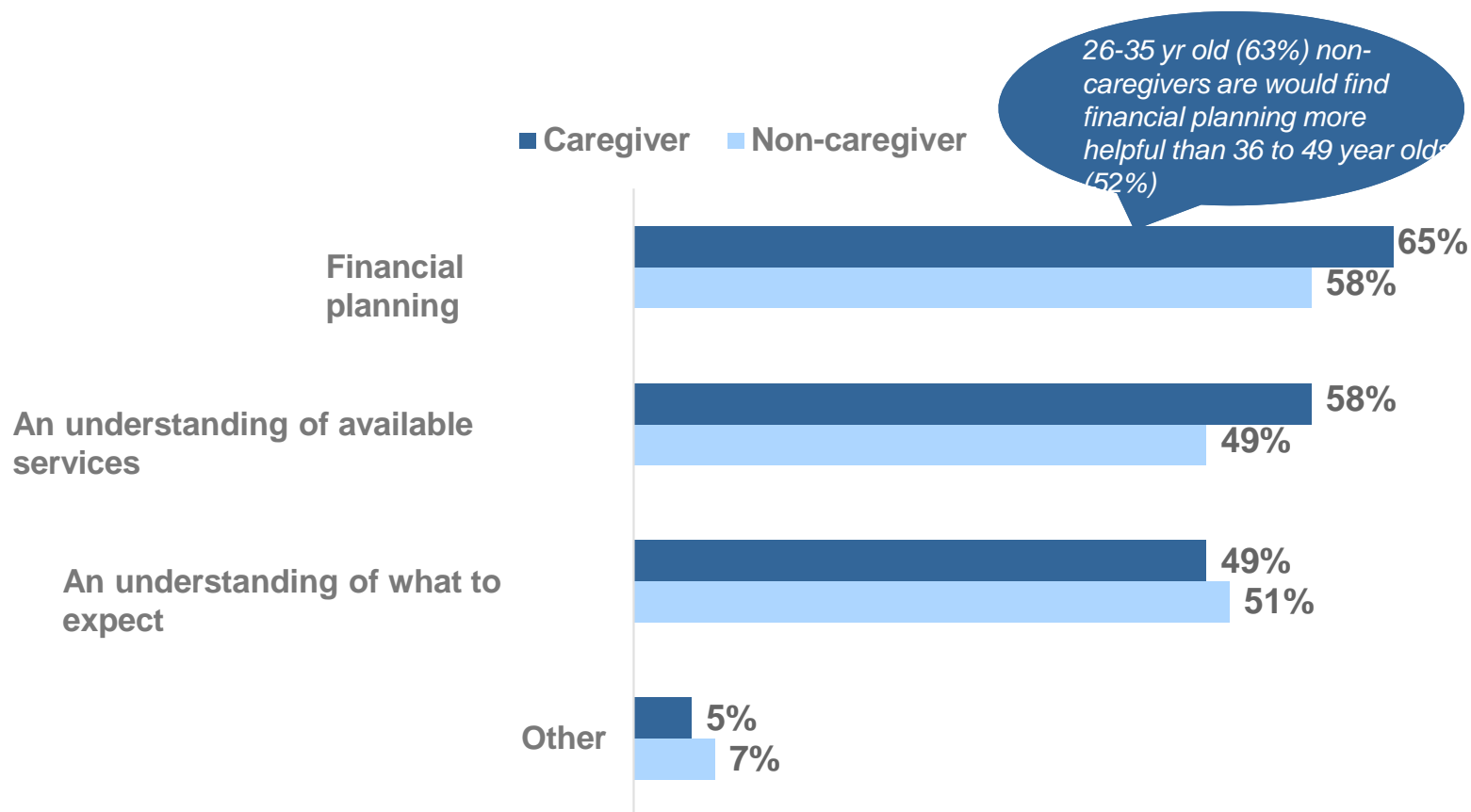
Many Faces of Caregiving Study



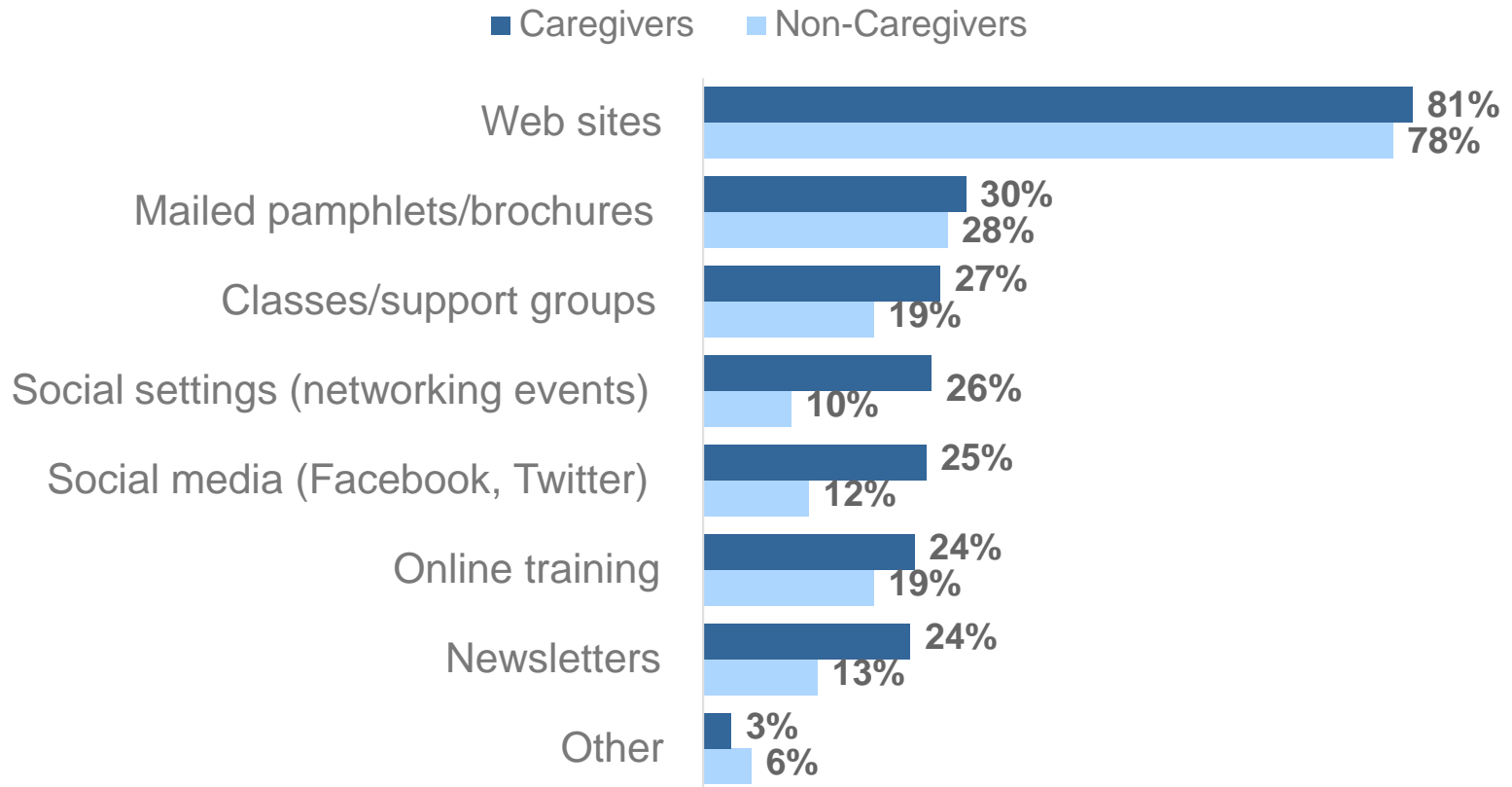
- **71%** of respondents have not yet had the critical conversation with their families and loved ones about the future as it relates to their **medical planning**, although **15%** are **“planning to”**
- **73%** have not yet talked to their loved ones about the future as it relates to **financial planning and retirement**, although **12%** are **“planning to”**
- Overall, 37% of respondents admitted to being **“not quite ready”** or **“not ready”** for handling a projected caregiving role (men – 33% and women – 42%)
- **Those already caregiving** – more likely to have initiated planning
- **70% “have concerns”** about taking on caregiving



There is solid demand for information to help plan for the future



Websites are the best way to reach caregivers and non-caregivers alike, Caregivers seek connections with others. . .





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Questions



Promising Practices

Family Support Research and Training Center

- University of Illinois at Chicago and UIC
- Conducting a scan of promising practices in family caregiver supports
 - Any population of caregivers
 - Any types of supports (i.e. information, peer support, respite, other services and supports)
- **Your Help Needed**
 - Nominate a promising program or practice
 - <https://www.surveymonkey.com/s/FamilySupportRRTC>