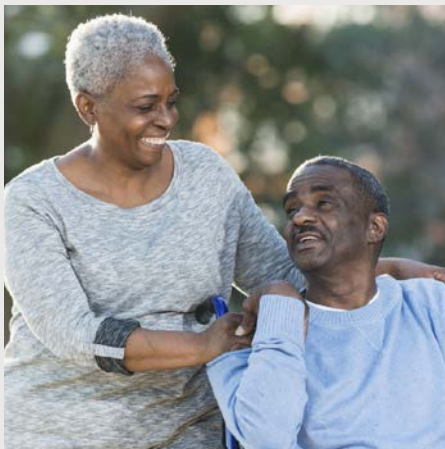


2020 Companion Report

Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 18 to 49



Conducted by



Acknowledgments

The National Alliance for Caregiving (NAC) and AARP are proud to present this special report *Caregiving in the U.S. 2020: A Focused Look at Caregivers of Younger Adults*. Many people played important roles throughout the research process, including:

C. Grace Whiting, JD, President and Chief Executive Officer, National Alliance for Caregiving

Patrice A. Heinz, Vice President, Strategy & Operations, National Alliance for Caregiving

Gabriela Prudencio, MBA, Hunt Research Director, National Alliance for Caregiving

Michael R. Wittke, BSW, MPA, Senior Director, Public Policy and Advocacy, National Alliance for Caregiving

Susan Reinhard, PhD, Senior Vice President and Director, AARP Public Policy Institute

Lynn Friss Feinberg, MSW, Senior Strategic Policy Advisor, AARP Public Policy Institute

Laura Skufca, MA, Senior Research Advisor, AARP

Robert Stephen, MBA, Vice President, Health & Caregiving, AARP Programs

Rita Choula, MA, Director, Caregiving Projects, AARP Public Policy Institute

ADVISORY PANEL

María P. Aranda, PhD, Associate Professor and Executive Director, USC Edward R. Roybal Institute on Aging, USC Suzanne Dworak-Peck School of Social Work

Joseph E. Gaugler, PhD, Robert L. Kane Endowed Chair in Long-Term Care and Aging and Professor, School of Public Health, University of Minnesota

Carol Levine, MA, Senior Fellow, United Hospital Fund, New York City (former Director of UHF Families and Health Care Project)

Feylyn Lewis, PhD, Research Fellow, University of Sussex

David Lindeman, PhD, Director Health, Center for Information Technology Research in the Interest of Society (CITRIS), UC Berkeley; Director, Center for Technology and Aging (CTA)

Nancy E. Lundebjerg, MPA, Chief Executive Officer, American Geriatrics Society

Steve Schwab, CEO, Elizabeth Dole Foundation (with special thanks to Laurel Rodewald)

Regina A. Shih, PhD, Senior Policy Researcher, RAND Corporation

Additional report feedback courtesy of:

Daniel E. Trucil, MA, MPH, Associate Director, Communication, American Geriatrics Society

Aimee Cegelka, MA, Senior Manager, Education and Special Projects, American Geriatrics Society

The research was conducted by Greenwald Research (formerly Greenwald & Associates, www.greenwaldresearch.com) with study direction by Lisa Weber-Raley, Chief Research Officer, and report by Sara Rubinstein, Account Manager.

This research was made possible through generous sponsorship from:

AARP
Best Buy Health Inc. d/b/a Great Call
EMD Serono Inc.
Home Instead Senior Care
TechWerks

The Gordon and Betty Moore Foundation
The John A. Hartford Foundation
Transamerica Institute
UnitedHealthcare

(c) 2020 NAC and AARP
Reprinting with permission

This page intentionally left blank.

Table of Contents

I. INTRODUCTION	1
Overview of Methodology	1
Reading This Report	1
II. EXECUTIVE SUMMARY	1
III. DETAILED FINDINGS	3
A. Prevalence of Caregiving	3
B. Basics of the Caregiving Situation	3
C. Living Situation	7
D. Care Recipient Condition	8
E. Caregiving Activities and Intensity of Care	10
F. Presence of Other Help	15
G. Well-Being of Caregivers.....	16
H. The Financial Situation of Caregivers.....	19
I. Impact of Caregiving on Work.....	22
J. Information Needs and Support.....	24
K. Technology	28
L. Long-Range Planning.....	31
M. Respondent Profile	33

Figures

Figure 1. Prevalence of Caregiving for an Adult Age 18–49, 2020 vs. 2015	3
Figure 2. Age of Care Recipient, 2020 vs. 2015	4
Figure 3. Race/Ethnicity of Caregiver, 2020 vs. 2015	4
Figure 4. Care Recipient Relationship to Caregiver, 2020 vs. 2015	5
Figure 5. Duration of Care.....	6
Figure 6. Where Care Recipient Lives by Age of Recipient.....	7
Figure 7. Types of Care Recipient Conditions by Age of Recipient.....	8
Figure 8. Care Recipient’s Main Problem or Illness by Age of Recipient	9
Figure 9. Hours of Care Provided Each Week	10
Figure 10. Help with Activities of Daily Living (ADLs).....	11
Figure 11. Help with Instrumental Activities of Daily Living (IADLs).....	12
Figure 12. Help with Instrumental Activities of Daily Living (IADLs) by Age of Recipient.....	12
Figure 13. Intensity of Care Index	14
Figure 14. Primary Caregiver Status by Age of Recipient	15
Figure 15. Presence of Other Help	16
Figure 16. Caregiver Health Status	16
Figure 17. Financial Impacts as a Result of Caregiving by Age of Recipient.....	20
Figure 18. Difficulty Finding Affordable Services.....	21
Figure 19. Workplace Benefits for Caregivers of Younger Adults	23
Figure 20. Caregiver Work Impacts by Age of Recipient.....	24
Figure 21. Caregiver Help and Information Needs by Age of Recipient	25
Figure 22. Respite Services	27
Figure 23. Sources of Help or Information Used by Caregivers of Younger Adults.....	28

Figure 24. Caregiver Use of Software and Monitoring Solutions	29
Figure 25. Caregiver Use of Online Solutions	30
Figure 26. Expectation of Future Caregiving by Age of Recipient	31
Figure 27. Long-Range Planning	32
Figure 28. Demographic Summary of Caregivers by Age of Recipient, 2020	33

I. Introduction

This is the second of two companion reports to the full report of the *Caregiving in the U.S. 2020* study.¹ This companion report focuses on 188 unpaid family caregivers² who provide care to an adult age 18 to 49 with trend comparisons to the 2015 study. The other companion report—*Caregiving in the U.S. 2020: A Focused Look at Caregivers of Adults Age 50+*—provides detail on caregivers of older adults.

OVERVIEW OF METHODOLOGY

All caregivers were interviewed using Ipsos’s (formerly Gfk) national, probability-based, online KnowledgePanel® as was used in the 2015 wave, with surveys conducted between May 29, 2019, and July 27, 2019, prior to the current COVID-19 pandemic. To see the complete study results, or for more information about the questionnaires or the methodology, please reference the full report and Appendices A and B.

READING THIS REPORT

The sample sizes (*n* sizes) shown throughout represent the unweighted number of people who answered each question. All substantive results (means, medians, percentages) have been weighted and rounded. In addition, “don’t know” or “refused” responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100 percent. The results for multiple-response questions may also add to greater than 100 percent.

To signal statistically significant differences at the 95 percent confidence level, the report uses two notations: (a) superscripts indicate any numerical result that is significantly higher for comparisons between subgroups; and (b) arrows indicate any numerical result in 2020 that is a significant increase (up arrow) or decrease (down arrow) from 2015.

Throughout this report, caregivers are referred to as “caregivers of a younger adult” or “caregivers of younger adults.” Younger adult or younger adults refers to any care recipient age 18–49 years old.

II. Executive Summary

Approximately 6.1 million adults in the United States provide unpaid care to a younger adult age 18–49. These caregivers of younger adults more often provide care to multiple people (24 percent, up from 14 percent in 2015).

Caregivers of younger adults are both women (60 percent) and men (40 percent) and are 44.7 years old, on average, with 61 percent ages 18–49 years old themselves. Caregivers of younger adults are diverse: 6 in 10 caregivers of a younger adult are non-Hispanic White (58 percent), 19 percent are African American, 15 percent are Hispanic/Latinx, 6 percent are Asian, and 2 percent are some other race/ethnicity.

The younger adult care recipient is usually a relative of the caregiver (92 percent, up from 79 percent in 2015), most often the caregiver’s own adult child (39 percent). The recipient is 32.4 years old, on average; younger than in 2015 (36.4 years). Six in 10 caregivers report that their younger adult care recipient lives with them in the caregiver’s home (59 percent), with co-residence more common than among caregivers of older adults ages 50 or older (37 percent). Nearly half say their younger adult

1 National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020* (Washington, DC: May 2020), <https://doi.org/10.26419/ppi.00103.001> or <https://www.caregiving.org/caregiving-in-the-us-2020/>

2 Family caregivers are not exclusively related to the person to whom they are providing care; they include any adult who provides unpaid care or support to a family member or friend.

recipient has multiple conditions requiring care (46 percent). More caregivers of younger adults say that a developmental or intellectual disorder or disability is their recipient's *main* problem for which they need care (13 percent in 2020 vs. 4 percent in 2015).

Caregivers of younger adults ages 18–49 spend 32.5 hours a week, on average, providing care—more than caregivers of older adults (22.3 hours a week). This time is spent helping their recipient with an average of 1.5 Activities of Daily Living (ADLs) and 4.5 Instrumental Activities of Daily Living (IADLs), with 50 percent helping with medical/nursing tasks. Compared to 2015, a greater proportion of caregivers of a younger adult report advocating for that recipient with health care providers (57 percent vs. 45 percent in 2015) and managing their recipient's finances (64 percent vs. 52 percent in 2015). One in three caregivers find this task of helping with bills, finances, or insurance to be time consuming (34 percent). Nearly half find their role as caregiver gives them a sense of purpose or meaning (47 percent).

The majority of caregivers of younger adults ages 18–49 are the primary caregiver—either the sole unpaid caregiver or the person providing the most unpaid care to the younger adult recipient among other unpaid caregivers (73 percent). In fact, half of caregivers of younger adults are completely alone, providing care without any other unpaid *or* paid help (52 percent), more so than caregivers of older adults (30 percent).

Nearly one in 4 caregivers of younger adults ages 18–49 say their health is *fair* or *poor* (23 percent). Only 35 percent say their health is *excellent* or *very good*, down from 51 percent in 2015. Three in 10 say caregiving has made their health worse (31 percent), significantly more than caregivers of older adults (21 percent).

When it comes to financial effects, caregivers of younger adults are particularly strained. One in 3 caregivers feel high financial strain as a result of providing care to his or her younger adult recipient (34 percent), up significantly from 22 percent in 2015. Many are also experiencing negative financial impacts due to caregiving, reporting 2.8 impacts, on average; more so than caregivers of older adults (1.5).³ Two in 10 have been unable to afford basic expenses like food (21 percent), twice as many as caregivers of older adults (10 percent). Six in 10 caregivers of younger adults have worked in the past year while providing care (59 percent),⁴ though they more often than caregivers of older adults experience work impacts like cutting back hours (23 percent vs. 14 percent), turning down a promotion (14 percent vs. 6 percent), and giving up work entirely (13 percent vs. 5 percent).

Perhaps because of these financial pressures, more caregivers of younger adults ages 18–49 report having requested information about how to get financial help for their recipient (40 percent), compared with caregivers of older adults ages 50 or older (23 percent). Three in 10 find it difficult to get affordable services in their recipient's local area (29 percent). While 77 percent have received help or information about caregiving from an outside source, a majority want additional training, help, or information (58 percent). More caregivers of younger adults are using outside transportation services to help them with their caregiving than in 2015 (30 percent vs. 17 percent).

While many caregivers of younger adults ages 18–49 rely on doctors or other health care professionals for help or information about providing care (42 percent), they do so less often than caregivers of older adults (57 percent). Just one in four caregivers report having had conversations with care professionals about what they need in order to provide care to their younger adult recipient (24 percent). Even fewer (13 percent) report having had these conversations about their own self-care needs—this is disturbing given the health impacts these caregivers are experiencing.

3 Financial impacts that caregivers of younger adults more often report experiencing include stopping saving (39 percent vs. 27 percent of caregivers of adults ages 50 or older), taking on more debt (38 percent vs. 20 percent), using up personal short-term savings (38 percent vs. 20 percent), leaving bills unpaid or paying them late (30 percent vs. 17 percent), or borrowing money from family or friends (28 percent vs. 13 percent).

4 Comparable to caregivers of older adults

Overall, caregivers of younger adults ages 18–19 are experiencing a unique set of challenges compared with other caregivers. Compared to 2015, these caregivers are now more often providing care to multiple recipients. Caregivers of younger adults also rate their own health lower and their financial strain higher than they did in 2015. Compared to caregivers of adults 50 years or older, caregivers of younger adults are providing care for more hours weekly (on average), with no additional paid or unpaid help, and experiencing worse health, more negative financial impacts, and more financial strain due to caregiving.

This report captures the need to provide services and information to help these caregivers provide care to both their younger adult recipient and themselves. While the data for this report were collected before the onset of COVID-19, the heightened uncertainty and high joblessness of the pandemic reinforces the need to be acutely aware of the implications the findings in this report may have for caregivers of younger adults ages 18–49 who were already experiencing detrimental effects on their own health and finances before the pandemic, and it is likely that the pandemic has heightened their challenges.

III. Detailed Findings

A. PREVALENCE OF CAREGIVING

An estimated 6.1 million adults in the United States have provided unpaid care to an adult family member or friend who is 18–49 years of age in the past 12 months (see Figure 1).⁵

Figure 1. Prevalence of Caregiving for an Adult Age 18–49, 2020 vs. 2015

	Prevalence	Estimated Number of U.S. Adults Who Are Caregivers of Younger Adults Ages 18–49
2020	2.5%	6.1 million
2015	2.3%	5.6 million

B. BASICS OF THE CAREGIVING SITUATION

CURRENT CAREGIVING STATUS

Three-quarters of caregivers of younger adults ages 18–49 take care of only one care recipient (76 percent) with 24 percent providing care to multiple people, up from 14 percent in 2015. Six in 10 are currently providing care (59 percent, up from 44 percent in 2015). Four in ten provided care in past 12 months.

5 Of the 7,309 people who were screened in the online survey, the proportion of initial respondents who had served as unpaid caregivers of someone between the ages of 18 and 49 was 2.5 percent (see Figure 1). Using a 2019 estimate of 249,193,093 Americans ages 18 and older, the study estimates 6.1 million adults have been caregivers to an adult 18–49 years old in the past 12 months. The estimated 2.5 percent prevalence of caregiving for a younger adult age 18–49 is a minimum prevalence. The survey asked whether the person is a caregiver for anyone age 18 or older; and then asked whether any of those adults for whom care is provided are ages 50 or older. Prevalence of caregiving for a younger adult age 18–49 is estimated by first estimating the prevalence of providing care to anyone age 18 or older; then backing out those who confirm that they are providing care to at least one person age 50 or older. Caregivers often provide care to multiple people who may be in both age ranges (18–49 and 50 or older), so the 2.5 percent prevalence in 2020 (and the 2.3 percent prevalence in 2015) is a minimum prevalence for caregiving for a younger adult.

CAREGIVER AND CARE RECIPIENT AGE AND GENDER

Caregivers of younger adults ages 18–49 tend to be women (60 percent), though 40 percent are men. Of care recipients, close to half are women (45 percent) and close to half are men (55 percent). The share of recipients who are men is higher compared with recipients ages 50 or older (37 percent men).

On average, caregivers of younger adults are 44.7 years old themselves, providing care to someone 32.4 years of age. Caregivers of younger adults ages 18–49 are, on average, about 5 years younger than caregivers of older adults ages 50 or older (50.1). While caregivers of younger adults are a similar age, on average, as they were in 2015, their care recipients are younger (36.4 years old in 2015), with a greater proportion of caregivers now providing care to an adult age 18–34 (see Figure 2).

Figure 2. Age of Care Recipient, 2020 vs. 2015

	Recipient Age 18–49	
	2020 (n = 188)	2015 (n = 159)
Average Care Recipient Age	32.4↓	36.4
Recipient age 18–34	58%↑	38%
Recipient age 35–49	41%↓	62%

Notes: Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

CAREGIVER RACE/ETHNICITY

Six in 10 caregivers of younger adults ages 18–49 are non-Hispanic White (58 percent), comparable to 2015 (see Figure 3).⁶ For more demographic detail about caregivers of younger adults, see this report's section M: Respondent Profile.

Figure 3. Race/Ethnicity of Caregiver, 2020 vs. 2015

	Recipient Age 18–49	
	2020 (n = 188)	2015 (n = 159)
Non-Hispanic White	58%	59%
African American	19%	12%
Hispanic/Latinx	15%	22%
Asian	6%	3%
Other	2%	4%

Notes: Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

⁶ Asian American is defined to align with the U.S. Census and is inclusive of those of origin, background, or descent of areas of Southeast Asia, the Indian subcontinent, and East Asia, as well as the Pacific Islands. Other is inclusive of multi-racial.

WORK AND INCOME STATUS WHILE CAREGIVING

Six in 10 caregivers of younger adults ages 18–49 were employed at some point in the past year while caregiving (59 percent). Among them, half worked full time (52 percent) and, on average, they worked 34.9 hours a week. Among caregivers of younger adults ages 18–49 who have not worked while providing care in the past year, 29 percent worked at some point while also providing care to their recipient.

Fifty-seven percent of caregivers of younger adults ages 18–49 have an annual household income of \$50,000 or more (compared to 65 percent of caregivers of adults 50 or older).

SUBGROUPS 2020:

- The age of the caregiver affects both employment status and household income. Caregivers of younger adults that are ages 18–49 themselves are more often employed (69 percent vs. 43 percent when the caregiver is age 50 or older), but less often report having a household income of at least \$50,000 (50 percent vs. 68 percent when the caregiver is age 50 or older).

CARE RECIPIENT RELATION TO CAREGIVER

Nine in 10 caregivers of a younger adult age 18–49 provide care to a relative (92 percent), up from 79 percent in 2015 (see Figure 4). More provide care to their own adult child than any other relation (39 percent), followed by a spouse or partner (20 percent), sibling/sibling-in-law (17 percent), or parent/parent-in-law (6 percent).

Figure 4. Care Recipient Relationship to Caregiver, 2020 vs. 2015

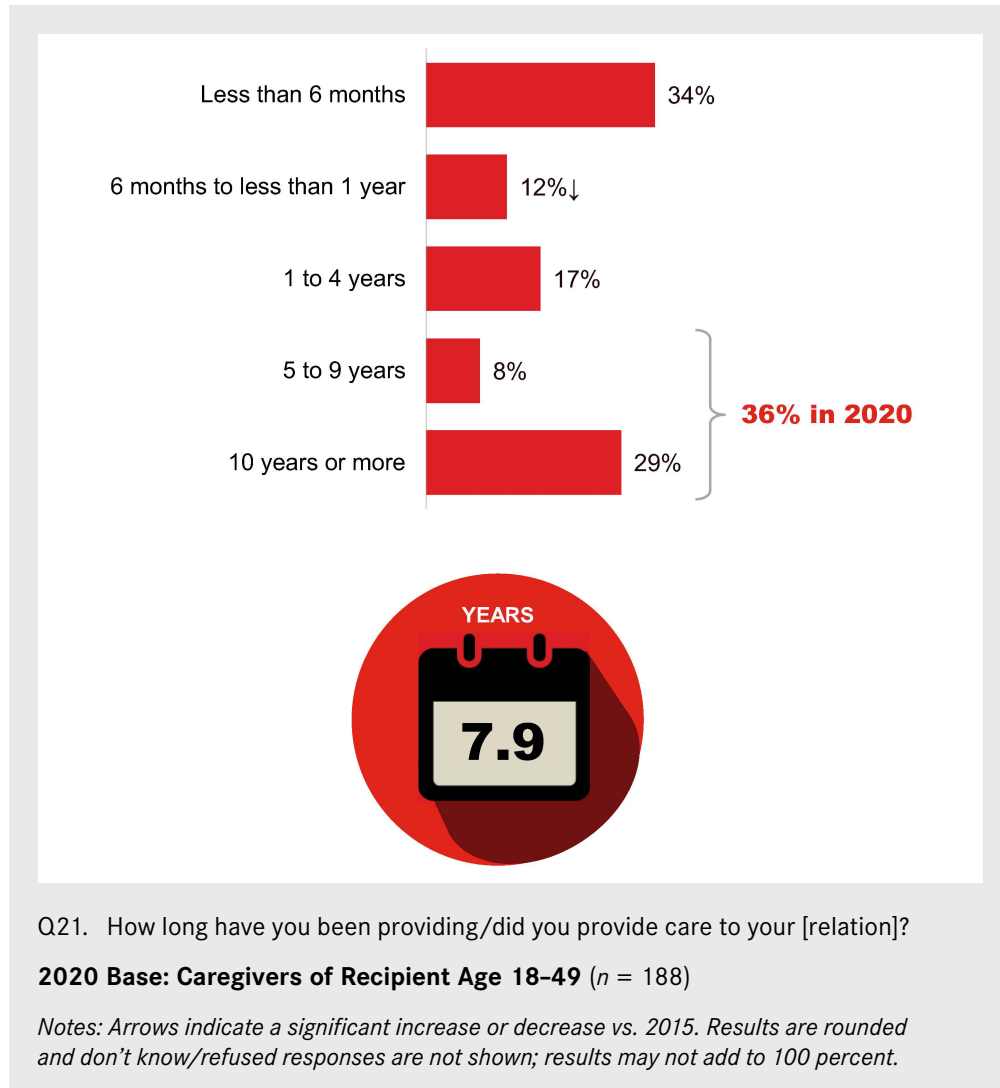
	Recipient Age 18-49	
	2020 (n = 188)	2015 (n = 159)
Care Recipient Is a Relative	92%↑	79%
Child	39%	32%
Spouse or partner	20%	17%
Sibling/sibling-in-law	17%	13%
Parent/parent-in-law	6%	9%

Notes: Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

DURATION OF CARE FOR RECIPIENT

More than one in three caregivers of younger adults ages 18–49 have been providing care for at least 5 years (36 percent). On average, caregivers of younger adults have provided care for 7.9 years (see Figure 5)—considerably longer than caregivers of older adults (3.9 years).

Figure 5. Duration of Care



SUBGROUPS 2020:

- Those providing care to their own adult child have been in their role as a caregiver for longer (14 years, on average) than those providing care for some other relative (4.4 years).

CHOICE IN TAKING ON CAREGIVER ROLE

When asked if they felt they had a choice in taking on their caregiving responsibility, 55 percent of caregivers of younger adults ages 18–49 say they had *no* choice.

C. LIVING SITUATION

Six in 10 caregivers of younger adults ages 18–49 say their recipient lives with them (the caregiver), in the caregiver’s home (59 percent), while one-quarter say their recipient lives in their own home (24 percent). In comparison, caregivers of an older adult are less likely to report they reside with their care recipient (37 percent) and are more likely to report that their recipient lives in his or her own home (46 percent; see Figure 6).

Figure 6. Where Care Recipient Lives by Age of Recipient

	Care Recipient Age 18–49 (<i>n</i> = 187) A	Care Recipient Age 50+ (<i>n</i> = 1,202) B
Lives with caregiver	59% ^B	37%
Lives in recipient’s own household	24%	46% ^A
Lives in someone else’s household	11% ^B	4%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don’t know/refused responses are not shown; results may not add to 100 percent.

CARE RECIPIENT LIVING ALONE

Most caregivers of a younger adult age 18–49 report their recipient does not live alone (93 percent, up from 84 percent in 2015)—more often reporting their recipient lives with some other person than caregivers of older adults (71 percent report their care recipient age 50 or older lives alone). Among caregivers of younger adults who do not live with their care recipient, 68 percent visit their recipient at least once a week. Two in 10 live within 20 minutes of their care recipient’s household (21 percent), 9 percent live between 20 minutes to an hour away, and 11 percent live an hour or more away.

D. CARE RECIPIENT CONDITION

TYPES OF CARE RECIPIENT CONDITIONS

Caregivers of younger adults ages 18–49 most commonly say their recipient has a long-term physical condition (46 percent, up from 32 percent in 2015), emotional or mental health issue (41 percent, comparable to the 36 percent in 2015), or a short-term physical condition (30 percent, down from 43 percent in 2015). Nearly half of caregivers report their younger adult recipient only has one ongoing problem or illness (46 percent, down from 58 percent in 2015), while another 46 percent report the younger adult recipient has multiple conditions. Younger adult care recipients have an average of 1.7 conditions. These conditions or reasons for care differ greatly from care recipients ages 50 or older (see Figure 7).

Figure 7. Types of Care Recipient Conditions by Age of Recipient

	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Any physical condition(s)	71%	86% ^A
Short-term physical condition(s)	30%	30%
Long-term physical condition(s)	46%	66% ^A
Emotional or mental health issues	41% ^B	24%
Developmental/intellectual disorder	24% ^B	6%
Behavioral issues	19% ^B	7%
Memory problems	13%	35% ^A
Average number of conditions	1.7	1.7

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple responses are allowed; results will not add to 100 percent.

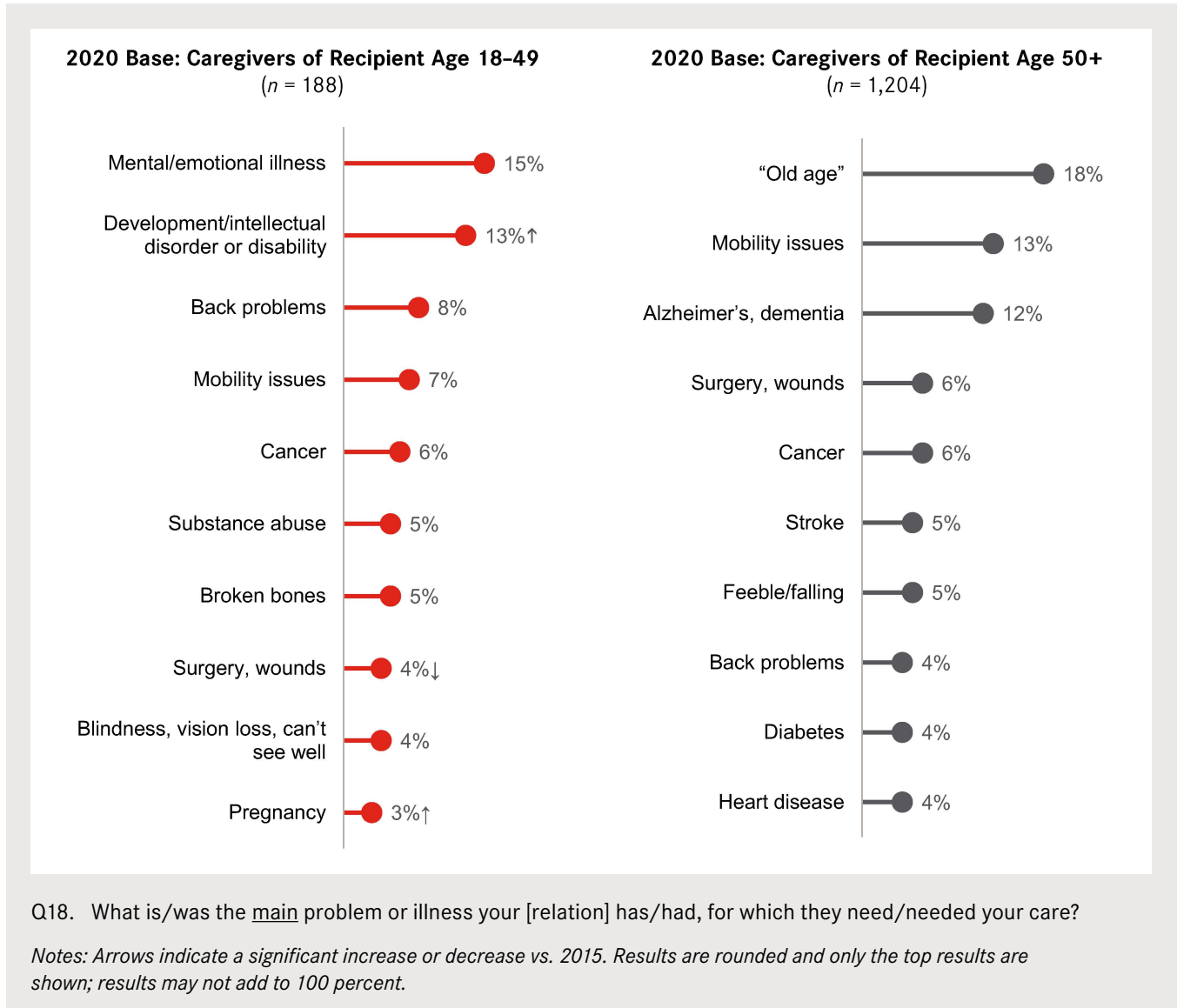
SUBGROUPS 2020:

- Caregivers who co-reside with their younger adult recipient report more conditions for their recipient on average (2.0 vs. 1.4 for those who do not co-reside), with care more often needed due to a developmental or intellectual issue (33 percent vs. 12 percent).
- Caregivers of their own adult child more often report care is needed due to a developmental or intellectual issue (36 percent vs. 18 percent for other younger adult relatives), while those providing care to other relatives more often provide care for physical conditions (short- or long-term: 78 percent vs. 64 percent when providing care to an adult child).

CARE RECIPIENT'S MAIN PROBLEM OR ILLNESS

When caregivers are asked what they perceive to be the *main* problem or illness for which their younger adult care recipient age 18–49 needs care, the top five named are mental or emotional illness (15 percent), developmental or intellectual disorder or disability (13 percent, up from 4 percent in 2015), back problems (8 percent), mobility issues (7 percent), and cancer (6 percent). One in eight recipients have some form of dementia or mental confusion (13 percent). *Main* problems or illnesses of recipients ages 18–49 differ from older recipients (see Figure 8).

Figure 8. Care Recipient's Main Problem or Illness by Age of Recipient



Nearly 4 in 10 caregivers of younger adults say their recipient was hospitalized in the past year (37 percent). This is lower than for those providing care to older recipients ages 50 or older (50 percent).

CARE COORDINATION

Three in 10 caregivers of younger adults ages 18–49 feel it is *somewhat* or *very difficult* to coordinate the various health care and service providers who give care or treatment to their recipient (28 percent).

SUBGROUPS 2020:

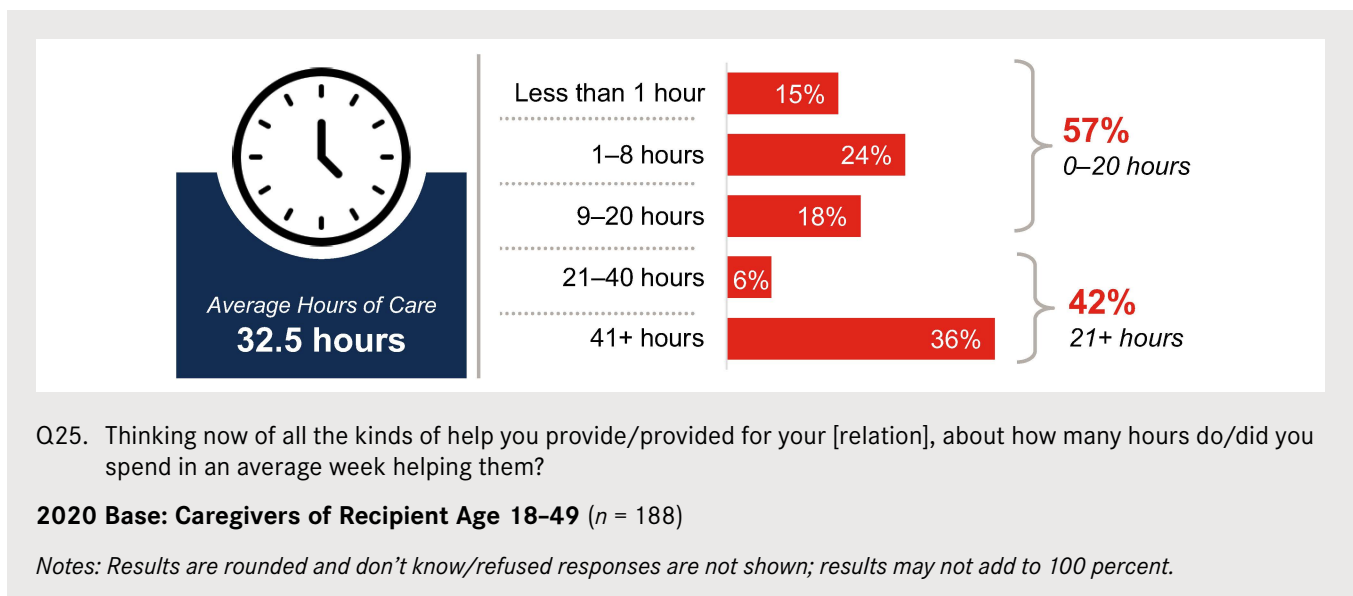
- Care coordination seems to be especially difficult for caregivers of younger adults with an emotional or mental health issue: 41 percent of caregivers of recipients with these issues find care coordination difficult compared with just 17 percent of caregivers of those without these issues.
- Caregivers of younger adults with \$50,000 or more in household income more often find coordinating care difficult (34 percent vs. 20 percent of caregivers with less household income).⁷

E. CAREGIVING ACTIVITIES AND INTENSITY OF CARE

HOURS OF CARE PROVIDED

On average, caregivers of younger adults ages 18–49 spend 32.5 hours a week providing care to their recipient,⁸ significantly more than caregivers of adults 50 years or older (22.3 hours). More than one in three caregivers provide more than 40 hours of care per week (36 percent; see Figure 9).

Figure 9. Hours of Care Provided Each Week



SUBGROUPS 2020:

- On average, caregivers of younger adults who co-reside with their recipient spend more hours a week providing care than those not co-residing (44.4 hours vs. 15.8 hours).

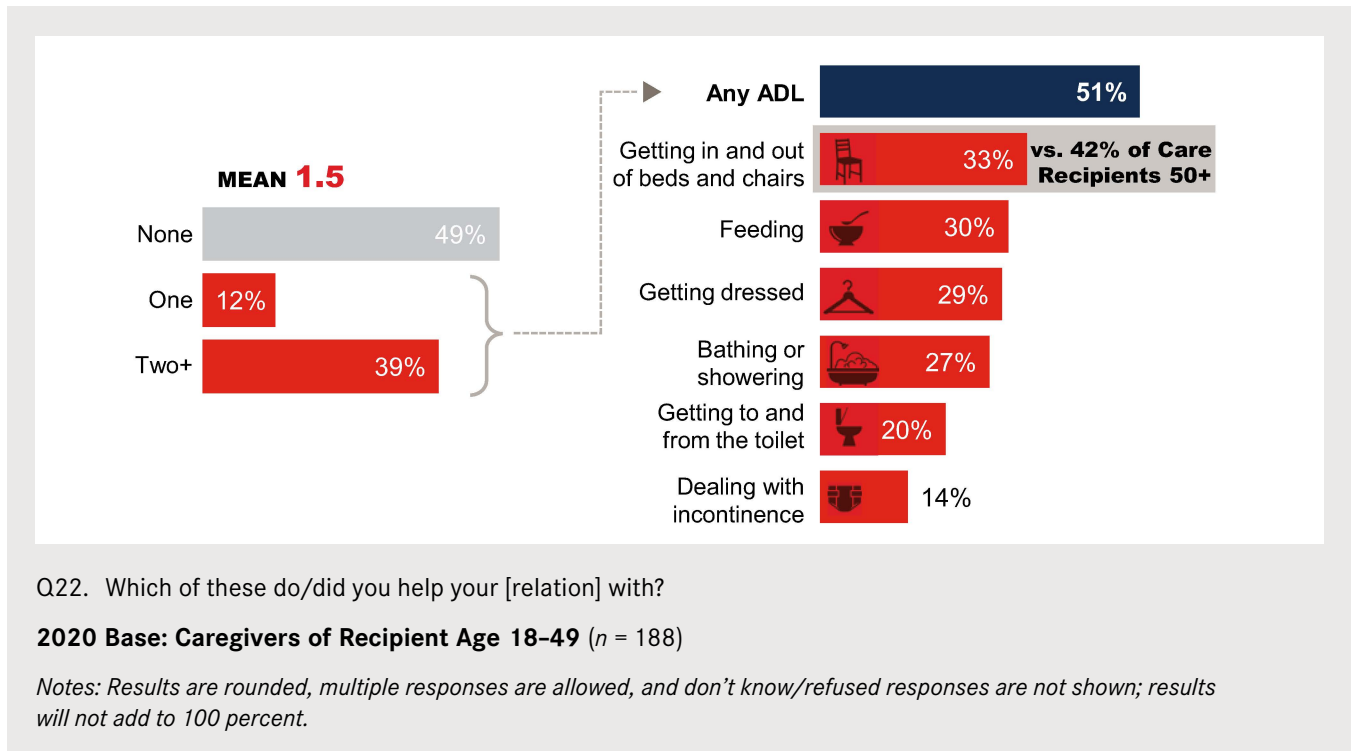
7 Higher-income caregivers of younger adults more often provide care to their own adult child (46 percent vs. 31 percent of those with a household income less than \$50,000), so further research is needed to tell if difficulty with care coordination is related to household income or to complexities around arranging care for one's own adult child.

8 Any caregiver who typed in hours of care in excess of 98 hours per week is capped at this level, equivalent to 14 hours per day. Caregivers who selected constant care were capped at 77 hours per week, the mean hours of care derived from an imputation model predicting hours of care provided. See Appendix B of National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. Washington, DC: May 2020.

HELP WITH ACTIVITIES OF DAILY LIVING (ADLS) AND DIFFICULTY

Just over half of caregivers of younger adults ages 18–49 help their recipient with at least one Activity of Daily Living (ADL, 51 percent), most commonly helping their recipient get in and out of beds and chairs (33 percent). On average, they help with 1.5 of the 6 ADLs (see Figure 10). Among caregivers of younger adults who assist with ADLs, 24 percent find it difficult to do so (rating a 4 or 5 on a 5-point scale).

Figure 10. Help with Activities of Daily Living (ADLs)



SUBGROUPS 2020:

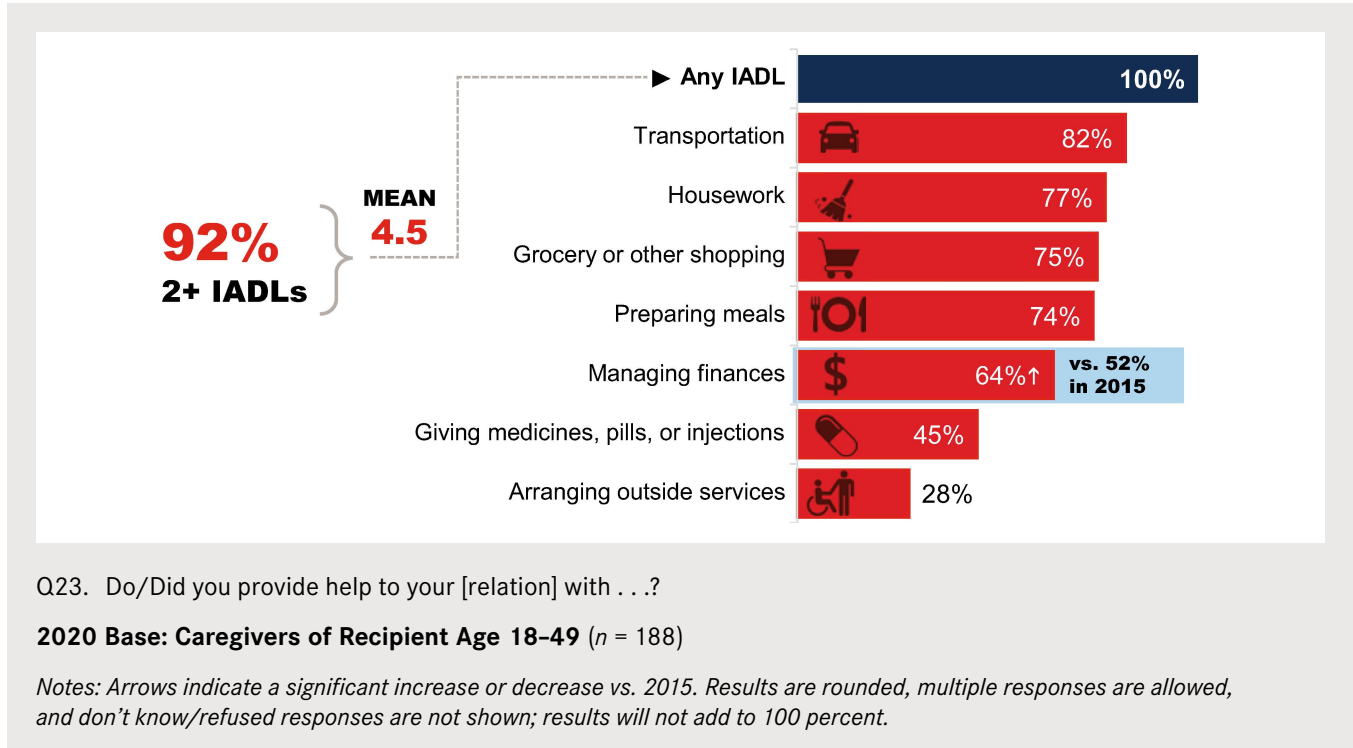
- High-hour caregivers—those providing 21 or more hours of care weekly—help with an average of 2.3 ADLs, more than lower hour caregivers (0.9), and more often help with each of the 6 ADLs.⁹
- Caregivers who themselves are younger more often assist with at least one ADL (58 percent of caregivers who are ages 18–49 themselves vs. 41 percent of caregivers ages 50 or older), perhaps because younger caregivers more often provide care to someone with back problems (11 percent vs. 2 percent) or mobility issues (10 percent vs. 2 percent)—who may require this kind of assistance.

⁹ These include: getting in and out of bed (45 percent vs. 22 percent), getting dressed (46 percent vs. 17 percent), getting to and from the toilet (31 percent vs. 10 percent), bathing or showering (42 percent vs. 15 percent), dealing with incontinence (23 percent vs. 6 percent), and feeding (42 percent vs. 21 percent).

HELP WITH INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLS)

Caregivers of younger adults ages 18–49 help with 4.5 out of 7 Instrumental Activities of Daily Living (IADLs), on average. Most commonly, they help with transportation (82 percent) and housework (77 percent). Nearly two-thirds help with finances (64 percent), up from 52 percent in 2015 (see Figure 11).

Figure 11. Help with Instrumental Activities of Daily Living (IADLs)



Caregivers of younger adults ages 18–49 are more likely to help with preparing meals and finances than those providing care for someone 50 or older, but are less likely to arrange outside services (see Figure 12).

Figure 12. Help with Instrumental Activities of Daily Living (IADLs) by Age of Recipient

	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Transportation	82%	80%
Housework	77%	76%
Grocery or other shopping	75%	78%
Preparing meals	74% ^B	63%
Managing finances	64% ^B	57%
Giving medicines, pills, or injections	45%	50%
Arranging or supervising services	28%	36% ^A

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple responses are allowed; results will not add to 100 percent.

One-third of caregivers of younger adults ages 18–49 find it time consuming to help their recipient with bills, finances, and insurance (34 percent rating a 4 or 5 on a 5-point scale among those who help with this task).

SUBGROUPS 2020:

- Similar to ADLs, caregivers of younger adults who are in more intensive or demanding care situations help with more IADLs, including:
 - Those who co-reside with their younger adult recipient (5.1 on average vs. 3.5 for those that do not co-reside)¹⁰ and
 - Higher-hour caregivers of younger adults (5.6 vs. 3.6 of those who provide 20 or fewer hours of care weekly).¹¹
- Caregivers of a younger adult with an emotional/mental health issue are also more likely to help with finances (74 percent vs. 59 percent of those providing care to someone without these issues), transportation (89 percent vs. 76 percent), and arranging outside services (36 percent vs. 21 percent).

OTHER KEY ACTIVITIES

Caregivers' responsibilities often extend to interacting with various providers, agencies, and professionals on their care recipient's behalf. Two-thirds of caregivers of younger adults ages 18–49 monitor the severity of their recipient's condition in order to adjust care accordingly (66 percent), while 6 in 10 communicate with health care professionals (60 percent) or advocate for their recipient (57 percent, up from 45 percent in 2015).

SUBGROUPS 2020:

- When caregivers of younger adults are in more intensive or longer-lasting care situations, they more often report doing each of the caregiving support activities. This includes:
 - Caregivers who co-reside with their younger adult recipient: advocating (72 percent vs. 38 percent of those who do not co-reside), monitoring (79 percent vs. 48 percent), and communicating (70 percent vs. 45 percent)
 - Higher-hour caregivers: advocating (79 percent vs. 41 percent when providing 20 or fewer hours of care weekly), monitoring (84 percent vs. 52 percent), and communicating (80 percent vs. 44 percent).
- Those who provide care to their own adult child age 18–49 more often communicate with health care professionals than caregivers of other younger adult relatives (70 percent vs. 54 percent).

10 Caregivers who co-reside with their younger adult recipient, in the caregiver's home, more often report helping with six of the seven IADLs: helping with medicines (56 percent vs. 30 percent of caregivers of younger adults who do not live together), finances (77 percent vs. 47 percent), grocery shopping (83 percent vs. 64 percent), housework (87 percent vs. 64 percent), preparing meals (89 percent vs. 53 percent), and transportation (87 percent vs. 74 percent).

11 *Higher-hour* refers to caregivers who provide 21 or more hours of care weekly. Higher-hour caregivers more often report helping with all seven of the IADLs compared with lower-hour caregivers: medications (67 percent vs. 29 percent), finances (79 percent vs. 53 percent), grocery shopping (92 percent vs. 62 percent), housework (93 percent vs. 65 percent), preparing meals (95 percent vs. 58 percent), transportation (92 percent vs. 73 percent), and outside services (42 percent vs. 18 percent).

MEDICAL/NURSING TASKS

Half of caregivers of younger adults ages 18–49 help with medical/nursing tasks (50 percent).¹² They are less likely to help with these tasks than caregivers of adults 50 years or older (59 percent).

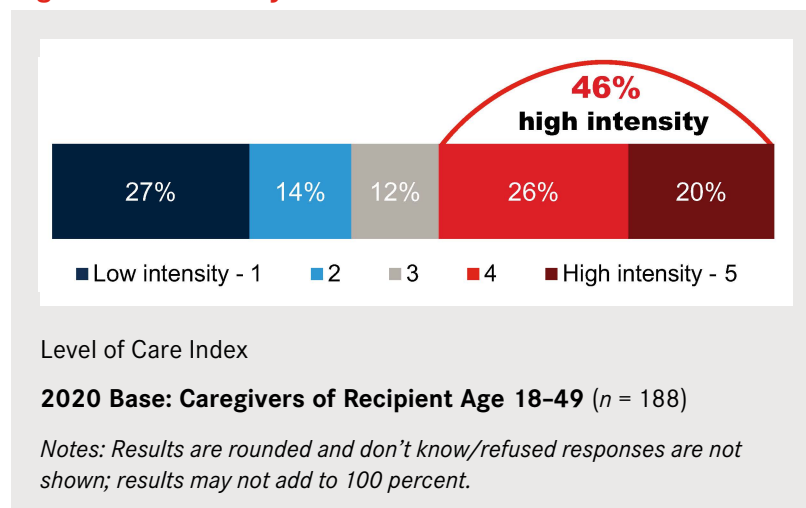
SUBGROUPS 2020:

- Again, caregivers of younger adults most likely to help with medical/nursing tasks are those who co-reside with their recipient (62 percent vs. 35 percent of those who do not co-reside) and are providing 21 or more care hours weekly (75 percent vs. 32 percent when providing 20 or fewer hours of care).

INTENSITY OF CARE INDEX

More than two out of five caregivers of younger adults ages 18–49 are in a high-intensity care situation (46 percent), 12 percent are in a moderate-intensity care situation, and 40 percent are in a low-intensity care situation (see Figure 13).

Figure 13. Intensity of Care Index



SUBGROUPS 2020:

- Of caregivers who co-reside with their younger adult recipients, 61 percent are in high-intensity care situations (vs. 25 percent among those who do not co-reside).¹³

SENSE OF PURPOSE OR MEANING

Nearly half of caregivers of younger adults ages 18–49 feel that being a caregiver gives them a sense of purpose or meaning in life (47 percent).¹⁴

12 “Medical/Nursing tasks,” are skilled activities that might include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. See Reinhard et al., *Home Alone Revisited*; S. C. Reinhard, C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP Public Policy Institute and United Hospital Fund, 2012).

13 On a 5-point scale, caregivers of younger adults who co-reside with their younger adult recipient have an average intensity of care index score of 3.5 (vs. 2.3 for those who do not co-reside).

14 Comparable to caregivers of older adults (51 percent).

F. PRESENCE OF OTHER HELP

OTHER UNPAID CAREGIVERS

Just 4 in 10 caregivers of younger adults ages 18–49 say someone else has also provided unpaid care to their recipient within the past 12 months (41 percent). Three out of 4 caregivers of younger adults consider themselves to be the primary unpaid caregiver (73 percent), including 59 percent who are sole caregivers and 15 percent who report that there are other caregivers but that they themselves provide most of the unpaid care. Caregivers of older adults are less likely to be the primary caregiver (63 percent; see Figure 14).

Figure 14. Primary Caregiver Status by Age of Recipient

	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Primary caregiver (sole or provides most unpaid care)	73% ^B	63%
Sole unpaid caregiver	59% ^B	45%
Provides most of unpaid care	15%	17%
Not primary caregiver	27%	37% ^A

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

SUBGROUPS 2020:

- Among caregivers of younger adults, women (81 percent vs. 62 percent of men) and those who co-reside with their recipient (79 percent vs. 65 percent of those who do not co-reside) are more often the primary caregiver.

CHILDREN AS UNPAID CAREGIVERS

Of those reporting someone else provides unpaid care, 23 percent say a child helps provide unpaid care to the younger adult recipient—meaning approximately 9 percent¹⁵ of all caregivers of younger adults have at least one child helping to provide care.

PAID HELP

Just one in six report their younger adult care recipient age 18–49 had paid help in the past 12 months from any aides, housekeepers, or other paid helpers (16 percent). Caregivers of older adults ages 50 or older are more likely to report their recipient receives paid help (33 percent).¹⁶

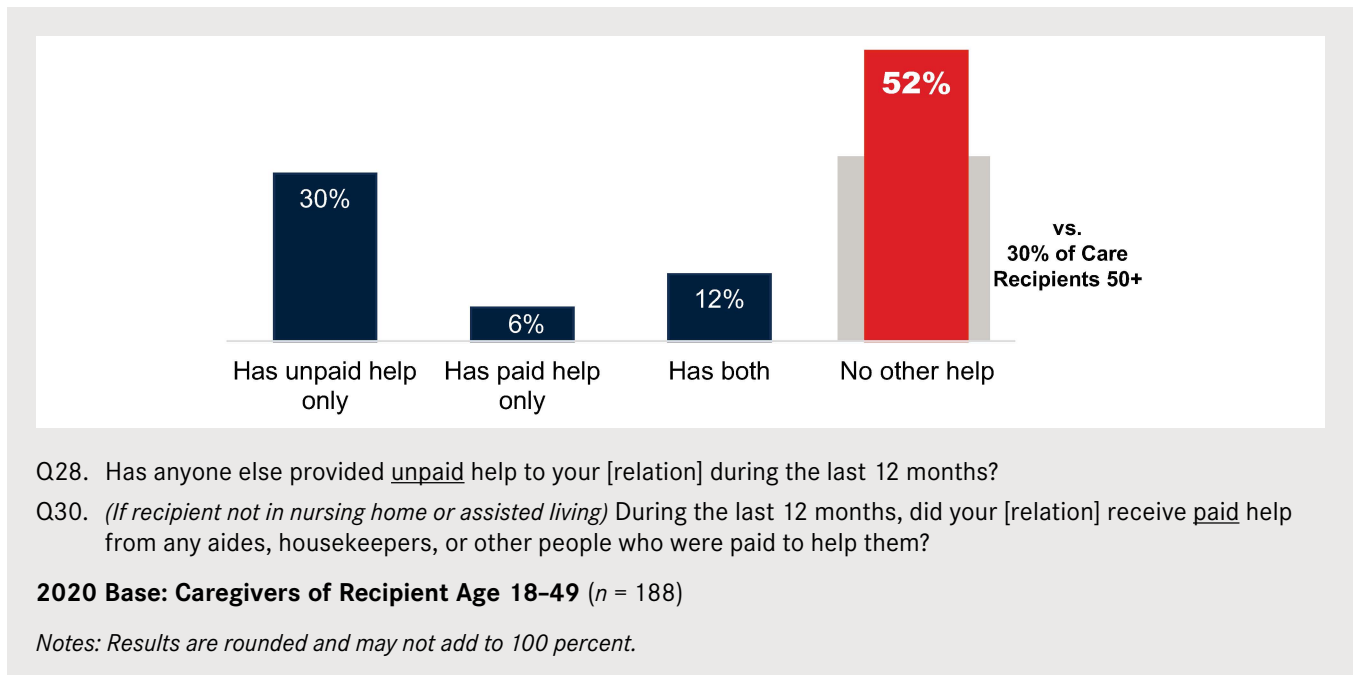
PRESENCE OF PAID AND UNPAID HELP

Overall, caregivers of younger adults seem to be going it alone. Half report having no other help, regardless of it being paid or unpaid (52 percent; see Figure 15). In comparison, 30 percent of caregivers of adults 50 years or older say they have no help.

¹⁵ Forty-one percent report the presence of other unpaid caregivers multiplied by 23 percent who report that at least one of these other unpaid caregivers is a child under age 18.

¹⁶ There are no significant differences in use of paid help by caregivers' household income among caregivers of younger adults.

Figure 15. Presence of Other Help

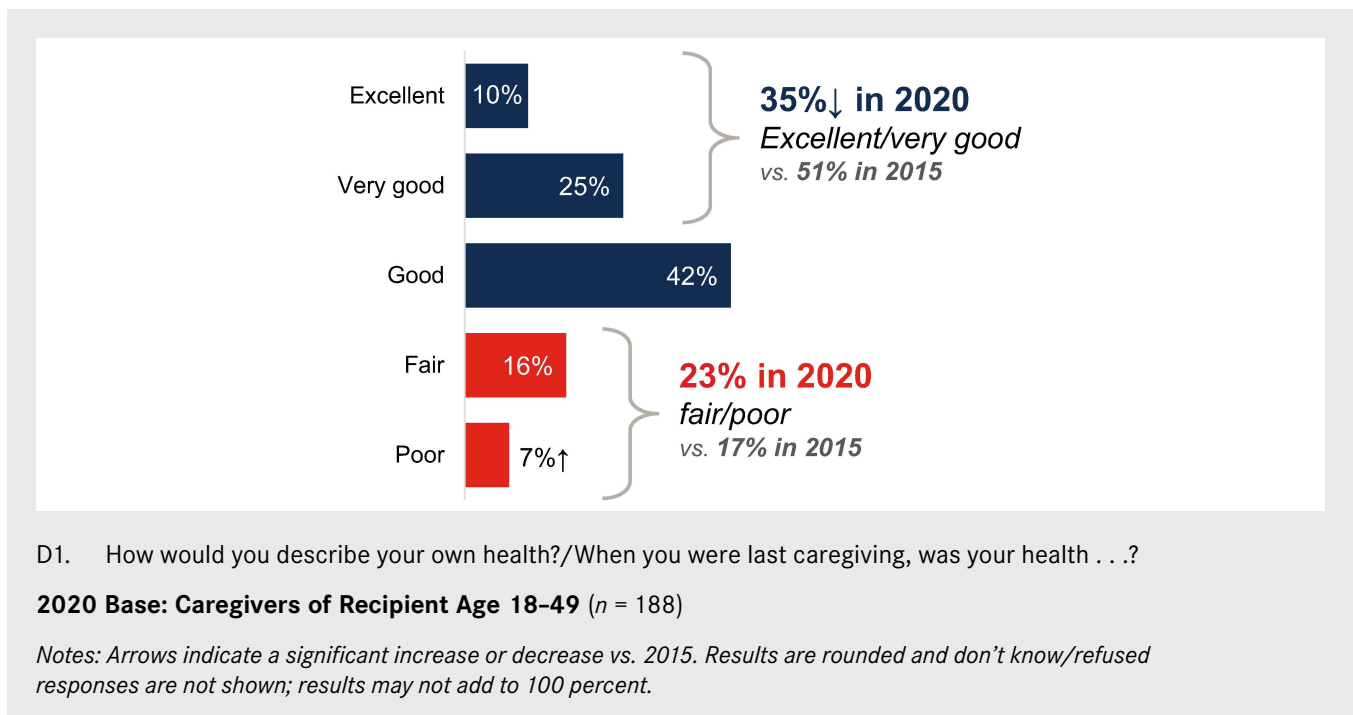


G. WELL-BEING OF CAREGIVERS

CAREGIVER HEALTH

One in three caregivers of younger adults ages 18–49 consider their health to be *excellent* or *very good* (35 percent, down significantly from 51 percent in 2015), 42 percent rate their health as *good*, and nearly one in four (23 percent) say it is *fair* or *poor* (see Figure 16).

Figure 16. Caregiver Health Status



Three in 10 caregivers of younger adults ages 18–49 find it difficult to take care of their own health (28 percent). A similar proportion (31 percent) of caregivers of younger adults feel caregiving has made their health worse, more than among caregivers of older adults (21 percent).

SUBGROUPS 2020:

- Caregivers of younger adults who more often rate their health as *fair* or *poor* include:
 - Those who are themselves ages 50 or older (33 percent *fair/poor* vs. 17 percent of caregivers ages 18–49),
 - Caregivers with a household income below \$50,000 (34 percent vs. 15 percent with a household income of \$50,000 or higher), and
 - Caregivers who co-reside with their younger adult recipient (29 percent vs. 15 percent of those not co-residing).
- Those providing care to a younger adult with an emotional or mental health issue are more likely to rate their health as *poor* (12 percent vs. 1 percent of those providing care to a younger adult without those issues).
- Caregivers of younger adults who more often find it difficult to take care of their own health include:
 - Higher-hour caregivers (37 percent vs. 22 percent of those providing 20 or fewer hours of care weekly),
 - Women (34 percent vs. 19 percent of men), and
 - Those providing care to a younger adult with an emotional or mental health issue (45 percent vs. 15 percent of those caring for someone without those issues).

PHYSICAL STRAIN

One in five caregivers of younger adults ages 18–49 report their role has caused a high level of physical strain (21 percent rating a 4 or 5 on a 5-point scale), 25 percent experience moderate strain (a rating of 3), and 54 percent say their physical strain is low (rating it 1 or 2).

SUBGROUPS 2020:

- Among caregivers of younger adults, those who are in intensive or demanding care situations often report that their physical strain is higher. This includes:
 - Those who provide care for 21 hours or more per week (37 percent vs. 9 percent of lower-hour caregivers) and
 - Those providing care to a younger adult with an emotional or mental health issue (30 percent vs. 12 percent of those caring for someone without those issues).

EMOTIONAL STRESS

Emotional stress is more common than physical strain among caregivers of younger adults ages 18–49, with 4 in 10 reporting a high level of emotional stress (40 percent rating 4 or 5 on 5-point scale), and 25 percent saying they feel moderate stress (rating of 3). Another 35 percent report a low level of emotional stress (rating of 1 or 2).

SUBGROUPS 2020:

- Similar to those likely to experience physical strain, caregivers of younger adults in intensive or demanding care situations also often report that their emotional stress is higher.¹⁷ This includes:
 - Those providing care to a younger adult for 21 hours or more per week (53 percent vs. 30 percent of lower-hour caregivers) and
 - Those who provide care to a younger adult with an emotional or mental health issue (52 percent vs. 26 percent of those caring for someone without those issues).

FEELING ALONE

Prior research has shown that caregivers may feel alone from avoiding social interactions due to the stigma attached to caregiving.¹⁸ One in five caregivers of younger adults ages 18–49 say caregiving makes them feel alone (20 percent).¹⁹

SUBGROUPS 2020:

- Caregivers who co-reside with their younger adult recipient are twice as likely to say they feel alone (25 percent) as those who do not live with their recipient (13 percent), despite having the physical presence of another adult in their home. Further research is needed to understand the loneliness of those who live with care recipient.
- Caregivers of younger adults providing 21 or more hours of care per week more often report feeling alone (30 percent vs. 14 percent of lower-hour caregivers).

17 These high levels of emotional stress and physical strain may also help to explain the noted health impacts (above) for the same subgroups of caregivers of younger adults.

18 Mitter, N., Ali, A., & Scior, K. (2018). Stigma experienced by family members of people with intellectual and developmental disabilities: multidimensional construct. *BJPsych Open*, 4(5), 332–338. <https://doi.org/10.1192/bjo.2018.39>

19 This is comparable to caregivers of adults ages 50 years or older at 21 percent.

H. THE FINANCIAL SITUATION OF CAREGIVERS

FINANCIAL STRAIN

One in three caregivers of a younger adult age 18–49 experience high financial strain (34 percent rating a 4 or 5 on a 5-point scale) due to caregiving.²⁰ This is a significant increase since 2015 (22 percent). By comparison, caregivers of older adults are less likely to report high levels of financial strain (16 percent).

SUBGROUPS 2020:

- Caregivers of younger adults in demanding care situations often report that their financial strain is higher. This includes higher-hour caregivers (53 percent when providing 21 hours of care or more weekly vs. 20 percent of lower-hour caregivers) and those providing care to a younger adult with an emotional or mental health issue (46 percent vs. 26 percent of those providing care to someone without those issues).
- Unemployed caregivers of younger adults more often experience high levels of financial strain (44 percent vs. 27 percent of employed caregivers).

FINANCIAL IMPACTS

Six in 10 caregivers of younger adults ages 18–49 have experienced at least 1 financial impact as a result of caregiving (61 percent), more often than caregivers of older adults (42 percent). Half of caregivers of younger adults have experienced 2 or more financial impacts (51 percent). On average, they experience 2.8 financial impacts compared with only 1.5 impacts for caregivers of older adults. Financial impacts are, in nearly every area explored, more commonly reported by caregivers of younger adults than by caregivers of older adults ages 50 years or older (see Figure 17).²¹

In terms of *savings*, most commonly caregivers of younger adults have stopped saving (39 percent) or have used up their personal short-term savings (38 percent). With regards to *debt*, nearly 4 in 10 have taken on more (38 percent), while 28 percent have borrowed money from friends or family.

In terms of *bills and living expenses*, 3 in 10 have left bills unpaid or paid them late (30 percent), while 2 in 10 have been unable to afford basic expenses like food (21 percent), much higher compared to caregivers of older adults (10 percent). Few have experienced *home* impacts, like moving to a less expensive home, apartment, or other living arrangement (8 percent). Some caregivers of younger adults ages 18–49 attempted to bridge the financial gap by finding more money through paid *work*. Two in 10 had to start working, work more, or find a second job due to caregiving financial impacts (20 percent).

20 Among caregivers of a younger adult, 19 percent report moderate financial strain (rating of 3) and 46 percent report low financial strain (rating of 1 or 2).

21 This could be due to a variety of reasons. Caregivers of older adults are older themselves (50.1 years, on average vs. 44.7 years for caregivers of younger adults) and are more likely to have a household income of at least \$50,000 (65 percent vs. 57 percent), which may buffer the financial impacts of providing care. Caregivers of older adults also provide care for fewer hours, on average, per week than caregivers of younger adults ages 18–49 (22.3 vs. 32.5, respectively), are less likely to co-reside with their care recipient (37 percent vs. 59 percent), and are less likely to provide care to someone with an emotional or mental health issue (24 percent vs. 41 percent), which may suggest that the care situation presents different challenges that may ripple out to impact the caregiver's finances. Further research is needed.

Figure 17. Financial Impacts as a Result of Caregiving by Age of Recipient

	Care Recipient Age 18-49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Financial impacts experienced (mean)	2.8 ^B	1.5
Experienced Change in At Least One Impact Related to . . .		
Debt	50% ^B	27%
Took on more debt	38% ^B	20%
Borrowed money from family or friends	28% ^B	13%
Missed or was late paying student loan	9% ^B	4%
Filed for bankruptcy	8% ^B	2%
Saving	49% ^B	32%
Stopped saving	39% ^B	27%
Used up personal short-term savings	38% ^B	20%
Used up long-term savings	19% ^B	11%
Bills or Expenses	34% ^B	20%
Left bills unpaid or paid late	30% ^B	17%
Was unable to afford basic expenses	21% ^B	10%
Work	26% ^B	15%
Had to start working, work more, or find a second job	20% ^B	9%
Put off retirement or decided to never retire	14%	8%
Home	10%	8%
Moved to a less expensive home	8%	7%
Was evicted or had home foreclosed	8% ^B	2%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple responses are allowed; results will not add to 100 percent.

SUBGROUPS 2020:

- Caregivers of younger adults who experience more financial impacts, on average, are higher-hour caregivers (3.8 vs. 2.2 when providing 20 or fewer hours of care weekly),²² those who co-reside with their recipient (3.4 vs. 2.0 when not co-residing),²³ and those providing care to a younger adult with an emotional or mental health issue (3.8 vs. 2.3 caring for someone without those issues).²⁴

22 Higher-hour caregivers of younger adults are more likely to have stopped saving (48 percent vs. 33 percent of lower-hour caregivers), taken on more debt (48 percent vs. 32 percent), left bills unpaid (42 percent vs. 21 percent), borrowed money from family or friends (37 percent vs. 22 percent), had to start working, work more, or find a second job (31 percent vs. 12 percent), used long-term savings (28 percent vs. 13 percent), moved to a less expensive home (13 percent vs. 4 percent), or put off retirement (24 percent vs. 7 percent).

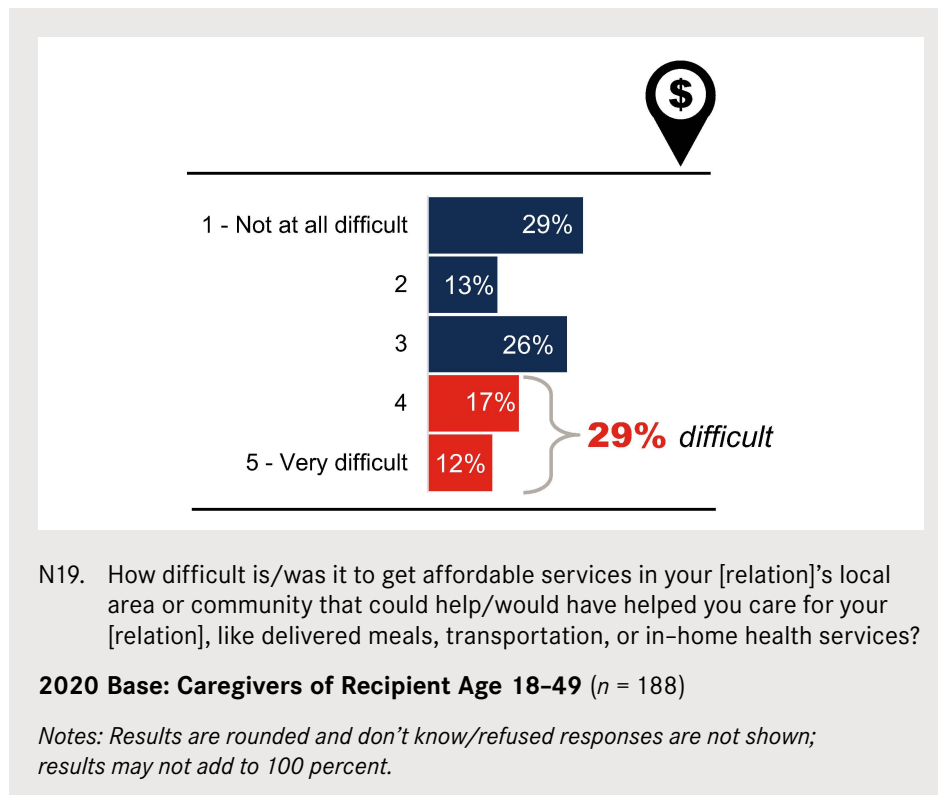
23 Caregivers who co-reside with their younger adult recipient are more likely to have stopped saving (47 percent vs. 29 percent of those not co-residing), taken on more debt (46 percent vs. 28 percent), borrowed money from family or friends (34 percent vs. 20 percent), used long-term savings (25 percent vs. 11 percent), put off retirement (19 percent vs. 6 percent), missed paying a student loan (13 percent vs. 4 percent), or filed for bankruptcy (11 percent vs. 4 percent).

24 Caregivers providing care to a younger adult with an emotional or mental health condition are more likely to have taken on more debt (52 percent vs. 29 percent caring for someone without those conditions), stopped saving (53 percent vs. 32 percent), used up personal short-term savings (54 percent vs. 28 percent), left bills unpaid (39 percent vs. 24 percent), or borrowed money from family or friends (40 percent vs. 19 percent).

AFFORDABILITY OF SERVICES

Three in 10 caregivers of younger adults ages 18–49 report it is difficult to get affordable services in their recipient’s local area or community (29 percent rating a 4 or 5 on 5-point scale; see Figure 18).

Figure 18. Difficulty Finding Affordable Services



SUBGROUPS 2020:

- Those experiencing the most difficulty finding affordable services are higher-hour caregivers (40 percent vs. 20 percent of those who provide care for 20 hours or less per week) and those who provide care to a younger adult with an emotional or mental health issue (42 percent vs. 17 percent of those who do not provide care for a younger adult with an emotional or mental health issue).

REQUESTS FOR FINANCIAL SUPPORT

Nearly twice as many caregivers of younger adults ages 18–49 have requested information about how to get financial help for their care recipient than caregivers of adults 50 years or older (40 percent vs. 23 percent).

SUBGROUPS 2020:

- Among caregivers of younger adults, those who are in intensive or demanding care situations more often report that they have requested help or information. This includes:
 - Those who co-reside with their younger adult care recipient (50 percent requested help or information vs. 25 percent of those who do not co-reside) and
 - Those providing care to a younger adult for 21 hours or more per week (55 percent vs. 28 percent of lower-hour caregivers).

POLICY PROPOSALS FOR CAREGIVER SUPPORT

Of three national policies or programs presented as potential ways to help them, two out of three caregivers of younger adults ages 18–49 would find an income tax credit helpful (67 percent) and a similar percentage would find a program to pay caregivers for some hours of their care helpful (65 percent). More than half feel a partially paid leave of absence from work would be helpful (55 percent).²⁵

SUBGROUPS 2020:

- Caregivers of younger adults especially likely find an income tax credit helpful include those who co-reside with their younger adult care recipient (74 percent vs. 57 percent who do not co-reside) and those providing care for 21 hours or more per week (81 percent vs. 57 percent of lower-hour caregivers).
- Caregivers of younger adults especially likely to find helpful a program to pay caregivers for some hours of care include:
 - Those who co-reside with their younger adult care recipient (72 percent vs. 55 percent when not co-residing),
 - Those providing care for 21 hours or more per week (83 percent vs. 51 percent of lower-hour caregivers), and
 - Women (72 percent vs. 54 percent of men).
- Caregivers of younger adults who themselves are ages 18–49 more often say a partially paid leave of absence from work would be helpful (60 percent vs. 46 percent of caregivers who are ages 50 or older).

I. IMPACT OF CAREGIVING ON WORK

TYPE OF EMPLOYMENT

Over half of employed caregivers of younger adults ages 18–49 are paid hourly (56 percent), while 32 percent report being salaried. This aligns with the 58 percent of U.S. workers who are paid hourly.²⁶ One-quarter of caregivers of younger adults are self-employed or own their own business (26 percent). This is higher than for caregivers of older adults ages 50 or older (13 percent). In comparison, 10 percent of U.S. workers are self-employed.²⁷

SUPERVISOR KNOWLEDGE OF CAREGIVER'S ROLE

Among employed caregivers of younger adults ages 18–49 who are not self-employed, 46 percent report that their supervisor at work is aware of their caregiving responsibility.

Few caregivers of a younger adult age 18–49 report feeling that their responsibilities as a caregiver led to them being penalized or discriminated against at work (12 percent), though this is higher compared with caregivers of older adults (6 percent).

25 This rises to 59 percent among caregivers of younger adults who worked while providing care in the past year.

26 Bureau of Labor Statistics, *Highlights of Women's Earnings in 2018*, Report 1083, Washington, DC, November 2019, <https://www.bls.gov/opub/reports/womens-earnings/2018/pdf/home.pdf>.

27 Current Population Survey, 2014 data, as analyzed and presented in: Pew Research Center, "10 Facts about American Workers," News in the Numbers Report, Pew Research Center, Washington, DC, August 29, 2019, <https://www.pewresearch.org/fact-tank/2019/08/29/facts-about-american-workers/>.

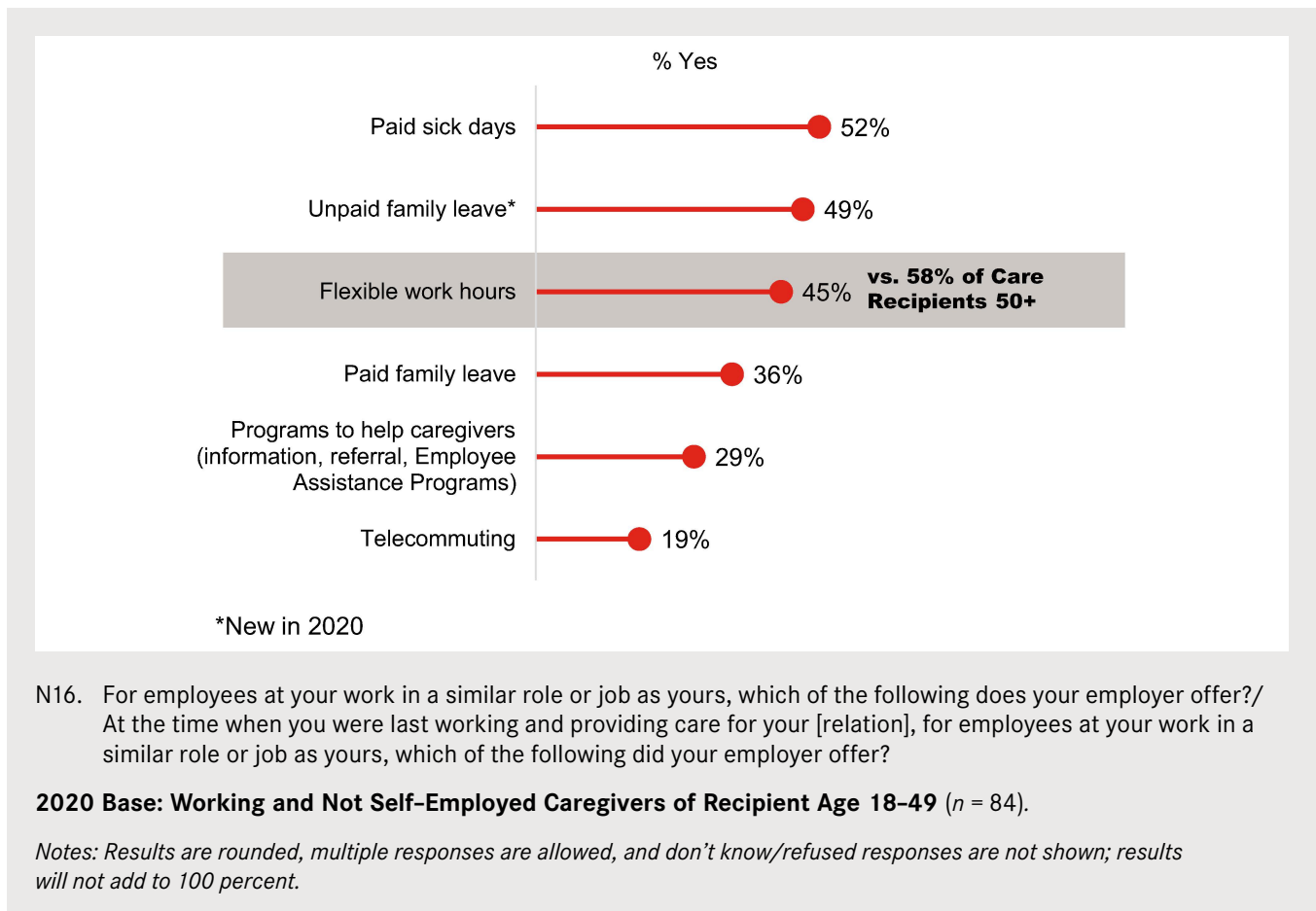
SUBGROUPS 2020:

- Among caregivers of younger adults, women more often say they have been penalized or discriminated against at work for being a caregiver (16 percent vs. 5 percent of men).

WORKPLACE BENEFITS FOR CAREGIVERS

In terms of the benefits and support that their employer provides, 52 percent of employed caregivers of younger adults ages 18–49 say they have paid sick days, 49 percent have unpaid family leave, and 36 percent say they have paid family leave. Fewer report having flexible work hours (45 percent) than caregivers of older adults (58 percent). Three in 10 report having programs like information, referrals, counseling, or an employee assistance program to help caregivers (29 percent). Just 19 percent of working caregivers of younger adults ages 18–49 say they can telecommute or work from home (see Figure 19).²⁸

Figure 19. Workplace Benefits for Caregivers of Younger Adults



28 The main report of *Caregiving in the U.S. 2020* suggests there are differences in benefits among working caregivers by the hours they work (full- or part-time). Our sample size of working caregivers of younger adults is limited, so further research is needed to determine if these same differences by work hours would hold among this subset of caregivers of younger adults.

WORKPLACE IMPACTS AS A RESULT OF CAREGIVING

When balancing caregiving with work becomes difficult, or the demands of work come into conflict with caregiving responsibilities, caregivers of younger adults ages 18–49 sometimes choose to or are forced to make changes to their work situation.

Two-thirds of caregivers of a younger adult age 18–49 report having experienced at least 1 impact or change to their employment situation as a result of caregiving (65 percent), with about half having to go in late, leave early, or take time off to provide care (52 percent). Other common impacts include cutting back on their working hours (23 percent), taking a leave of absence (20 percent), turning down a promotion (14 percent), or receiving a warning about performance or attendance (14 percent). On average, employed caregivers of a younger adult report having experienced 1.5 work impacts, while employed caregivers of older adults report fewer work impacts (1.1 on average; see Figure 20).

Figure 20. Caregiver Work Impacts by Age of Recipient

	Care Recipient Age 18–49 (n = 110) A	Care Recipient Age 50+ (n = 727) B
Work impacts experienced (mean)	1.5 ^B	1.1
Work Impacts Experienced . . .		
Went in late, left early, or took time off to provide care	52%	53%
Went from working full to part-time or cut back hours	23% ^B	14%
Took a leave of absence	20%	13%
Turned down a promotion	14% ^B	6%
Received a warning about performance or attendance at work	14%	7%
Gave up working entirely	13% ^B	5%
Retired early	8%	5%
Lost any of your job benefits	7%	4%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple responses are allowed; results will not add to 100 percent.

J. INFORMATION NEEDS AND SUPPORT

INFORMATION NEEDS

Nearly 6 in 10 caregivers of younger adults ages 18–49 feel they need more help or information about at least one topic related to caregiving (58 percent). Most commonly, caregivers of younger adults would like assistance with managing their own emotional and physical stress (34 percent). One in 4 would like help or information figuring out forms, paperwork, or eligibility for services or support (27 percent) and 2 in 10 would like help or information on activities to do with their younger adult recipient (22 percent).

Caregivers also need help and information for managing their own finances (17 percent), keeping their recipient safe at home (17 percent), managing their recipient’s challenging behaviors (12 percent), making end-of-life decisions (11 percent), and using technology to provide care for their younger adult recipient (11 percent). The need for help and information on these topics depends on the age of the recipient (see Figure 21).

Figure 21. Caregiver Help and Information Needs by Age of Recipient

	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Managing your emotional or physical stress	34% ^B	24%
Figuring out forms, paperwork, or eligibility for services or support for your recipient	27%	25%
Activities you could do/have done with your recipient	22%	20%
Managing or handling your own personal finances	17%	13%
Keeping your recipient safe at home	17%	28% ^A
Managing your recipient’s challenging behaviors, such as wandering	12%	11%
Making end-of-life decisions	11%	13%
Using technology to provide care for your recipient	11%	12%
Choosing a home care agency, assisted-living facility, or nursing home	6%	14% ^A
Finding non-English language educational materials	3%	3%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple responses are allowed; results will not add to 100 percent.

SUBGROUPS 2020:

- Those providing care to a younger adult with an emotional or mental health issue are especially likely to feel they need help or information on a multitude of topics.²⁹ Those who co-reside with their younger adult recipient are also likely to report that they need help or information.³⁰
- Caregivers of younger adults likely to feel they need further help or information on managing their own finances tend to be younger themselves (22 percent of caregivers ages 18–49 vs. 9 percent of older caregivers).
- Those most likely to want help or information for filling out forms are higher-hour³¹ caregivers (37 percent vs. 21 percent when providing 20 or fewer hours of care).
- Forty percent of women feel they need help managing their own stress (vs. 24 percent of men) while 25 percent of men feel they need help managing their own finances (vs. 12 percent of women).

29 Caregivers of a younger adult with an emotional/mental health issue are more likely than caregivers of those without one to feel they need help with or information about keeping their recipient safe at home (24 percent vs. 12 percent), managing challenging behaviors (20 percent vs. 4 percent), activities to do with their recipient (32 percent vs. 14 percent), choosing a home care agency (10 percent vs. 2 percent), managing their own stress (52 percent vs. 19 percent), and using technology to care for their recipient (22 percent vs. 4 percent).

30 Caregivers who co-reside with their younger adult recipient feel they need more help or information on managing their own stress (43 percent vs. 20 percent) and managing their own finances (22 percent vs. 11 percent).

31 Higher-hour refers to caregivers who provide 21 or more hours of care weekly.

CONVERSATIONS ABOUT RECIPIENT AND SELF CARE

Few caregivers of a younger adult age 18–49 report having had conversations with health care providers, like doctors, nurses, or social workers, about their own needs (13 percent). Nearly twice as many have had a conversation about what is needed to take care of their recipient (24 percent). Of note, 76 percent of caregivers of younger adults have *not* had discussions about what they need to provide care to their recipient.

SUBGROUPS 2020:

- Caregivers of younger adults who provide care for 21 hours or more per week are more likely to have had a conversation about what they need to provide care to their recipient (34 percent vs. 16 percent of those providing care for fewer hours).

SERVICES USED: TRANSPORTATION AND HOME MODIFICATIONS

Three in 10 caregivers have used an outside service to provide transportation for their younger adult recipient age 18–49 (30 percent), up from 17 percent in 2015, and 1 in 4 had modifications made to the home where their recipient lives (27 percent). Caregivers of older adults ages 50 or older more often made modifications (38 percent).

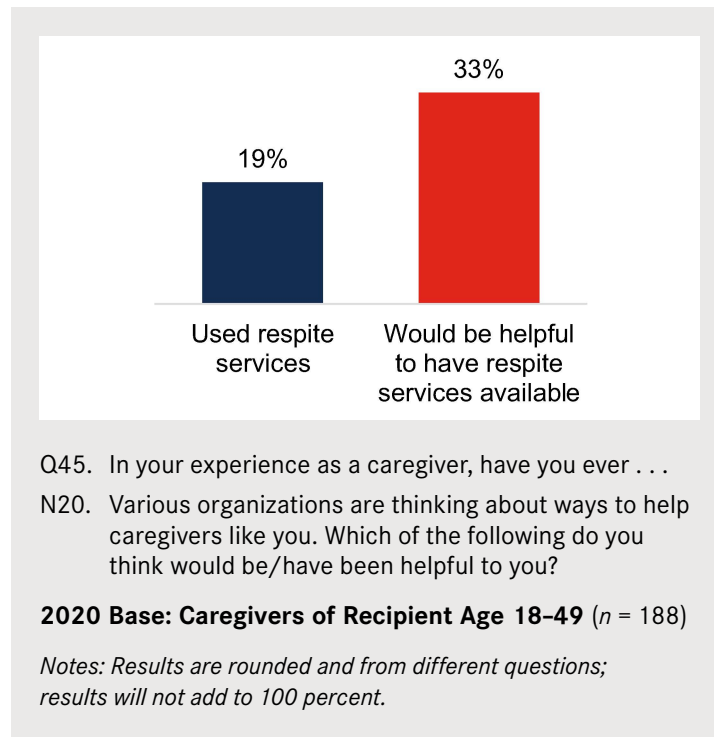
SUBGROUPS 2020:

- Caregivers of younger adults especially likely to have used an outside transportation service include:
 - Those who co-reside with their younger adult recipient (36 percent vs. 21 percent of those not co-residing) and
 - Caregivers of a younger adult with an emotional or mental health issue (37 percent vs. 22 percent of those providing care for a younger adult without an emotional or mental health issue).
- Caregivers of younger adults especially likely to have made modifications to their recipient's home include those who co-reside with their younger adult care recipient (34 percent vs. 18 percent of those not co-residing) and higher-hour caregivers (39 percent for those providing care for 21 or more hours per week vs. 18 percent of those providing care for fewer hours).

RESPITE SERVICES

One-third of caregivers of younger adults ages 18–49 feel having respite services available would be helpful (33 percent). However, only 19 percent report having used these services, where someone provided care to the recipient to give the caregiver a break (see Figure 22).

Figure 22. Respite Services



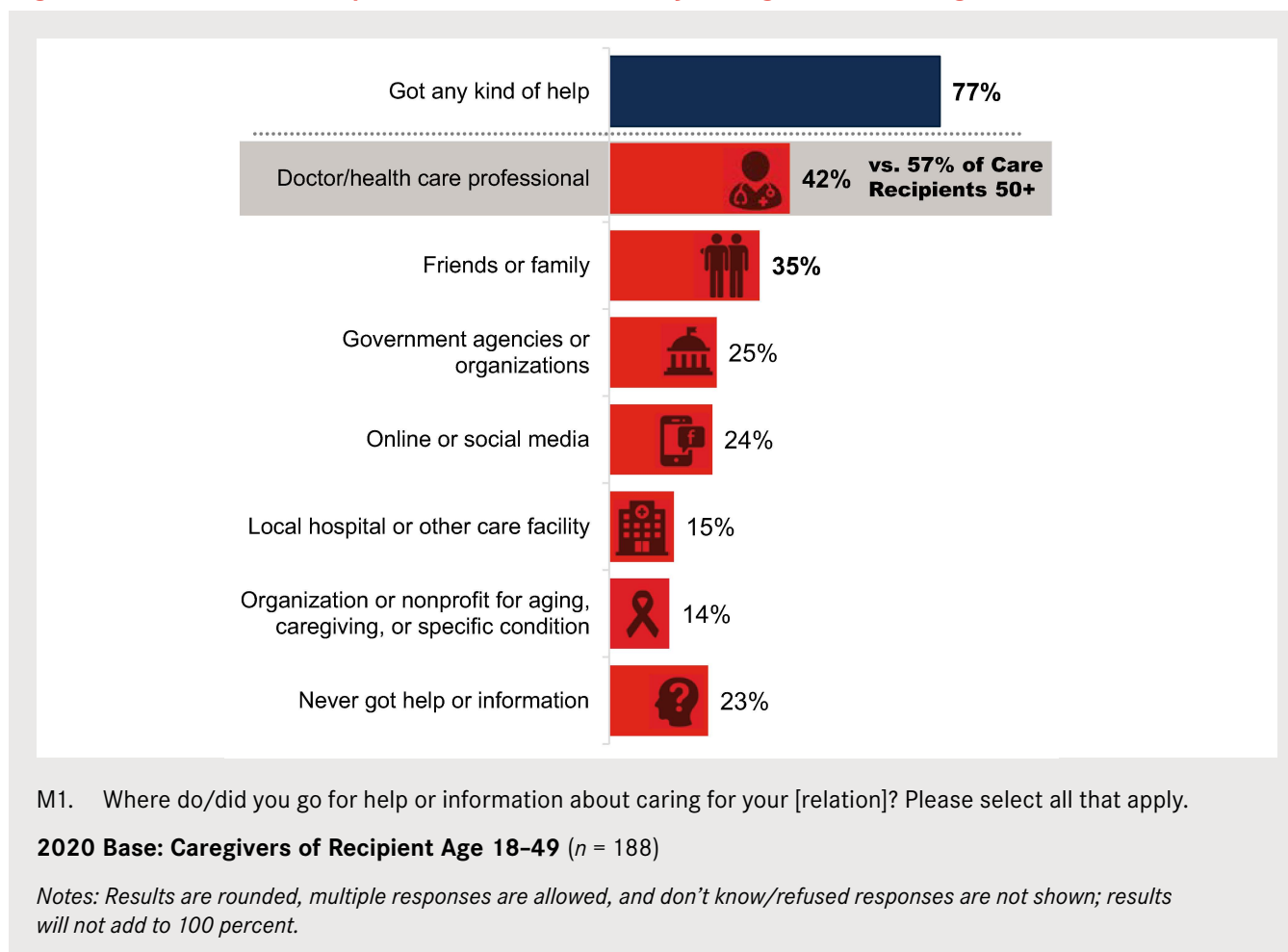
SUBGROUPS 2020:

- Caregivers of younger adults who more often *use* respite services include higher-hour caregivers (28 percent vs. 11 percent when providing care for 20 or fewer hours). Nearly half of those providing care to a younger adult with an emotional or mental health issue would find respite services helpful (46 percent vs. 21 percent of those providing care to someone without those issues).

SOURCES OF HELP OR INFORMATION

Three-quarters of caregivers of younger adults ages 18–49 report having at least one source of help or information about providing care (77 percent). Most commonly, caregivers of younger adults rely on health care professionals (42 percent, compared with 57 percent of caregivers of older adults age 50 or older), followed by family and friends (35 percent, compared with 45 percent of caregivers of older adults ages 50 or older). About one in four rely on government agencies or organizations (25 percent) or online or social media (24 percent). One in seven rely on their local hospital or care facility (15 percent) or an organization or nonprofit for aging, caregiving, or a specific condition (14 percent; see Figure 23).

Figure 23. Sources of Help or Information Used by Caregivers of Younger Adults



SUBGROUPS 2020:

- Caregivers of younger adults who more often report receiving help of any kind include:
 - Those who co-reside with their younger adult recipient (84 percent vs. 66 percent of those who do not co-reside) and
 - Those providing care for 21 hours or more per week (88 percent vs. 69 percent of those providing care for fewer hours).
- Those who provide care to their adult child are more likely to receive help or information from government agencies (35 percent vs. 19 percent of those providing care to some other relative).

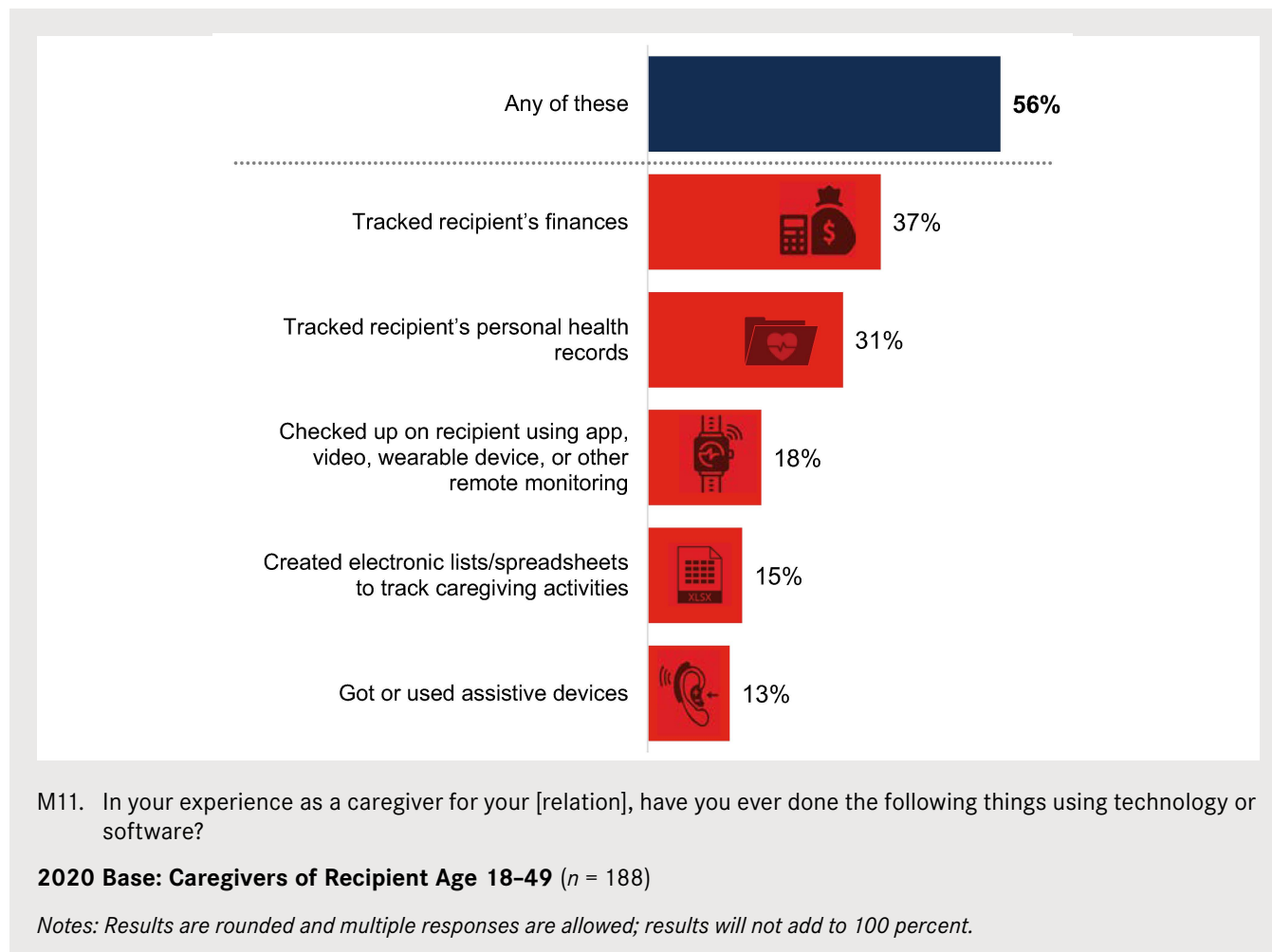
K. TECHNOLOGY

SOFTWARE AND MONITORING SOLUTIONS

More than half of caregivers of younger adults ages 18–49 have used at least one type of technology or software to help with caregiving (56 percent), including more than one-third who have used two or more (36 percent). Most commonly, nearly 4 in 10 caregivers of younger adults have used technology or software to track their recipient’s finances (37 percent). Three in 10 have tracked their recipient’s personal health records with technology or software (31 percent). Fewer have used apps, video,

wearables, or other remote monitoring to check up on their recipient (18 percent) or gotten or used assistive devices for their recipient (13 percent). Fifteen percent have created electronic lists to track activities related to providing care (see Figure 24).

Figure 24. Caregiver Use of Software and Monitoring Solutions



SUBGROUPS 2020:

- Some groups of caregivers of younger adults use technology more than others. This could be indicative of the digital divide with some groups having a harder time accessing technology.³² Those who more often report using technology for any kind of assistance include:
 - Those who co-reside with their younger adult recipient (64 percent vs. 45 percent of those who do not co-reside) and
 - Those providing care for 21 hours or more per week (68 percent vs. 48 percent of those providing care for fewer hours).
- Those who provide care to their adult child are more likely to use technology to track their recipient's personal health records (43 percent vs. 26 percent of those providing care to some other relative).

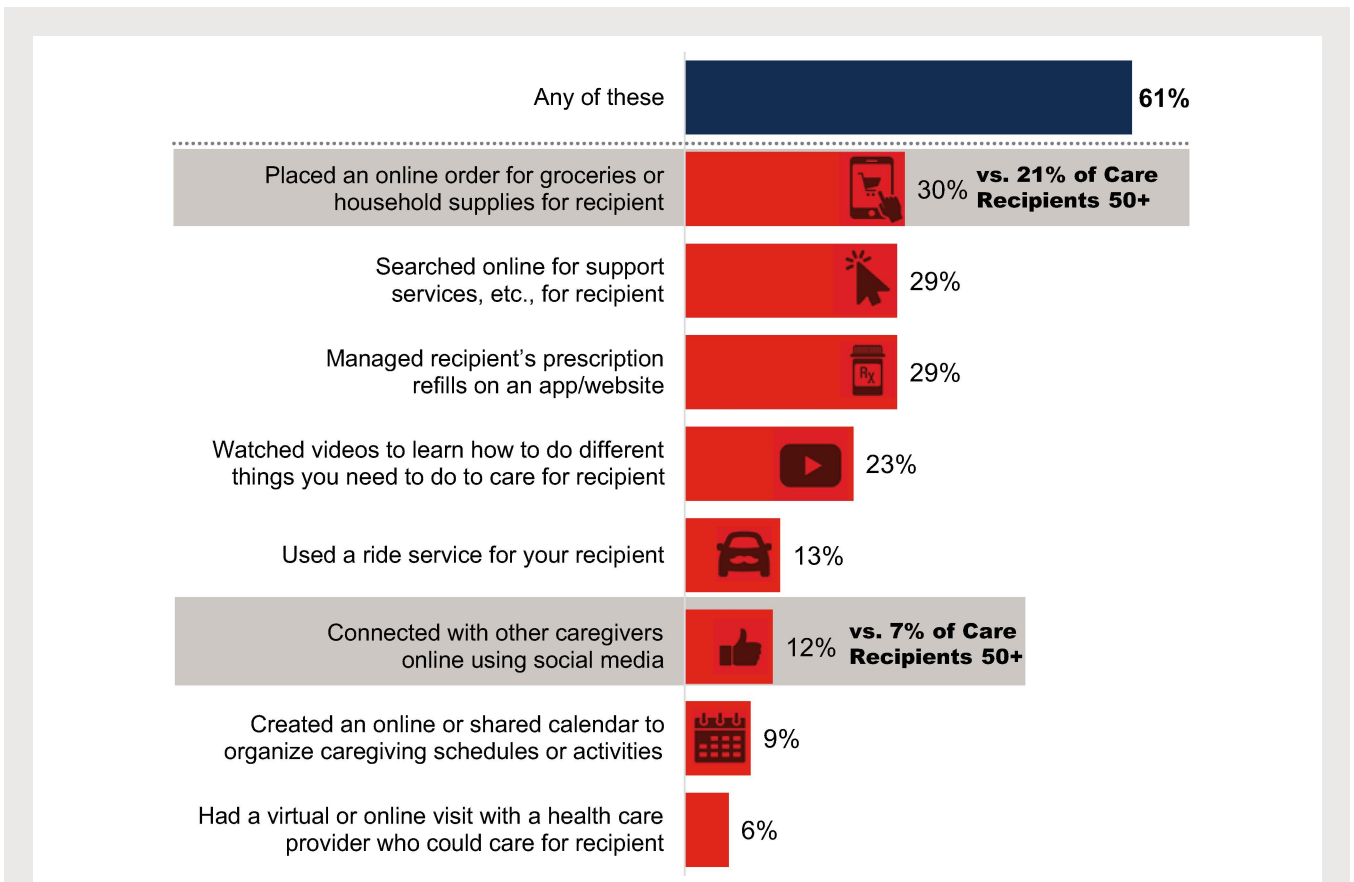
³² This is important to note given the increased necessity of technology in the era of the COVID-19 pandemic, which emerged following the collection of the data analyzed and reported here.

ONLINE SOLUTIONS

Six in 10 caregivers of younger adults ages 18–49 have performed at least one of a variety of tasks online to help with caregiving (61 percent), including more than 4 in 10 who have completed two or more tasks online (42 percent). Most commonly, caregivers of younger adults rely on the Internet for ordering groceries or household supplies (30 percent), for searching for services, aides, facilities or other help (29 percent), or for managing their recipient’s prescriptions (29 percent; see Figure 25 for additional online solutions).

Caregivers of younger adults more often report using online ordering for grocery or household supplies and connecting with other caregivers using social media than do caregivers of older adults.

Figure 25. Caregiver Use of Online Solutions



M7. In your experience as a caregiver for your [relation], have you ever done the following things online?

2020 Base: Caregivers of Recipient Age 18–49 (n = 188)

Notes: Results are rounded and multiple responses are allowed; results will not add to 100 percent.

SUBGROUPS 2020:

- Caregivers of younger adults who more often report going online for any kind of assistance include:
 - Those who co-reside with their younger adult recipient (72 percent vs. 46 percent of those who do not co-reside) and
 - Those providing care for 21 hours or more per week (78 percent vs. 49 percent of those providing care for fewer hours).
- Caregivers who co-reside with their younger adult recipient are especially likely to have gone online to order groceries or household supplies (37 percent vs. 19 percent of those who do not co-reside).

L. LONG-RANGE PLANNING

EXPECTATIONS OF FUTURE CAREGIVING ROLE

About 4 in 10 caregivers of younger adults ages 18–49 expect they will have some caregiving responsibility for an adult (either their current recipient or someone else) during the next five years (37 percent), with roughly equal proportions saying they do not expect to have some responsibility as a caregiver in the future (32 percent) or are not sure (31 percent). Caregivers of older adults are more likely to expect to continue their role (see Figure 26).

Figure 26. Expectation of Future Caregiving by Age of Recipient

	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Expects to provide care in next five years	37%	57% ^A
Does not expect to provide care	32% ^B	17%
Not sure	31%	26%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

SUBGROUPS 2020:

- Caregivers of younger adults most likely to expect to have to continue providing care over the next 5 years include:
 - Those with a household income of \$50,000 or more (45 percent vs. 26 percent of caregivers with lower household incomes),
 - Those providing care to their adult child (56 percent vs. 28 percent providing care to another younger adult relative),
 - Higher-hour caregivers (52 percent vs. 26 percent of those providing 20 or fewer hours of care weekly), and
 - Those who co-reside with their younger adult recipient (47 percent vs. 23 percent of those who do not co-reside).

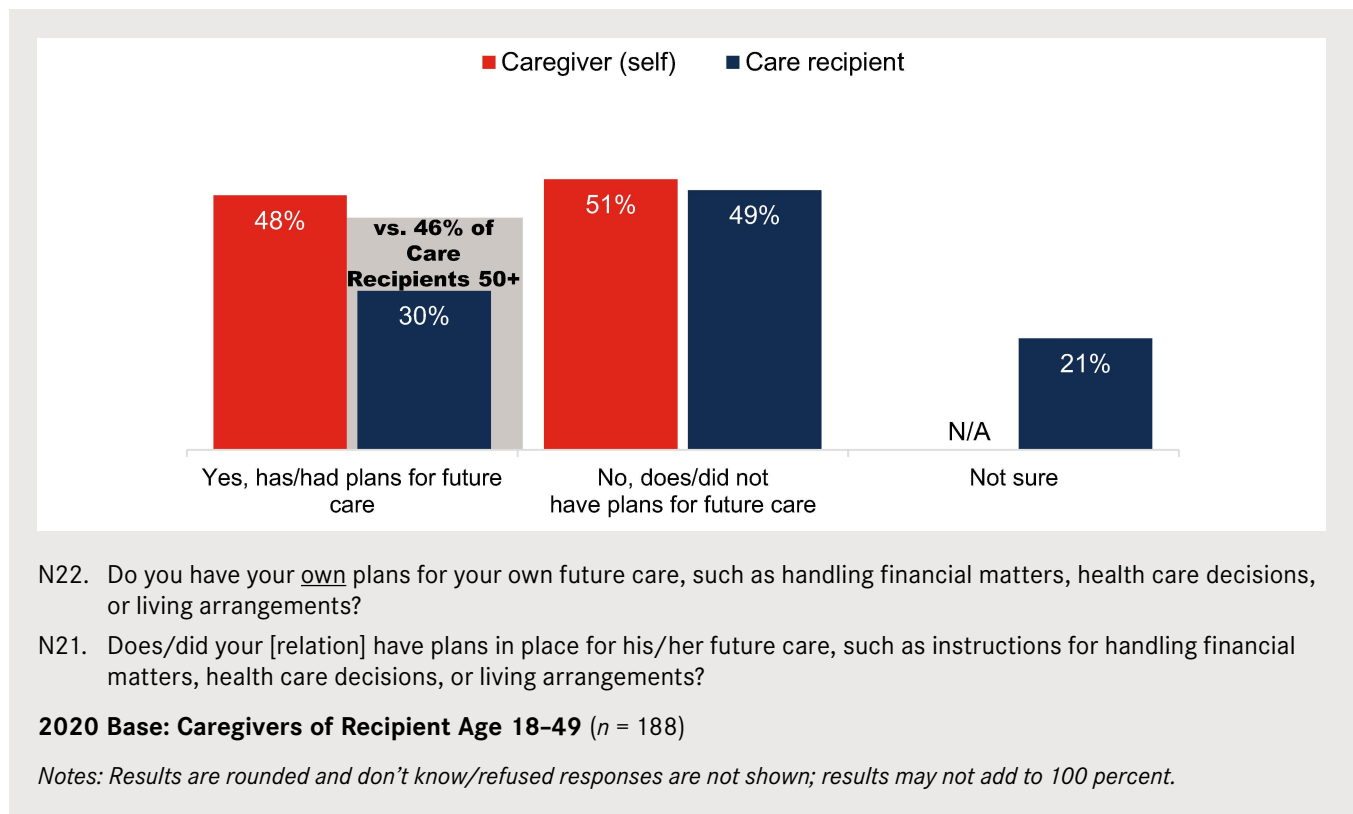
LONG-RANGE PLANNING

Only 3 in 10 caregivers of younger adults ages 18–49 report their recipient has plans in place for their future care, such as instructions for handling financial matters, health care decisions, or living arrangements (30 percent).³³ By comparison, caregivers of older adults ages 50 or older are more likely to report their recipient has these kinds of arrangements (46 percent).

Nearly half of caregivers of younger adults ages 18–49 have plans in place for their own future care (48 percent; see Figure 27).

33 Further research is needed to determine why and who will care for the younger adult if and when the caregiver is no longer able to provide care.

Figure 27. Long-Range Planning



SUBGROUPS 2020:

- Caregivers of younger adults who *less often* have plans in place for their own future care are younger themselves (38 percent of caregivers ages 18–49 vs. 65 percent of caregivers age 50 or older) and provide care to a relative who is not their adult child (41 percent vs. 59 percent when caregiving for their adult child).

M. RESPONDENT PROFILE

Six in 10 caregivers of younger adults ages 18–49 are women; the average age is 44.7 years old; 6 in 10 are non-Hispanic White; and 3 in 10 have a Bachelor’s degree or higher (see Figure 28).³⁴

Figure 28. Demographic Summary of Caregivers by Age of Recipient, 2020

Demographic	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Caregiver Gender		
Men	40%	39%
Women	60%	61%
Age of Caregiver		
18–34	32% ^B	22%
35–49	29% ^B	22%
50–64	27%	36% ^A
65–75	7%	13% ^A
75+	4%	7%
Mean age	44.7	50.1 ^A
Race/Ethnicity of Caregiver		
Non-Hispanic White	58%	61%
African American	19%	14%
Hispanic/Latinx	15%	17%
Asian	6%	5%
Other	2%	3%
Caregiver Education		
Less than high school	10%	6%
High school graduate	32% ^B	25%
Some college	17%	23%
Technical school or Associates degree	12%	11%
College graduate	19%	21%
Graduate school	9%	15% ^A

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

34 The demographic profile of caregivers of younger adults in 2020 is comparable to the profile in 2015, so those data are not shown for brevity; rather, caregivers of younger adults are contrasted with caregivers of older adults in 2020.

Two in three caregivers of younger adults are married or living with a partner. Household incomes for caregivers of younger adults ages 18–49 are lower compared with caregivers of older adults, with a median income of \$55,000. Three in 10 caregivers of younger adults have a child or grandchild living in their home at the time of care.

Figure 28. Demographic Summary of Caregivers by Age of Recipient, 2020 *continued*

Demographic	Care Recipient Age 18-49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Caregiver Marital Status		
Married	53%	54%
Living with a partner	14% ^B	6%
Widowed	8% ^B	3%
Separated	4% [↑]	2%
Divorced	5%	9%
Single, never married	13%	23% ^A
Caregiver Household Income (unadjusted)		
Less than \$50,000 (net)	43% ^B	35%
Less than \$15,000	7%	8%
\$15,000–\$29,999	17%	12%
\$30,000–\$49,999	18%	15%
\$50,000 or more (net)	57%	65% ^A
\$50,000–\$74,999	19%	17%
\$75,000–\$99,999	12%	14%
\$100,000+	26%	34% ^A
Median household income (2015 inflation adjusted)	\$55,000	\$67,500
Children/Grandchildren Living in Caregiver's Home		
Yes	31%	30%
No	65%	68%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Just 14 percent of caregivers of younger adults ages 18–49 live in a rural area. Six in 10 are employed while providing care, while 15 percent report being a student while caregiving. One in 5 (20 percent) say they do not have health insurance.

Figure 28. Demographic Summary of Caregivers by Age of Recipient, 2020 *continued*

Demographic	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Caregiver Living Location		
Urban/suburban	86%	89%
Rural	14%	11%
Caregiver Employment Status		
Employed in past year while caregiving	59%	62%
Not employed	41%	38%
Caregiver Student Status		
Yes	15%	10%
No	84%	89%
Caregiver Has Health Insurance		
Yes	80%	88% ^A
No	20% ^B	11%
Caregiver Source of Health Insurance		
	(n = 154)	(n = 1,076)
Employer-sponsored	53%	57%
Medicare	18%	21%
Medicaid	11%	9%
Direct purchase	10%	7%
Military/veterans	5%	4%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Less than 1 in 10 caregivers of younger adults ages 18–49 have served in the U.S. Armed Forces and 10 percent self-identify as LGBTQ.³⁵ More than one-third report their younger adult recipient lives in a rural area and only 6 percent say their recipient is a veteran, compared with 16 percent of older recipients.

Figure 28. Demographic Summary of Caregivers by Age of Recipient, 2020 *continued*

Demographic	Care Recipient Age 18–49 (n = 188) A	Care Recipient Age 50+ (n = 1,204) B
Caregiver Service in Armed Forces	(n = 173)	(n = 1,105)
Served on active duty	8%	10%
Did not ever serve	92%	90%
Caregiver LGBTQ Status		
Yes	10%	7%
No	87%	92%
Care Recipient Living Location		
Urban/suburban	64%	69%
Rural	36%	30%
Care Recipient Service in Armed Forces		
Served on active duty	6%	16% ^A
Did not ever serve	90% ^B	82%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

35 This includes anyone self-identifying as gay or lesbian, bisexual, or some other sexual orientation other than “straight, that is, not gay,” as well as anyone self-identifying as transgender or some other transgender status other than “male” or “female.”

National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 18 to 49*. Washington, DC: AARP. November 2020.
<https://doi.org/10.26419/ppi.00103.023>

THIS REPORT WAS MADE POSSIBLE WITH GENEROUS SPONSORSHIP FROM

