

# Living with Paralysis & Caregiver National Survey

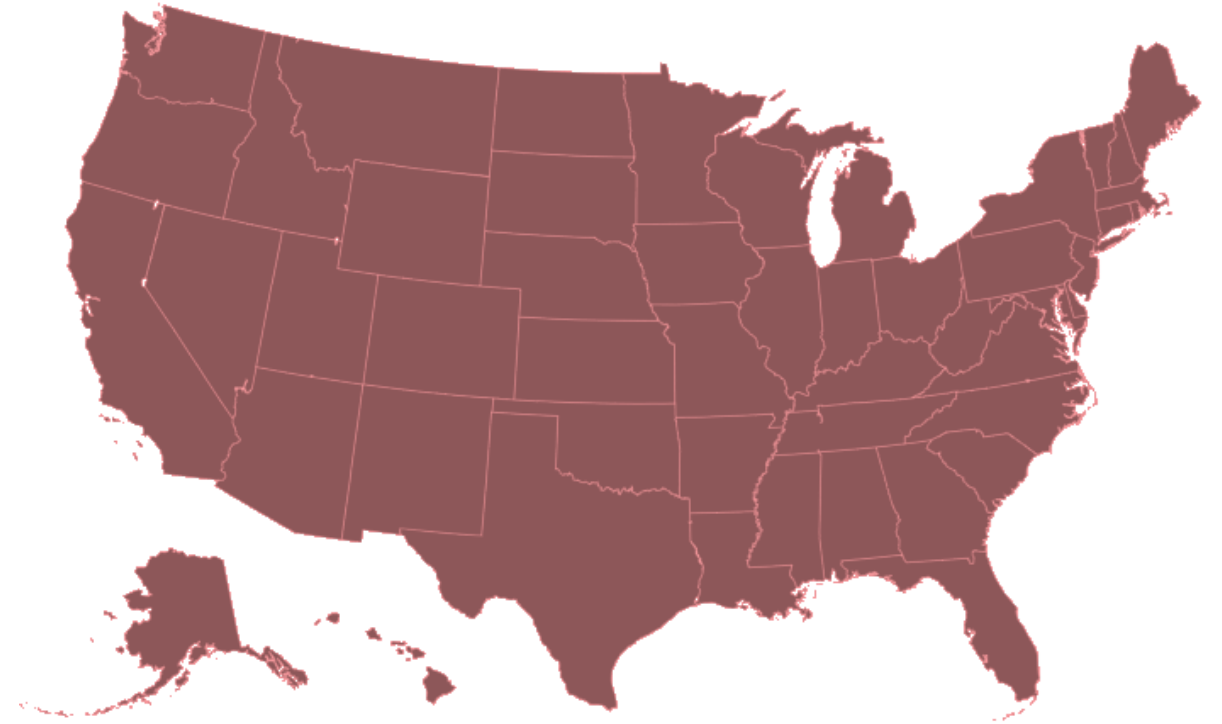
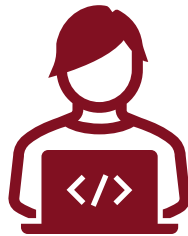
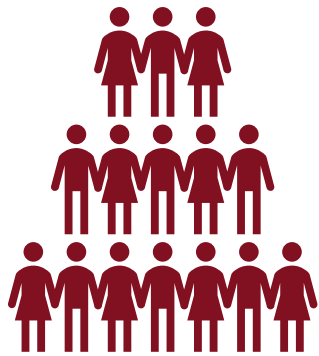
Christopher & Dana Reeve Foundation

Nov 7, 2022

# METHODOLOGY

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- This report presents the findings of a U.S. survey conducted by Finn among a representative sample of 1,004 U.S. adults ages 18 and older. Online interviews took place September 23-25, 2022. Respondents were members of an online panel and had agreed to participate in online surveys and polls.



# Highlights

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## Prevalence of paralysis and wheelchair use

- A large majority of Americans (69%) underestimate the prevalence of those living with paralysis in the US (paralyzed and in a wheelchair).

## Experience

- About 1/3 of Americans know someone living with Paralysis.

## Belief in Govt Compensation

- Most Americans (79%) believe that a family member providing long-term care for someone who is paralyzed should have some form of compensation from the govt, with half believing they need the financial help, or they are unable to work/work full time.
- Concerning compensation, women are more likely to be concerned about the need for money/income from a job vs. men. Gen Z is twice as likely than other generations (33% vs. about 15%) to believe that the gov't can/should financially help.
- Most Americans (77%) do not serve as a caregiver. However of those who are caregivers to a family member (18%) and regularly assist with daily living activities of someone who is disabled, sick or elderly, 2/3 are unpaid.

## Income source

- Many American's (65%) believe that some form of insurance (Medicare/Medicaid), or health/disability insurance would be the main source of funds to cover the cost of day-to-day living if they were to become paralyzed.

## Knowledge

- Most Americans (77%) do not serve as a caregiver.
- Many Americans (69%) do not know a caregiver to someone who is paralyzed.

## ADA

- Nearly all Americans are familiar with the ADA (96%), of those, most (74%) believe there is a need for additional support from the US Government for wheelchair users beyond the ADA.

## Traveling Issues

- Most Americans (96%) do not choose traveling on airplanes as one of the more difficult challenges in life for those living with paralysis. (This indicates Americans either don't believe that it is, don't believe it is as necessary as the other items, or haven't thought about it).
- Most Americans (94%) do not think of enduring possible wheelchair damage as the most difficult for those traveling in a wheelchair and paralyzed. However, using the restrooms and boarding/deboarding were challenges that about half of Americans would believe is most difficult.

# EXECUTIVE SUMMARY

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## Majority Underestimate the Number of Americans Living with Paralysis

- Fewer than one in four adults (23%) correctly estimated the number of Americans living with paralysis at *about 2 out of every 100 Americans*, with Millennials the most inclined of all generations to answer accurately (29%).
  - Respondents were more likely to believe *about 2 out of every 10,000 Americans* (34%) or *about 2 out of every 1,000 Americans* (35%) are paralyzed and require a wheelchair for mobility.
- When asked to name the main cause of paralysis in the U.S. on an unaided basis, respondents were most inclined to cite an *auto/motorcycle/traffic accident* (30%) or an unspecified *accident/injury/trauma* (29%).
  - Women (32%), Gen X (31%) and particularly Baby Boomers (37%) were the most likely to name an unspecified *accident/injury/trauma* as the primary cause of paralysis.



## One in Three Americans Know Someone who is Paralyzed

- Thirty-four percent of Americans know someone who is paralyzed and using a wheelchair for mobility.
  - Millennials (38%) and Gen X (40%) are more inclined than Gen Z (28%) and Baby Boomers (29%) to know someone who is paralyzed.
- Most respondents identified the paralyzed person they know as either a friend (36%), an acquaintance (29%), or an extended family member (20%).
- In terms of living situation, three in four (76%) do not currently live in the same household as the paralyzed person/people they know; 8% share the same household; and 6% have a paralyzed client in their care.

# EXECUTIVE SUMMARY

## Most Believe Additional Government Support is Needed Beyond ADA

- Opinions are fairly split when it comes to whether mobility-impaired wheelchair users have adequate accessibility within businesses across the U.S.: 38% of adults believe they do, 33% think they do not, and 29% say they may or may not have adequate accessibility.
  - Men (47%) are much more likely than women (30%) to feel U.S. businesses provide sufficient accessibility to wheelchair users.
  - Among generations, Baby Boomers (30%) are less inclined than all other generations to express this same view.
- Three-quarters (74%) of Americans believe there is a need for additional support from the U.S. government for wheelchair users beyond the Americans with Disabilities Act (ADA).
  - This viewpoint is more prevalent among women (78%) than men (70%); the same holds true for Gen X (79%) compared to Gen Z (69%) and Millennials (72%).

## Under Two in Five Feel Wheelchair Users Can Live Best Quality of Life

- Thirty-six percent of Americans think wheelchair users in the U.S. are currently able to live their best quality of life.
  - Men (42%) are more inclined than women (31%) to express this belief.
  - This opinion is also held by roughly two in five respondents across generations with the exception of Baby Boomers, only 27% of whom feel the same.
- Most adults (62%) think it costs less than \$55,000 per year, on average, for a full-time professional caregiver of someone who is paralyzed and requires a wheelchair; this is particularly true of Gen Z (72%) versus all other generations.
  - Over half (52%) of all respondents estimate the annual cost to be in the range of \$20,000 - \$54,999.



# EXECUTIVE SUMMARY

## Government Compensation for Family Members who are Caregivers to Paralyzed Person has Strong Support

- According to four in five Americans (79%), there should be some form of compensation from the government for a family member providing long-term care for someone who is paralyzed, with agreement levels highest among Gen X (83%).
  - Additionally, half (49%) of all adults **strongly** agree this type of government compensation is necessary.
- Those who agree there should be some form of government compensation for family members who are caregivers to someone who is paralyzed are most likely to cite the following as reasons: *they need the help/money/compensation* (24%); *they can no longer work/hold a full-time job* (24%); and/or *government can/should help/we pay taxes for this* (16%).
  - Women are more inclined than men to feel *they need the help/money/compensation* (30% vs. 17%) and *they can no longer work/hold a full-time job* (32% vs. 15%).
  - Gen Z (33%) is more likely than all other generations to express the view that *government can/should help/we pay taxes for this*.

- Although few respondents disagree with this type of government compensation, those who do are most inclined to think it is *not the government's responsibility/government can only help/pay so much* (35%).
- If they were to become paralyzed and unable to care for themselves independently, most adults say their main source of funds to cover daily living costs would be either *Medicare* (20%), *Medicaid* (18%), *health insurance* (17%) or *disability insurance through work* (10%).



# EXECUTIVE SUMMARY

## One in Four Americans Know a Caregiver to Paralyzed Person

- Over two in five adults (43%) know someone who regularly cares for or assists a sick, elderly, or disabled person.
  - Nearly half (48%) of women know someone who is a caregiver, compared to 38% of men.
  - Among generations, Gen X (50%) is the most likely – and Gen Z (36%) the least likely – to know someone who is a caregiver.
- One in four respondents (26%) know someone who is a caregiver to a person that is paralyzed and requires a wheelchair.
  - Millennials (32%) and Gen X (28%) are more likely than Baby Boomers (19%) to know someone who regularly cares for a paralyzed person.



## Mental Strain Perceived as Top Challenge for Both Caregivers and Paralyzed People

- When presented with a list of caregiver roles, seven in ten respondents (70%) were surprised by at least one, chief among them *bowel and bladder care management* (24%).
- The *mental or emotional strain of caregiving*, chosen by 22%, tops the list of perceived challenges for those who provide full-time, in-home caregiving, followed closely by *financial challenges* (20%).
  - Women (25%) are more likely than men (19%) to view the *mental or emotional strain of caregiving* as most challenging.
- The *mental strain of navigating in their day-to-day life* is perceived by 29% as the most difficult challenge for someone who is paralyzed, trailed by *financial challenges* (16%).
  - One-third of women (34%), Baby Boomers (34%) and Gen X (33%) view the mental strain of navigating daily life as most difficult.
- When it comes to air travel, 34% of adults believe the greatest challenge for a paralyzed person is the *inability to use restrooms on the airplane*.



# EXECUTIVE SUMMARY

## Nearly One in Four Adults are Caregivers Themselves

- Twenty-three percent of respondents currently serve as a caregiver, including 18% who care for a family member.
  - Millennials (31%) are the most likely – and Baby Boomers (14%) the least likely – to currently serve as a caregiver.
  - Additionally, Millennials (25%) are much more likely than all other generations to be a caregiver to a family member.
- Three in ten adults (29%) have an immediate family member who currently serves as a caregiver, including 22% who care for another family member.
  - Once again, Millennials (38%) are the most likely – and twice as likely as Baby Boomers (19%) – to have an immediate family member who acts as a caregiver.
  - Twenty-nine percent of Millennials say their immediate family member cares for another member of the family, higher than both Gen X (21%) and Baby Boomers (16%).



# DETAILED FINDINGS

# NOTES ON DETAILED FINDINGS

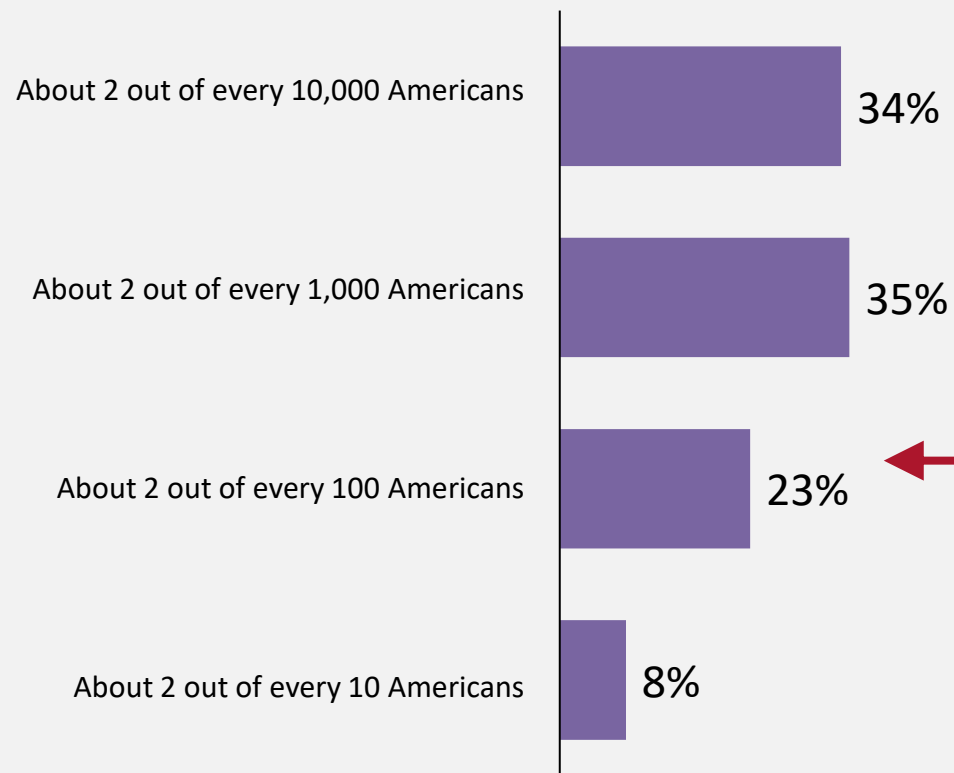
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- ❖ In certain charts in the Detailed Findings section, numbers may not add due to rounding.
  
- ❖ Results among gender, generation, and age subgroups are noted in this report where statistically significant differences exist at the 95% confidence level. Generations are defined as follows:
  - Gen Z, ages 18-25 (N=101)
  - Millennials, ages 26-41 (N=376)
  - Gen X, ages 42-57 (N=228)
  - Baby Boomers, ages 58-76 (N=272)
  
- ❖ The Detailed Findings will also include charts where statistical significance is indicated by upper case letters next to the percentages. These letters correspond to specific demographic subgroups. Using generation results as an example, with (C) for Gen Z, (D) for Millennials, (E) for Gen X, and (F) for Baby Boomers, significant differences among these subgroups will be identified with the appropriate letter. For instance, if the Gen Z percentage is statistically higher than the percentages for Gen X and Baby Boomers, “E” and “F” will appear next to the percentage for Gen Z.

# Number of Americans Living with Paralysis

**HEADLINE: A LARGE MAJORITY OF AMERICANS (69%) UNDERESTIMATE THE PREVALENCE OF THOSE LIVING WITH PARALYSIS IN THE US.**

When asked how many Americans of any age are paralyzed, just under one in four respondents (23%) correctly answered *about 2 out of every 100 Americans*. Roughly seven in ten adults underestimated the number of paralyzed people living in the U.S. at *about 2 out of every 10,000 Americans* (34%) or *about 2 out of every 1,000 Americans* (35%).



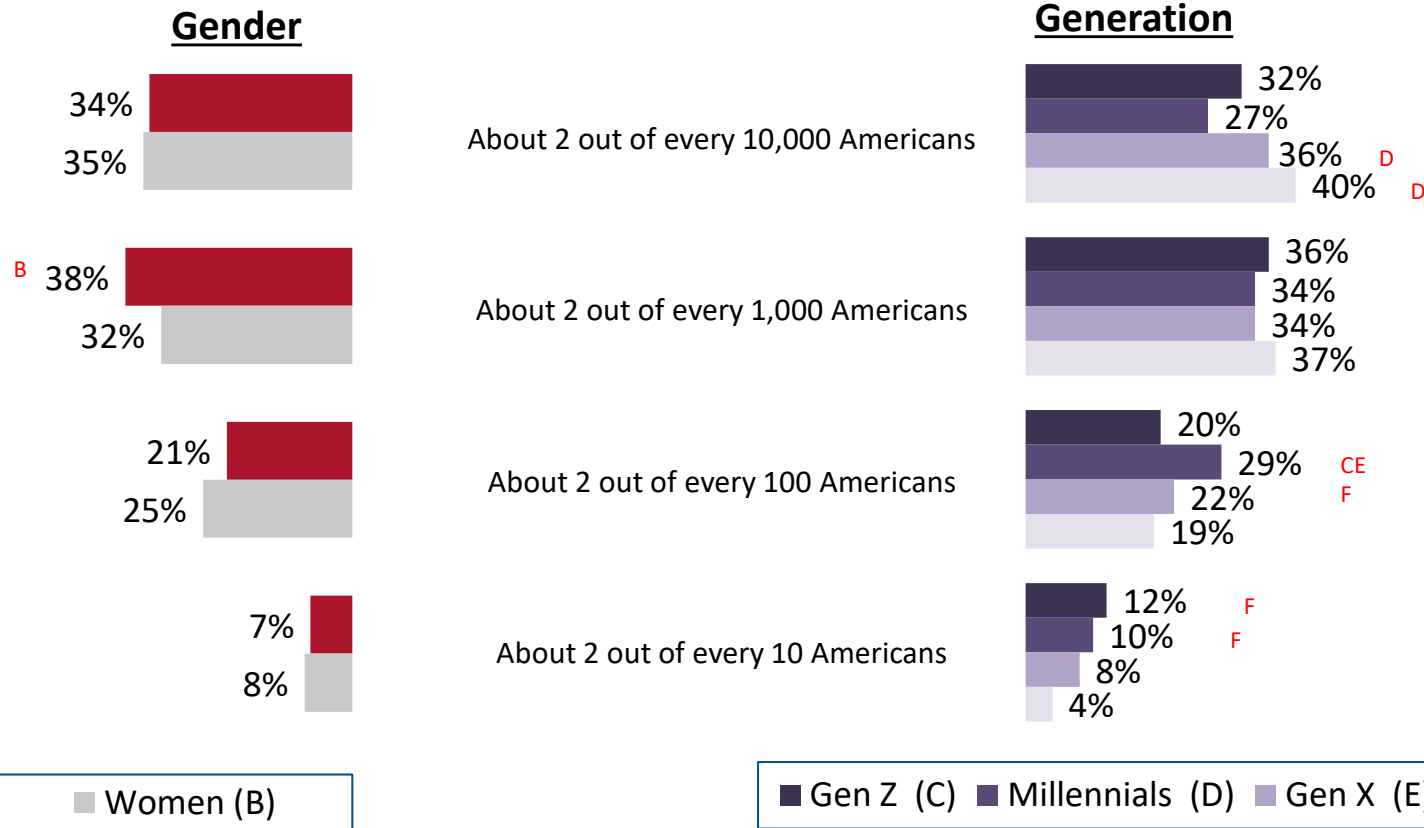
Correct answer (1.7 out of every 100 in America (or 17 per 1,000 live with paralysis\*)



# Number of Americans Living with Paralysis

## HEADLINE: OLDER AGE GROUPS ARE SLIGHTLY MORE LIKELY TO UNDERESTIMATE THE PREVALENCE OF THOSE LIVING WITH PARALYSIS IN THE US

Gen X (36%) and Baby Boomers (40%) are much more inclined than Millennials (27%) to underestimate the number of paralyzed people in the U.S. at *about 2 out of every 10,000 Americans*. This is especially true of adults aged 45-54 (39%) and 65+ (42%). On the other hand, Millennials (29%) are more likely than all other generations to correctly approximate the number of paralyzed U.S. residents at *about 2 out of every 100 Americans*. Those aged 35-44 (31%) are particularly inclined to estimate correctly.



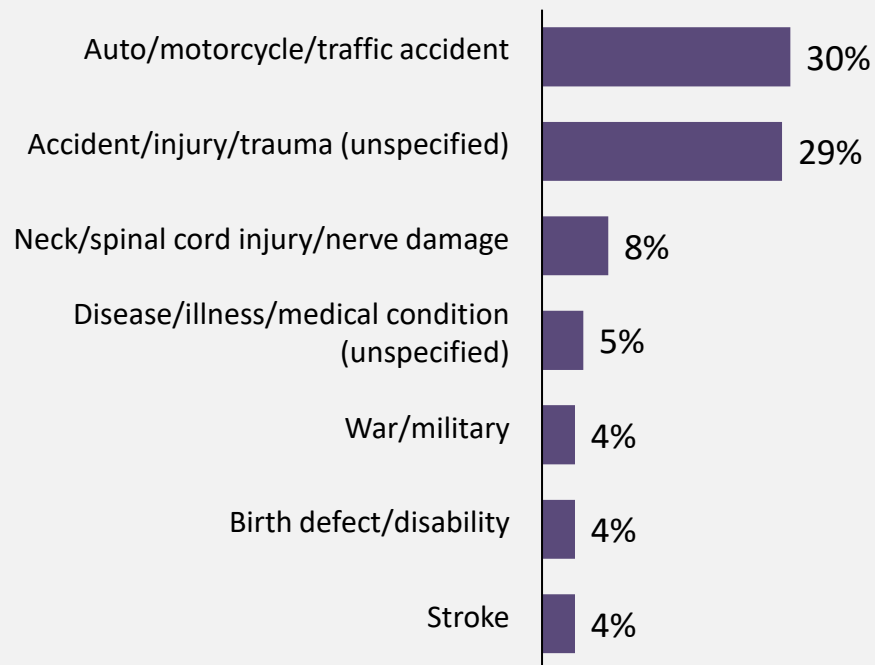
P1. Off the top of your head, which category best represents how many Americans of any age are paralyzed, that is people who are paralyzed from the neck down or from the waist down, rendering their legs incapable of movement and requiring a wheelchair for any mobility?

Base: Men (N=498), Women (N=500), Gen Z (N=101), Millennials (N=376), Gen X (N=228), Baby Boomers (N=272)

# Main Cause of Paralysis in the U.S. – Top Mentions

**HEADLINE:** WHEN AMERICANS THINK OF THOSE IN WHEELCHAIRS AND PARALYZED, THEY ARE LIKELY TO BELIEVE THE MAIN CAUSE IS A CAR ACCIDENT OR GENERAL INJURY, AS OPPOSED TO A DISEASE, WAR, OR BIRTH DEFECT.

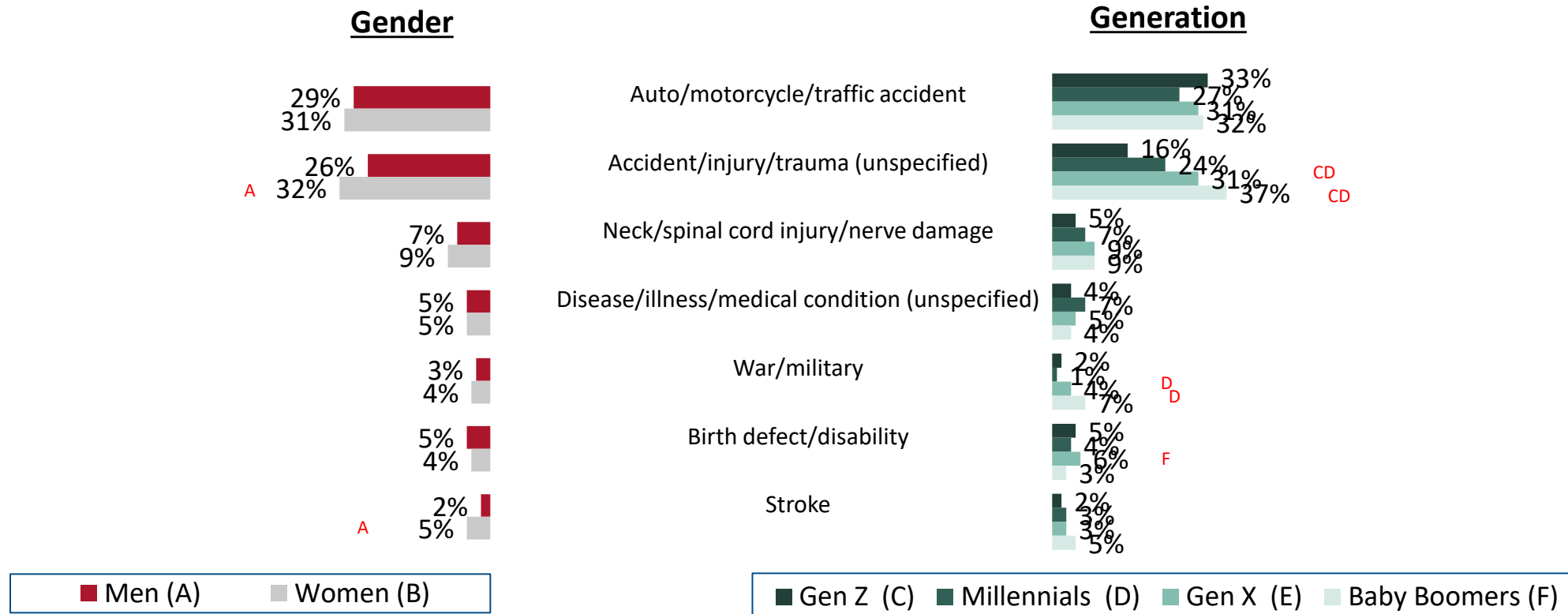
When asked to identify the main cause of paralysis in the U.S. on an unaided basis, respondents were most likely to cite an *auto/motorcycle/traffic accident* (30%) or an unspecified *accident/injury/trauma* (29%). Although mentioned by comparatively fewer adults, other top causes include *neck/spinal cord injury/nerve damage* (8%) and an unspecified *disease/illness/medical condition* (5%).



# Main Cause of Paralysis in the U.S. – Top Mentions

**HEADLINE:** WHEN AMERICANS THINK OF THOSE IN WHEELCHAIRS AND PARALYZED, OLDER AMERICANS ARE MORE LIKELY TO BELIEVE THE MAIN CAUSE IS A GENERAL INJURY. THOUGH FEW AMERICANS THINK OF WAR AS THE CAUSE, THE OLDER GENERATION IS MORE LIKELY TO COMPARED TO YOUNGER AMERICANS.

Baby Boomers (37%) and Gen X (31%) are more likely to name an unspecified *accident/injury/trauma* as the main cause of paralysis in the U.S. compared to Millennials (24%) and particularly Gen Z (16%). Those aged 65+ (40%) are the most likely of all age groups to view an unspecified *accident/injury/trauma* as the primary cause of paralysis.

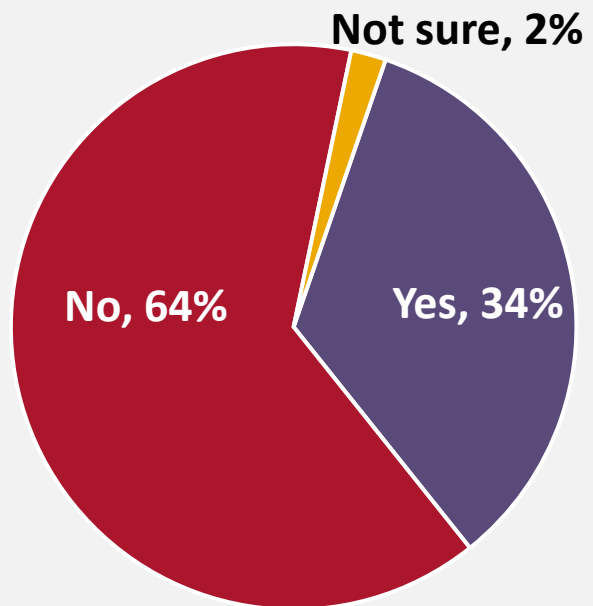




# Know Someone who is Paralyzed

**HEADLINE:** ABOUT 1/3 OF AMERICANS KNOW SOMEONE LIVING WITH PARALYSIS.

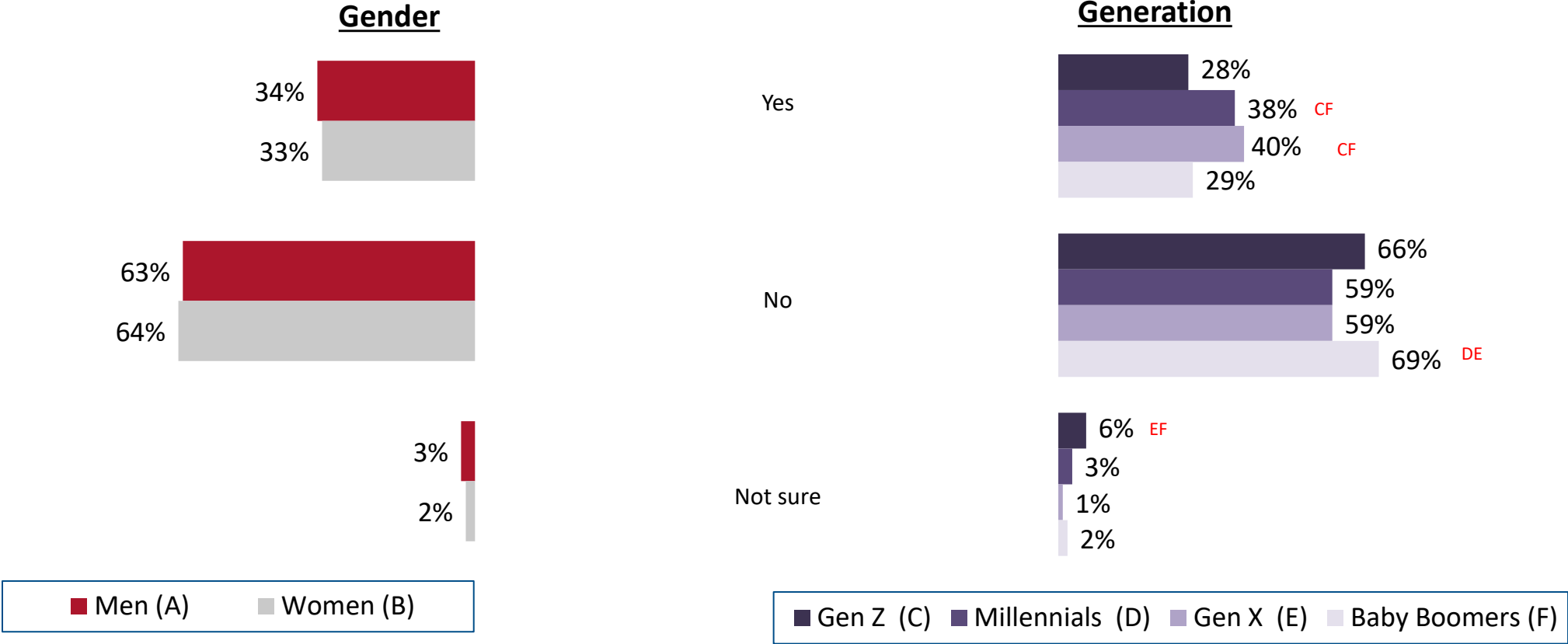
One-third (34%) of Americans know someone who is paralyzed and using a wheelchair for mobility.





# Know Someone who is Paralyzed

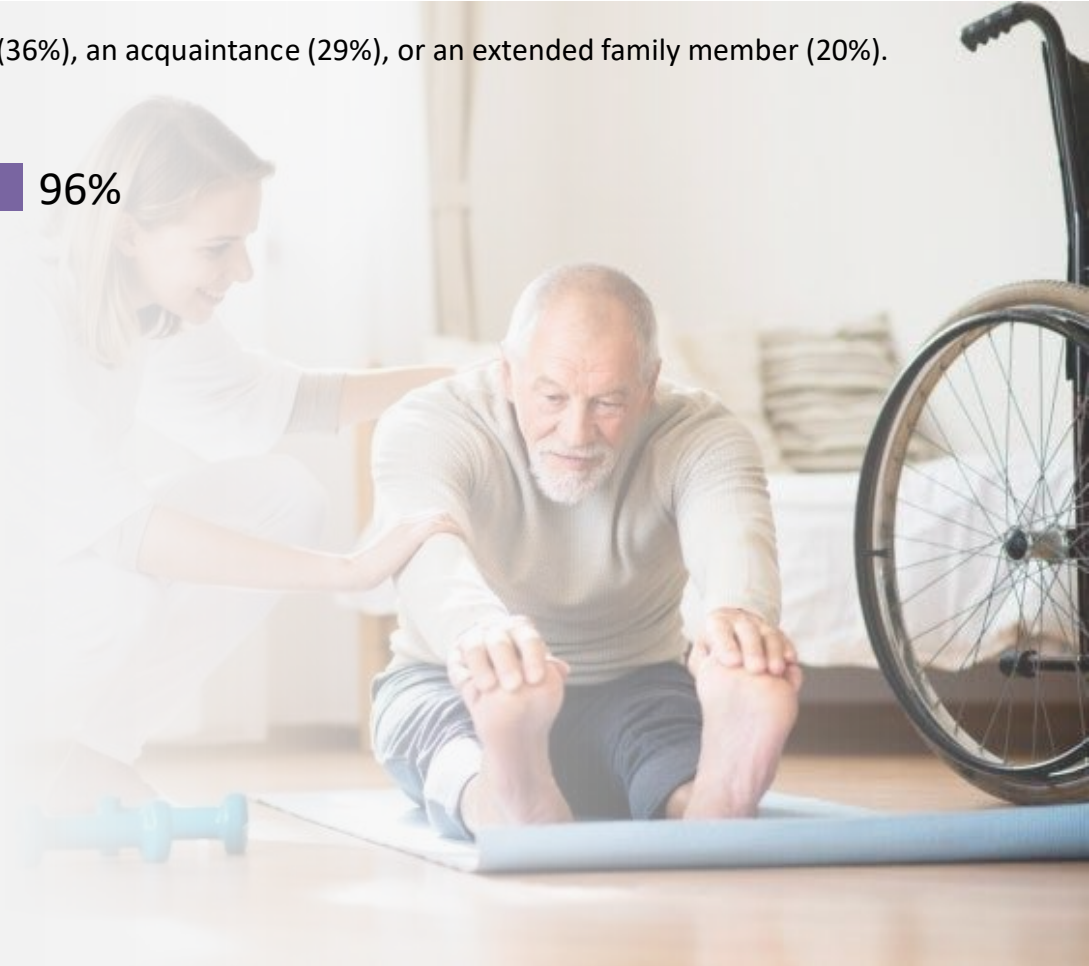
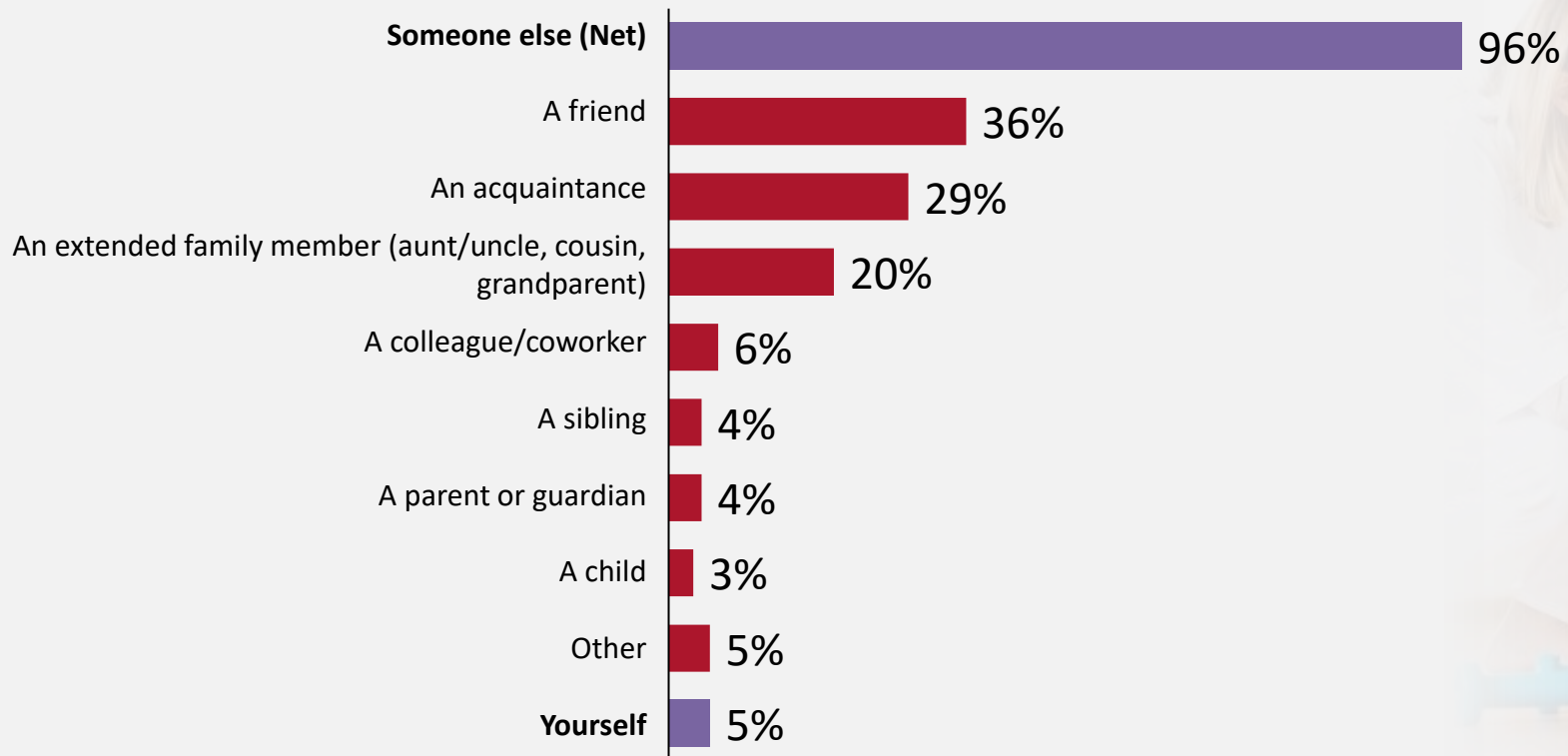
While there are no differences by gender, Millennials (38%) and Gen X (40%) are more likely than Gen Z (28%) and Baby Boomers (29%) to know someone who is paralyzed and using a wheelchair for mobility.



# Relationship of Paralyzed Person to Self

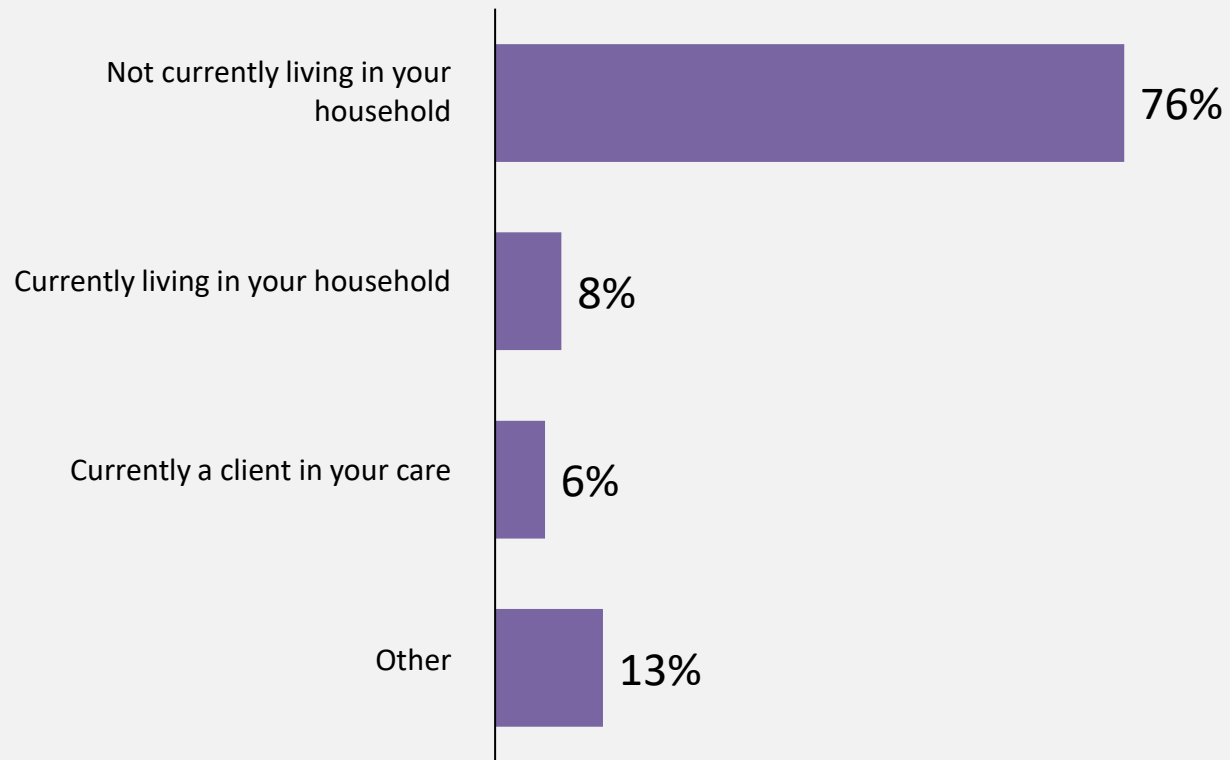
**HEADLINE: IF AMERICAN KNOW SOMEONE WHO IS LIVING WITH PARALYSIS, IT'S TYPICALLY A FRIEND OR ACQUAINTANCE (65%) AS OPPOSED TO A RELATIVE OR COLLEAGUE**

In most cases, the relationship of the paralyzed person to the respondent is best described as a friend (36%), an acquaintance (29%), or an extended family member (20%). Five percent of respondents identified themselves as paralyzed.



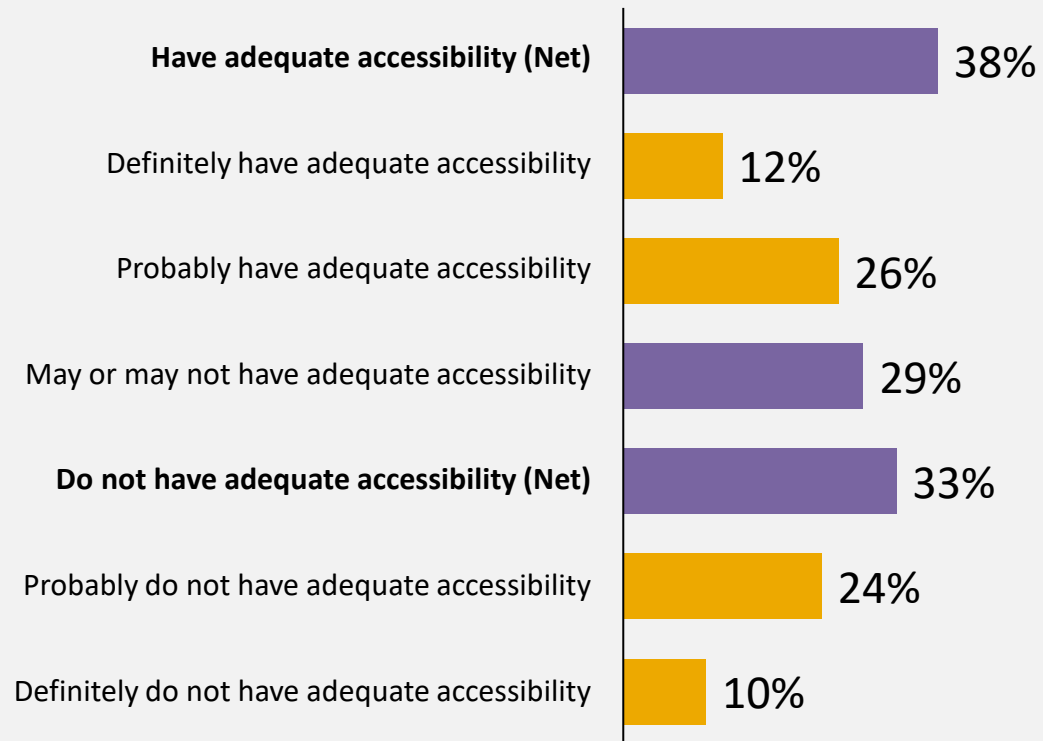
# Situation in Relation to Paralyzed Person

Three in four adults (76%) do not live in the same household as the paralyzed person/people they know. Just 8% share the same household, while 6% currently have a paralyzed client in their care.



# Adequate Accessibility Within Businesses Across U.S.

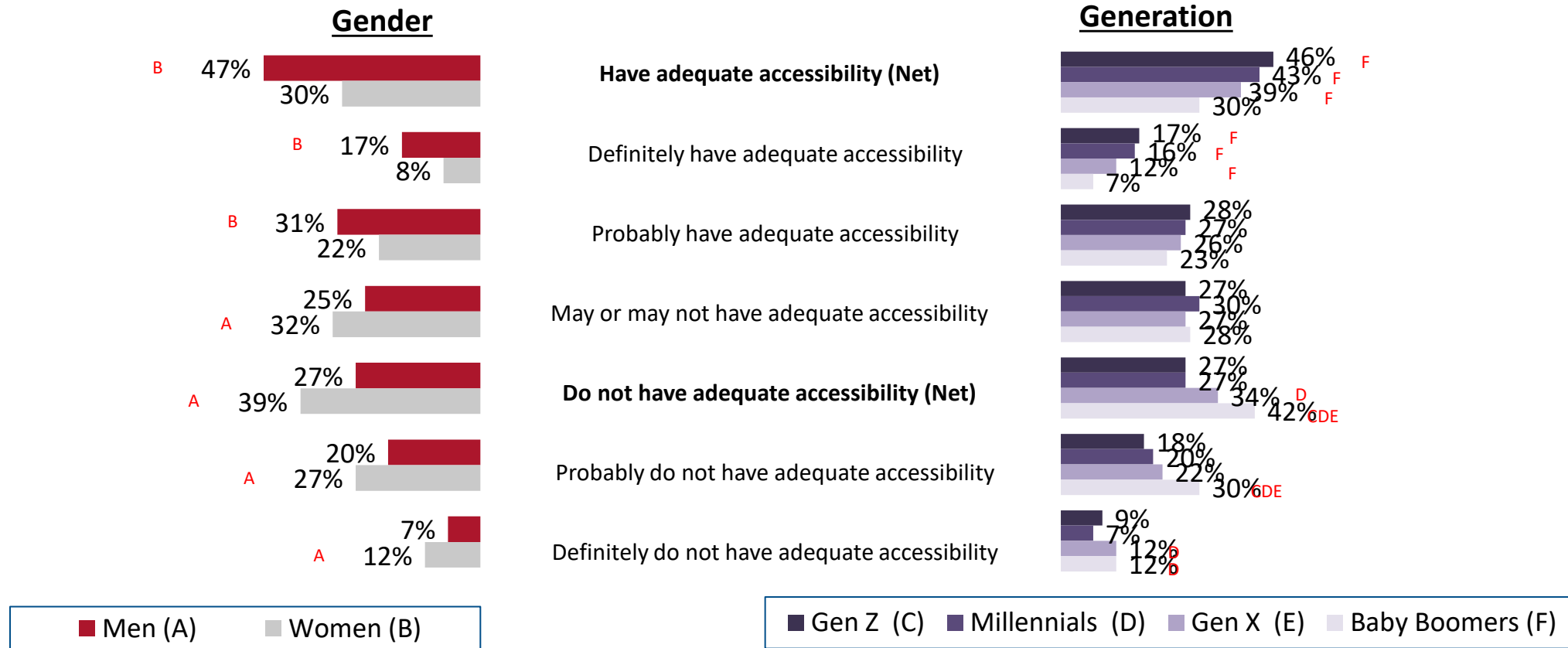
When asked if mobility-impaired wheelchair users have adequate accessibility within businesses across the U.S., respondents were divided in their views. Nearly two in five (38%) feel they definitely or probably have sufficient accessibility, while one-third (33%) believe they do not. Another 29% take a neutral stance.



# Adequate Accessibility Within Businesses Across U.S.

**HEADLINE:** YOUNGER GENERATIONS ARE MORE LIKELY TO SAY THERE IS ADEQUATE ACCESSIBILITY THAN OLDER GENERATIONS.

Men (47%) are more inclined than women (30%) to think those who are mobility-impaired wheelchair users have adequate accessibility within businesses across the U.S. This opinion is also more common among Gen Z (46%), Millennials (43%), and Gen X (39%) versus Baby Boomers (30%). When viewed by age groups, nearly half (48%) of adults aged 35-44 feel wheelchair users have adequate accessibility, compared to just 29% of those aged 55-64 and one-third (33%) of those aged 65+.

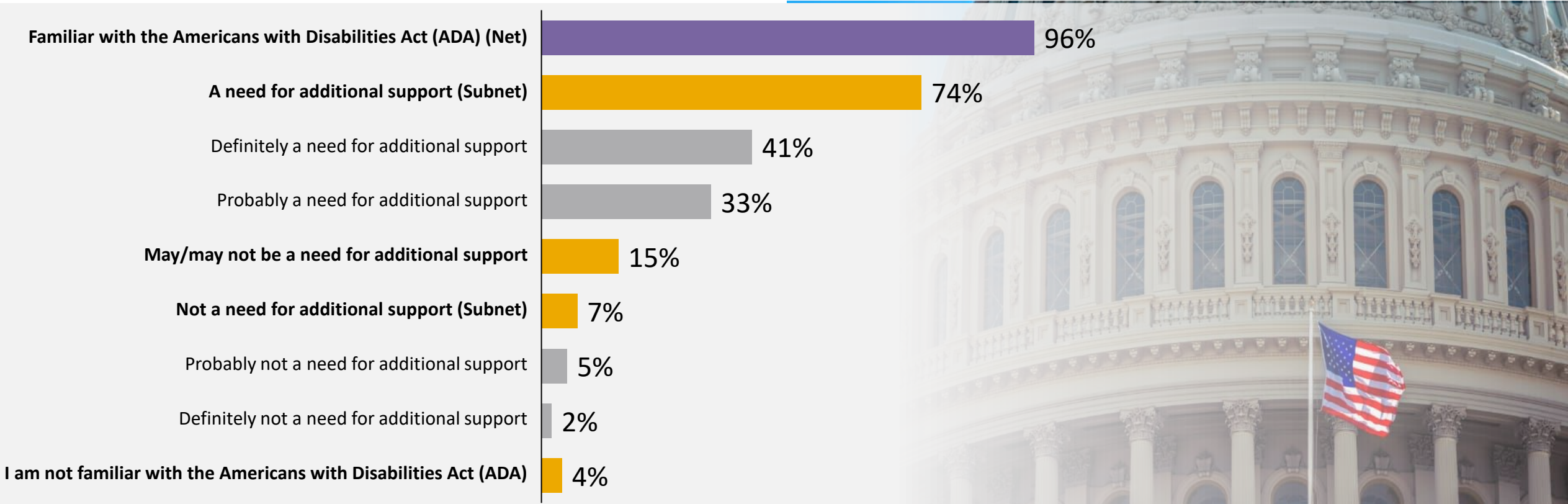




# Need for Additional Support from U.S. Government Beyond ADA

**HEADLINE:** NEARLY ALL AMERICANS ARE FAMILIAR WITH THE ADA (96%), OF THOSE, OF THOSE MOST (74%) BELIEVE THERE IS A NEED FOR ADDITIONAL SUPPORT FROM THE US GOVERNMENT FOR WHEELCHAIR USERS BEYOND THE ADA.

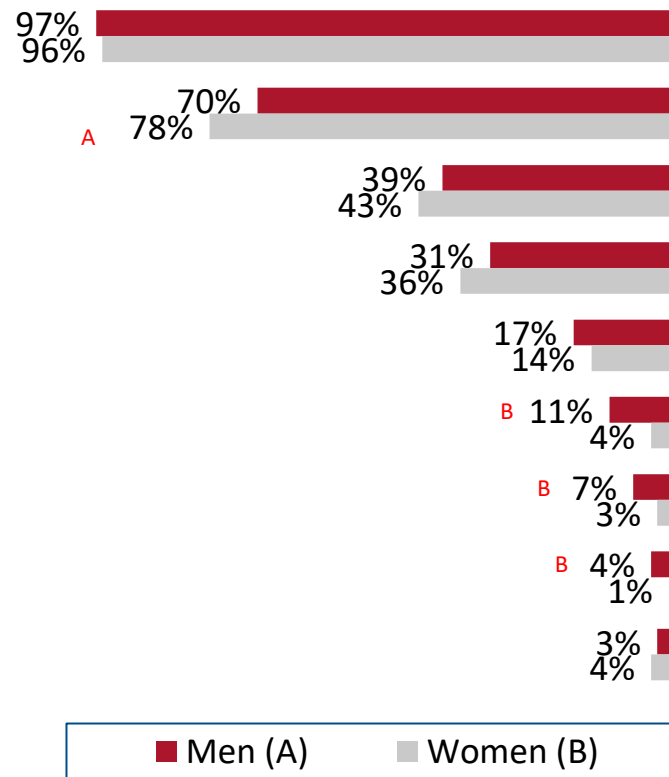
Nearly all Americans (96%) are familiar with the Americans with Disabilities Act (ADA), and three in four (74%) believe there is a need for additional support from the U.S. government for wheelchair users beyond the ADA.



# Need for Additional Support from U.S. Government Beyond ADA

Women (78%) are slightly more likely than men (70%) to believe there is a need for additional support from the U.S. government for wheelchair users beyond the ADA. Across generations, Gen X (79%) is the most inclined to feel additional government support is necessary, more so than Gen Z (69%) and Millennials (72%). By age, this belief is most common among adults aged 55-64 (82%), and least common among their counterparts aged 18-34 (69%) and 65+ (70%).

## Gender



## Generation

### Familiar with the Americans with Disabilities Act (ADA) (Net)

#### A need for additional support (Subnet)

Definitely a need for additional support

Probably a need for additional support

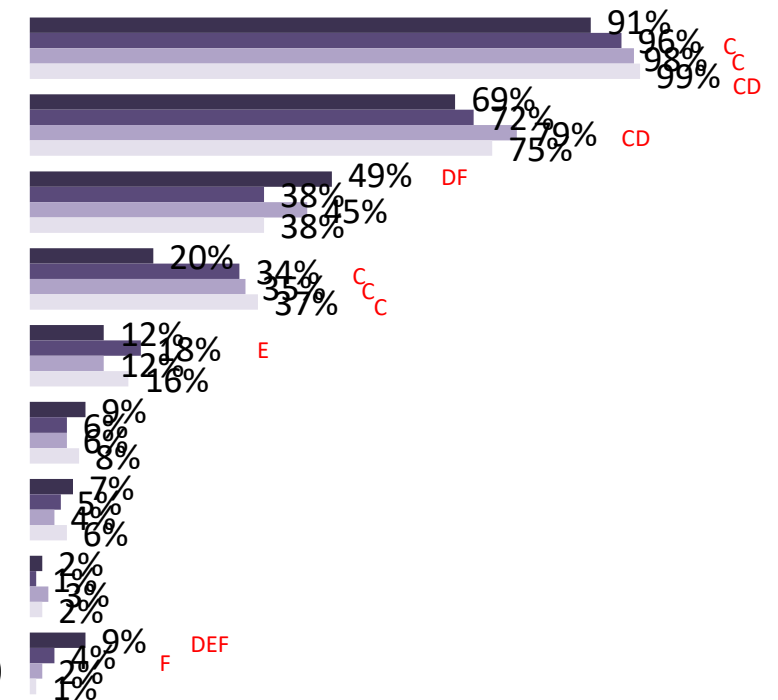
#### May/may not be a need for additional support

#### Not a need for additional support (Subnet)

Probably not a need for additional support

Definitely not a need for additional support

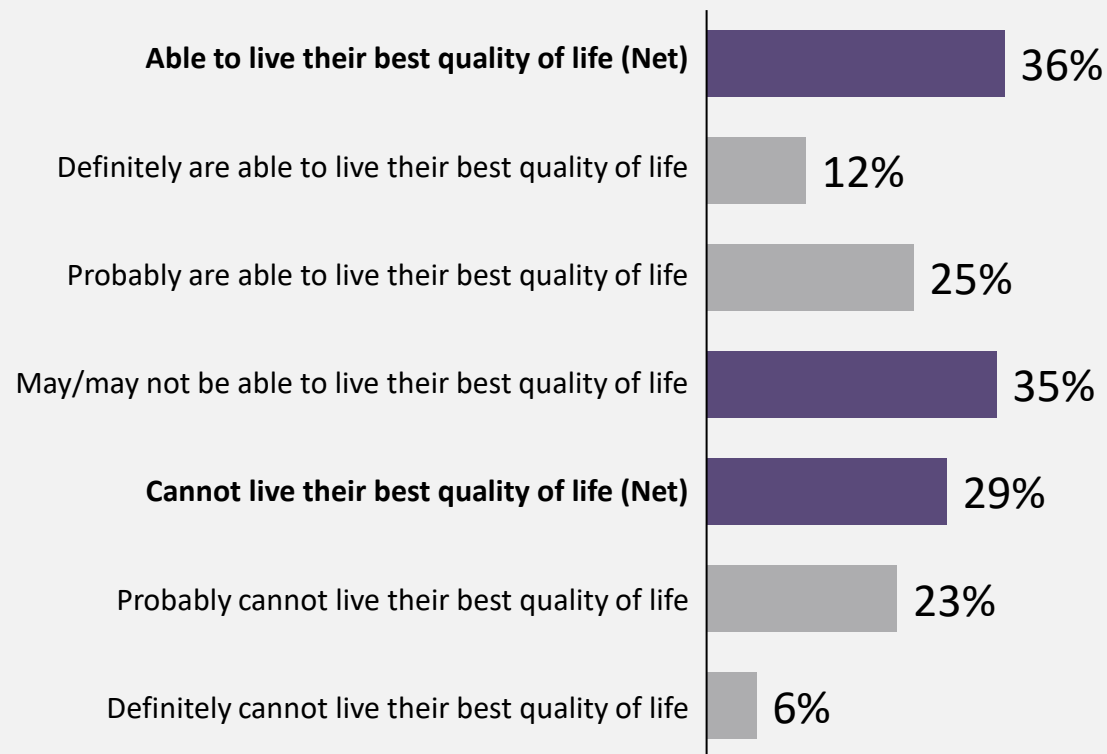
#### I am not familiar with the Americans with Disabilities Act (ADA)



# Ability of Wheelchair Users in U.S. to Live Best Quality of Life

Overall, the general population cannot come to a consensus on this concept of living the best quality of life.

At this point in time, just over one-third (36%) of adults think wheelchair users in the U.S. are able to live their best quality of life. A neutral view is expressed by an equal proportion (35%) of respondents, while 29% feel wheelchair users probably or definitely **cannot** live their best quality of life.

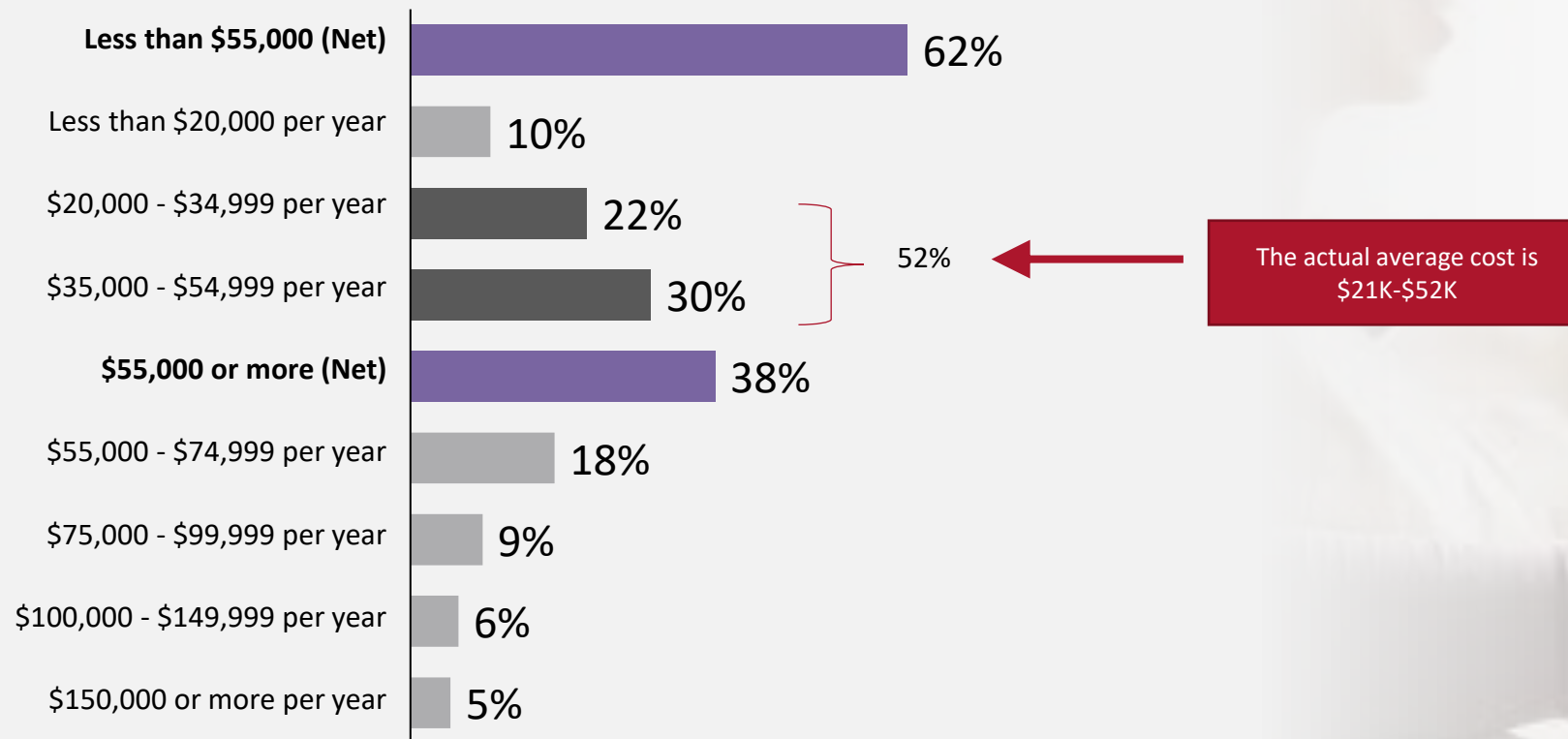




# Average Cost for Full-time Professional Caregiver of Paralyzed Person

**HEADLINE:** A MAJORITY OF AMERICANS (62%) BELIEVE THE AVERAGE COST OF A FULL-TIME PROFESSIONAL CAREGIVER FOR SOMEONE WHO IS PARALYZED AND REQUIRES A WHEELCHAIR IS UNDER \$55K (GENERALLY BETWEEN \$20K AND \$55K).

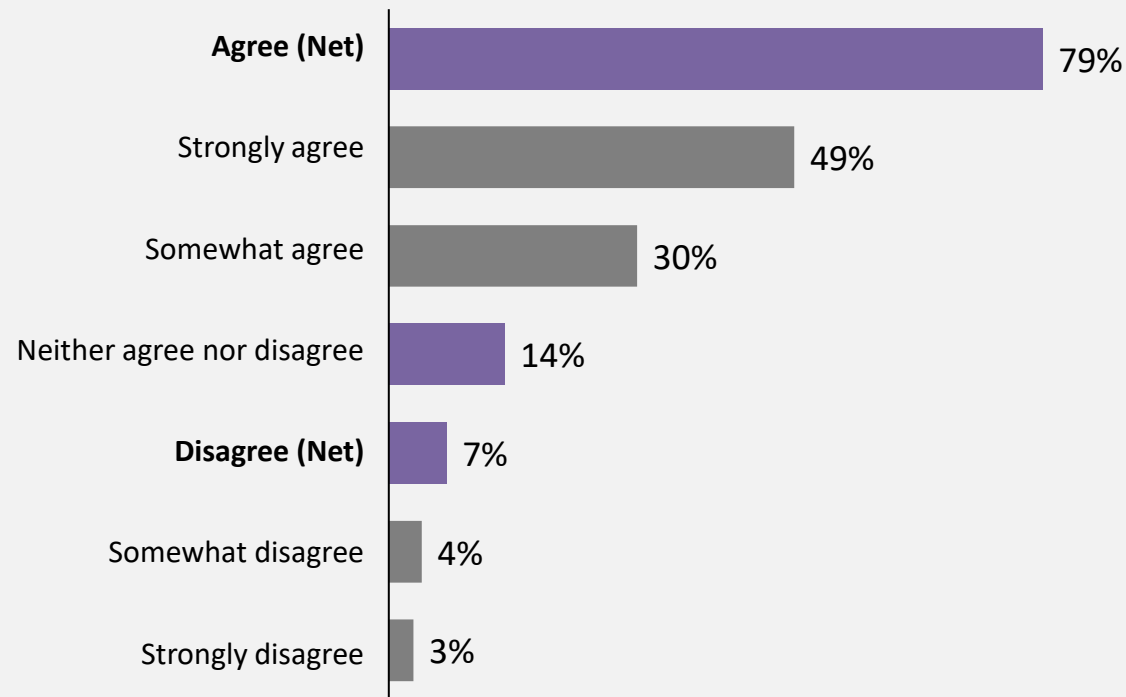
Over three in five Americans (62%) think it costs less than \$55,000 per year, on average, for a full-time professional caregiver of someone who is paralyzed and requires a wheelchair. More than half (52%) of adults estimate the annual cost to be in the range of \$20,000 - \$54,999.



# Government Compensation for Family Member Providing Long-term Care

**HEADLINE: MOST AMERICANS (79%) BELIEVE THAT A FAMILY MEMBER PROVIDING LONG-TERM CARE FOR SOMEONE WHO IS PARALYZED SHOULD HAVE SOME FORM OF COMPENSATION FROM THE GOVT.**

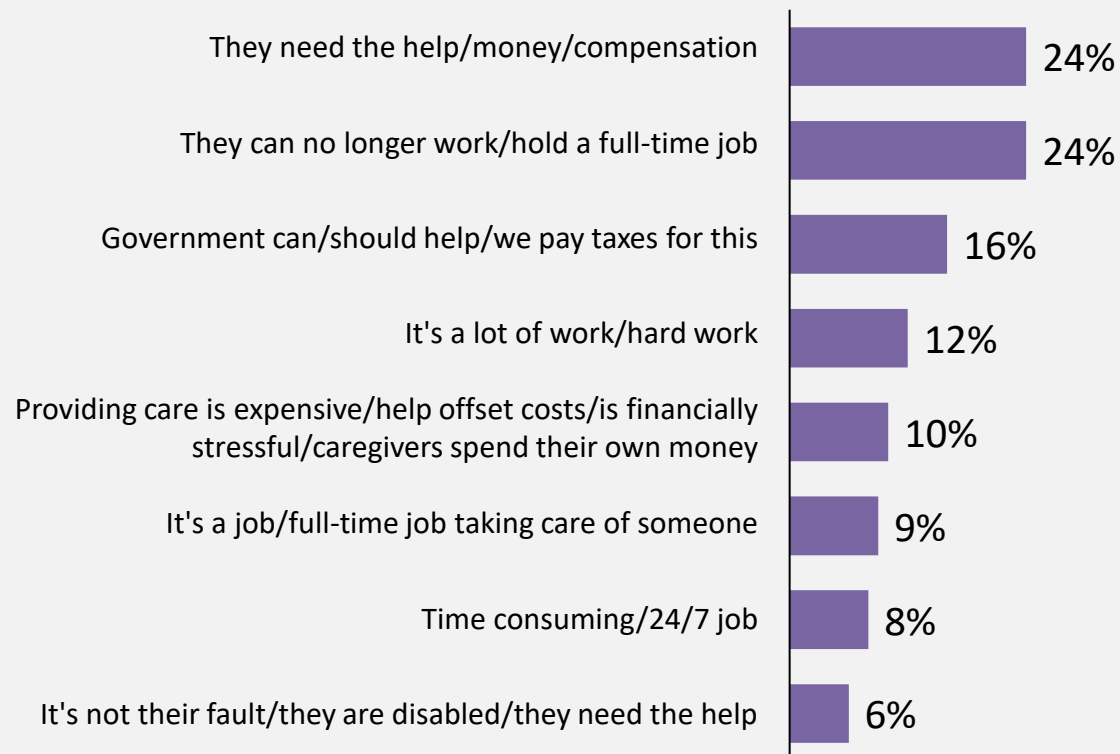
Most Americans (79%) agree there should be some form of compensation from the government for a family member who is providing long-term care for someone who is paralyzed, including half (49%) who **strongly** agree. Only 7% disagree with this type of government compensation.



# Reasons for Agreement with Government Compensation – Top Mentions

**HEADLINE:** HALF OF THOSE WHO AGREE WITH GOV'T COMPENSATION BELIEVE THE FAMILY MEMBER NEEDS THE FINANCIAL HELP AND/OR CAN NO LONG WORK/HOLD FULL TIME JOB.

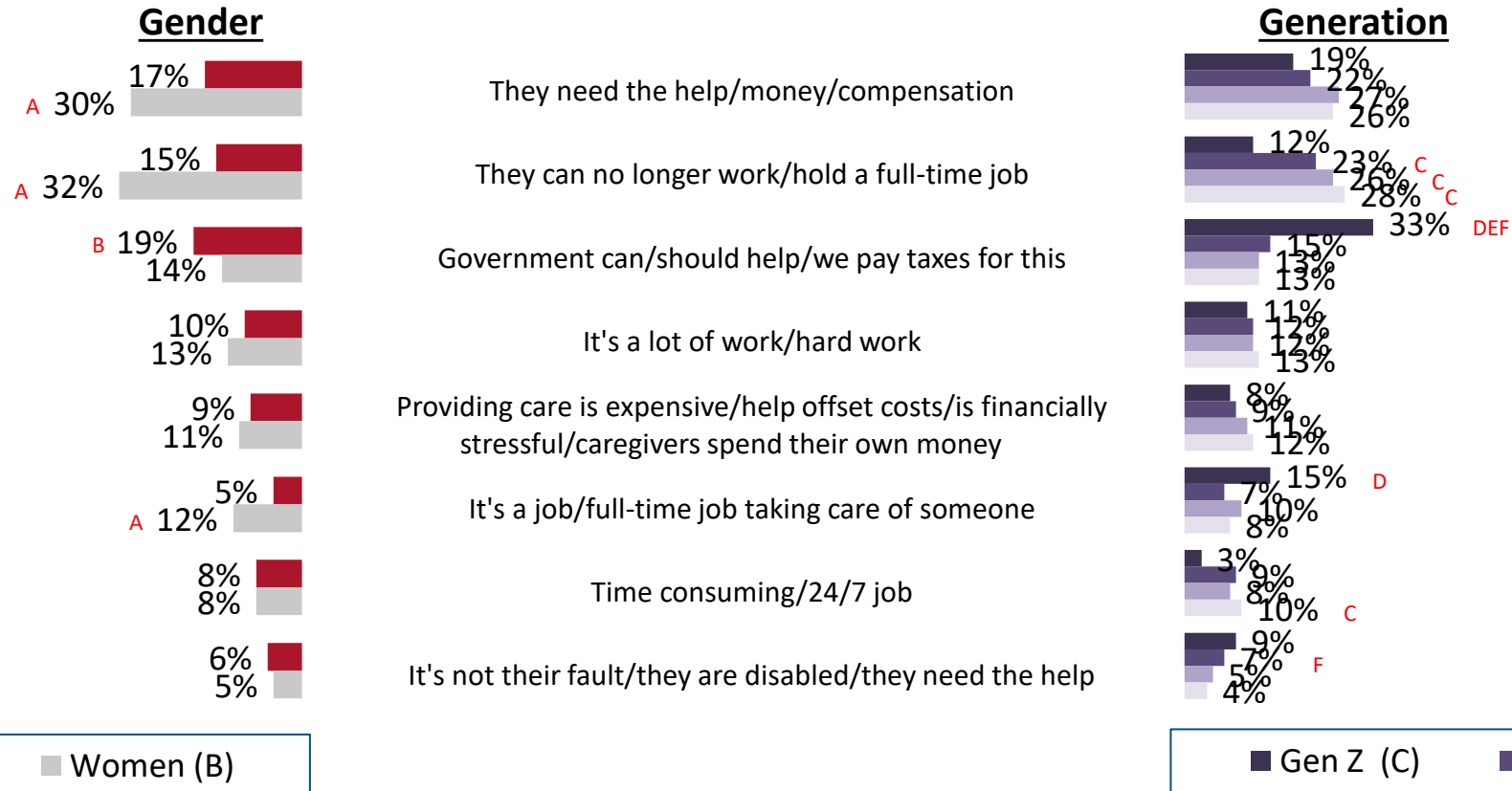
Those who agree the government should provide some form of compensation to family members providing long-term care for someone who is paralyzed are most likely to cite the following as reasons: *they need the help/money/compensation (24%); they can no longer work/hold a full-time job (24%); and/or government can/should help/we pay taxes for this (16%).*



# Reasons for Agreement with Government Compensation – Top Mentions

**HEADLINE:** ON COMPENSATION REASONS, WOMEN ARE MORE LIKELY TO BE CONCERNED ABOUT THE NEED FOR MONEY/INCOME FROM A JOB, GEN Z IS TWICE AS LIKELY THAN OTHER GENERATIONS (33% VS. ABOUT 15%) TO BELIEVE THAT THE GOV'T CAN/SHOULD FINANCIALLY HELP.

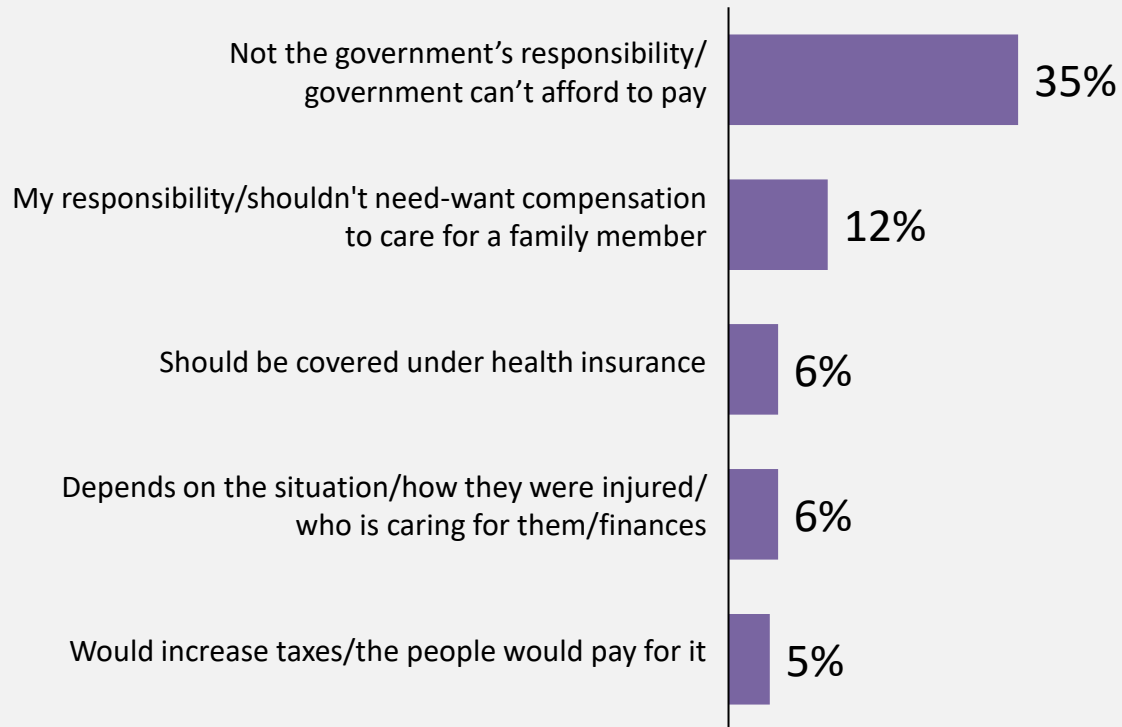
Among those who agree the government should provide compensation to family members providing long-term care for someone who is paralyzed, women are more inclined than men to mention the following as reasons: *they need the help/money/compensation* (30% vs. 17%); *they can no longer work/hold a full-time job* (32% vs. 15%); and *it's a job/full-time job taking care of someone* (12% vs. 5%). Across generations, Millennials (23%), Gen X (26%), and Baby Boomers (28%) are more likely than Gen Z (12%) to feel family members providing long-term care *can no longer work/hold a full-time job*. In contrast, Gen Z (33%) is over twice as likely as all other generations to believe the *government can/should help/we pay taxes for this*.



# Reasons for Disagreement with Government Compensation – Top Mentions

**Summary:** For those that disagree with gov't compensation, 35%-40% believe the gov't shouldn't be obligated and a few saying it would increase taxes.

While relatively few Americans disagree that the government should provide some form of compensation to family members providing long-term care for someone who is paralyzed, those who do are most likely to express the belief that it is *not the government's responsibility/government can only help/pay so much* (35%). Along these same lines, 12% feel it is *their responsibility/they shouldn't need/want compensation to care for a family member*.

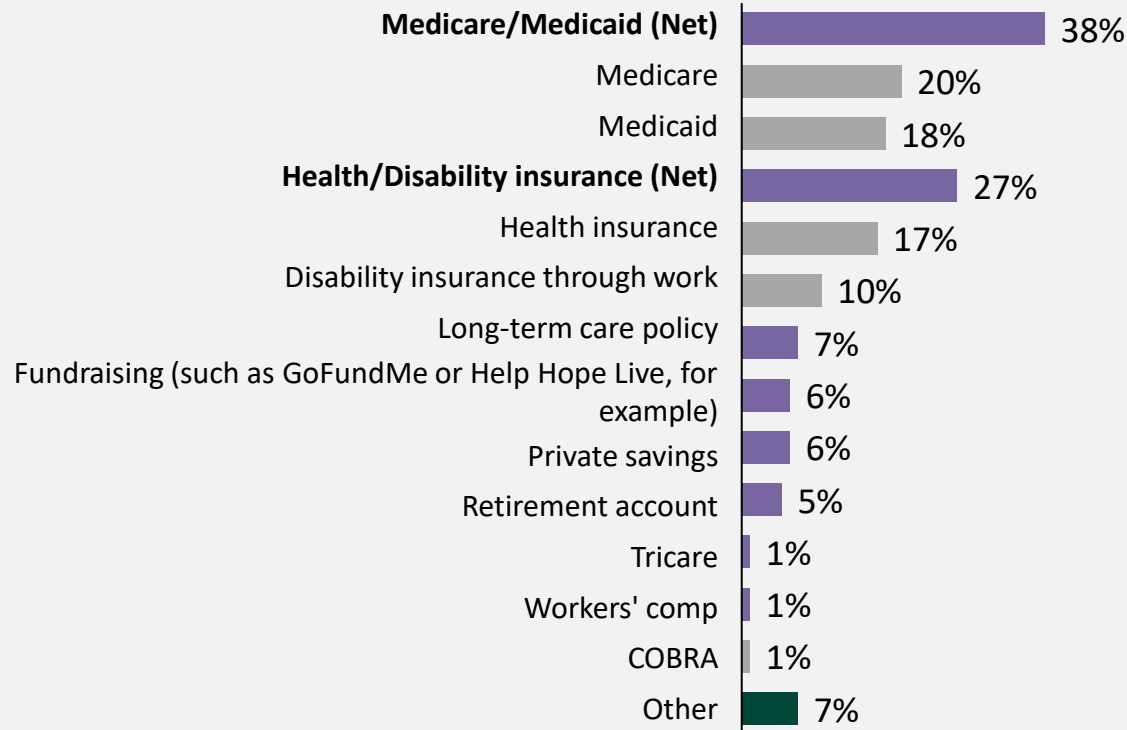


# Main Source of Funds to Cover Daily Living Costs if Paralyzed

**Summary:** Most believe that some form of insurance (Medicare/Medicaid), or health/disability insurance would be the main source of funds to cover the cost of day-to-day living.

If they were to become paralyzed and unable to care for themselves independently, many respondents say their main source of funds to cover the daily cost of living would be either *Medicare* (20%), *Medicaid* (18%), *health insurance* (17%), or *disability insurance through work* (10%).

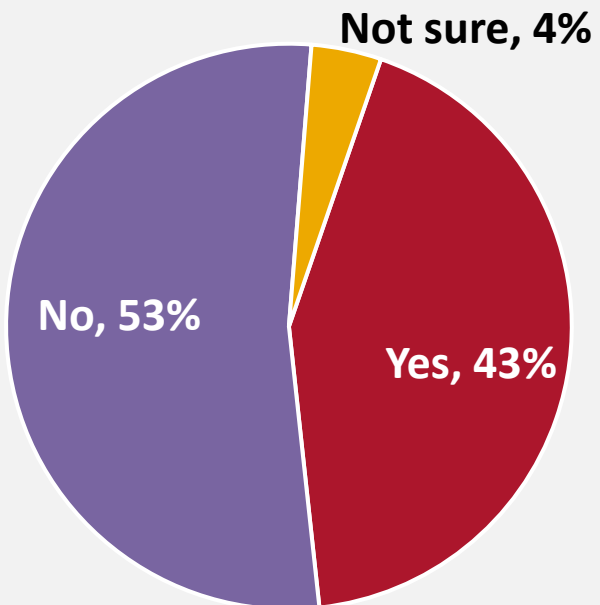
Not surprisingly, those aged 65+ (48%) are four times as likely as their younger counterparts aged 18-64 (12%) to say they would rely on *Medicare*. The opposite is true when it comes to *Medicaid* (**21%** 18-64 vs. **8%** 65+) and *health/disability insurance* (**31%** 18-64 vs. **12%** 65+). Additionally, younger respondents aged 18-34 (12%) are the most inclined to think *fundraising* would be their main source of funds.





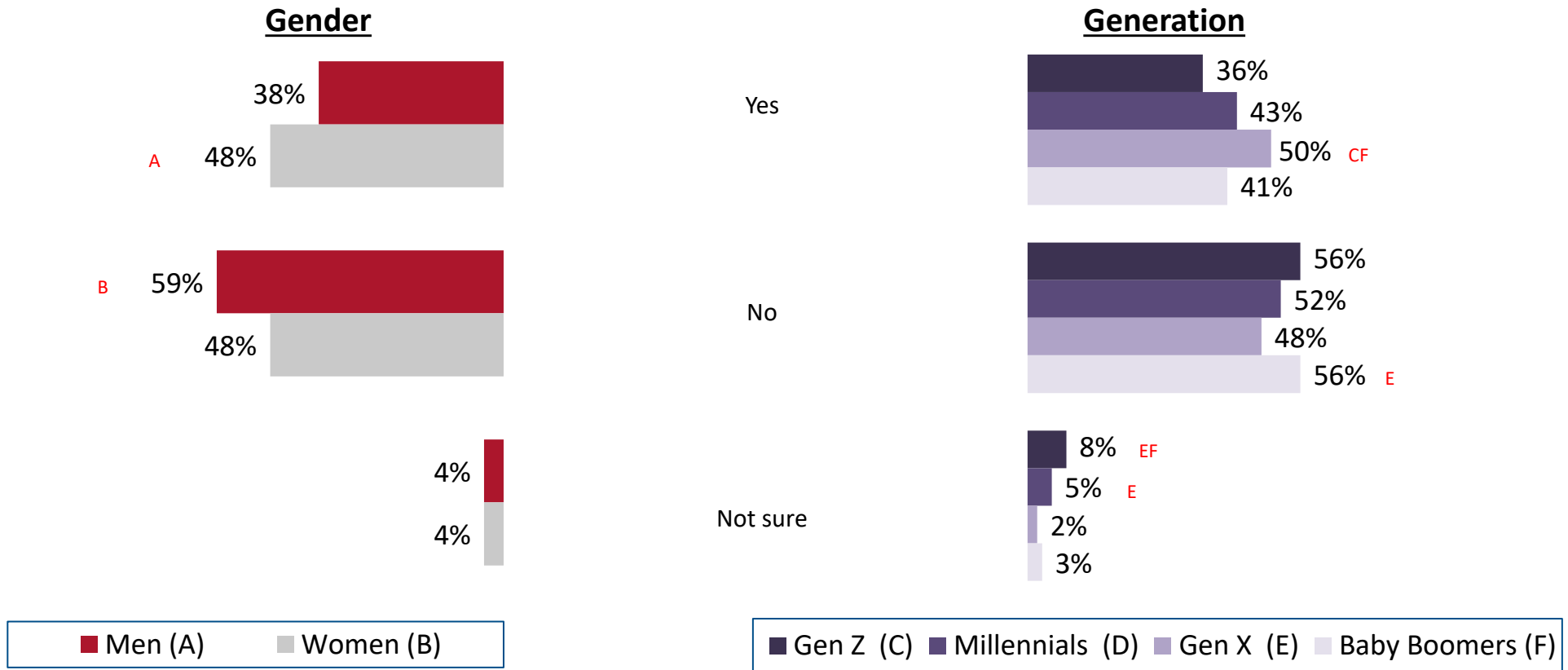
# Know a Caregiver to Sick, Elderly, or Disabled Person

Overall, 43% in American know someone who is a caregiver regularly caring for a sick, elderly, or disabled person.



# Know a Caregiver to Sick, Elderly, or Disabled Person

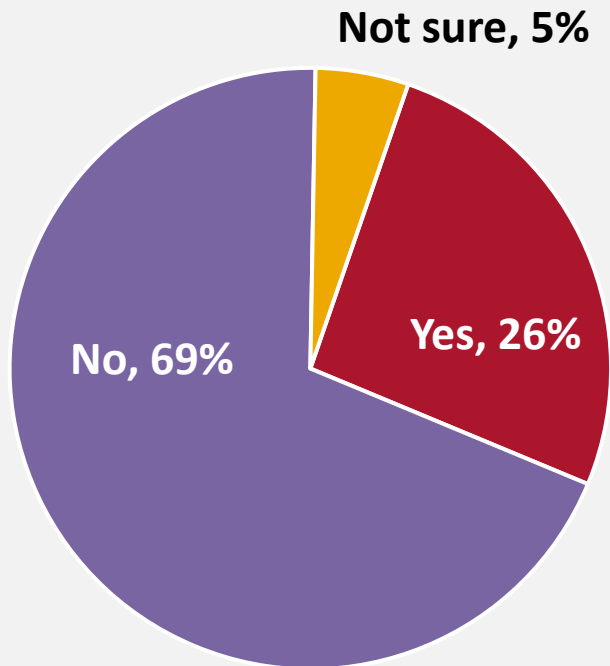
Women (48%) are more likely than men (38%) to know someone who is a caregiver to a sick, elderly, or disabled person. Additionally, one in two Gen Xers (50%) know a caregiver, compared to just 36% of Gen Z and 41% of Baby Boomers.





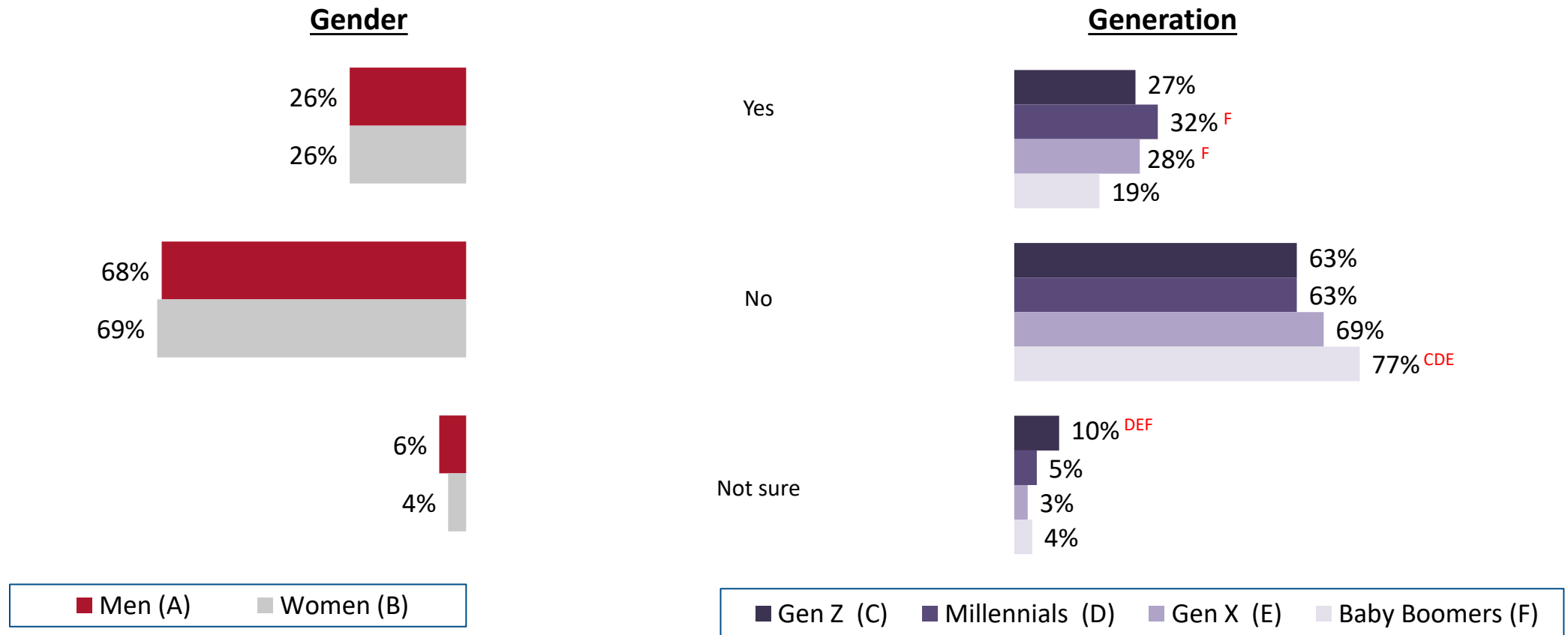
# Know a Caregiver to Paralyzed Person

One in four Americans (26%) know someone who is a caregiver to a person that is paralyzed and requires a wheelchair. Many Americans (69%) do not know a caregiver to someone who is paralyzed



# Know a Caregiver to Paralyzed Person

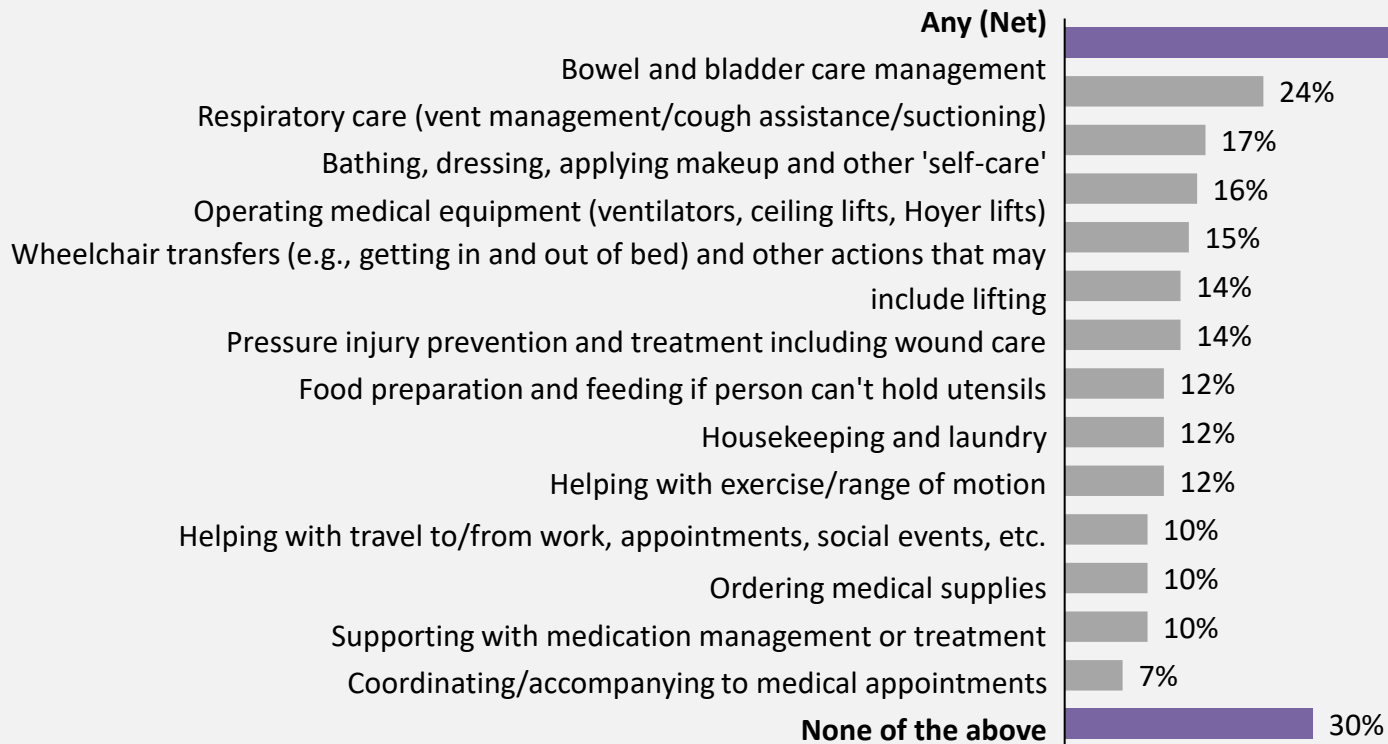
While there are no differences by gender, Baby Boomers at 77% are less likely to know someone who is a caregiver compared to GenZ/Millennials (63%) and Gen X (69%)



# Most Surprising Caregiver Roles

**Summary:** The most common caregiver role that was a surprise to Americans was care management of bowel and bladder at 24%. About 1/3 of Americans (30%) were not surprised concerning any of these duties.

- When presented with a list of caregiver responsibilities, 70% of Americans expressed surprise at one or more, with *bowel and bladder care management* (24%) topping the list of “most surprising” roles. Ranking second is *respiratory care* (17%), followed closely by *bathing, dressing, applying makeup and other ‘self care’* (16%).
- Men (75%) and adults aged 18-44 (74%) are the most likely to express surprise at any of these caregiver roles.

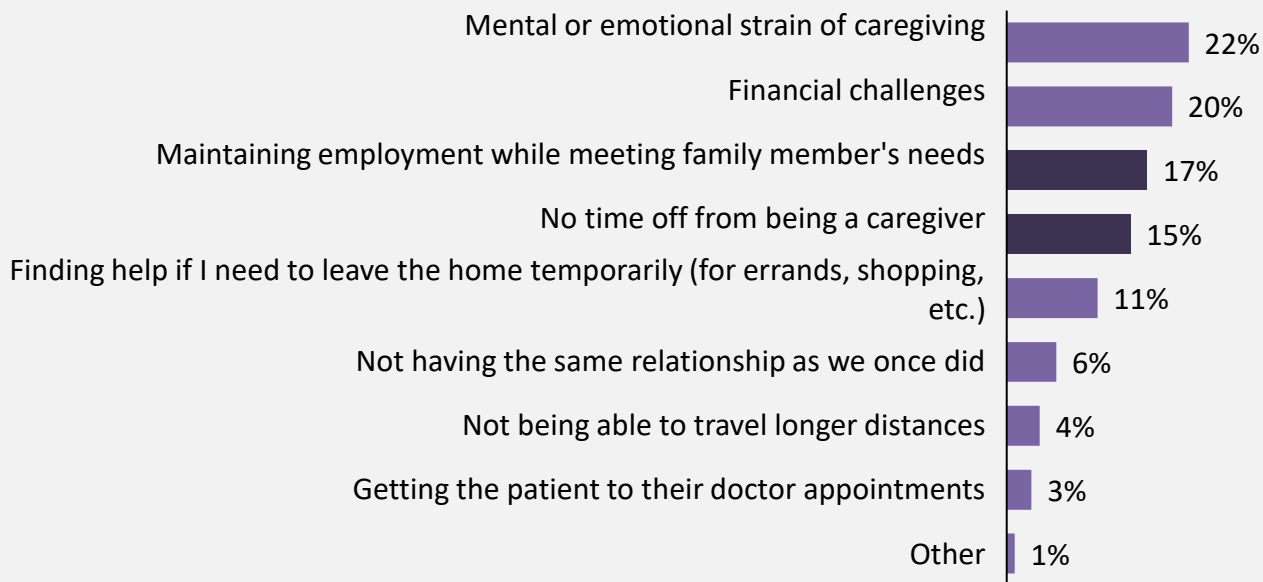


# Most Challenging Aspects of Full-time, In-home Caregiving

- 32% are citing reasons concerning their ability to handle the time needed (maintaining employment, no time off)
- 20% are most concerned with finances
- 22% are most concerned with the mental strain in general

If the respondent were responsible for someone who needed full time, in-home caregiving, 22% believe the *mental or emotional strain of caregiving* would be the most challenging aspect. Nearly as many (20%) cite *financial challenges*, while 17% feel the greatest challenge would be *maintaining employment while meeting family member's needs*.

Women (25%) are more inclined than men (19%) to believe the *mental or emotional strain of caregiving* is most challenging. Among age groups, adults aged 65+ (23%) are more likely than their younger counterparts aged 18-64 (13%) to view *no time off from being a caregiver* as the most difficult aspect.

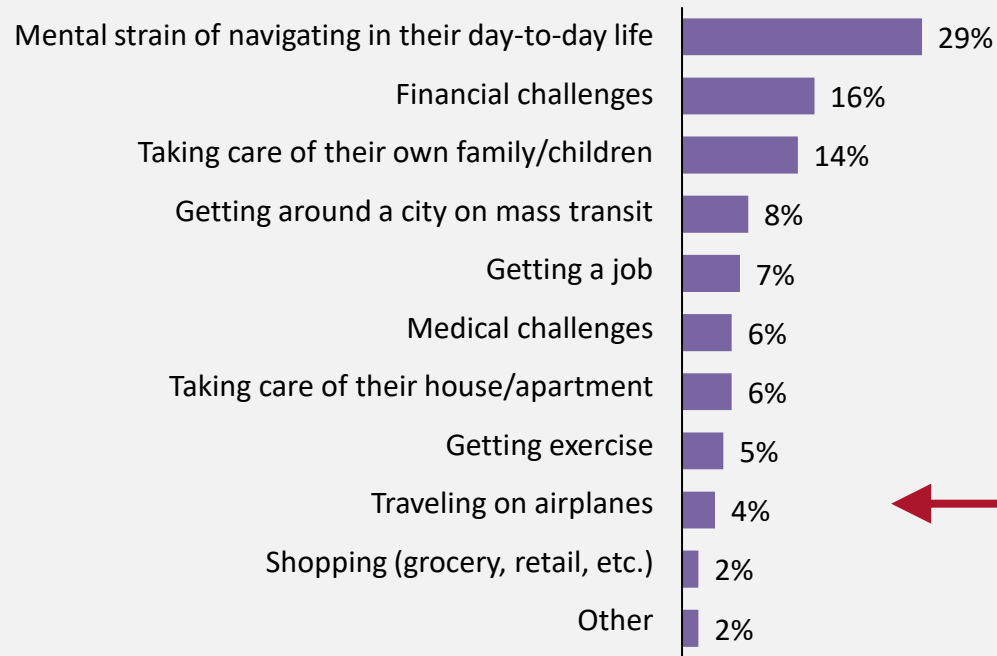


# Most Difficult Challenges for Paralyzed Person

**SUMMARY:** MOST AMERICANS DO NOT CHOOSE TRAVELING ON AIRPLANES AS ONE OF THE MORE DIFFICULT CHALLENGES IN LIFE. (THIS INDICATES AMERICANS EITHER DON'T BELIEVE THAT IT IS, DON'T BELIEVE IT IS AS NECESSARY AS THE OTHER ITEMS, OR HAVEN'T THOUGHT ABOUT IT)

The challenge perceived to be most difficult for someone who is paralyzed and using a wheelchair is the *mental strain of navigating in their day-to-day life*, chosen by 29% of respondents. *Financial challenges* ranks a distant second at 16%, with *taking care of their own family/children* ranking a close third (14%).

One-third (34%) of women believe the *mental strain of navigating in their day-to-day life* is most difficult for someone who is paralyzed, higher than the 23% of men who feel the same. This is also true of Baby Boomers (34%) and Gen X (33%) versus Millennials (20%) and Gen Z (23%). Additionally, Baby Boomers (21%) are the most likely of all generations to perceive *financial challenges* as most difficult, while *getting a job* is more commonly viewed as the top challenge by Gen Z (16%).



Only 4% chose traveling on airplanes as being the most difficult



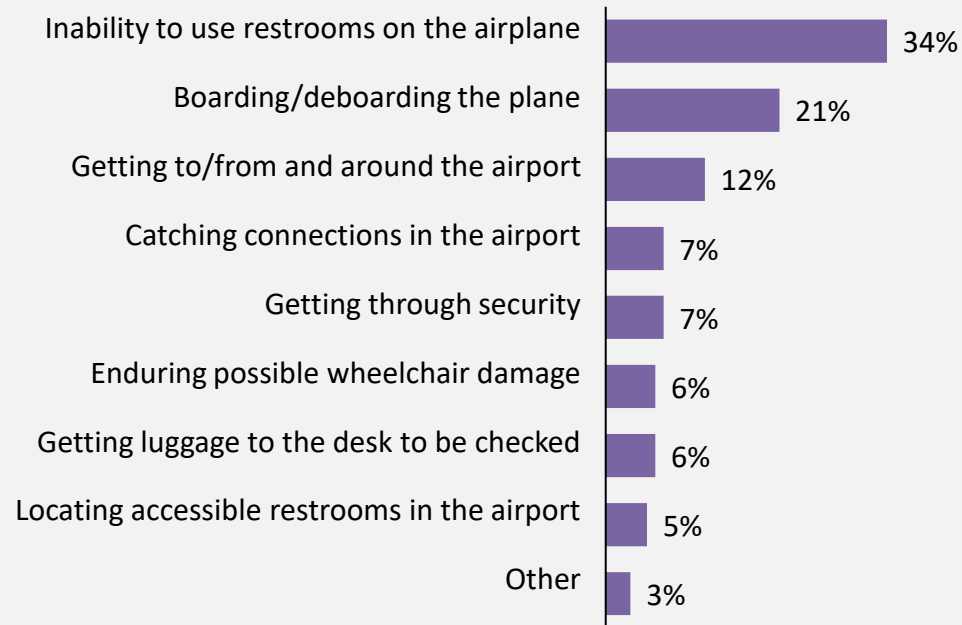


# Most Difficult Air Travel Challenges for Paralyzed Person

**SUMMARY:** MOST AMERICANS (94%) DO NOT THINK OF ENDURING POSSIBLE WHEELCHAIR DAMAGE AS THE MOST DIFFICULT FOR THOSE TRAVELING IN A WHEELCHAIR AND PARALYZED. HOWEVER, USING THE RESTROOMS AND BOARDING/DEBOARDING WERE CHALLENGES THAT ABOUT HALF OF AMERICANS WOULD BELIEVE IS MOST DIFFICULT.

When it comes to air travel, the challenge perceived to be most difficult for someone who is paralyzed and using a wheelchair is the *inability to use restrooms on the airplane*, selected by one-third (34%) of respondents. Another one in five adults (21%) believe *boarding/deboarding the plane* is most challenging, while 12% say the same about *getting to/from and around the airport*.

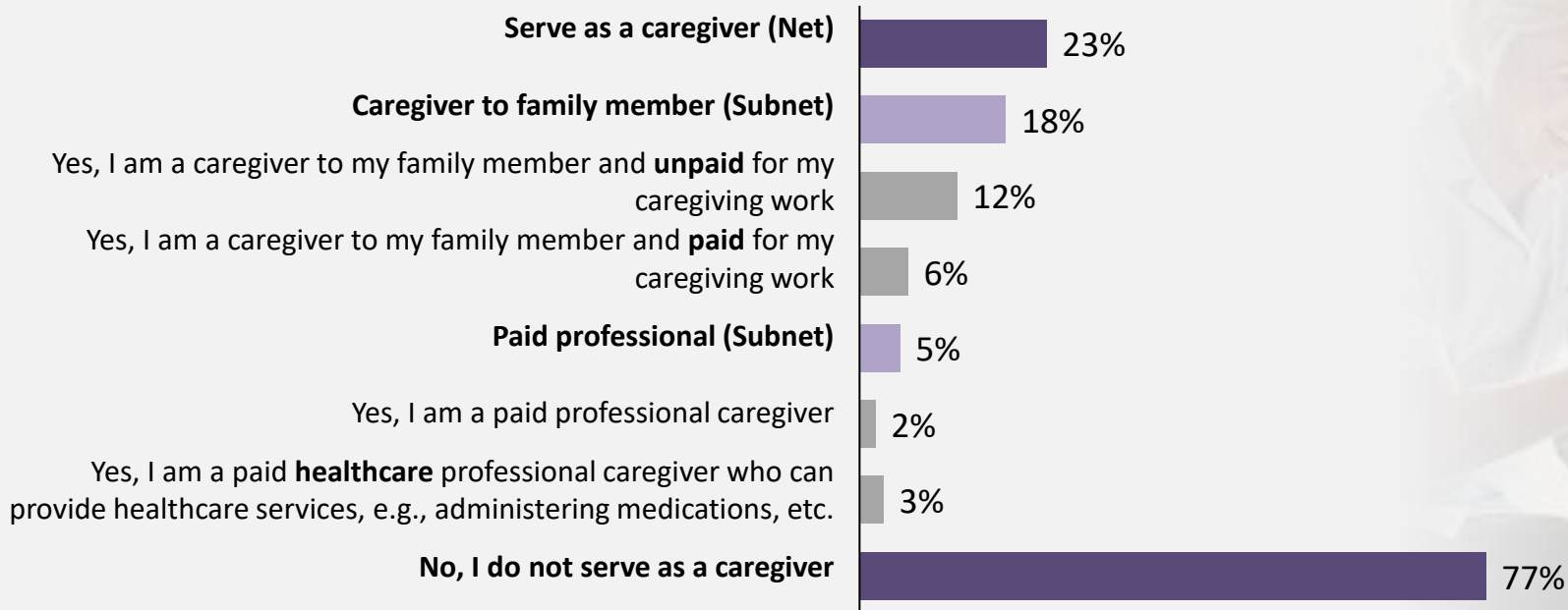
Women (38%) are more likely than men (29%) to view the *inability to use restrooms on the airplane* as the top challenge for a paralyzed person concerning air travel. This perception also steadily rises by generation, with Gen Z the least likely (17%) and Baby Boomers the most likely (42%) to regard the inability to use restrooms as most difficult.



# Currently Serve as Caregiver

**SUMMARY:** MOST AMERICANS (77%) DO NOT SERVE AS A CAREGIVER. HOWEVER OF THOSE WHO ARE CAREGIVERS TO A FAMILY MEMBER (18%) AND REGULARLY ASSIST WITH DAILY LIVING ACTIVITIES OF SOMEONE WHO IS DISABLED, SICK OR ELDERLY, 2/3 ARE UNPAID

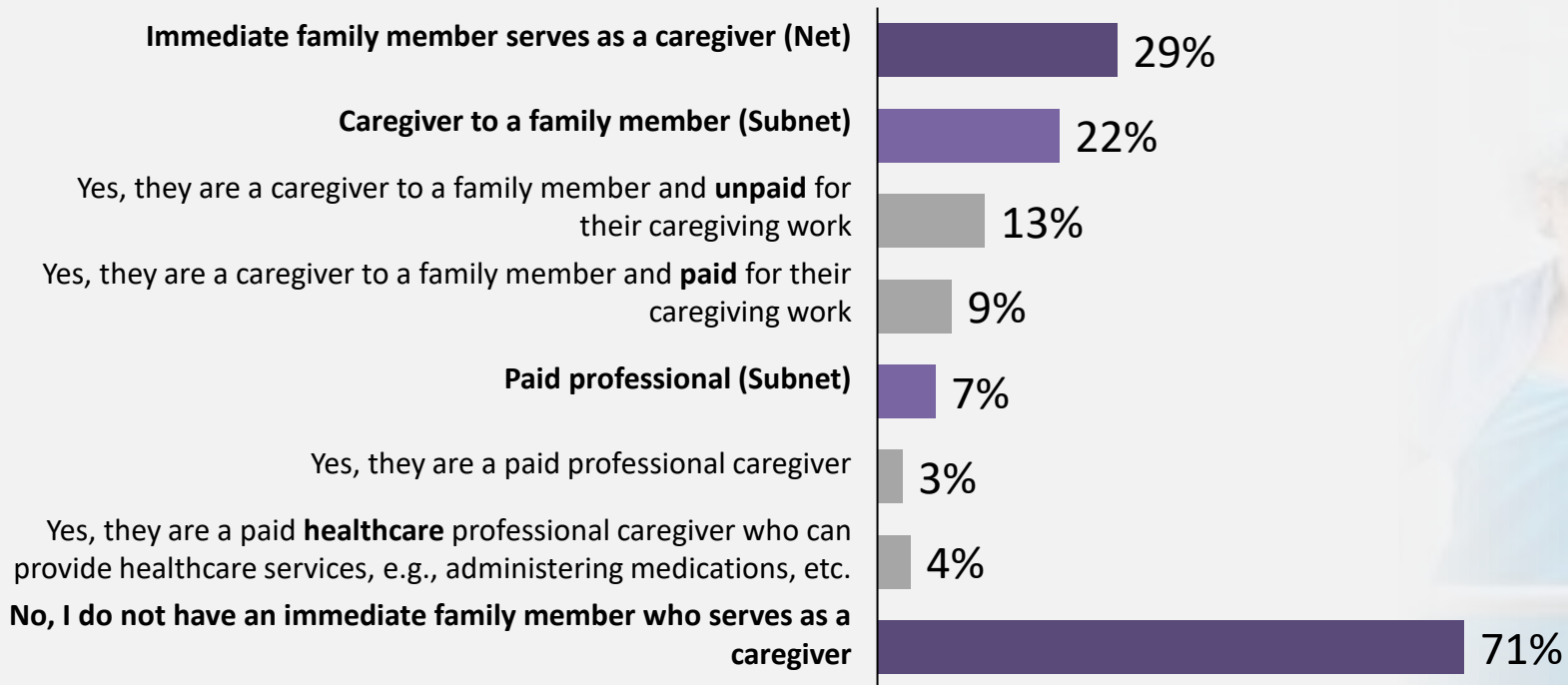
- Close to one-quarter (23%) of respondents currently serve as a caregiver.
- Eighteen percent say they are a caregiver to a family member, including 12% who are unpaid for their caregiving work.



# Immediate Family Member Serves as Caregiver

Summary: 71% do not have an immediate family member who serves as a caregiver

Three in ten adults (29%) have an immediate family member who currently serves as a caregiver. Twenty-two percent are a caregiver to a family member, with 13% who are unpaid for their caregiving work.





# APPENDIX

# RESPONDENT PROFILE

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## Gender:

- Men 48%
- Women 52%

## Generation:

- Gen Z (18-25) 13%
- Millennials (26-41) 29%
- Gen X (42-57) 26%
- Baby Boomers (58-76) 29%

## Age:

- 18-34 29%
- 35-44 17%
- 45-54 16%
- 55-64 17%
- 65+ 22%



# QUESTIONNAIRE

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P1 Off the top of your head, which category best represents how many Americans of any age are paralyzed, that is **people who are paralyzed** from the neck down or from the waist down, rendering their legs incapable of movement and requiring a wheelchair for any mobility?

- 01 About 2 out of every 10,000 Americans
- 02 About 2 out of every 1,000 Americans
- 03 About 2 out of every 100 Americans
- 04 About 2 out of every 10 Americans

P2 What do you think is the main cause of paralysis in the U.S.? - *Unaided*

P3 Do you know someone who is paralyzed and using a wheelchair for mobility?

- 01 Yes
- 02 No
- 03 Not sure

*Asked of those who know someone who is paralyzed and using a wheelchair for mobility...*

P4 Which of the following best describes the relationship of the paralyzed person to you?

- 01 A colleague/coworker
- 02 An acquaintance
- 03 A friend
- 04 A parent or guardian
- 05 A child
- 06 A sibling
- 07 An extended family member (aunt/uncle, cousin, grandparent)
- 08 Yourself
- 09 Other

# QUESTIONNAIRE

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*Asked of those who know someone other than self who is paralyzed and using a wheelchair for mobility...*

P5 Which of these best describes your situation in relation to the paralyzed person/people you know?

- 01 Currently living in your household
- 02 Not currently living in your household
- 03 Currently a client in your care (as a healthcare worker or professional caregiver)
- 04 Other

- A. A colleague/coworker
- B. An acquaintance
- C. A friend
- D. A parent or guardian
- E. A child
- F. A sibling
- G. An extended family member (aunt/uncle, cousin, grandparent)
- H. Other

P6 Do you think those who are mobility-impaired wheelchair users have adequate accessibility within businesses across the U.S.?

- 01 Definitely have adequate accessibility
- 02 Probably have adequate accessibility
- 03 May or may not have adequate accessibility
- 04 Probably do not have adequate accessibility
- 05 Definitely do not have adequate accessibility

# QUESTIONNAIRE

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P7 Do you believe there is a need for additional support from the U.S. government for wheelchair users beyond the Americans with Disabilities Act (ADA)?

- 01 Definitely a need for additional support
- 02 Probably a need for additional support
- 03 May/may not be a need for additional support
- 04 Probably not a need for additional support
- 05 Definitely not a need for additional support
- 06 I am not familiar with the Americans with Disabilities Act (ADA)

P8 At this point in time, do you think wheelchair users in the U.S. are able to live their best quality of life?

- 01 Definitely are able to live their best quality of life
- 02 Probably are able to live their best quality of life
- 03 May/may not be able to live their best quality of life
- 04 Probably cannot live their best quality of life
- 05 Definitely cannot live their best quality of life

P9 On average, **about how much** do you think it **costs** for a **full-time professional caregiver** of someone who is paralyzed and requires a wheelchair? **Please provide your best guess if you're not sure.**

- 01 Less than \$20,000 per year
- 02 \$20,000 - \$34,999 per year
- 03 \$35,000 - \$54,999 per year
- 04 \$55,000 - \$74,999 per year
- 05 \$75,000 - \$99,999 per year
- 06 \$100,000 - \$149,999 per year
- 07 \$150,000 or more per year

# QUESTIONNAIRE

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P10 If a **family member** is providing long-term care for someone who is paralyzed, to what extent do you agree or disagree that there should be some form of compensation from the government?

- 01 Strongly agree
- 02 Somewhat agree
- 03 Neither agree nor disagree
- 04 Somewhat disagree
- 05 Strongly disagree

*Asked of those who agree or disagree that there should be some form of compensation from the government if a family member is providing long-term care for someone who is paralyzed...*

P11 Why do you [INSERT ANSWER FROM P10] that there should be some form of compensation from the government if a family member is providing long-term care for someone who is paralyzed? - *Unaided*

P12 If you were to become paralyzed and unable to care for yourself independently, what would be your main source of funds to cover the cost of day-to-day living?

- 01 CHAMPUS
- 02 COBRA
- 03 Disability insurance through work
- 04 Health insurance
- 05 Long-term care policy
- 06 Medicaid
- 07 Medicare
- 08 Private savings
- 09 Retirement account
- 10 Tricare
- 11 Workers' comp
- 12 Fundraising (such as GoFundMe or Help Hope Live, for example)
- 13 Other



# QUESTIONNAIRE

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P13 Do you know someone who is a caregiver, that is, regularly cares for or assists a sick, elderly, or disabled person?

- 01 Yes
- 02 No
- 03 Not sure

P14 Do you know someone who is a caregiver to a person that is paralyzed and requires a wheelchair?

- 01 Yes
- 02 No
- 03 Not sure

P15 Of the following **caregiver roles, which is most surprising** to you?

- 01 Helping with travel to/from work, appointments, social events, etc.
- 02 Coordinating/accompanying to medical appointments
- 03 Bathing, dressing, applying makeup and other 'self-care'
- 04 Supporting with medication management or treatment
- 05 Bowel and bladder care management
- 06 Helping with exercise/range of motion
- 07 Food preparation and feeding if person can't hold utensils
- 08 Housekeeping and laundry
- 09 Wheelchair transfers (e.g., getting in and out of bed) and other actions that may include lifting
- 10 Pressure injury prevention and treatment including wound care
- 11 Respiratory care (vent management/cough assistance/suctioning)
- 12 Ordering medical supplies
- 13 Operating medical equipment (ventilators, ceiling lifts, Hoyer lifts)
- 14 None of the above

# QUESTIONNAIRE

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P16 If you were **responsible for someone who needed full time, in-home caregiving**, which one of the following do you believe would be **the most challenging**?

- 01 No time off from being a caregiver
- 02 Finding help if I need to leave the home temporarily (for errands, shopping, etc.)
- 03 Getting the patient to their doctor appointments
- 04 Mental or emotional strain of caregiving
- 05 Not having the same relationship as we once did
- 06 Financial challenges
- 07 Maintaining employment while meeting family member's needs
- 08 Not being able to travel longer distances
- 09 Other

P17 For **someone who is paralyzed and using a wheelchair**, which one of the following do you believe would be **the most difficult**?

- 01 Getting around a city on mass transit
- 02 Traveling on airplanes
- 03 Getting a job
- 04 Shopping (grocery, retail, etc.)
- 05 Taking care of their own family/children
- 06 Taking care of their house/apartment
- 07 Financial challenges
- 08 Medical challenges
- 09 Getting exercise
- 10 Mental strain of navigating in their day-to-day life
- 11 Other

# QUESTIONNAIRE

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P18 For someone who is paralyzed and using a wheelchair, which one of the following, **concerning air travel**, do you believe would be the **most difficult** for them?

- 01 Getting to/from and around the airport
- 02 Getting luggage to the desk to be checked
- 03 Getting through security
- 04 Boarding/deboarding the plane
- 05 Enduring possible wheelchair damage
- 06 Inability to use restrooms on the airplane
- 07 Locating accessible restrooms in the airport
- 08 Catching connections in the airport
- 09 Other

P19 Do **you** currently **serve as a caregiver**, that is, you regularly assist with the daily living activities of someone who is disabled, sick or elderly?

- 01 Yes, I am a caregiver to my family member and **unpaid** for my caregiving work
- 02 Yes, I am a caregiver to my family member and **paid** for my caregiving work
- 03 Yes, I am a paid professional caregiver
- 04 Yes, I am a paid **healthcare** professional caregiver who can provide healthcare services, e.g., administering medications, etc.
- 05 No, I do not serve as a caregiver

P20 Do you have **an immediate family member** who currently **serves as a caregiver**, that is, they regularly assist with the daily living activities of someone who is disabled, sick or elderly?

- 01 Yes, they are a caregiver to a family member and **unpaid** for their caregiving work
- 02 Yes, they are a caregiver to a family member and **paid** for their caregiving work
- 03 Yes, they are a paid professional caregiver
- 04 Yes, they are a paid **healthcare** professional caregiver who can provide healthcare services, e.g., administering medications, etc.
- 05 No, I do not have an immediate family member who serves as a caregiver