Catherine Cutler Institute
Prepared by the Catherine Cutler Institute for
the Office of Aging and Disability Services

Maine State Plan on Aging **Needs Assessment**

FINAL REPORT, JANUARY 2024

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- Southern Maine Area Agency
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Part One: Introduction and Background

Introduction & Purpose

The Department of Health and Human Services' Office of Aging and Disability Services (OADS) partnered with the Catherine Cutler Institute, Muskie School of Public Service, University of Southern Maine (USM) to conduct a statewide assessment of community needs of older adults and caregivers. The goal of the statewide assessment was to gather information directly from older Mainers living in diverse regions across the state, in both urban and rural settings, to inform the State and its community partners about the most pressing needs of older people around Maine, and to shed light on how best to prioritize existing services - or develop new ones - to meet those needs.

Key objectives of this assessment were to identify:

- Community assets and existing services that are valued by older Mainers;
- Service and support needs and gaps in service delivery to older adults; and
- Barriers impacting access to services and opportunities for mitigating those barriers.

The information collected through the assessment will assist the State in the development of the 2025-2028 Maine State Plan on Aging which strategizes the most effective ways to support older adults in aging comfortably in their homes and communities, particularly for those services and supports funded through the Older Americans Act (OAA). This information will also assist the Governor's Cabinet on Aging on settings its priorities in the coming years.

This report provides background information on the OAA State Plan on Aging process, demographic and other trends informing the State context, and an

overview of the data collection strategies. It summarizes assessment findings of both critical and important needs, overarching themes of navigation and caregiving, and strengths and opportunities in the landscape of services for older adults.

Background of the State Plan on Aging

The Office of Aging and Disability Services (OADS) is the federally designated State Unit on Aging (SUA) within the Maine Department of Health and Human Services. As the SUA, OADS receives funding under the Older Americans Act (OAA). This funding helps support the activities of the State and Maine's five Area Agencies on Aging (AAAs) in providing community supports and services to older Mainers and caregivers. OAA services support Mainers 60 years and older, including caregivers, and are designed to help older people remain as independent as possible and experience a high quality of life as they age.

OAA services are provided through Maine's five AAAs and include supportive services and senior centers; nutrition services and programs; health promotion and disease prevention; information and referral assistance; and family caregiver support. OAA services also support advocacy and legal assistance services.[i] The SUA is responsible for monitoring OAA services and funding according to federal requirements. As required by the OAA, any state receiving federal funding under the Act is required to submit a State Plan on Aging to the United States Department of Health and Human Services' Administration for Community Living (ACL). Maine submits a State Plan on Aging every four years. Once approved, the next plan will be effective for federal fiscal years 2025-2028.

[i] This includes services provided by Legal Services for the Elderly (LSE) and the Maine Long-Term Care Ombudsman Program (LTCOP).

The State Plan provides a framework for ongoing operations of programs funded through the OAA and describes the coordination and advocacy activities the SUA will undertake to meet the needs of older adults across the State. Maine's five AAAs are required to develop and submit their own area plans covering the same period. The AAA plans set forth goals and objectives for the coordination of services and supports within their designated geographic service area. To help inform the development of the State Plan on Aging, OADS partnered with USM to conduct a statewide needs assessment. OADS convened a group of stakeholders to help inform and guide the scope of work. The State Plan on Aging Advisory Committee (Advisory Committee) met two times in July and August 2023. Members actively engaged in the planning process, identifying project objectives, outreach strategies and methods, data collection measures, and a project timeline. The Advisory Committee agreed on the use of direct surveys, virtual listening sessions targeting the five AAA regions, special population focus groups, and key informant interviews. This report includes the results from all data collection activities conducted for this needs assessment.

Maine's Older Adults

This section provides a high-level overview of the older adults living in Maine today.

Diversity

Maine's racial demographic characteristics are becoming more diverse. Although predominately White, this varies between those under 60 and over 60 years of age. As the population ages, Maine's older adults will likely continue to grow in diversity, (Figure 1).

Figure 1 Racial demographic characteristics in Maine's younger and older populations.

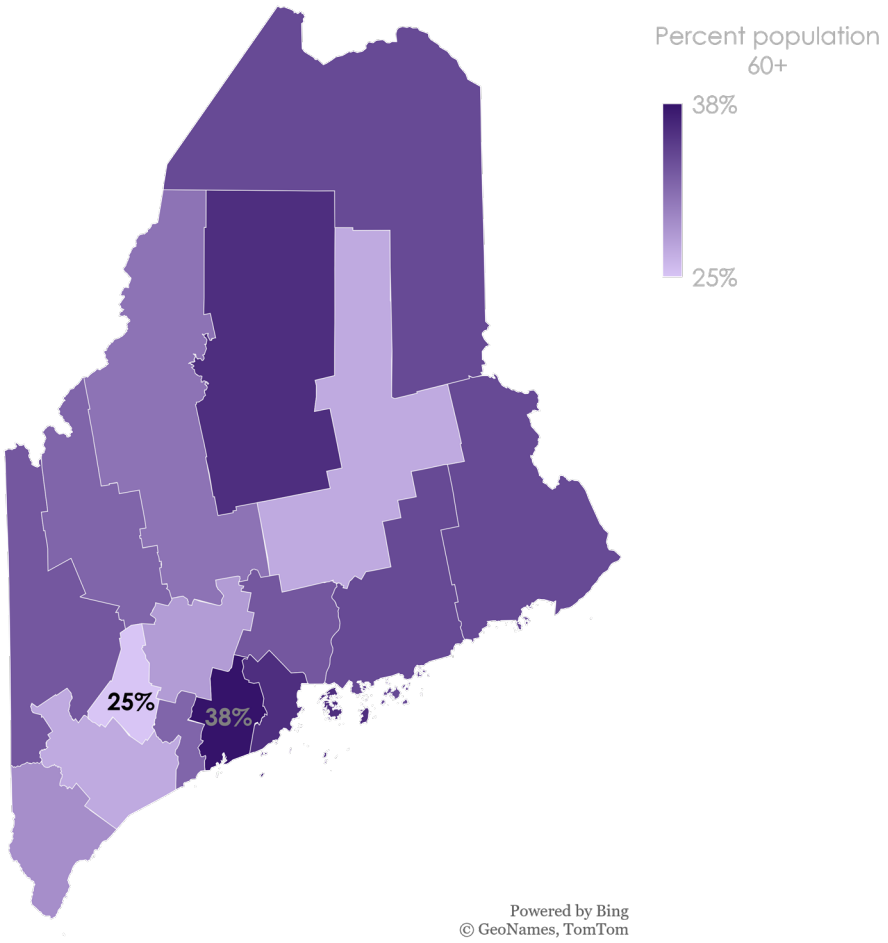
Demographic Characteristic	Under 60	Over 60
RACE (ONE RACE)		
White	91%	97%
Black or African American	2%	0.4%
American Indian or Alaska Native	1%	0.4%
Asian	1%	0.6%
Native Hawaiian and Other Pacific	0%	0.0%
Some other race	1%	0.2%
ETHNICITY		
White alone, not Hispanic or Latino	90%	96%
Hispanic or Latino	2%	0.7%

U.S. Census Bureau. (2021). POPULATION 60 YEARS AND OVER IN THE UNITED STATES. American Community Survey, ACS 5-Year Estimates Subject Tables, Table S0102. Retrieved December 1, 2023, from https://data.census.gov/table/ACSST5Y2021.S0102.

County Population Differences

Maine's counties have different concentrations of older adults. Thirty-eight percent of the population of Lincoln County is over 60 years old compared to 25% of Androscoggin County's population (Figure 2).

Figure 2 Lincoln County has the highest percentage of adults 60+ at 38%.

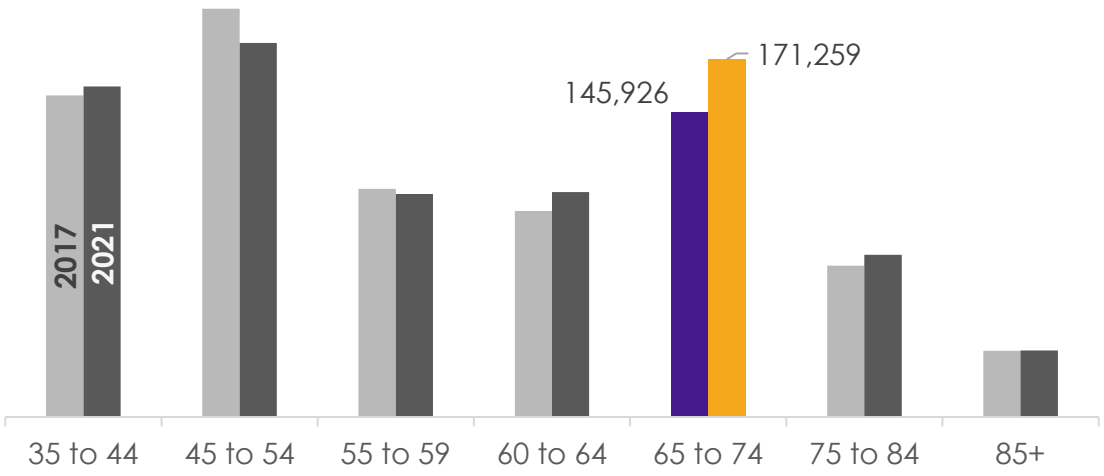


U.S. Census Bureau. "Age and Sex." American Community Survey, ACS 5-Year Estimates Subject Tables, Table S0101, 2022. Retrieved from https://data.census.gov/table/ACSST5Y2022.-S0101.

Rate of Aging

The older population in Maine is already rapidly changing. The last Maine State Plan on Aging Needs Assessment featured data from the 2017 U.S. Census. From 2017 to 2021, Maine's 65 to 74-year-olds grew by over 25,000 people (Figure 3).

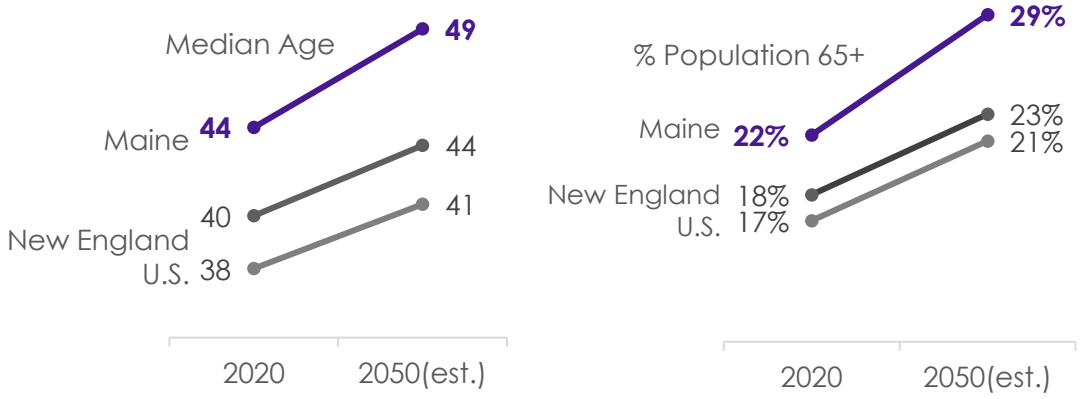
Figure 3 Between 2017 and 2021, Maine's 65 to 74-year-olds increased by over 25,000.



U.S. Census Bureau. (2017 and 2021). ACS DEMOGRAPHIC AND HOUSING ESTIMATES. *American Community Survey, ACS 5-Year Estimates Data Profiles, Table DP05*. Retrieved from https://data.census.gov/table/ACSDP5Y2017.DP05 and from https://data.census.gov-/table/ACSDP5Y2021.DP05.

Compared to other states, Maine's median age is higher and will rise from 44 in 2020 to 49 in 2050, and the older population is likely to grow at a much faster rate during that time (Figure 4).

Figure 4 Maine's **median age will be 49** years old and **people 65+ will make up 29%** of the population by 2050.

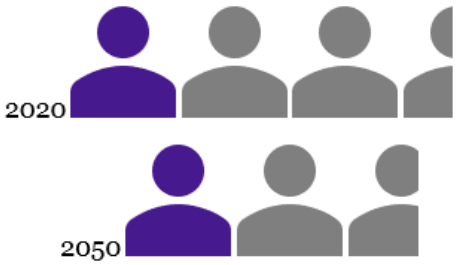


2023 Woods and Poole Economics, Inc., *2023 State Profile: 2023 Regional Projections and Database*.[ii]

The ratio of people ages 20-64) persons per person ages 65 and older is projected to decline from 2.6 people in 2020 to 1.8 in 2050. This declining ratio has significant implications for the available workforce to serve Maine's aging population (Figure 5).

[ii] All charts in this document projecting future population trends used Woods & Poole Economics, Inc. projections. Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the University of Southern Maine.

Figure 5 **People ages 20 to 64** per **person 65+** will decrease from 2.6 to 1.8.

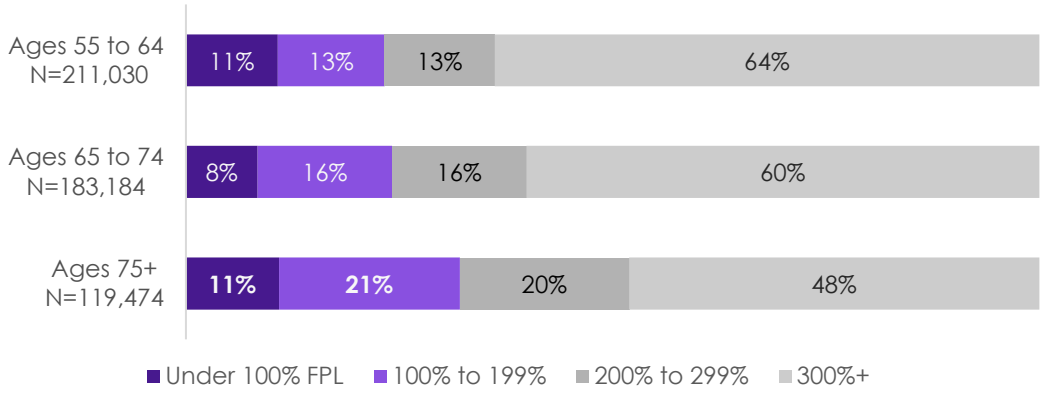


2023 Woods and Poole Economics, Inc., *2023 State Profile: 2023 Regional Projections and Database*.

Poverty

For older adults, poverty rates increase with age. While under one-quarter of 55- to 64-year-old Mainers have incomes below 200% of the federal poverty level (FPL) ($34,000 in 2022), nearly one-third of people 75+ have incomes below that level (Figure 6).

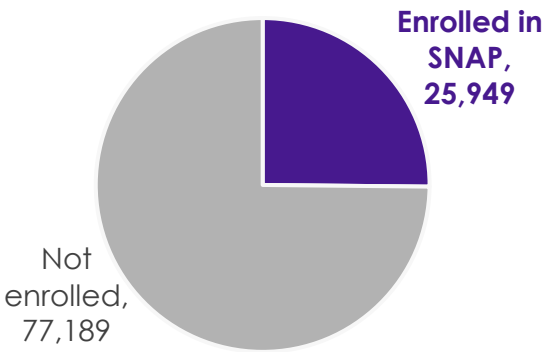
Figure 6 Nearly **one-third of Mainers 75+** have **incomes below $34,000** (200% FPL).



U.S. Census Bureau. (2022). Age by Ratio of Income to Poverty Level in the Past 12 Months. *American Community Survey, ACS 1-Year Estimates Detailed Tables, Table B17024*. Retrieved from https://data.census.gov/table/ACSDT1Y2022.B17024.

Over 100,000 Mainers 60 and older have annual income below 200% FPL ($34,000) and would likely be eligible for the Supplemental Nutrition Assistance Program (SNAP). Yet most are not enrolled (Figure 7).

Figure 7 Only one-quarter of low-income adults 60+ (<200% FPL) are enroll in SNAP.

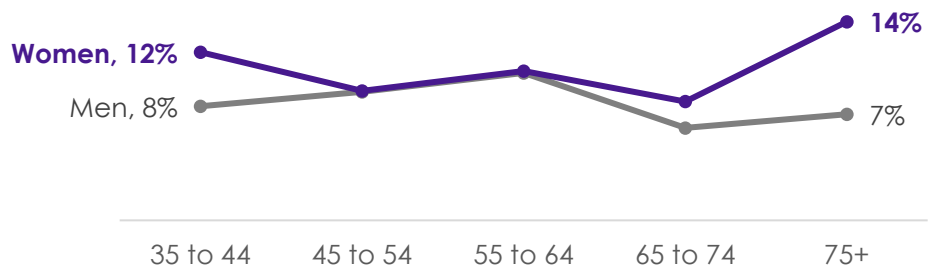


U.S. Census Bureau. (2022). Age by Ratio of Income to Poverty Level in the Past 12 Months. *American Community Survey,* ACS 5-Year Estimates Public Use Microdata Sample (2021). Retrieved from https://data.census.gov/mdat/#/search?ds=ACSPUMS5Y2021.

Gender and Poverty

Younger Maine women experience higher rates of poverty compared to men. While this improves in middle age, as they get older, the disparities return. Figure 8 shows Maine women over 75 live in poverty at twice the rate of men.

Figure 8 Maine women over 75 live in poverty at twice the rate of men.

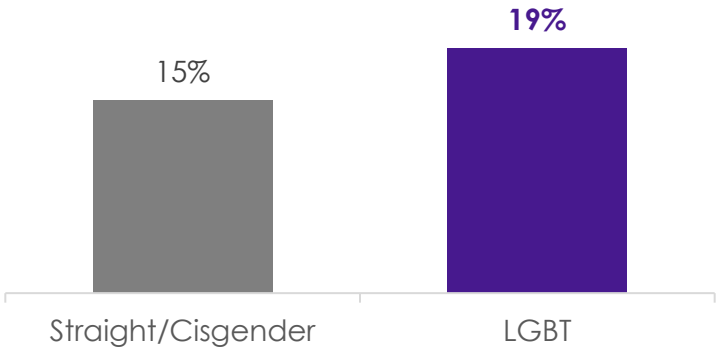


U.S. Census Bureau. (2021). POVERTY STATUS IN THE PAST 12 MONTHS BY SEX BY AGE. *American Community Survey, ACS 5-Year Estimates Detailed Tables, Table B17001*. Retrieved from https://data.census.gov/table/ACSDT5Y2021.B17001.

LGBT Older Adults and Poverty

Although Maine-specific data are unavailable due to small sample size, national data indicate that older adults who identify as LGBT experience higher rates of poverty than straight/cisgender older adults (Figure 9).

Figure 9 **LGBT adults 65+ live in poverty at a higher rate** than straight/ cisgender older adults.



Bouton, L.J.A., Brush, A.M., & Meyer, I.H. (2022). LGBT Adults Aged 50 and Older in the U.S During the COVID-19 Pandemic. Los Angeles, CA: The Williams Institute, UCLA School of Law.

Living Arrangement

Older adults often live with family, including spouses and partners, but not always. In 2022, an estimated twenty-five percent of adults 65+ in Maine lived alone (Figure 10). These adults may have greater needs for formal long-term services and supports (LTSS) than those who live with family members.

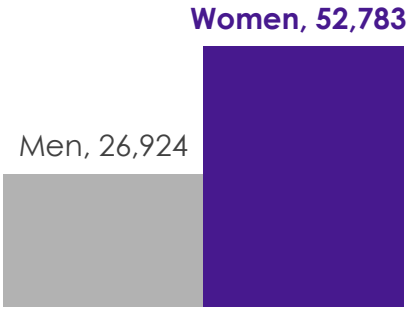
Figure 10 **One-quarter** of adults 65+ **live alone**.

Living Arrangement	Percentage
In family households	66%
Alone	**25%**
With others	5%
In group setting	4%

U.S. Census Bureau. (2022). Relationship by Household Type (Including Living Alone) for the Population 65 Years and Over. American Community Survey, ACS 1-Year Estimates Detailed Tables, Table B09020. Retrieved from https://data.census.gov/table/ACSDT1Y2022.B09020.

Women have a longer life expectancy than men, and many outlive their male spouses and partners. With this longevity comes an increase in the likelihood of living alone in later years. Compared to men, twice as many women over 65 live alone (Figure 11).

Figure 11 **Twice as many women over 65 live alone** compared to men.



U.S. Census Bureau. (2021). NONFAMILY HOUSEHOLDS BY SEX OF HOUSEHOLDER BY LIVING ALONE BY AGE OF HOUSEHOLDER. *American Community Survey, ACS 5-Year Estimates Detailed Tables, Table B11010*. Retrieved from https://data.census.gov/table/ACSDT5Y2021.B11010.

Kinship Caregiving

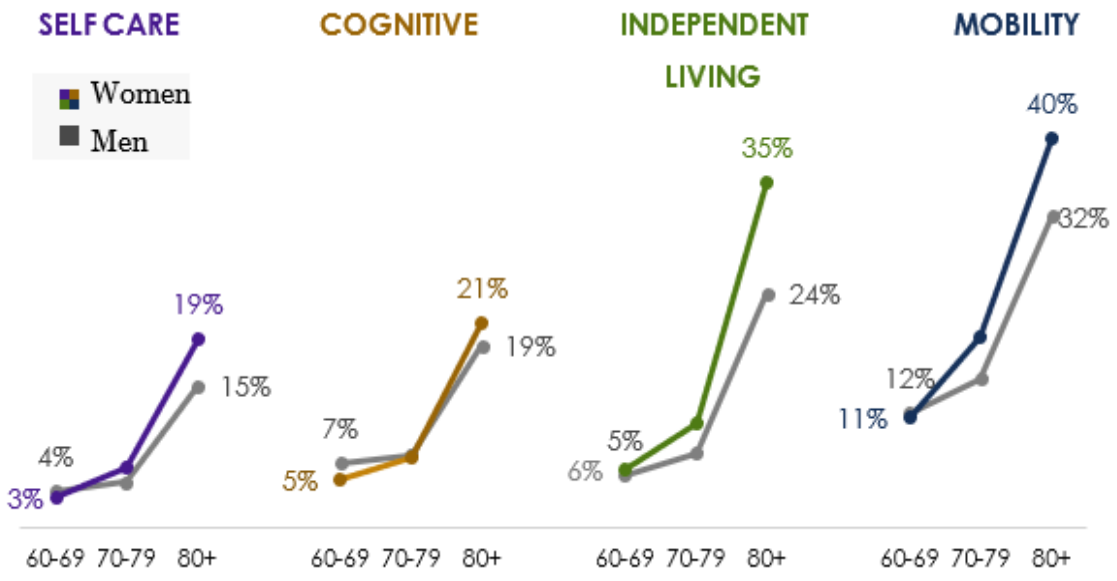
There is growing awareness in Maine of grandparents caring for their own grandchildren due to factors such as changes in family structure, economic factors, and the opioid crisis**. Five thousand Maine grandparents living with their grandchildren have assumed responsibility for them.**[iii] The needs of these grandparents may straddle two systems, one supporting older adults and one supporting children.

[iii] U.S. Census Bureau. (2021). Disability Status of Grandparents Living with Own Grandchildren Under 18 Years by Responsibility for Own Grandchildren and Age of Grandparent. American Community Survey, ACS 5-Year Estimates Detailed Tables, Table B10052. Retrieved from https://data.census.gov/table/ACSDT5Y2021.B10052.

Disability and Age

The percentage of older adults with disabilities tends to increase with age. Women experience higher rates of disability in later life compared men, especially in independent living and mobility (Figure 12).

Figure 12 Women experience increasing rates of disabilities with age compared to men.



U.S. Census Bureau. (2022). Disability Characteristics. American Community Survey, ACS 1-Year Estimates Subject Tables, Table S1810. Retrieved November from https://data.census.gov/table-/ACSST1Y2022.S1810?q=Disability+characterisitics&g=040XX00US23.

Domains of Need

In keeping with the overall statewide needs assessment goal of identifying areas of need that affect older people's daily lives in fundamental and important ways, all the data collection activities centered around seven key domains: **Health, Housing, Food & Nutrition, Transportation, Safety, Caregiving,** and **Socialization.**

To provide context for the data collected and understand how the experiences of older people in Maine relate to larger state or national trends or recent external factors, the project team reviewed current peer-reviewed and grey literature on the intersection of aging and older adults with each of these domains. Relevant highlights from the literature are offered below. In choosing highlights, the project team considered the key themes emerging from needs assessment data.

Health

Health access

Access to healthcare is defined as the timely use of health services to achieve the best possible health outcomes, and includes insurance coverage, availability of services, and provider workforce.[1]

National studies of the healthcare of older adults highlight significant access challenges, including lack of providers (both primary care and specialists)[2-5] and financial constraints. Many older adults delay or forego needed care due to the cost, often needing to choose between healthcare services, paying their bills, or meeting their daily needs.[6-12] Older adults with disabilities,[10] immigrants,[9, 13] LGBTQ+,[7, 14, 15] or persons with HIV[16] are especially vulnerable to stigma or lack of culturally competent care, and thus often avoid needed healthcare; this is exacerbated for these populations residing in rural areas.

Rural residents who tend to be older, sicker, low-income, and un- or under-insured,[11,17,18] often face additional challenges of long travel distances, lack of transportation to access health services, and poor internet or cellular services to take advantage of telehealth services.[17] Rural communities in which everyone knows each other often prevents older adults from seeking local healthcare, particularly for mental health issues.[6, 17, 19]

Navigating the healthcare system is increasingly complex and is especially difficult for older adults or foreign-born adults.[20] Nearly one in five immigrant adults ages 18 and older say they use the emergency room when they are sick or need health advice.[9] The burden of healthcare administrative paperwork is overwhelming for many older adults[21] and those with limited English proficiency.[9, 20]

Access to care in Maine was identified as a top priority of older adults in the recent statewide community health needs assessment (CHNA).[22] Nearly half of participants in the CHNA raised key concerns of provider shortages and turnover as well as the need for culturally competent providers. In 2019, 8.0% of Mainers were uninsured, and persons with disabilities stressed the challenges in obtaining health insurance. As one participant noted: "There are copays and what you have to pay out of pocket is the difference between buying food, medicine, or healthcare." Health disparities in Maine are seen across race/ethnicity/gender identity. The 20-Year Retrospective of the State of Health in Maine shows a persistent challenge of older adults to access needed health and dental care, noting that racial and ethnic populations (Black, Indigenous, and other Maine residents of color) were significantly more likely than white, non-Hispanic Mainers to report a lack of care due to cost.[23]

Falls

Falls and fear of falling are prevalent in adults ages 65 and older. Studies show that having a fall can lead to future falls and increases the fear of falling.[24, 25] Data show that 25% of adults experience a fall every year, and one in five falls leads to

serious injury and can result in death; approximately 30,000 people die each year as a result of a fall.[26, 27] Older adults who are in poor health and experience multiple symptom burden (pain, insomnia, breathing difficulty, depression, anxiety, fatigue) are more likely to experience falls.[25] To combat this, one study recommended tailoring fall risk assessments to include symptom assessment and management strategies for community-dwelling older adults.[25] Additional strategies include increasing mobility[27] and combining physical and cognitive interventions.[24] Factors related to mobility and falls include:[27]

- Neighborhood and environmental characteristics (e.g., walkable sidewalks and safe communities).
- Financial resources—the inability to purchase assistive devices such as canes/walkers or make home modifications can lead to a potential fall.
- Cognition—one study[28] found the relationship between mobility and cognition was bidirectional (one does not cause the other).
- Access to shopping, healthcare, and social events play a significant role in promoting mobility.
- For racial/ethnic populations and those living in food deserts, limited mobility may reduce the ability to obtain fresh foods that promote health.

In Native American/Tribal populations, the role of the elder is sacred. Finding ways to reduce falls for the elders can be difficult as many Indian Health Service facilities are in rural areas and lack falls-related resources.[29]

Maine is also a highly rural state and leads the nation in persons ages 65 and older. In 2021, there were 325 deaths in Maine attributed to older adult falls and Maine ranked 8th highest in the nation per capita on the rate of deaths due to falls. In October 2023, Senator Angus King presented the “Stand Strong” legislative package (including the Preventive Home Visits Act and the WELL

Seniors Act), designed to cover home modifications, telehealth services and comprehensive preventive screenings.[30]

Housing

The ability to stay in one's home is both a desire and a fear of adults as they age. Mobility and accessibility issues compounded by financial concerns are prevalent in this population.[31, 32] One study found that housing support was a critical need in the non-medical and care coordination process.[33] Additionally, homelessness is on the rise for adults now nearing retirement age.[34]

In 2015, the Joint Center for Housing Studies at Harvard University (JCHS) projected that over the course of the next decade, 40% of older adults ages 65 and older are projected to live in inaccessible homes, and the need for housing modifications will rise considerably.[35] In 2019, the JCHS reported that 18% of households headed by persons 80 years or older have difficulty using their homes.

Jennifer Molinsky, Project Director of the Housing an Aging Society Program at JCHS has written extensively on the growing issues facing older adults as they seek to remain in their homes. In 2020 she highlighted the intersecting concerns of the lack of affordable housing, accessibility modifications, and transportation.[31] In her testimony before the U.S. Senate Committee on Banking, Housing, and Urban Affairs, Molinsky raised the alarming and immediate need for affordable and accessible housing—that "without concerted action, we are on track for even graver deficiencies that may diminish older people's health and ability to remain in their communities; increase the cost of public programs; and exacerbate deep and longstanding inequalities in housing and financial security."[32] In 2023, funding was increased for the Older Adult Homes Modification Program and eligibility was expanded to include renters, aiding more older adults to age in place.

Maine is facing a severe housing shortage, and many existing homes are older which leads to homes in need of reinvestment. This supply shortage, along with the lack of housing quality, limits options for older Mainers to age in place and contributes to high housing burden and increased homelessness.[36] Key findings from the 2023 Maine housing needs study indicate that older homeowners in Maine tend to be lower income than other households and rely on fixed incomes, and, in aggregate, face higher rates of cost burden.[36]

Food and Nutrition

Food insecurity among older adults is rising. Studies show a dramatic increase (45% since 2001) in the prevalence of food insecurity among older adults. In the absence of mitigating interventions, food insecurity is projected to rise as the number of adults 65 and older increases.[37-39] Food insecurity disproportionately affects those who live alone or homebound, are unemployed or disabled, low-income, and those who live with grandchildren in the home.[37, 39-41]

The impact on health outcomes for food insecure older adults is significant, with the association of multiple chronic conditions either because of food insecurity or resulting in food insecurity.[40] A 2019 survey of community-dwelling older adults (ages 50-80) found that 54% of food insecure adults had multiple chronic conditions, and 45% reported poor health compared to 14% of food secure adults. Overall, one in seven adults in the study experienced food insecurity. Ziliak & Gunderson note that in 2019 the number of food insecure older adults (ages 60 and older) increased by 128%.[39]

Additionally, many older adults face the financial trade-off between food and medication, negatively impacting disease management and overall health status. *Maine's Roadmap to End Hunger by 2030* states, "In hunger-free communities, everyone has access to the resources they need, and no one is forced to make the impossible trade-offs that result in food insecurity— trade-offs like skipping meals to pay for housing, medicine, or heat…"[42]

Culturally Appropriate Food

A scoping review[43] examining access of culturally appropriate food for immigrant populations highlighted common barriers, including structural barriers (cost of food, low income, transportation options, and time); socio-cultural barriers related to religious dietary requirements, family preferences, and language barriers; a lack of nutritional education; and lack of/lack of access to ethnic grocery stores. Immigrant populations residing in rural areas are especially challenged due to the well-known barriers of transportation, travel distance, and availability of grocery stores. These issues are found across several immigrant populations,[43, 44] including Latinx,[45] Arabic-speaking,[46] and Congolese.[47] A strong social network is a protective factor against food insecurity for immigrant populations.

Transportation

Studies of older adults show that as adults age, their need for transportation services increases.[22, 48-50] Transportation barriers include not having a vehicle as well as the cost of maintaining a vehicle. Additionally lack of access to public transportation is a barrier for persons residing in rural areas as well as culturally and ethnically diverse older adults and people with disabilities who do not drive and are reliant on public transportation. This lack of access to transportation impacts both the health and socialization needs of older adults, and is especially exacerbated in rural areas, where residents have longer travel distances to healthcare providers, grocery stores, or social events.[48]

The 2022 CHNA report highlighted the lack of transportation as one of the top four identified needs across the state, impacting the ability to access healthcare.[22] "While transportation is typically discussed as a social determinant of health, lack of transportation is a real barrier to all modes of care." This was supported by focus group participants consisting of Black/African Americans, Immigrants, Deaf/Hard of Hearing, and LGBTQ+ participants who all raised

concerns about transportation barriers relative to access to healthcare, socialization, and rurality. A key takeaway in the report noted the need for better knowledge of available transportation resources and how to access them.

The Maine Department of Transportation's long range planning efforts focus on a high-level multi-modal transportation system for Maine over the next twenty years, "with equitable solutions" to best meet the diverse needs of Maine's population. [50] Their needs assessment takes into consideration factors such as population density, amount of travel, housing units without vehicles, low-income household, persons with disabilities, ethnic populations, and persons over the age of 65. A separate 2.5-year pilot project to be administered by the Western Maine Transportation Services will focus on the transportation needs of Maine's veterans.[49]

Safety

Physical safety

The World Health Organization recognizes elder abuse as an important global public health issue and that the COVID-19 pandemic increased its occurrence.[51] While common, elder abuse is often unreported. Based on the current prevalence rate of nearly 1 in 6 adults 60 and older, there were nearly 61,000 older Mainers who experienced some form of abuse in the community in 2021.[iv] Yet most abuse cases are never reported to authorities.[52] Older adults with poor physical health, functional disability and dependence, cognitive impairment, poor mental health, low income, substance use issues, shared living situations, or limited social support are at heightened risk of elder abuse.[53-55]

[iv] Estimate calculated using a 15.7% prevalence rate and 2021ACS 5-Year Estimates Subject Tables, Table S010 estimated 388,470 Maine adults 60 and older.

Financial safety & security

Older adults are vulnerable to scams that seek to strip them of their identity and financial resources. According to the Internet Crimes Complaint Center, in 2020 the top 10 types of crime for victims over the age of 60 focused on fraud or scam-related activity. These crimes include extortion, non-payment or non-delivery, tech support, identity theft, phishing-related activities, spoofing, romance fraud, personal data breach, government impersonation, and other types of misrepresentation.[56]

A recent study using an experiment to mimic a real scam highlighted the risk to adults without cognitive impairment of engaging with government impersonation scams.[57] The median age of participants was 85.6 years, with an annual household income between $50,000 and $75,000. Findings revealed that while less than 20% engaged without skepticism, nearly 75% of those participants also provided personal information. This could potentially lead to other financial losses for older adults.

Caregiving

Informal caregivers, typically family members, are the backbone of Maine's system of long-term services and supports. Each year, they provide millions of hours of unpaid care to their loved ones who need assistance due to age, chronic illness, or disability.[58, 59] With the shortages in direct care workers and the expense of formal services, family caregivers play a central role in assisting their loved ones with activities such as bathing, dressing, eating, grocery shopping, housekeeping, and paying bills. This assistance enables people to remain safely at home in the communities of their choice and delay nursing home placement.[60-62] Some older adults also play an important caregiver role in the absence of a parent to their grandchildren[63-65] or other relatives who are minor children.

Caregiving can have adverse impacts on the physical and mental health of caregivers, resulting in increased anxiety and depression as well as decreased

preventive health activities.[65-68] In addition, family caregivers may need to reduce working hours or leave the workforce entirely, causing financial strain. Job performance can suffer when workers go in late, leave early, or take time off due to caregiving responsibilities. [59] Similar to findings in a national survey,[69] a survey of Maine caregivers[70] found that 58 percent of caregivers went in late, left early, or took time off during the day to provide care, and 21 percent went from working full-time to part-time or cut back on hours. Over half of caregivers reported that caregiving was somewhat or very much a financial strain.

Supporting caregivers through assessing their burden and referring them to available community resources has been shown to improve their burden and depressive symptoms. [71] Respite services that allow caregivers to take a break from caregiving responsibilities result in decreased burden, improved emotional well-being, and the ability to attend to personal tasks.[72-74]

Socialization

As adults age, the ability to socialize diminishes due to physical limitations (e.g., decreased mobility and increased health issues) and environmental constraints (e.g., lack of transportation, fewer activities during the day). A national survey in 2018 of adults over the age of 50 found that 60% of participants who lived alone reported feelings of loneliness, and 34% of adults who lived with other adults also reported feelings of loneliness, highlighting the complexity of the connection between loneliness and social isolation.[75] Older adults residing in rural areas,[76] LGBTQ+,[77] and immigrant populations[78, 79] are disproportionally at risk for social isolation.

There are negative health consequences associated with social isolation and loneliness.[80-82] In his 2023 Advisory, the U.S. Surgeon General raised the importance of social connectivity for the overall health and wellbeing of an individual and the community, noting that even prior to the COVID-19 pandemic, one-in-two adults reported experiencing loneliness.[81] Further, loneliness and

isolation are associated with higher risks of heart disease, stroke, as well as dementia, depression, and anxiety. "The mortality impact of being socially disconnected is similar to that caused by smoking up to 15 cigarettes a day, and even greater than that associated with obesity and physical inactivity."[81]

Several studies[75, 76, 83-85] provide strategies to combat these risks, including cross-sector collaborations, social networks of peers, physical activity, volunteering, age-friendly communities and faith-based organizations, and the use of technology.

Maine's age friendly communities have focused work on reducing social isolation among older adults. For example, Age-Friendly Bowdoinham conducted stakeholder focus groups in 2022 to help identify how their town could improve the connectedness of older residents to the life of the community, reduce social isolation and age well in place.[83] Additional efforts in Maine to identify and mitigate social isolation include a statewide community needs survey as part of HRSA's Geriatrics Workforce Enhancement Program. Findings from the survey indicated a high priority by providers and consumers alike to identify opportunities to keep older adults socially connected to improve their emotional and mental health and overall well-being.[86]

COVID-19

The COVID-19 pandemic negatively impacted older adult's well-being in many ways. Older adults experience increased risks of chronic disease and social isolation, and the effects of the pandemic were magnified in this population, as seen in their delay of care[87-89] and social isolation.[87, 88] Ageism (or healthcare stereotype threat) was also compounded during COVID-19. One survey of persons ages 50 and older found that the respondents who worried about their providers judging them on their age also reported more negative COVID-19 reactions.[90] This was also seen in the *Aging Through the Time of COVID Survey*[8] which included questions related to healthcare access, social connectedness, and

COVID-19 highlighting the intersection of ageism and COVID-19. Persons with disabilities and non-White populations experienced higher rates of hospitalizations and death due to COVID-19, underscoring the vulnerabilities and inequities across sociodemographic groups.[10] In fact, one study calls COVID-19 a social disease requiring the integrated approach that social medicine brings to address these inequalities: "integrating health, social, and economic responses; bringing care to the points of greatest need; and focusing on broad equity-driven reforms in the pandemic's wake."[91]

COVID-19 saw a rise in the use of telehealth across all sectors of the population. For adults 65 years and older, facility with technology and access to the internet were factors that positively impacted their use of telehealth. A systematic review of the use of telehealth in the primary care of older adults found that in general, older adults expressed positive experiences and high satisfaction with this model of healthcare delivery.[92] Additionally, the benefits of increased access to providers along with the time-saving convenience of telehealth was particularly seen in rural areas. Lu et al. note in their study of Medicare beneficiaries that rural residence, low income, and lack of access to the internet were barriers to the use of telehealth services.[93] Results from the *Aging Through the Time of COVID Survey* highlight facility with telehealth access by older adults who were in good health, reported greater income and less social isolation.[8]

Part Two: Assessing the Need

Study Components Overview

The full statewide needs assessment envisioned a broad study comprising mixed methods data collection through surveys, listening sessions, focus groups, and key informant interviews. The study components were designed to reach older Mainers – or sub-populations of older Mainers - using various platforms. Findings across all data gathering components are presented in Part Three. Separate findings for the focus groups of special populations and surveys are included in Part Four and Part Seven, respectively.

While intentional efforts were made to include hard-to-reach populations (e.g., oldest old, people geographically or otherwise isolated, those with significant health challenges, or individuals not engaged in services, etc.), future efforts could build on this work. Future efforts might include strategies such as in-person or one-on-one interviews and may require additional partnerships outside of the aging network to capture these voices more fully.

Study components were designed to be inclusive and represent the broadest spectrum of older adults and caregivers, recognizing that data are currently lacking for many sectors. For this reason, questions on sexual orientation and gender identity were included in both the statewide and caregiver surveys.

All study components centered the **Domains of Need** described in Part One. healthcare, housing, food and nutrition, transportation, safety, caregiving, and socialization. Each of the data collection methods is briefly summarized below.

Listening Sessions

Five virtual listening sessions were conducted online in September and October using the Zoom platform. To ensure that the sessions represented the service area of each AAA, participants were encouraged to register for the session date corresponding to their county.

- Eastern Area Agency on Aging: September 25, 2023, for residents of Hancock, Piscataquis, Penobscot, and Washington Counties
- Aroostook Area Agency on Aging: September 28, 2023, for residents of Aroostook County
- SeniorsPlus: October 4, 2023, for residents of Androscoggin, Franklin, and Oxford Counties
- Southern Maine Area Agency: October 4, 2023, for residents of Cumberland and York Counties
- Spectrum Generations: October 12, 2023, for residents of Kennebec, Knox, Lincoln, Sagadahoc, Somerset, and Waldo Counties

Ninety-two people across all five sessions participated in facilitated conversations around what is working well and what needs improvement in the Domains of Need. The sessions were designed to hear nuances and details about community assets and the needs of older adults and caregivers.

Focus Groups

USM collaborated with several community organizations to convene focus groups of older adults from different communities who have been underrepresented in other data gathering activities. We utilized convenience sampling for the focus groups, relying primarily on trusted community partners to help with recruitment and publication of the groups. Cross Cultural Community Services

(CCCS), the Maine Council on Aging (MCOA), Khmer Maine, Equality Maine, Maine TransNet, In Her Presence, Legal Services for the Elderly, and several age-friendly community organizations helped to identify older adults willing to participate in the different focus groups.

Several groups were conducted in-person in the greater Portland area, and others were conducted online via Zoom. Sessions ranged from 90 to 120 minutes and covered the same domains of need as the listening sessions. Participants gave informed consent to take part in the groups and received a $50 Hannaford gift card and a $50 Visa/Mastercard gift card in appreciation for their participation. Seven focus groups were conducted, with a total of 64 older individuals in the following categories:

- Asian older adults
- US-born Black and African American older adults
- LGBTQ+ older adults living in the greater Portland area
- LGBTQ+ older adults living in rural areas of the state
- Low-income older adults
- New Mainers—Somali and Arabic speakers
- New Mainers — French and Portuguese speakers

Because focus groups are typically conducted with a small number of participants, findings are not expected to be representative of the experiences of an entire population. However, focus group findings can help identify issues and concerns and provide insight into individuals' experiences and perceptions.

Key Informant Interviews

To learn about underserved and underrepresented older adult populations who might be less likely to participate other needs assessment data gathering activities, we reached out to key informants who provided valuable insight into unique populations of older adults. Nine interviews were conducted in September - November with twelve aging services representatives and other experts who serve and interact with older people in the following areas:

- Food insecurity
- Homelessness and housing insecurity
- Intellectual and developmental disabilities (IDD)
- Island communities
- Kinship care
- Legal issues
- Long-term care
- Low income
- Refugees/asylees

Qualitative Analysis

Four members of the research team conducted thematic analysis using NVivo 20 to identify common themes across listening session, focus group, and key informant interview qualitative data sources. Two of the researchers are subject matter experts in the field of aging. The team used a consensus approach to develop the codebook and each member test-coded two key informant interviews to determine level of agreement (inter-rater reliability) across coding.

NVivo defines percentage agreement as the number of content units on which coders agree, divided by the total number of units and reports this as a percentage. The test coding showed high inter-rater reliability, indicating that the research team agreed with the thematic coding. The team updated the codebook based on discussion of the test coding and transcript review, and two coders were assigned to each of the remaining qualitative data sources. In our analysis, we achieved over 90% agreement across all codes and sources indicating a robust understanding of the issues and themes presented in the interviews, focus groups, and listening sessions.

Quotes used throughout the report have been lightly edited as needed for clarity.

Statewide Surveys

Aging Survey

In conjunction with the USM Survey Research Center (SRC), project staff conducted a statewide survey of adults ages 55 and older. Using the same survey questions as in the 2019 needs assessment aging survey, primary topic areas included transportation, housing, food and nutrition, health status, information and services, and community. New topics included the impact of the COVID-19 pandemic, emergency preparedness, feeling respected in one's community, and employment and volunteering.

Methodology

Distribution

The statewide survey was distributed in several ways. First, it was distributed by mail to a sample frame of 15,000 individuals ages 55 and older. This random sample frame was obtained from Dynata and included names, addresses, and phone numbers when available. A total of 3,000 records were requested from each of five geographical areas. These areas correspond roughly to the five AAA service areas:

- Aroostook Agency on Aging: Aroostook County
- Eastern Area Agency on Aging: Hancock, Penobscot, Piscataquis, and Washington Counties
- Seniors Plus: Androscoggin, Franklin, and Oxford Counties
- Southern Maine Agency on Aging: Cumberland and York Counties
- Spectrum Generations: Kennebec, Knox, Lincoln, Sagadahoc, Somerset, and Waldo Counties

Those who received the mail survey were given the option of completing the paper survey and returning it in a postage paid envelope or accessing an online (Qualtrics) version using the provided QR code or link. The survey was also distributed by flyer. These flyers, describing the survey, likewise included a QR code and link for online completion and were provided to 232 town offices across Maine. Flyers were also posted to the OADS listserv and given to the AAA agencies to post. Data collection across these methods began on August 29 and continued through November 2, 2023.

Follow-up calls were made from September 18 to October 7, 2023. These calls targeted demographic groups that were underrepresented in the data collected to date. Interviewers asked respondents if they remembered receiving the mailing and encouraged them to complete the survey if they had. If they did not receive the survey, interviewers offered to email a link to the online survey. If respondents asked if they could do the survey over the phone, interviewers complied. Roughly 100 hours of calls were made to approximately 2,700 respondents.

The final sample of 3,094 surveys comprised 2,358 mail surveys (76%), 564 online surveys from flyers (18%), 145 online surveys from mailing distribution (5%), and 16 (.5%) phone surveys from follow-up calls made to the mail distribution. Thus, 82% of responses came from the random sample frame.

Because Dynata estimates an 85% deliverability rate, the response rate to this distribution was 20%.

Mail surveys were scanned using Remark software and were merged with Qualtrics data using SPSS software. To determine which surveys should count as completed, core questions were identified. Core questions were those that were asked of everyone—those not part of a skip pattern. Demographic questions were not considered core except for county. Surveys that were at least 75% completed across these core questions were counted as complete and included in analysis.

Weighting

Some counties were oversampled to obtain enough responses to present findings by agency. Responses were then weighted to be representative of the state in terms of county, age, sex, and income. Weights ranged from 0.14 to 5.11.

Caregiver Survey

Using the same questions as in the 2019 needs assessment caregiver survey, we asked about the relationship of the caregiver to the care receiver, how much and what type of care was provided, if caregiving had impacted the respondent's work life, and caregiving stress and strain. A new question on remote caregiving was added to help understand the different modalities of care that many adults provide to their loved ones.

Methodology

Distribution

The caregiving survey was distributed as both a standalone caregiving survey and as a section of the larger statewide survey, and both surveys were distributed in several ways. First, the standalone survey was distributed by mail to a sample frame of 5,000 individuals ages 45 and older, and the statewide survey was distributed by mail to a sample frame of 25,000 individuals ages 55 and older. These random sample frames were obtained from Dynata and included names, addresses, and phone numbers when available. For the standalone survey, a total

of 1,000 records were requested from each of five geographical areas, and for the statewide survey, a total of 3,000 records were requested from each. These areas correspond roughly to the five AAA service areas described above.

Those who received the mail surveys were given the option of completing the paper survey and returning it in a postage paid envelope or accessing an online (Qualtrics) version using the provided QR code or link. The surveys were also distributed by flyer. These flyers, describing the survey, likewise included a QR code and link for online completion and were provided to 232 town offices across Maine. Flyers were also posted to the OADS listserv and given to the AAA agencies to post. Data collection across these methods began on August 25th and continued through November 2nd.

The final sample of 627 surveys comprised 418 statewide mail surveys (67%), 108 online aging surveys from flyers (17%), 47 caregiver mail surveys (7%), 24 online caregiver surveys from flyers (4%), 19 online statewide surveys from mail (3%), and 11 online caregiver surveys from mail (2%).

Mail surveys were scanned using Remark software and were merged with Qualtrics data using SPSS software. To determine which surveys should count as completed, core questions were identified. Core questions were those that were asked of everyone—those not part of a skip pattern. Demographic questions were not considered core except for county. Surveys that were at least 75% completed across these core questions were counted as complete and included in analysis.

Weighting

Some counties were oversampled to obtain enough responses to present findings by agency. Responses were then weighted to be representative of the state in terms of county, age, sex, and income. Weights ranged from 0.07 to 9.59.

Part Three: Findings Across all Sources

As the project team reviewed the broad, diverse, and often achingly candid information collected from older adults across the state, a hierarchy of needs emerged: those that represent 1) the **critical needs** of people as we age that pose current or impending danger to individual health and safety, including needs that might trigger severe or tragic outcomes; and 2) those that represent **important needs** impacting the quality of daily life in important ways, though may not be particularly hazardous.

We also heard dozens of stories about situations where a single unmet need or overlooked condition unleashed – or could unleash - a cascade of hardships, bad outcomes, increased hazards, health risks, or significantly reduced quality of daily life. These **intersecting needs** are often nuanced, less visible or entirely invisible to others (e.g., family, service providers, volunteers), yet they require attention so that preventive strategies can be taken to avoid undue distress, harm, and financial and emotional burden.

This Findings section is organized according to each of these three categories and includes stories and lived experiences shared across all data gathering activities and in each of needs assessment domains.

Critical Needs

CRITICAL NEEDS are unmet needs that threaten individual life and health status.

Across statewide conversations, participants repeatedly mentioned the many instances where critical needs were not met. Many others expressed worry or outright fear that a single unfortunate event might deprive them of an essential need, thereby putting their health and life at considerable risk. For some individuals, several critical needs were unmet, putting them at extreme risk for accident, exploitation, or a poor health outcome.

Health

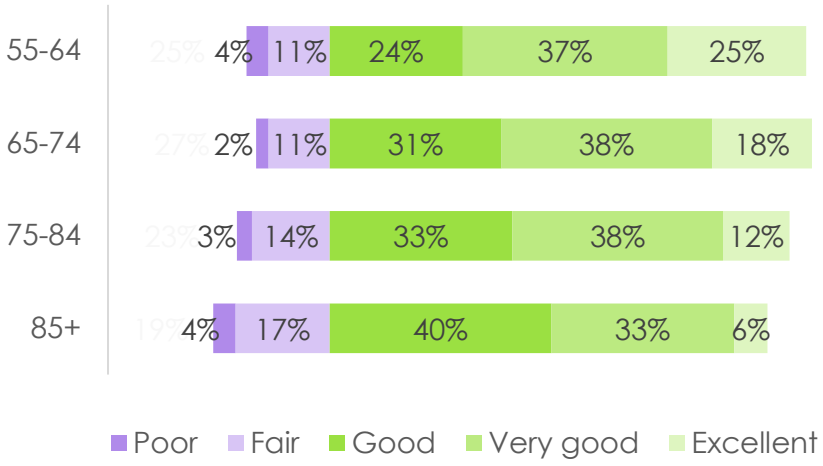
Snapshot

CRITICAL HEALTH NEEDS include decreasing delays and disruptions in care due to labor shortages, addressing ageism in the downplaying of health conditions, increased availability of trauma-informed care, greater access to affordable oral health care, and attention to fall prevention and care.

Wellness

While many older Mainers report Good, Very Good, or Excellent health, 17% of people 75–84-year-olds and 21% of adults 85+ report Fair or Poor health. These individuals are likely at greatest risk that some event or circumstance in any domain of daily life will trigger a critical health need (Figure 13).

Figure 13 Twenty-one percent of adults 85 and older are in fair or poor health.



While participants in listening sessions and focus groups often discussed their health worries in the context of not being able to access the care they needed and wanted (see **Workforce**), some were quite open about their specific health conditions and their fears. “I have kidney failure, and they said I had heart problems. When I went to the doctor, they said I was fine. I got upset and the doctor was mad at me because I confronted them. I need a kidney transplant, but they sent me to a heart specialist when that is not the problem. I am not getting the care I need.”

Several people responding to the open-ended survey question about what would make things better for you, stated they wanted better health: “more pain management”; “my back is destroyed”; “not being in chronic pain”; “greater physical mobility”; “fewer medical issues”. Almost 20% of survey respondents (582) reported they had fallen in the last six months. People who had recent falls were more likely to self-report their health status as fair or poor. While it is not possible to know from these data whether fair or poor health was a contributing factor to the falls, or vice versa, older people who have fallen may need a variety of health, environmental, or care interventions to stabilize or improve their health status.

And while only 3% (99) of survey respondents stated that in the last six months they had gone without medications because they could not afford them, this intersection of health conditions and financial precarity often generates critical needs that directly impact health status and outcomes. For older people earning less than $20,000 per year, 12% report poor health and 28% report fair health, as compared to 1% and 4%, respectively, for those earning over $75,000.

> I need dental and hearing aid assistance. It is too expensive to even consider seeking help to resolve. My eating problems are due to missing and rotten teeth. I need dentures but I cannot afford them.
>
> **SURVEY RESPONDENT**

Workforce

The lack of access to providers, the ubiquitous staffing shortages in healthcare, and the overall unavailability and affordability of services, was raised in nearly every needs assessment conversation. Despite efforts to focus on positive aspects of healthcare (see **Strengths and Opportunities**), participants often opened the discussions with deep fears and concerns about getting the health services they need.

Focus group and listening session participants consistently and repeatedly spoke of long wait times, sometimes months, to get primary and specialty care in Maine. Older adults in rural areas described having to travel several hours to urban centers for specialty care and preventive screenings like colonoscopies, requiring transportation and in some cases, an overnight stay, particularly for islanders in the off-season when ferry schedules are infrequent or weather interferes. Workforce shortages in medicine have resulted in decreased continuity in provider relationships with some saying they see a new primary care provider every time they go to the doctor. Participants across the state wished there were

more geriatricians and other providers who understood the unique health needs of older people.

Provider shortages result in delayed or disrupted care which, for many, precipitated worsening health and poor outcomes. The lack of communication between and among providers, and the absence of healthcare navigation services, leaves older adults having to manage their own care at times, often when they are least able to do so, as one key informant said, “The best case [is] when we can involve a Community Health Outreach worker, who is there to answer questions, who's available to help them navigate. But there is a lot of healthcare navigation support that's needed with this population.”

Non-English-speaking older people expressed concerns about follow up care, and several specifically noted they were prescribed medication without clear end dates or instructions. Others were ineligible or unable to coordinate or afford necessary care for serious conditions, such as kidney disease, in a timely manner and suffered as a result or have significantly shortened life expectancies. “I was diagnosed with stage 3 kidney disease and had to wait 9 months for a consultation with a specialist in Portland”.

Ageism

There are circumstances where ageist attitudes toward older patients result in serious or life-threatening situations. Several older people described feeling that providers discounted their health conditions. This was particularly the case for those 85+ as described by several caregivers who were unable to effectively advocate for care for an aging relative, despite considerable effort. One caregiver described being treated like a “helicopter daughter” by the physician even though she was advocating for her mother’s clear wishes who, “by the way, was playing the piano until two weeks before she died.”

> With my mom, you go into the doctor and it's like, 'She's in her 90's, we'll just put a 'Band-Aid' on it because she's probably not going to be here much longer.' That's how she feels, and it's really hard because she's extremely intelligent, she lives by herself. They don't look at the longevity of her family and that her sisters lived to 103 and 108. She still has a lot of years left and she should feel that they care about her and her medical needs.
>
> **FOCUS GROUP PARTICIPANT**

Trauma

Key informants spoke of the lack of trauma-informed, sensitive care that older immigrants, refugees, and asylees receive in our US healthcare system. Many of these older adults have left war, deprivation, suffering, and some have left children and close family members behind in their home countries.

> A lot of them are shocked. A lot of them have health problems, a lot of them have been traumatized. These folks tend to struggle a lot, especially if they're arriving alone.
>
> **KEY INFORMANT**

Oral health

The lack of oral health providers came up in several conversations. Older adults are frustrated that they must often travel long distances to get oral health services or, if it is nearby, it is unaffordable or hard to get appointments. A few key informants noted that lack of oral healthcare is also a barrier to other critical health treatments, such as cancer care. "A lot of my cancer patients can't get their

treatment unless they have dental work done. And that's a huge problem for a lot of cancer patients, because they don't have the funds to get the dental work done, and it delays them from getting their treatment."

> A big challenge is being on MaineCare and Medicare and not having dental insurance. Even though, there are ways that MaineCare can help with dental, there are no dentists where I live in Knox County. I'm a Mainer who grew up in Bangor, always had dental care as a kid and as an adult I worked full time and had benefits. That ended because of an illness and now it is very difficult. I have spent thousands of dollars on dental care because there are no dentists within a 50-mile radius.
>
> **LISTENING SESSION PARTICIPANT**

When asked about dental problems, 12% of survey respondents stated their tooth or mouth problems make it hard for them to eat. And we heard from many more focus group and listening session participants who simply want to stay on top of their oral healthcare to prevent serious problems. The lack of providers in rural communities around the state makes that unattainable for many.

Technology

With the increased use and user-friendliness of patient portals, many older people could be better supported in managing complex or multiple health conditions if the technology was more affordable or accessible to them. Older patients who do not use technology or who do not have reliable access to online health information may be deprived of the opportunity to benefit from care coordination and navigation pathways that accompany health technology. One adult daughter witnessed her mother struggling with coordinating many specialists and suggested use of the patient portal, but the mother was a "deer in the headlights" at that suggestion. Continued efforts by agencies to make even incremental progress with technological literacy would help many older patients.

> Not everyone has a computer or knows how to use one. I'll give my parents as an example. They are in three different systems for healthcare. They see specialists in Boston, Bangor, and their primary care is here. And the three systems don't talk well to each other. I spoke to my mother and said, we need to get you on the patient portals. Her eyes got that deer in the headlights look - that was a struggle. And while I can help her with that, not everybody has someone to ask for assistance. Not everybody knows where to go for assistance.
>
> **LISTENING SESSION PARTICIPANT**

Housing

Snapshot

CRITICAL HOUSING NEEDS include the availability of safe and suitable housing, the affordability of housing and associated taxes, the affordability of major housing repairs, relief from no-cause eviction from current housing, and housing that is inaccessible in fundamental ways (e.g., bathrooms).

Availability

For an increasing number of older Mainers, the lack of available housing or the threat of eviction without cause precipitates a crisis where there are virtually no available housing options. Unhoused older people resort to shelters or temporary housing with friends or relatives which, in turn, often generates conflict and even abuse. In these situations, healthcare is disrupted, and physical and mental health can decline rapidly. Many older individuals with mental health conditions or unaddressed habitual behaviors (e.g., hoarding, smoking, outbursts) are

targeted for eviction by property owners, and no-cause evictions leave attorneys with few options to prevent the eviction.

Key informants reported that there are more frequent calls for housing needs given the current highly competitive market where property owners are easily able to charge higher rents to individuals who present fewer challenges. No-fault evictions leave older Mainers open to discriminatory rental practices resulting in housing disruption with very little notice and few options. Some unhoused older people resort to living in their cars which, in the winter months, can be deadly. They may be forced to give up beloved pets, have little access to healthy food, health and personal care, and communication with family, friends, and services is interrupted.

Affordability

Just over 16% (485) of survey respondents indicated that their home does not meet their current needs. Unaffordable repairs, home modifications, heating or cooling expenses, and taxes are the primary reasons housing does not meet the current needs of older people. Twenty-seven respondents offered additional reasons, including: inability to find tradespeople; housing that is too big for current needs; bad water; no laundry; fear of neighbors; long driveway that is hard to navigate; on waitlist for older adult housing. These and similar concerns were also raised in the focus groups and listening sessions. As noted in the quote below and in **Important Needs**, the worry is that minor home repairs left unaddressed for long periods inevitably become critical health and safety needs for the homeowner. Not being able to afford or find help for home repairs can turn disastrous, particularly in Maine's harsh winters.

> The main thing that's worrying me is I didn't have my chimney relined. When I bought the house, the contractors report said it should be relined. It's not being used for fires, but the exhaust from the oil heater in the basement does go up through the chimney. I got bids that came in around $12,000. I don't have that so I'm not doing it. Though I know it should be done. I have carbon monoxide detectors, but it's an odorless gas. So that's on my mind. But it goes to the bottom of the list.
>
> **LISTENING SESSION PARTICIPANT**

Survey responses confirm that a troubling percentage of older people (12%) fear losing their current housing for any reason. Over 300 respondents offered reasons for their fears, nearly all of which had a financial component such as cost of living, fixed income, real estate taxes or insurance is too costly, rising rent, possible divorce, or death of spouse, cost of upkeep, maintenance, and chores. Others mentioned that the property owner might sell the property; concern about their own health; and the possibility of losing subsidy eligibility.

Alarmingly, nearly half (49%, 1,460) of survey respondents indicated they would not have other options if they lost their current housing.

> Rising taxes, rising costs, rising grocery costs, depletion of 401(k). Thanks to COVID-19, the housing market, my home was valued at twice its former valuation. Taxes increased over $2000. I bought this house to retire in and it was affordable in 2019, but not anymore. Something needs to be done to help older people to remain in their homes and not drive them out. Eliminate our taxes.
>
> **SURVEY RESPONDENT**

A costly major repair such as furnace replacement was cited as a crisis event, given the few options and high demand for repair personnel and their general lack of responsiveness. Some people need repairs to major systems that are essential for safe living, but they cannot afford them. "I need chimney repairs for proper [fumes] exhaustion, but I cannot afford it." These events are particularly acute for older people who are full time caregivers and may have limited time and attention to find or coordinate repair work.

Maintenance

Home maintenance tasks frequently rise to the *critical need* category given safety and sanitation concerns, both for individual older people and for their service providers and community at large. For example, affordable, reliable snow removal was frequently noted as essential to managing other daily tasks such as getting food, medical care, or getting services delivered (e.g., fuel delivery). Snow removal assistance was also cited as a safety factor related to avoiding falls or shoveling-related injuries.

Similarly, unmanageable maintenance issues such as insect or rodent infestations (e.g., fleas, bed bugs, mice) or hoarding were noted by several key informants as creating unsafe conditions for the older person and as barriers to service entry

since many agencies prohibit workers from entering premises with obvious infestations or worker hazards. Key informants expressed frustration and sadness at their inability to help or recommend effective, affordable, feasible solutions that did not jeopardize the older person's privacy and autonomy. Another noted instances when homes are in such disrepair that repairs can no longer be accomplished. "My roof is rotting, and even more damage is happening. But there's nothing I can do about the process. And I do follow up phone calls. And it's quite exhausting."

Accessibility

Maine's old housing stock presents challenges for aging at home. Many older people spoke about the acute fear of not being able to remain in their homes as their needs increase because they cannot afford home modifications or even if they can, they cannot find workers to do the jobs. Key informants noted many instances where older people could not safely navigate their homes.

> For old houses, we're finding more people are trapped in their homes without smoke alarms, with leaking roofs, or with porches that are falling apart or needing a ramp, but they are not able to afford one. People want to age in their own homes or feel they have to because of finances, so they are kind of trapped without the ability to improve it or make it safe.
>
> **LISTENING SESSION PARTICIPANT**

Older adults at one listening session mentioned that while there were some local programs available to fund home modifications for safety such as portable ramps, "the agency says they're short of staff, short of funds and it's not getting done."

Islanders, in particular, struggle with clutter that presents home safety issues given the cost and logistical challenges of removing unwanted items from the islands. For individuals in rented housing, property owners are sometimes not responsive to making repairs for accessibility. Others noted that older people with existing mortgages often cannot qualify for loans for home modifications given their limited incomes, or if they do qualify, they cannot afford the additional debt service.

Food & Nutrition

Snapshot

CRITICAL FOOD & NUTRITION NEEDS include enhanced nutrition support programs and access to fresh food, especially in rural areas.

SNAP benefits

The increase in SNAP benefits during the COVID-19 public health emergency along with relaxation of burdensome eligibility requirements such as participating in a screening interview offered meaningful relief until the end of the public health emergency in May 2023. However, listening session and focus group participants and key informants in the fields of food insecurity, homeless services, and community action programs said current SNAP benefits are not adequate to meet older adults' needs. New Mainer and Asian focus group participants noted that they had been able to receive food stamps at one time but then became ineligible or that the amount was not enough.

> It's hard to get by on $23 a month in food stamps.
>
> **SURVEY RESPONDENT**

Key informants said that although SNAP is effective at increasing access to food, older adults often don't enroll. Although many of Maine's older adults are eligible for SNAP benefits, some are reluctant to enroll due to the perceived stigma around using food stamps. Changes in eligibility requirements at federal and State-levels also make it hard for older adults to know if they are eligible for help and to access assistance. For older adults with unstable housing, limited phone access, or who have to work, scheduling the required interview is challenging. Listening session participants suggested food pantries could put more effort toward assisting with applying SNAP.

In conversations with older adults, there was broad enthusiasm for the Maine Harvest Boxes that allow older adults with SNAP to purchase produce at farmers' markets at half-price. However, some participants said that using SNAP benefits at some farmers markets was difficult because small farms don't often have the equipment to handle EBT payments, "Only big farmers markets can handle [SNAP EBT cards] because it's cumbersome and expensive to have the right equipment. If that was made a little bit easier, so that even in the smaller farmers markets, people could use their SNAP benefits, and that would make healthy food seasonally a lot more available."

Access to food in rural areas

Across conversations and in survey responses, older adults said they wanted better access to nearby grocery stores. Key informants and listening session participants said that the corner stores in rural communities and islands have limited and often expensive food options, "I heard an islander once say, 'I can get a jar of caviar on my island, but I can't get a can of tuna fish.'" On the mainland, older adults in rural areas must often travel to larger towns to grocery shop. Transportation challenges can complicate this regular activity, and survey respondents worried that when they can no longer drive, they will not be able to grocery shop.

Transportation

Snapshot

CRITICAL TRANSPORTATION NEEDS include scheduling transportation when an older adult no longer drives, rural access to transportation, public transportation improvements, and more and better maintained sidewalks.

Transportation is key to older Mainers' ability to remain safe and healthy in their homes and communities. In statewide conversations and surveys, older adults consistently raised their current or future lack of access to transportation as a significant source of worry, and few have a plan in place if the need arises.

> For driving, it's been the head in the sand sort of approach to looking at the future on that particular front.
>
> FOCUS GROUP PARTICIPANT

Many older adults (including nearly 20% of survey respondents) have friends and family to meet their transportation needs. But many are also concerned about burdening others. Those without friends or family have limited options, especially outside of more urban areas. Over 300 survey respondents said better access to public transportation, transport services including CAP agencies, Lyft, or Uber, or improved sidewalks and bike paths would make aging in their home or community easier.

Scheduling alternatives to driving self

When older adults cannot drive themselves and have limited access to public transportation, they must devote considerable time arranging rides to medical appointments, shopping, and socializing. Transportation to MaineCare-covered

appointments is provided through one of three transportation brokers in Maine. Across statewide conversations and surveys, participants said the two-day advanced notice requirement created challenges in scheduling rides when they were needed. Participants said they often had to wait for their ride to show up either to take them to their appointment or bring them home.

The scheduling process and having to document the appointment adds complexity to arranging for a ride to the doctor. For older adults with chronic health conditions or behavioral health needs requiring multiple weekly appointments, the scheduling process can be overwhelming. Service agency key informants said they act as case managers to organize rides for clients, "We're very thankful that option exists, and it certainly works –when it works. But it requires a case manager to manage it – to call the number, wait on hold, fax the appointments." For individuals dealing with homelessness or who have limited access to reliable phones or internet, the management of this MaineCare benefit is overwhelming. Some listening session participants noted that they make too much to qualify for MaineCare but not enough to pay for other types of transportation services themselves.

Across statewide conversations, participants said some non-medical transportation services provided through CAP agencies required a three-day notice, limiting their utility for older adults needing to get somewhere quickly that isn't a medical appointment. Others said that volunteer drivers with the CAP agencies do not always have accessible vehicles. Although CAP agencies may have wheelchair accessible vans, sometimes there is not a qualified driver available. CAP agency transportation programs can also be affected by limited funding. One listening session participant gave the example of a CAP agency running out of funding before the end of its fiscal year, creating a "mad scramble" to find alternative accessible transportation for an older adult who needed twice-weekly wound care.

Rural transportation concerns

Older adults in rural areas have limited alternative transportation options. Listening session participants noted that availability of volunteer-based systems in rural areas can be affected by downturns in volunteerism or a lack of recruitment of drivers in these areas. As described earlier, rural Mainers sometimes must travel long distances to specialist care, incurring increased expenditures in fuel and lodging costs.

Rural older adults also worry about what will happen in the future if they are unable to drive. Some said they might consider moving to a more urban area to be closer to services and transportation. Others said they had purposely moved to rural Maine to be away from cities and had no intention of moving, but they also said they did not know what they would do if they could not drive anymore.

> We live way out in the country. And my ability drive is quickly coming to an end. We have nobody to fall back on to drive. I'm going to be concerned about our transportation.
>
> **LISTENING SESSION PARTICIPANT**

Public transportation

Across statewide conversations, participants consistently raised the lack of public transportation as a need. Public transportation options help older adults preserve their independence and decrease the need to rely on family or friends for rides. Dependable, routine schedules allow older adults to plan their activities around available transportation options rather than having to cobble together other transportation to meet the schedule of the activity. Over 100 survey respondents across the state said access to or improved public transportation would make their lives easier, “Access to public transportation, even once a day would be ok.”

In listening sessions and focus groups, some participants said their communities had public transportation but that the stops were too far from their homes or destinations to be useful. Older adults with mobility challenges have difficulty walking to and from bus stops.

Asian focus group participants said they would use public transportation, but the bus schedules and routes were not printed in their language (Khmer). Although one key informant praised the Portland Metro for its multilingual materials and bus ambassador program that teaches people how to use the bus, some New Mainer focus group participants said they had encountered drivers who did not lower the step for them to get on, making them fearful of falling.

Sidewalks

Sidewalks are a significant part of the transportation system for many adults. Eleven percent of survey respondents said they walk or ride a bike to get where they need to go. This varied by age, but the only significant drop was in the 85 and older age group. Walking and riding bikes also varied by county with 19% of Cumberland County respondents saying they walk or bike compared to 3% in Somerset County (see **Figure 34** in **Part Seven: Survey Results**).

Across conversations, many people said they wished there were more sidewalks in their area or that they were kept in better repair and had better ice and snow removal. A key informant representing homeless services said that when transportation services are limited to medical appointments, people without alternatives must walk everywhere else. When sidewalks are in disrepair or there are no benches for resting, older adults are at risk for falls and injuries. A listening session participant echoed this, “I think having safe sidewalks is number one for me where I live. It can be very dangerous, and it is a health issue.”

Safety

Snapshot

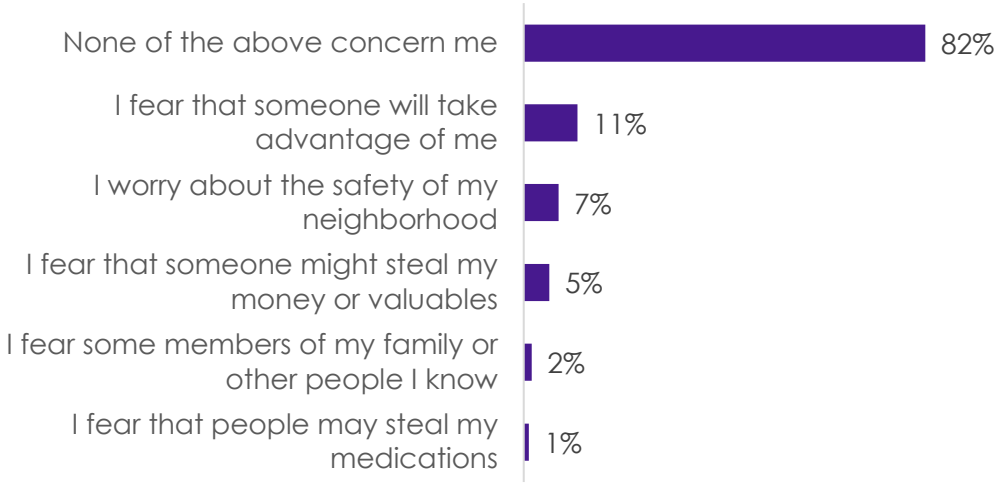
CRITICAL SAFETY NEEDS include physical safety related to having health and housing needs met, and concerns about inadequate police presence or response. Financial safety needs include being free from exploitation and online and text scamming.

Physical safety

While many older people noted unsafe situations that felt threatening to their life or health, these were primarily situations related to the lack of available or timely health services or unsafe housing issues (see **Health** and **Housing** in **Critical Needs**). A limited number of listening session and focus group participants mentioned feeling unsafe due to the risk of criminal activity, though these comments mostly faulted poor police presence or response in their community. Poor police response could be related to post-pandemic, persistent labor shortages or to ageist beliefs and behavior. One participant noted that there were insufficient state police to respond to needs across an enormous county, and this made them feel very much at risk.

Although most survey respondents did not have safety concerns, a notable number of survey respondents (7%, 214) do worry about the safety of their neighborhood, and 5% (158) fear that someone will steal from them. Two percent responded they are afraid of family members (Figure 14).

Figure 14 Most older adults do not have concerns for their safety, but 18% do, n=3,028.



Financial safety

Older adults consistently noted their frustration with the ubiquity of telephone calls and text messages from scammers. While for many these calls were annoyances, for some they represented a very real threat to financial security; "financial safety is a huge concern." Many older Mainers knew people – sometimes their own parents or relatives – who had been scammed out of considerable assets. Older people with cognitive changes are particularly susceptible. Even young older people with long experience with sophisticated technologies expressed frustration at not being able to distinguish between real calls or texts, from their bank for instance, from scamming communications. One adult daughter noted "my mother wants to donate money all the time." Several participants mentioned that there isn't enough training on internet security for older people; that it seems more geared toward younger people. "Advice would be very helpful because we are so afraid and so vulnerable to scams."

> My mother wants to donate money all the time.
>
> **LISTENING SESSION PARTICIPANT**

Several adult caregivers noted that older people are using the internet for socialization and for home-delivered items – in ways that meaningfully improve their daily lives – and yet that puts them at substantially greater risk for online scamming. Older people mentioned that there are so many scams and robocalls that "we don't even answer the phone anymore," which, in turn, puts them at risk for greater social isolation or missing important calls.

Caregiving

Snapshot

CRITICAL CAREGIVING NEEDS include easing emotional and financial hardship resulting in exhaustion and helplessness and the burden of managing highly complex health needs.

Emotional burden

Many caregivers spoke about the anger, sadness, exhaustion, and frustration they felt with caregiving responsibilities that interfered with their ability to work, socialize or, alarmingly, tend to their own health needs. These caregivers expressed deep emotion during these conversations; "every day is a living nightmare." Several specifically noted that the lack of care help in their communities has contributed to declines in their loved one's health and their own. Even placing family members in long-term care communities did not relieve the burden and feelings of extreme stress; in fact, one adult caregiver thought it was more burdensome to have family in a care setting because it required navigating "a middleman," "The burden of supporting anyone, even though I was a trained person, put me on my butt." Caregiving family spoke of how hard it is to

navigate issues in care settings such as staff shortages, high turnover, and even daily services like "the food being served…it becomes very stressful and complicated."

Older adults caring for young grandchildren worry about their own health given the effort and stress of caring for and keeping up with the needs of young children and the grief and loss accompanying the mental health issue or, often, the death of their own adult child. Kinship caregivers sometimes comment "'At my age, with my health conditions and the behaviors of this child, should I be taking this on?'" Similarly, older adults caring for their adult children with IDD or other disabilities worry not only about their own need for care as they age but also for their children who may have significant needs.

Several caregivers spoke in terms of feeling "helpless" in the face of caregiving duties. "I have struggled through it for past several years, I've had a lot of sleepless nights, and a lot of less-than-happy feelings and that this is a helpless situation…And it seems to me people should not have this much difficulty when they need help."

> We can do a lot - and sometimes we have limitations ourselves on our time, or knowledge. We do the best we can. You don't want to abandon your parents or anybody you're caring for, but you have to have your own life to take care of in the meantime.
>
> **LISTENING SESSION PARTICPANT**

Financial burden

Several older adults and key informants discussed the financial impact of caregiving, which often interferes with paid employment and requires relying on the caregiver's personal finances to cover myriad daily expenses. "There is a lot of unpredictability in the amount of time and money and intensive care at the end of

life. It just makes for a lot of uncertainty." One adult child commented on the financial burden of putting gas in her car to take her mother to respite care in the afternoons, stating that when her mother was in the hospital for two weeks, she saved a lot of money on food and gas. These comments are harsh reminders of the many family caregivers who are living in financial precarity in large part resulting from caregiving obligations.

> Family members are not able to work as much because they're providing that care, when then causes them to be behind on bills. What I see is that caregiving takes away from the ability to work and make a decent wage. If they do get reimbursed, it's not enough for a livable wage so then they have to maybe move in together or get some type of accommodation with their housing to live together. The financial impact is the biggest impact I see.
>
> **KEY INFORMANT**

Complex care

The issue of caring for those with complex health needs arose primarily in the context of the island communities where residents must rely almost exclusively on one another for help and support during difficult times. When older islanders with complex needs wish to remain on the island, key informants expressed the difficulty of finding neighbors and friends willing to provide high levels of what is often difficult clinical care. "Islanders are already pretty stretched…and they are just sort of surviving day to day. And so, adding [complex care] on top of everything that they already do, is as a big ask."

Socialization

Snapshot

CRITICAL SOCIALIZATION NEEDS include resuming activities in a post-pandemic environment, transportation alternatives to social activities, and reassurance check-ins.

Many older adults described a continuing need for social opportunities as they age but increasing difficulty in finding and accessing them. Across all survey respondents, 20% said they had *Sometimes* felt lonely or disconnected from other people in the last six months, 5% said *Often*, and 1% said *Always*. Feelings of loneliness and lack of connecting increased with age with over one-third of 85+ year olds saying they were lonely *Sometimes*, *Often*, or *Always* (see **Figure 36** in **Part Seven: Survey Results**).

COVID-19

A key factor limiting socializing identified in discussions and the survey was lasting impact of the COVID-19 pandemic. Older adults and key informants said some previous social opportunities before the pandemic were no longer available or were not as widely attended. Discussion and survey participants cited fear of catching the virus as a reason they no longer attend social activities in the community or large gatherings. Some said that online social opportunities have helped them feel connected. Others said the technology is too difficult for them to use, their internet is not reliable enough, or that online meetings do not provide the same level of connections as in-person gathering. Most survey respondents who said that online meetings with friends or family had improved since the pandemic were 55-74 years old. “I tell people about the iPad from Agency on Aging and that it is a lifesaver for me to be able to interact with people on a safe level. You have total control over how much give and take you do, and you get to meet people from everywhere, all different walks of life.”

Transportation

Another key factor limiting socializing was not having transportation. Focus group and listening session participants said they would like to participate in social activities in their communities or visit friends and family, but without transportation, they were unable to go. Some participants said their church helped them with transportation to services, but others whose churches are outside their local community have more difficulty.

When older adults must make special arrangements with a family member, friend, or volunteer to get to and from an event, it impacts their decision about whether or not to go at all. One focus group participant worried, "I go to Houlton to go to the [Unitarian Universalist] church. I just can't imagine that I would keep asking my congregation members to do a two-hour loop to pick me up and then go back." Even when older adults still drive themselves to appointments and shopping, some said driving in winter and after dark presents challenges and limits participation in in-person activities.

Check-ins

Thirteen survey respondents specifically said a daily check-in call from someone would make aging in the home and community easier. One respondent's answer was particularly poignant and showed the depth of loneliness and grief experienced by many older adults.

> Having someone visit or call me. My old car is my antidepressant. I've gone days with no one to call & check on me. I would love to find someone to play Scrabble with. My friends are all dead.
>
> **SURVEY RESPONDENT**

Important Needs

IMPORTANT NEEDS are unmet needs that interfere with quality of life and weaken older adult resilience.

Many older adults reported life and health circumstances that, while manageable and not severe, were suboptimal and could, with a shift in circumstances, cause a cascade of adversity. As an example, many older adults rely on one specific person to help with transportation to and from essential services like grocery stores and healthcare appointments. In communities around Maine where there are no transportation options, if this key person becomes unavailable, the older person is put at risk for daily needs and immediately worsening circumstances. Recognizing these shortcomings and supporting older people to create contingency plans offers a safety net for individuals and relieves downstream pressure on systems and services.

Health

Snapshot

IMPORTANT HEALTH NEEDS include system-related issues, technology access, preventive care, culturally appropriate care, and ageism.

System issues

Across the state, older people talked about their many frustrations with what is best described as system-level concerns that impacted the quality, efficiency, or value of their healthcare encounters, thereby putting them at greater risk for poor health outcomes. Older people are dissatisfied with how little providers speak to one another and how difficult it is to coordinate care across the system. For example, managing multiple medications and drug interactions, or the difficulty

of seeing the same provider in a practice and developing a relationship. One person noted that "since COVID, I've probably had six different primary care providers, and I've only met with two of them one time, that's how many times it's switched."

Technology

As noted above, technological innovations like patient portals, though intended to provide patients with quick access to their health information, can be intimidating for older patients with limited computer literacy. For older adults with complex health conditions and many providers, navigation and care coordination inaccessibility could have dire consequences. For others, however, inaccessibility to reliable tech and internet access can make interfacing with the healthcare system that much more difficult. Many older patients know they can benefit from accessing health services online, and they "want better internet access."

Others noted that technologies such as the Apple Watch apps can provide health or safety alerts to the wearer or to a family member. Several adult children wished their older parents had greater access to technology so there were more options for monitoring or providing health-related support. "Maybe the next generation of seniors coming up will be more savvy with the computer, but my mom's age and a bunch of her friends just don't have much of an interest in it."

Provider relationships

Other people described their healthcare encounters as "checking boxes but no real discussion"; that "the average PCP has only 7-10 minutes to see you." Several bemoaned the lack of a relationship with their provider or the lack of geriatric expertise available in their communities or in Maine generally. An adult child caregiver noted that "in the past there used to be geriatric physicians and they seem to care more about the elderly. In my case, my parents have lived to be late

80s, early 90s. And it's just that you just want somebody to be able to have an idea of what they're going through."

Older people with very specific needs, such as those with developmental disabilities, need and want healthcare providers who know them and the very specific health challenges they face. "One problem is that relationship and trust between doctors didn't work, we didn't deal with the trauma of doctors of the past. The other is we never taught doctors how to work with people with developmental disabilities. And that's a pretty important piece."

> And we only have one geriatric doctor in [this community] and that is really not satisfactory. I agree with [X], it's really an issue of quality. It's just a mess and we don't have geriatric doctors. The way I look at it is when we have babies, they have a pediatrician. But when you're older, you're lumped into the general population.
>
> **LISTENING SESSION PARTICIPANT**

Preventive care

The value of preventive healthcare and health services is well documented; when it is free or affordable and when it is easily accessible, it saves lives, reduces suffering, and saves money. Several key informants discussed the importance of removing barriers to preventive care; for example, establishing a program for older islanders to get regular wellness assessments and support for scheduling screenings such as colon cancer screening and mammograms. For many older people who are managing the fulfillment of daily needs, preventive care drops to the bottom of their list. "Preventative care is not there, if it's an emergency you go to the ER. And annual wellness exams are a total waste of time, you can't ask any useful questions."

> It seems like investing in primary prevention would be better than on the back end waiting until someone has a stroke or high blood pressure and gets hospitalized. It's better if we focus on the prevention aspect of nursing and checking in weekly, or twice a month. It's very low cost compared to an ER visit.
>
> **LISTENING SESSION PARTICIPANT**

Culturally appropriate care and ageism

Participants identified not enough tests and too many tests as concerns about their healthcare. Others complained about how hard it is to advocate for oneself as an older patient. What these complaints may have in common is that clinicians are not listening carefully to the wishes of their patients; these annoying features of the healthcare encounters of older people are likely evidence of pervasive, covert ageism that feels dismissive to older people.

> There's a bias against older adults, we're kind of thrown on the back burner. They no longer want to do some of the exams - the colonoscopy, breast cancer exams because you're no longer needing a cure; that's not important. From my point of view, I find that frustrating.
>
> **LISTENING SESSION PARTICIPANT**

Older people for whom English is a second language repeatedly expressed dismay at the difficulty of getting and using interpretation services in healthcare. For some, the language barrier was an impediment to receiving care and for others, it

made healthcare encounters confusing, frustrating, or culturally offensive. Several African immigrants discussed that in their cultures they did not speak about death and that physician conversations about death and dying made them "feel unsafe." Others noted the importance of privacy when talking about various health and safety matters.[v]

Relatedly, some LGBTQ+ older people, particularly trans older adults, expressed frustration with the lack of time available in healthcare appointments to discuss concerns specifically related to gender or sexual orientation. They noted that there was an assumption by providers that patients are heterosexual "unless you say otherwise." They are concerned about attitudes and discrimination by staff and other residents in long-term care settings should they ever have to move into one.

Housing

Snapshot

IMPORTANT HOUSING NEEDS include the affordability of interior and exterior home repairs and chores and the availability of labor for both.

Many of the issues noted under **Critical Needs** can be categorized as *important needs* when they are still at the "inconvenience" stage. Many older people described annoyance at, for instance, not being able to accomplish regular household chores such as cleaning, minor home repairs, or yard work (e.g., lawn mowing, raking leaves). Rarely will the neglect of these household tasks create a threatening or hazardous situation, but they represent a psychic weight on older people, most of whom prided themselves on the state of their homes when they

[v] This comment also applied to discussion during the focus group itself; some participants were unwilling to share health and safety concerns in front of the entire group.

were younger. Further, there is often shame associated with being unable to maintain the look and cleanliness of one's home which can, in turn, impact one's desire to socialize or invite visitors. "I was physically fit to do the lawn mowing, snow shoveling and all of those things that come with year-round living in Maine, but there's no system or wraparound funds for having somebody to come mow your lawn or do snow removal – which are at exorbitant prices."

> Snow shoveling is a huge thing, and getting the driveway plowed. And I have people that will call sometimes and say I can't get out of my driveway, and we you can't get anybody because now most of them are big companies that want a minimum of like $350 for the season, regardless if they come once or you know, 20 times. And a lot of people can't shell that out.
>
> **LISTENING SESSION PARTICIPANT**

Of the nearly 200 survey respondents that specifically mentioned housing-related concerns, many spoke about home modifications and chores as being something that would make their lives easier. "Eventually my husband and I would have to move to a downstairs bedroom and maybe convert our tub to a walk-in shower. This would take money we do not have;" "If I could hire someone for the lifting & climbing that's required for certain household chores such as curtains, shades, ceiling lights. Problems with my legs and feet prevent me from climbing." Another noted, "[I need] someone to help me with chores/repairs, little projects like hanging curtains, fixing things, mowing, shoveling."

Many older people are very aware of the challenges they face if they wish to age at home and some are actively planning. "When I retire, I will have to sell my house in York County because taxes & utilities are too expensive. [I will be] moving to a 'camp' in Franklin County--[there are] fewer services there but it's much cheaper

to live." Others want to actively plan are finding there are roadblocks, "For an elevator or device for access to 2nd floor and basement, I have tried to contact an architect about building changes to our home without response." Another noted: "I have friends needing help…when faced with not being able to find affordable housing." Others have asked for changes they need right now, such as easier access to their mailbox but have not gotten a helpful response: "I asked in the office, they said it was up to the post office."

Food & Nutrition

Snapshot

IMPORTANT FOOD & NUTRITION NEEDS include ensuring food options available through nutrition support programs meet dietary and cultural needs.

Meals on Wheels

Although there are resources for older adults with food insecurity, they are not uniformly acceptable or appropriate for all older adults, limiting their usefulness. Meals on Wheels provides a regular source of nutrition for many older adults. However, several listening session and survey participants said the meals provided were too starchy and did not meet their dietary needs. There may be misinformation or miscommunication about how the meals can be tailored to meet dietary needs and restrictions. Survey respondents wished there was choice in the meals delivered.

Commodity boxes

Key informants said the food available through the Commodity Supplemental Food Program boxes was not always appropriate or acceptable to those who receive them. One example was an older adult with arthritis receiving a box that had included a large turnip – even if the person cared for turnips and wanted to

eat it, preparing such a vegetable would require considerable hand strength and dexterity they did not have. A key informant who works with asylees and refugees said older non-English speaking adults do not eat the canned foods provided in the boxes because they cannot read the labels to know what the product is and if it meets cultural or religious dietary laws.

Cultural preferences

In focus groups, older immigrants said they did not care for American food and missed certain foods from their home countries that are either not available or too expensive. Asian focus group participants said they cannot find winter melon or mustard greens. Somali focus group participants said they can only find frozen Halal meats locally and the only butcher they knew of with fresh goat meat was in Vermont and very expensive. Not having culturally appropriate or familiar foods available impacts overall food security.

Transportation

Snapshot

IMPORTANT TRANSPORTATION NEEDS include affordable options for car maintenance and assistance with winter and nighttime driving alternatives.

Affordability

The cost of car maintenance and gas was brought up in several listening sessions and survey respondents. For older adults with limited and fixed incomes, even if they can drive, their ability to afford routine maintenance, fuel, and taxes , let alone a major repair may be at risk. Being unable to afford the car repair might be the precipitating factor in losing their ability to drive, and as described in **Critical Needs**, alternative transportation options come with some significant challenges.

Winter and nighttime driving.

Even when older adult still drives, environmental conditions may impact their driving ability. Listening session and focus groups participants said driving in the winter, especially in rural areas, or at night is challenging, and there are few, if any alternatives.

> AAA [American Automobile Association] recommends that we do not drive at night. They're very realistic about that, and I appreciate that they're honest about it, it does limit what activities I can attend. I don't drive at night, but I miss it. And I don't have a solution to that.
>
> LISTENING SESSION PARTICIPANT

Safety

Snapshot

IMPORTANT SAFETY NEEDS include the reliability of local police presence, changing demographics (i.e., fewer young people), and the issues of psychological and emotional safety as an older person.

Police presence

While safety issues are almost always in the *critical needs* category (**Safety**), across the state many older people expressed more general safety-related concerns reflecting system-level attention. For instance, dozens of survey respondents and several listening session attendees mentioned they wanted greater local law enforcement presence and response and they worried that it was – or would be – inadequate for when help was needed. “I want my town leaders to enforce litter/junk control in people's yards and make people repair

ramshackle houses…and ensure a 24-hour a day, 7-day a week police force in [my town].” Another stated: “We need stronger police presence.” And another noted they want “police actually giving tickets for speeding and tailgating.” Typically, there is a high level of trust between town officials and older Mainers and the many comments of older people otherwise may reflect shifting attitudes possibly related to pandemic conditions, increased levels of ageism, increased numbers of older people, or myriad other factors.

Troubling demographics

A few mentioned the discouraging demographics, including the out-migration of younger people and Maine’s failure to attract young and middle-aged people to help support those in later life. Many more expressed that finding young people willing to provide household help and chores would make their life much easier. For instance, one stated that we need “a central listing of young people and teenagers willing to volunteer or do services for pay.” And a few spoke about wishing their own younger family members were nearby to help out.

Cognitive, emotional, or psychological safety

Almost a quarter of survey respondents (23%, 702) indicated they had concerns about their own memory, and a handful of open-ended responses noted worries about cognition—“better diagnosis of cognitive difficulties.”

Some listening session participants mentioned that healthcare providers are often inattentive to the cognitive side effects of many medications, which is particularly problematic for older people who are still working and may not want to disclose their health conditions or ask for accommodations. As greater numbers of older people delay retirement or return to the workforce in later life, there should be heightened awareness of the need to discuss medication side effects and available options.

> My husband was sitting with the two neurologists who were blithely describing the side effects if his medications as if, because he's 76 years old, they aren't an issue. A couple of times he tried to say 'my work requires that I not have these kinds of effects. Can you offer me something that is going to allow me to maintain my ability to work?', but they were just dismissive of his request.
>
> **LISTENING SESSION PARTICIPANT**

Adult children of older adults experiencing cognitive changes spoke about their own worries because the parent no longer reliably answers the phone or sometimes forgets how to use the phone. "Often when we call, there's no answer, and it's not that she's not there, it's that she doesn't understand how to answer the phone." For caregivers not living with the care recipient, changing cognition and function precipitates concerns about safety and about what services, living arrangements, or additional care and oversight may soon be required.

Some older people expressed frustration that health and service providers don't take a more strengths-based view of aging and that they sometimes view older people as not, for instance, amenable to learning new things. "There's a lot of pernicious ageism, sort of under the rubric of, you're too old to learn new things. As an elder myself, learning is at the core of my aging plan. I really wish the agencies could look at aging not as of an inevitable problem to struggle with, but rather as something to become competent in; learning how to age."

Several older people and some adult children of older parents called out healthcare providers who are insensitive about either including or excluding the older patient in the conversation. Some adult children were put off by the elderspeak of many providers, and others expressed concern that when providers only speak to the older patient, they do get reality-based information due to cognitive changes. "They ask her questions she can't possibly answer. And so, she

gives them a sunny, cheerful answer that isn't connected to reality. They should know going into an appointment, who in fact, will have the actual information [needed for treatment]."

Caregiving

Snapshot

IMPORTANT CAREGIVING NEEDS include shifting family roles and training and competency of home care staff.

Role shifting

One of the less-discussed consequences of caregiving between older people and their spouses or their adult children, is the shifting of roles. The consuming responsibilities of providing care distort the parent-child relationship or the spousal relationships or the grandparent-grandchild relationship, causing anger and resentment.

> For grandparents who have taken over the care of their grandchildren, for example, there's a role shift where you don't get to be the grandparent anymore; you have to be the parent. And there's a similar shift when you start caregiving for a relative. You don't get to be a daughter anymore. I'm a case manager; I'm a bill payer; I'm all these things. It's very stressful, feeling like the wellbeing of my parents is on my shoulders.
>
> LISTENING SESSION PARTICIPANT

In addition, caregivers must navigate nuanced interactions with health and service providers. There can be a tension between engaging an older patient with cognitive change in a dignified way and recognizing the obvious reality that it is

the caregiver who has information clinicians need and who is charged with making medical and other decisions for the older patient. One service provider noted that we need training on shared decision-making; “for providers, for community members, and caregivers, so everybody's involved in the conversation, and everybody has a voice, and the center of the bubble is the patient. [Let’s] look into to bringing to an educating our communities, caregivers, patients and providers.”

Comments from caregivers across the state confirm that as a society we are still working out how best to interact in these encounters so that all needs are met. “I've heard of stories where doctors don't know how to take care of their parents. Nurses don't know how to take care of the elderly sister and that kind of thing…there's no immediate answer so we have to keep talking.” “We [caregivers] have a common thread; we are bound together in our struggles and challenges.”

Training

A few caregivers spoke about the need for other caregiver training topics, both for themselves and for care workers in long term services and supports including long-term care settings and home care, particularly when the older adult has behavioral health needs. “I'm not sure there's specialized training out there, even a doctor or a nurse will run up against challenges in a caregiving situation. Because you're dealing with individuals, people have different personalities and different health issues.” For kinship caregivers, there is the concern that if they express to service providers that they need more training to deal with behavior issues, they will be reported for being unable to care for their grandchild who might then be put into foster care. As a result, kinship caregivers are in a bind – sometimes feeling ill-equipped for the enormity of the task, yet unable to safely ask for help and support.

Some family members witnessed poor care in nursing homes and attributed some of it to lack of training. When asked about healthcare worries, one focus group attendee reported witnessing care staff pulling on their “mother’s arms and

hurting her…the CNAs are not taught properly and need better training." Another noted that volunteers doing community service work "just don't have the capacity or the training to do what they need to do."

Socialization

Snapshot

IMPORTANT SOICALIZATION NEEDS include increased opportunities to engage with the wider community as well as within special population, community-specific groups.

Community-wide options

Across discussions and in open-ended survey responses, older Mainers said they wished their communities had a "senior center" or more age-specific social opportunities. "I would like to see a senior center in this area like I had in Massachusetts. They would give the elderly a place to congregate, talk, play games, have yoga classes, etc. Gave flu and COVID shots, helped seniors with doing their taxes, etc." Some survey respondents specified their centers were not very active, "Senior centers are dying because coming-of-age seniors are not joining." Another respondent said, "Actually having an active senior center with an outreach program" would make aging in their community easier.

Other older adults wanted more inclusion in intergenerational community activities. One key informant said older adults with IDD have difficulty accessing social opportunities outside of their group home-planned activities, yet they might have the same interests as other older adults in the community and could be included in community-organized activities.

Community-specific options

In addition to wanting more social activities options in general, some focus group participants and key informants expressed needs for community-specific

activities. For example, older LGBTQ+ adults in Southern Maine noted there were few social or networking groups for lesbians. Rural LGBTQ+ older adults expressed frustration with not being approached by AAAs or community organizations to be included in activities. They also said they wanted younger people to organize Pride Parades and other events as they had done. A key informant said there was need for social activities in languages other than English, especially in senior housing. Social activities organized by house managers tend to be geared toward English speaking Americans, leaving non-English speaking or non-fluent adults out. There is a need for more sensitivity in organizing culturally appropriate activities that all residents can join in.

Finances

Snapshot

IMPORTANT FINANCES NEEDS include the inability to cover basic needs across the domains of daily life and having to make trade-offs among essential items.

Finances was not a separate "domain" in the needs assessment protocols but, as expected, the topic came up in nearly all the domains. The affordability of healthcare, housing, transportation, food, home care and chore work, long-term care – was on nearly everyone's mind. Older people are often making trade-offs among the items or services they purchase – even among essential items such as food and medicine. "I have to get to my appointments. It's really hard. When you can't get any help because, as they say, your income is too high, which is a joke. Managing the groceries, gas, lights - everything has gone up. We can't afford $40 for a [physical therapy] visit."

Low-income older Mainers mentioned cost-related concerns when asked *What worries to you have?* as did key informants for the island communities. "Older islanders could use more resources with heating, for instance. Many heated with

wood when they were younger, but now chopping wood and bringing it in and keeping the woodstove going is too much for them. And transitioning to a different form of heat they can afford is a challenge."

In the open-ended survey responses, over 100 older people wrote in comments such as "bring down prices on food, medications, insurance, home insurance & taxes" in response to the question *What would make aging in your home or community better or easier for you?*

Intersecting Needs

Although we have long known that lacking essential human needs like food or housing precipitates poor health and other bad outcomes, we heard many older people and key informants describe how other less obvious unmet needs often light a fuse sparking a host of problems. Some events are truly unpredictable such as when an essential caregiver is injured and no longer available, but many are entirely foreseeable and preventable, such as snow removal to give access for fuel delivery. There are more older people who need this service and many fewer service providers, leaving older adults to take on the chore of shoveling with its attendant risks, or risk running out of fuel when temperatures drop. Yet, taking care of many of these mundane aspects of life can remain out of reach due to unavailability of services, unaffordability, or lack of ability.

Figure 15 Examples of **small interventions** that participants suggested would have **large impacts on their daily lives.**

Intervention	Prevents…
Snow removal	Older people are unable to leave the house to go to medical appointments, grocery shopping, etc.

Intervention	Prevents…
	If a driveway isn't plowed, homecare or other providers can't get to them. Oil delivery may be interrupted, risking freezing. Slippery walkways cause falls when people go out to get mail, put trash out, get to their car
Trash removal	Inability to remove trash attracts pests; results in tripping and hygiene hazards
Sidewalk condition	Unhoused older people walk more than others and are at risk for tripping and other physical injuries. Without maintained, de-iced, plowed sidewalks, older adults can't get to appointments, groceries, or the pharmacy, ultimately impacting their health. lack of fitness opportunities; can't get out in the fresh air, participate in social activities
Personal care	Older adults who cannot take care of their own needs for personal care risk deteriorating health status through poor nutrition, hygiene, and safety. Social isolation
Home repair (e.g., roof, infestations, safety equipment)	Older people who have physical or financial difficulty maintaining their homes risk their own health and safety and others'. Care workers cannot enter homes that are unsafe from hoarding or infestations. Small repairs, if not attended to, can lead to crisis situations, e.g., small leak in roof can lead to structural damage and mold.

Intervention	Prevents…
Transportation	Older people who cannot drive themselves must rely on others to get to healthcare appointments, grocery shopping, pharmacies, banking, laundromat, and social activities. Relying on friends, family, or public or regional transportation requires extensive planning and can be disrupted by things outside of the older person's control—driver sick days, inaccessible vehicle, weather, cost.
Translation assistance	For non-English speakers, the lack of translated materials impacts older adults' ability to take public transportation and participate in community social activities. Non-English speakers may not understand automated reminder calls from healthcare providers and miss appointments. When non-English speakers cannot read a food label, they might not eat it as it could violate dietary laws e.g., canned goods in Commodity food boxes.
Computer/internet access	Not having computer or internet access impacts ability to connect with friends and family. Healthcare providers increasingly use patient portals to communicate. Without access, patients must rely on telephone interactions and wait for callbacks from providers. Without internet or computer access, applying for benefits can be difficult, especially if the only alternative is by phone. Application forms may be inaccessible without a computer and printer.

Intervention	Prevents…
Food support program	Lack of nutritious food can cause deteriorating health status, cognitive issues, and ability to care for one's daily needs due to lack of energy.
Home delivery	Without home delivery of groceries, meals, medications, and other supplies older adults with limited transportation options can experience declines in health.

Navigation Assistance

NAVIGATION ASSISTANCE NEEDS include prominent, accessible information in different communication modalities, up-to-date information on available services and eligibility criteria, and case management to assist with accessing and coordinating health and social services, including housing supports.

Across statewide conversations and in the surveys, older adults and caregivers repeatedly said they needed help navigating the health and social service systems. In listening sessions and focus groups, participants were eager to both receive and share information on helpful resources. However, finding, applying for, and accessing everything from caregiving support, food, housing, healthcare, social activities, and transportation services is challenging for many older adults and their families.

> We've called the aging people, the veterans' people, and everybody has a different answer to a different thing. It's like bowl of spaghetti.
>
> **FOCUS GROUP**

> I think it's very confusing between the state or community services and the private services. You have independent sites all over the place. You need to drop breadcrumbs to find your way back to where you started because it links to one thing and the next thing and the next thing, and you're 50 sites further … and you end up having no information after spending an hour looking for information.
>
> **FOCUS GROUP PARTICIPANT**

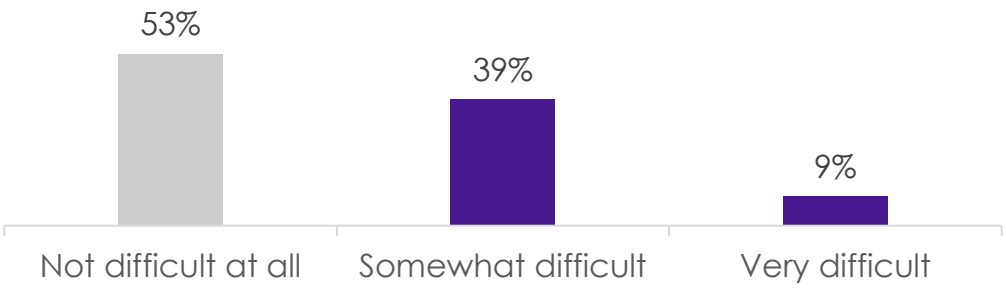
Some participants said that although they could find information, they did not know if it was the right or most useful information, and they wanted a trusted person to help make sense of it all.

> I have much too much information coming at me here at home. And the idea of someone like a navigator, who can help sift and sort through it is a very important distinction. So, I just want to second that thought about [needing] a navigator as opposed to more information.
>
> **LISTENING SESSION PARTICIPANT**

Getting information

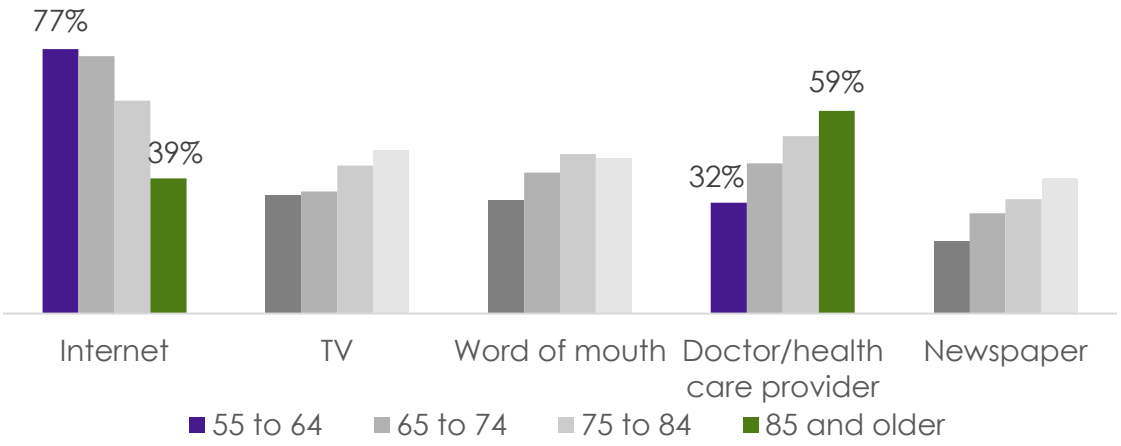
When asked how difficult it is to find information about available services and programs for older adults, nearly half of survey respondents said they had not tried. Of those who had, 39% said it was somewhat difficult and 9% said it was very difficult (Figure 16).

Figure 16 **Forty-eight percent said it was somewhat or very difficult to find information** about available services, n=3,047.



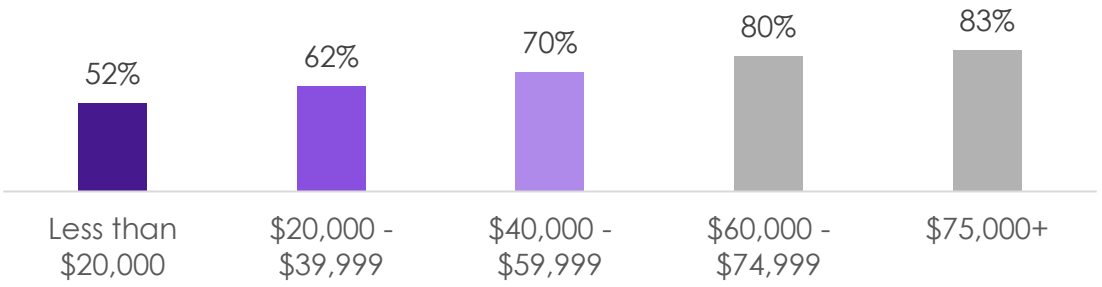
Overall, nearly three-quarters of respondents used the internet to find information on available services, but this varied by age (Figure 17). Other common sources of information among survey respondents were doctors or health care providers, word of mouth, television, newspapers.

Figure 17 The **youngest group** of older adults **uses the internet,** and the **oldest group** seeks information from their **doctors**, n=2,919.



Although the internet was identified one of the best ways to get information about services, this varied by income.[vi] Using the internet was strongly associated with higher income. A little over half (52%) of older adults with incomes below $20,000 use the internet to find information about available services compared to 83% of those with incomes over $75,000 (Figure 18).

Figure 18 **Low-income older adults use the internet to find information less** compared to those with higher incomes, n=2,713.



[vi] Using other sources of information was not strongly or at all associated with income.

This finding of the digital divide by age and income echoes themes brought up across statewide conversations. We heard from many participants who pointed out that not everyone uses the internet, has access to it, or has enough digital literacy to use it. This has implications for how state and community agencies communicate with those most in need of assistance in learning about available services and how to access them. Older adults with limited access to the internet either through lack of broadband in their communities, the resources to pay for it, or unstable housing might have limited options to learn about services.

Familiarity with State and Community Agencies

There was varying familiarity and contact with Area Agencies on Aging across listening sessions, focus groups, and survey responses. Maine's five AAAs assisted USM with publicizing the listening sessions, so it is unsurprising that many participants knew of and had used services and programs administered by the AAAs. There was some familiarity among focus group participants except non-English speaking participants. None of the non-English speakers were familiar with AAAs.

When asked what the best sources of information about available services for older adults were, only 20% said communication with state or local agencies. Of respondents who said they needed help in the previous six months but had not received all the help they needed, 41%percent said it was because they did not know who to ask.

Case management for health and social services

In many listening session and focus group discussions, older adults and their caregivers described the healthcare system as complex, complicated, confusing, and difficult to navigate. Managing the relationship between healthcare providers, long-term services and supports, and social service providers in the community falls to older adults themselves or their family caregivers.

There are no case management navigation services for older adults to connect people to health care and community-based services. You're given a phone number, you're given a flyer, but there's no one actually helping you navigate the complexity of a CAT scan, a wellness class, a hospital stay, Meals on Wheels, and so on. Navigating your mother's healthcare, navigating your own healthcare, it gets really complex and confusing, and people need help.

LISTENING SESSION PARTICIPANT

You shouldn't have to have a mental illness and be incredibly low income to access case management support. I have two jobs already. But I have a third job as a case manager for my parents, filling out paperwork, making phone calls, sending emails, doing all those things that are just not manageable...There are a lot of people that could benefit from case management support who are not eligible under the current guidelines of our state.

LISTENING SESSION PARTICIPANT

Housing navigation

When older adults need different housing to meet their needs, either financial, physical, or both, they often do not know where to look for information.

> People are confused. They don't know where to go for housing related services—they do Go Fund Me's on Facebook, they put out requests for neighbors to help each other. They go to the town office, or they ask their doctor. As a hub Information Resource agency in a small area, we get a lot of people who are kind of at a loss about where to go.
>
> **LISTENING SESSION PARTICIPANT**

For those pursuing subsidized housing, the lack of a common application requires the submission of separate applications to different management companies, all asking for the same type of information like birth certificates and Social Security numbers to prove eligibility. For people in a housing crisis, the process is very cumbersome. One key informant described the benefit of helping people manage the process.

> The difference between getting somebody that is homeless into housing or having them remain homeless is really sitting down and doing the applications with them. It's so vital. If you're homeless in your vehicle, you might not have access to a computer, mail, all of those things. When we're able sit down with people and do the application and prepare them for what's needed for when their name comes up on the list, those yield really good outcomes.
>
> **KEY INFORMANT**

Strengths and Opportunities

Participants in the listening sessions and focus groups mentioned several positive aspects of growing older in Maine. A few noted the beauty of their rural community, even though there were often trade-offs in healthcare access or the availability of transportation. People do feel safe living here[vii] and they find support, companionship, and sometimes extensive hands-on assistance from relatives, friends, neighbors, and local communities. Almost three-quarters of survey respondents (73%) rated their community either *Good*, *Very Good* or *Excellent* as a "place to live for people as they age" and 170 respondents to the open-ended survey question, *What would making aging in your home or community better or easier?* took the time to write in something like "all is well" or "nothing comes to mind." Looking across the needs assessment data, those existing and potential authentic, helpful, and trusting relationships are both a strength for older people living in Maine and an opportunity for improvement that will generate important dividends across populations and geographic regions.

Health

Snapshot

HEALTH STRENGTHS & OPPORTUNITIES include long-standing provider relationships, availability of telehealth services, and system level improvements.

[vii] All needs assessment data were collected before the mass shooting in Lewiston on October 25, 2023.

What is working well

When participants spoke about the parts of the healthcare system that was working well for them, they most often mentioned the relationships they have either with their own doctor - “I love my PCP; couldn’t be better and very responsive” - or with the organization who provides care and services, such as with Seacoast Mission, a trusted provider for the island communities; “There’s a high level of trust between the Mission and the islands.” The several older people who had long-standing relationships with their physicians felt fortunate, “I have a primary care physician, thank goodness, who is wonderful, and I can go to her with various things.” These comments align with those of older Mainers who expressed dissatisfaction precisely because their relationships with PCPs have been disrupted by high turnover or by continually having to see different providers. It is notable that a few older veterans spoke favorably about the VA care they received.

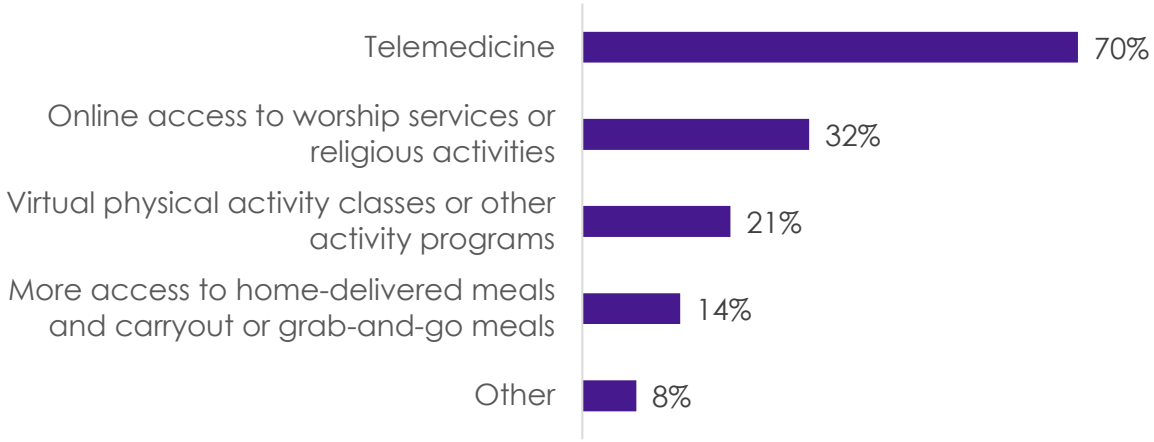
Some older people are comfortably using patient portals and telehealth services, and this works well for them; they appreciate the ready access this provides, “We use the patient portals and we even send messages that way”; “Telehealth is evolving and making it easier to access care - on personal devices in one's home.”

For certain populations, such as people with IDD, telehealth has been “awesome” because it eased the need to find transportation – which was a “nightmare” - and it eliminated the social anxiety and fear that often accompanies going out into the community for appointments. Key informants noted that new technologies offer convenient ways to remotely monitor, supervise, or assist those older patients with physical or cognitive conditions for which monitoring is needed.

A noteworthy 70% of survey respondents indicated that telemedicine made access to services easier for them since the pandemic. Of the 8% selecting Other, several mentioned benefits such as online access to mental health therapy, access to visiting nurses, access to vaccination information, ordering COVID-19 test kits, and virtual AA meetings. And over one-fifth of respondents were or are currently

benefiting from online exercise and activity classes, which surely contributed to increased physical and mental wellness during the turbulence and uncertainty of the pandemic (Figure 19).

Figure 19 **Seventy percent reported that telemedicine made access to services easier** for them since the pandemic, n=1,435.



Older Asian participants seemed particularly satisfied with their healthcare. They experienced good relationships with doctors, they experienced that Medicaid covered the services they needed, translation services are adequate, and since many live with their adult children, they can get transportation to needed appointments, or they experienced that transportation to appointments was paid for.

What are the opportunities for improvement

Participants across the state offered suggestions for improving various aspects of our healthcare delivery system. Some offered system-level suggestions such as a single-payer system and universal healthcare. Another suggested opening a second medical school and offering incentives to keep graduates here in Maine so there is a pipeline of providers for rural communities.

Housing

Snapshot

HOUSING STRENGTHS & OPPORTUNITIES include sense a of community and camaraderie among neighbors, proximity of housing to town centers, real estate tax relief program, home repair programs

Older people who live near one another in housing complexes frequently identified a feeling of community, safety, and reliance on one another for support when unwell, for socialization, and for cultural camaraderie. The proximity to a downtown area also afforded easier access to public transportation and other needed services.

Participants expressed gratitude for the affordable housing units provided by Avesta Housing and similar organizations, and for the support staff helping older people find available units. Similarly, those individuals who obtained rural development loans through AmeriCorps for essential repairs like roof repair were particularly appreciative for the help and support, despite the challenge of finding responsive labor to perform the work.

Several participants and key informants noted the time intensive process to identify and apply for housing benefits; however, staff at CAP agencies, AAAs, and other service agencies provide valuable, patient, and informed navigation and application assistance for those in need, often going above and beyond to assist people with what are sometimes dire circumstances.

Older Mainers repeatedly mentioned gratitude for the real estate tax relief program. In the survey responses, well over 200 individuals wrote in responses stating that tax relief makes things easier for them and they want more of it.

Participants mentioned that local home repair initiatives, when available, are very helpful for installing grab bars, ramps, and similar safety-related home

modifications. In several communities, the "network" of individuals available to help with home repairs are known to each other and that facilitates getting help quickly to those in need. While several organizations and groups offer these services (e.g., age-friendly initiatives, Housing Authority initiatives, CAP agencies), based on the collective responses to the needs assessment, more are needed.

> I had a call from an older person whose electricity in half their home was not working. He is a caregiver for his wife who is bedridden with a neurological condition. They didn't have access to hot water because of the electrical issues. They were referred to our home repair program which there's a long wait list for. I asked if he had an estimate; a lot of people don't start there because in your mind you think it's a way bigger problem. He reached out to an electrician who, after hearing the story, made the repairs for free. It was a $3,000 repair but hearing the severity of it, it touched their hearts. This contractor will now be vetted to provide services through our home repair when we have funding. Those are the things that really help in our area.
>
> **KEY INFORMANT**

In addition, Maine's Housing First program and buildings offering shelter and services to those who have been chronically unhoused are truly lifesaving for many individuals, including older unhoused people who are at greater risk for physical and chronic health conditions.

Food & Nutrition

Snapshot

FOOD & NUTRITION STRENGTHS & OPPORTUNITIES include food pantries and greater food-related home delivery services.

Food Pantries

Across statewide conversations, older adults said they use food pantries to help meet their nutrition needs, but listening session participants, key informants, and survey respondents said that access to pantries beyond more urban areas is challenging.

> I feel that even bedroom communities need to have services like senior food distributions - not expecting people in the smaller outlying communities to travel into the more urban areas to pick up disbursements.
>
> **LISTENING SESSION PARTICIPANT**

Key informants said pantries with flexible hours of operation, benches to sit on, and brightly lit, plowed parking areas work well for older Mainers. Having pantries at locations older adults are already attending such as at churches, doctors' offices, and senior housing help older people access food without having to arrange a separate trip. It also reduces the stigma around receiving food assistance, "Everyone gets a bag of food when they leave."

A food security key informant was enthusiastic about the expansion of the Preble Street Food Security Hub. The Food Security Hub currently prepares 2,000 meals per day, but when fully operational, it will produce up to 10,000 meals

every day. Working with Good Shepherd Food Bank, the Food Security Hub can distribute frozen meals to the 300 food pantries around the state.

During the COVID-19 public health emergency, many pantries adopted a "trunk model" of delivery where bags or boxes of food were placed in the trunk of the person's car. Although this model grew out of the need to reduce the transmission of the virus, it also helps those older adults with mobility challenges.

There are definite opportunities to increase awareness of and enrollment in food security programs. Across conversations, older adults shared wide support for the Senior Farm Share program and Harvest Boxes but noted that more older adults need to be made aware of these opportunities.

Home Delivery

Older adults and key informants said the contactless pick-up or home delivery of meals and groceries that reached new heights during the COVID-19 pandemic has notably improved access to food. However, many listening session and survey participants cited wanting more home delivery options, especially in rural areas. Although DoorDash® worked with food pantries to deliver pantry meals during the pandemic, the company now charges a fee that some pantries are unable to afford. Expanding support for delivery of groceries and pantry foods could help more older adults with physical mobility and transportation challenges to maintain good nutrition.

Transportation

Snapshot

TRANSPORTATION OPPORTUNITIES include mileage reimbursements, expanded bus routes, car repair partnerships, MaineCare bus passes.

Listening session and survey participants made suggestions for improving transportation options for older adults. Several wanted mileage reimbursement for volunteers to take them to social opportunities. Others said that more buses and better bus routes, especially in rural areas, would help them get to appointments, grocery stores, and other errands.

To help defray the cost of car repairs, several listening session participants shared that Maine's Career and Technical Education high schools provide auto repair services to teach students. The driver would still pay for parts, but the labor is free.

When Maine stopped providing the MaineCare monthly bus pass to comply with federal rules regarding paying for Medicaid-covered services, many people without other transportation options lost their ability to take public transportation to grocery shop, go to the laundromat, and other activities of daily life. Key informants from several service organizations said many older adults are not aware that they are eligible for discounted monthly bus passes. Increasing awareness of this option, including in non-English speaking communities, could help more older adults access public transportation.

Safety

Snapshot

SAFETY STRENGTHS & OPPORTUNITIES include feeling secure in neighborhoods and communities, sense of belonging among cultural, ethnic, and affinity groups, community programs and services.

Overall, older people do feel secure in their communities and in their neighborhoods, with a few exceptions (see **Safety**). An encouraging 82% of survey respondents (2,472) responded that they did not have any of the listed

safety concerns. Of note, even many lower income older people (72%) are also not concerned about their personal safety.

In several needs assessment conversations, non-White older people noted efforts they made to be friendly to White neighbors (e.g., "we do a lot of waving to show we are friendly, even though we do not speak the language"). Though participants mentioned that they experience occasional unfriendly comments and actions by White people, "generally, we feel safe in the community."

The rise in multiculturalism in Maine affords a sense of belonging among older people of different races, ethnicities, genders, sexual orientations, and religions. In many rural communities, people know each other well and rely on each other for filling in the care and service gaps; "I have a friend I leave my keys with to check on things for me. I completely trust him."

Many of the noted strengths in the Safety domain revolve around services and supports provided by the AAAs and other community agencies, programs, and initiatives. When programs are known, and when they are affordable and accessible, they are used and appreciated by older Mainers. For example, the salt bucket programs, home repair programs, immigrant assistance programs, Meals on Wheels – were all noted as particularly helpful in keeping people safe. If the organization itself has established trust with the groups served, then its programs are more likely to be widely used and its staff also trusted as a source of information.

Older Mainers who live near family or have a close relationship with neighbors derive a sense of safety and security from that geographic proximity. "I am in a very good position. I have my daughter who looks out for me, so I have a feeling of safety. I live right next door to her."

Lifeline and Life Alert programs offer a feeling of safety to many older people, particularly those who live in rural locations or who do not see people every day. Sometimes these programs provide greater comfort to adult children than to the

older person themself. Similarly, a few participants mentioned new smartwatch technology that can detect falls and provide alerts to external parties.

Caregiving

Snapshot

CAREGIVING STRENGTHS & OPPORTUNITIES include help from family, friends, neighbors, and community services staff.

The caregiving strengths most often mentioned were the availability of help from family, friends, and neighbors who generously offer time, attention, transportation, and companionship. In addition, several caregivers specifically pointed out the support they receive from Maine's many available service providers: visiting nurses, case management workers, hospice staff, AAA support groups, kinship caregiver support groups, CAP agencies, caregiver training classes (e.g., Savvy Caregiver®), emergency response staff, Lifeline staff, Meals on Wheels volunteers who check-in with genuine care about matters other than food. "I was caring for my mother and what worked wonderfully for us was visiting nurses. An older person must have some medical condition that qualifies them, so it may not apply in a lot of caregiving situations, but those visiting nurses really saved what was left of my sanity."

Several caregivers noted the benefit of, for instance, available respite services, employers who offer flexible working hours for caregivers, the convenience of scheduling appointments with an online portal, and local resource "closets". "I took a Savvy Caregiver® class just this last spring and I liked that class so much because it wasn't just solely about taking care of the family member, but also taking care of yourself. I was able to learn some tips and tricks to help me manage."

Older adults and service providers alluded to the diverse needs of caregivers driven largely by the individual needs of the care recipients but also by the caregiver's age, geographic location, work status, income level, and levels of support among family, friends, and neighbors. Caregiver programs and services that can be targeted or personalized may be one way to further benefit and support individual caregivers.

Socialization

Snapshot

SOCIALIZATION STRENGTHS & OPPORTUNITIES include age-friendly community initiatives, social programs through the AAAs, and university course offerings.

Age-friendly Communities

Maine's age-friendly communities and the University of Maine Center on Aging's Lifelong Communities were brought up many times in conversations around socialization opportunities. In addition to implementing community-based home repair, chore, transportation, and food programs, these rich resources throughout Maine provide opportunities for many older adults and people of all ages to socialize and connect with each other.

AAA Opportunities

In several conversations, participants suggested AAAs could help older adults in special populations establish social networking groups. For individuals who use the AAA services, they are often a "lifesaver". One participant stated, "I would really love to see the Agency on Aging, expand its iPad program…it was another lifesaver for me to be able to interact with people on a safe level, and have total control over how much give and take you do."

Key informants and listening session participants said that Meals on Wheels administered by AAAs provide social connections by virtue of their meal deliveries. When otherwise isolated older adults have this type of check-in, loneliness is alleviated and Meals on Wheels drivers might also be alerted to signs of illness, dementia, or even abuse and neglect and help connect older people to needed services.

Educational Opportunities

Several Listening session and focus group participants described the benefits of Senior College, Osher Life-long Learning, and other educational opportunities in keeping connected and socially engaged. Survey respondents wanted more educational, social, and cultural opportunities to connect with others their age. Some wished there were more physical activities available to them like pickleball and swimming classes as ways to be engaged with their communities.

> The University of Maine offers free tuition for seniors for any of their courses, either taking them in person or taking them online. That has that has proven to be a social outlet for me. There's quite a long list, and there's absolutely no charge if you're over 65. And this is probably a resource that people in my age group are not all aware of, and are maybe intimidated because they think, 'Well, you know, I'm such and such an age and I've never been to college before something like that.' I have felt warmly welcomed in the classes that I've signed up for—even though most of my fellow students are about 20! That's great.
>
> **LISTENING SESSION PARTICIPANT**

Other Opportunities & Factors for Success

Recurring themes emerged across statewide data collection activities around those factors that make - or would make - resources and services more available, accessible, and trusted by older people around the state. These experiences and preferences voiced by older people can be used strategically to improve, strengthen, or expand key policies and programs supporting all of us as we age.

Trust

The trustworthiness of others, of information, and of services is extremely important to many older people. Before asking for or accepting help, older people said they want to know if the person or the agency can be trusted and be assured that they or their finances or their information will be safe. The desire for trust is universal, but in older people may also be related to past unsafe experiences or historic, long-standing marginalization or oppression, such as with women, people of color, LGBTQ+ people, or individuals from very rural communities. In addition, older people are aware of their own devalued state as older adults in an ageist society. They also hear from other older people who have been mistreated, scammed, or experienced bad outcomes with certain people, organizations, or with technology. Participants repeatedly referenced how difficult it is to "find someone I trust" to clean, or do home repair, or provide care. "I don't trust healthcare in my county"; "I do think it's mistrust of the system, and in an ineffective organization"; "repeatedly asking for the same information builds mistrust"; "there's not a lot of resources or trustworthiness of someone you might call to get that sort of help" are some examples of the trust-related worries weighing on older people.

> I would like to have group sessions - perhaps monthly - of neighbors to inspire more trust among us.
>
> **SURVEY RESPONDENT**

Many key informants spoke about the long-standing mistrust of a society and systems that have, for instance, deprived them of rights, violated their privacy, mistreated their children, or otherwise failed to recognize their essential humanity. “We have PTSD from past experiences, such as during the AIDS epidemic;” “Neighbors cannot protect me if someone wants to commit a hate crime against an older person.”

Establishing trust may take time but certainly requires building and sustaining relationships over time by consistently demonstrating inclusion. Several older adults expressed sadness and frustration that their experiences and expertise did not seem to be needed or wanted by their communities, despite obvious relevance and need. “No one approaches us to ask us to be included/supported. We reached out before with HIV/AIDS when no one else was supporting us, but now we are getting too old to initiate it.”

Related to trust, a continued focus on creating diverse opportunities for older people to socialize, engage, and contribute to community expands social capital which, in turn, generates individual and community strength and resilience. Across conversations, older participants confirmed the diversity of social connection needs and preferences that exist among humans and hinge on personal, situational, and environmental circumstances. Aligning social connection policies and programs with the people who need or prefer what is offered is key to older people feeling visible and valued. This requires deepening our skills for really listening – without discounting, judging, or minimizing – people's lived experiences, their feelings, and requests.

> We need to connect with people at the human level - what they think, what they feel what they've experienced – and start from there. If people believe that the person they're communicating with believes in them and trusts them, they're more likely to cooperate. You've got to get that trust established. When people are refused help because you're short of staff or the funding's not available, it's hard to maintain that trust.
>
> **LISTENING SESSION PARTICIPANT**

Reliability

Unsurprisingly, the issue of finding reliable help was a key theme in the data collection. In the open-ended survey responses, "reliable" or "reliability" was mentioned twenty times. In response to the question "what would make aging in your home or community easier for you", people mentioned: "Being able to easily access potential in-home support help that is reliable"; and "more reliable skilled services like gutter cleaning, landscape work, and home repairs"; "reliable healthcare, utilities, and food." Quite possibly, older adults for whom reliability is important have had unpleasant and unreliable experiences in the past and are concerned about wasting money and time on service providers who underperform.

In listening sessions and focus groups, several participants talked about reliability in the context of transportation. Even when communities offered volunteer transportation options, participants said those services were not always reliable due to their dependence on older volunteers. Older people need transit options that are "reliable, convenient, fast, comfortable, safe."

> We need transportation to be reliable, and we need it to be convenient, fast, comfortable, safe.
>
> **LISTENING SESSION PARTICIPANT**

User-friendly

> If you don't have regular internet access…we need to request a paper application and we are asked that things be done by regular mail, as opposed to online and that's hard.
>
> **KEY INFORMANT**

Participants provided many examples of roadblocks and frustrations they encountered to access resources and services, many of them essential services such as SNAP benefits or transportation. Glaring examples include navigating multiple people, agencies, or forms to be eligible for a benefit or a support. "I have called multiple agencies that all have different answers and different eligibility forms and I always end up at the same spot – we can't help you." The repeated comments about the complexity and dysfunction of the system and the repeated requests for navigators (see **Navigation Assistance**) confirm the need for easy-access information, eligibility, resources, and services that are designed with older people in mind. "If you don't have regular internet access…we need to request a paper application and we are asked that things be done by regular mail, as opposed to online and that's hard. You have to apply for 50 different places. So, I wish there was one universal housing application."

While young-older people are comfortable with technology and use the internet to access information, older-old people do so much less. People ages 85 and older are far more likely to get information from their healthcare providers. This means that for the next 10-15 years, healthcare providers will continue to be an

important source of easy access information about state and local services supporting older adults.

Even providers participating in statewide conversations expressed frustration at the difficulty of helping clients and patients navigate requests for information or services. “I was really frustrated as a provider, I just don't have the capacity to sit on hold with clients…because things aren't even getting processed, in terms of, if somebody's submitting proof. And they'll get a letter saying they need proof, you know, two months down the road where they've already submitted it. So, I'm trying to troubleshoot and it's not like people can drive 40 minutes away, to go into the office in wait. It's a big frustration, and people get so scared that if they have a review, of not getting the review; there is a sense of panic, because they depend so heavily on those programs, that it's really heartbreaking.”

Non-stigmatizing

Many older people come into older adulthood draped with existing stigmas from other aspects of their identities – race, ethnicity, culture, gender, class, LGBTQ+ status – and then those are coupled with the age-related stigma pervasive in American society. Older people find this treatment “degrading and insulting”.

Some groups have experienced subtle but troubling discrimination. One Asian older person noticed that sometimes bus drivers do not put down the steps as readily as they do for white people, making it harder for them to climb on the bus. Some white neighbors do not greet them and even though “we want to interact with our American neighbors, they do not want to interact with us.” Older people of color do worry about racism when they are in public settings or in rural communities. And older LGBTQ+ people in rural communities sometimes feel unsafe.

Key informants said that older unhoused people sometimes refuse shelter services because of the stigma associated with them in our society. Similarly, there is stigma associated with substance use or having an adult child with

substance use or mental health needs and the stigma can be a barrier to older relatives caring for grandchildren. There is stigma attached to needing food assistance which some older people refuse as a result. “Stigma is a huge problem with seniors; they are so proud. I know [people] who would never even apply for a benefit or service, even if they qualified for it.” Community service providers have seen this attitude with basics such as food, even when older people are very food insecure. Similarly, some older people with IDD prefer to access services through the older adult programs because it is less stigmatizing than the IDD service programs, even though there may be fewer services available.

Older people feel the weight of stigma in their daily lives, and it detrimentally impacts their health, wellbeing, and feelings of security. Many older people are going without instead of asking for the help they need because they experience asking for help as stigmatizing and shameful due to societal attitudes.

> Stigma is a huge problem with older people, who are so proud. I know my parents would have qualified for things but they would never even apply for it.
>
> **KEY INFORMANT**
>
> The stigma around it is self stigma. Everyone knows they're aging but nobody asks for help. I think the reaching out for help gets worse as you get older, because you don't want to be seen as needing help.
>
> **LISTENING SESSION PARTICIPANT**

Creating ease of access

Issues of access barriers came up in many and varied contexts across all conversations. These included a lack of access to personal, professional, and social spaces (e.g., entry ramps, bathrooms, tech barriers, weather-related

barriers); access barriers to services (e.g., eligibility barriers, information barriers; waitlists); barriers to online access; barriers to telephone access (e.g., screens too small, people with hearing loss, endless waiting on hold or multiple touchpoints); language barriers (e.g., lack of interpreters, lack of signage). Anticipating access issues, proactively reducing or eliminating them, and improving or designing programs with the specific intention to facilitate access is a significant opportunity for improvement across systems, sectors, agencies, and programs.

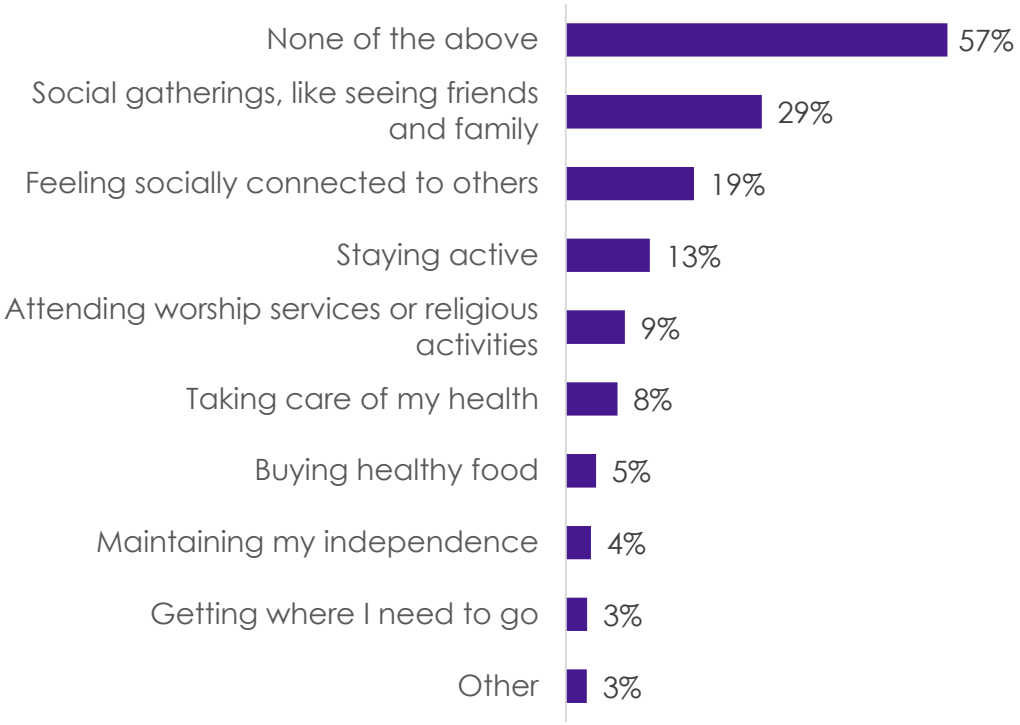
> They'll get a letter from DHHS indicating a time to call back and do the interview. And it's, you know, an hour wait on the phone. Or a lot of times the call volume is so high, they say to call back. So, they can't even get to that interview portion of completing the application. So again, it's a lot of frustration and people say, why bother even applying because it's not going to get anywhere. Again, it's a lot of frustration and people say, why bother even applying because it's not going to get anywhere.
>
> **KEY INFORMANT**

COVID-19

Direct impacts

The COVID-19 pandemic ushered in fundamental change in systems, relationships, individual and population health, and in daily life. Much of the change has been harmful, though there were a few key benefits that may be instructive for policymakers and service providers. Overall, older people in Maine, like everyone, were impacted by the pandemic. Interestingly, however, over half of survey respondents (57%, 1,689), indicated that none of the listed options were more difficult for them because of the pandemic, but 29% said socializing had become more difficult (Figure 20). The responses of the 90+ individuals who offered an *Other* response to this question are a reminder of the diversity of circumstances of older people. People mentioned social activities, volunteering, visiting relatives in nursing homes, anxiety about vaccines, inability to travel, inability to attend large gatherings, inability to do home repair, family conflict over pandemic response. Some also made political comments, reflecting the politicization of government response.

Figure 20 Nearly 30% of older adults said socializing has become more difficult since the pandemic, n=2,959.



Disruptions in healthcare

Several older people complained about the disruptions in care occasioned by the complete shutdown of services in 2020. People who needed surgeries, for instance, were sometimes routed to emergency departments which, because they were overwhelmed with COVID-19, were ill-equipped to manage specialty care. "A gentleman died last year because he was misplaced. He needed a hip replacement during COVID, he ended up going to the emergency room and then ended up in a nursing home -- for lots of reasons that should never have happened." Others experienced different types of disruptions in care: "there used to be more opportunities for where specialists would travel to the county so that people could see them locally; maybe COVID messed that up."

In response to the survey question *Which of the following have become more difficult for you because of the COVID-19 pandemic?* 8% (228) of respondents chose the option, *Taking care of my health*.

Disruptions in socialization

In addition to the obvious social disconnections that occurred for everyone during the height of COVID, many older people felt particularly alone and at risk because of their significantly heightened risk of contracting COVID in the year before the vaccine was available and during the subsequent variant-drive surges. “When the pandemic hit, [the older person] was listening to all the precautions, and she's afraid to go to work, but if she doesn't go to work, she can't pay the rent. And she's worried about her health because she knows she's at higher risk. It’s a tough situation.”

Older people are often managing multiple health conditions and the added COVID risks create further worry, forcing them to remain isolated beyond when conditions have eased for others. “I stay more isolated. It was right at the beginning of COVID when I got the cancer, and with the diabetes, I'm pretty much homebound now. Because going out there -- you know, it's a risk.”

Programs that closed down during COVID have not entirely restarted and many older people feel those losses. “I hope that after now that COVID is done – well, it's not gone, I guess it's ramping up again – but that sense of community connection of being in person, I hope that can happen again, because that does make a major difference.” A few noted that many of the community gatherings that occurred regularly before the pandemic have not all returned, and this is unfortunate. “We have some really nice community time. But they all stopped during COVID. They're starting to come back, and we need them to come back. We need them to come back.”

> We have some really nice community time. But they all stopped during COVID. They're starting to come back, and we need them to come back. We need them to come back.
>
> **FOCUS GROUP PARTICIPANT**

In response to the survey question *Which of the following have become more difficult for you because of the COVID-19 pandemic?* 19% (563) of respondents chose the option, *Feeling socially connected to others* (Figure 20).

Improved public benefits (e.g., SNAP, freedom from eviction)

The direct benefits provided to older people, and others, during the pandemic significantly eased many daily burdens. Direct payments, increased SNAP benefits, and freedom from evictions were all noted as helpful. Older people have felt the cessation of those benefits and again worry about the affordability of food and housing.

> They had given everybody across the board, through the State of Maine food stamp program, I think it was $95 or $100 extra a month. And then in February, they sent the letter out, and they said come March that was going to be cut. Oh my god, I was just making ends meet with the prices going so high. And I had a process all figured out how to do it. And I would have enough food, and I would save on my energy bill. I mean, I really had to put some thought into it.
>
> **LISTENING SESSION PARTICIPANT**

Telehealth and Technology Platforms

For older people who use technology, the increase in telehealth and online options throughout the pandemic made healthcare access, service access, and socialization much easier. Many expressed hope that healthcare systems would make telehealth options permanent since they often eliminate the need to find transportation. Participating providers also noted the convenience of telehealth options for accessing their services. For certain populations, online socializing was an important link to family, friends, and community life, including religious services, though most expressed a desire to return to in-person socializing when possible. “A lot of the LGBTQ+ community wanted to do things virtually, but it’s not personal connection.”

For many older individuals who did not use technology in daily life before the pandemic, the availability of telehealth and online socializing during the pandemic did not appreciably change their daily lives. “They don't view technology in the same way that you know, younger people view technology.” And while this broad statement about older people and technology has a trace of age-stereotyping, there are some people who either do not see the value of technology or have a difficult time using it. Even when devices were available for free through special pandemic programs, one key informant noted that some older people with vision changes cannot easily see an iPad, cell phone, or computer’s small type and would need help with the accessibility functions. “If you have any kind of vision issue at all, even the smallest vision issue with a little tiny phone just becomes impossible to use various apps or even on the iPad, without a very clear way to access apps or you know, things like that, it becomes just a useless thing that you put on your shelf.”

In response to the survey question *Which of the following options made access to services and activities easier for you since the pandemic?* a significant 70% (999) of respondents chose the option, *Telemedicine*.

Home-delivery

Participants repeatedly noted the convenience of increased home-delivery options during the pandemic and the ongoing benefit of home-delivery even now that the pandemic emergency is over. “We love those [programs] that have continued to be able to home deliver meals; there were quite a few home delivery models that kind of popped up during the pandemic. Not all of them have had the capacity to continue, but quite a few have." Several food insecurity programs, realizing the value of home delivery, are looking for ways to make delivery a permanent option. “I was in a pantry recently, just a couple of weeks ago, and they've really built up their volunteer capacity specifically for home delivery… the home delivery model is really, really great, but it takes capacity. It takes a volunteer with a car and gas.”

In response to the survey question *Which of the following options made access to services and activities easier for you since the pandemic?* 14% (197) of respondents chose the option, *More access to home-delivered meals and carryout or grab-and-go meals.*

New or Noteworthy

NEW OR NOTEWORTHY FINDINGS include deep concerns about internet scams, extent of remote caregiving, rise of telehealth, feeling respected, solo aging, emergency preparedness, and emotional content.

Looking across the issues and themes raised in all the data collection activities, a few were new or noteworthy; some were in response to new survey questions and others raised by older people themselves in the open-ended survey response or in listening sessions and focus groups. A few of the issues reflect societal changes in technology and in associated norms of behavior. Others reflect the demographic

shift generally and the attendant increased visibility and attention to issues of concern to older people. These may be areas to watch in the years ahead.

Scamming concerns

The project team was struck by how many participants talked about scamming when asked about safety or technology. They expressed a range of negative emotion, from annoyance to outright fear when, for instance, describing the vulnerability of aging parents who have come to rely on the internet for socialization and information yet are less informed about how to remain safe from scammers. Several younger older adults who are savvy with computers talked about their own inability to distinguish between legitimate online or cell phone activities and scamming, despite experience with technology. Others related stories about older parents who thought legitimate activity such as calls from healthcare providers, were scams, thereby interrupting or delaying needed care.

Across the state, people are worried about being scammed and have either been scammed themselves or know someone who has. They would like more resources for scam prevention or avoidance. There were few, if any, comments about steps individuals were taking to feel safer from scams. The federal government recently held hearings[viii] on the increase of scams using AI; thus, updated safety guidance, information, or resources may be forthcoming.

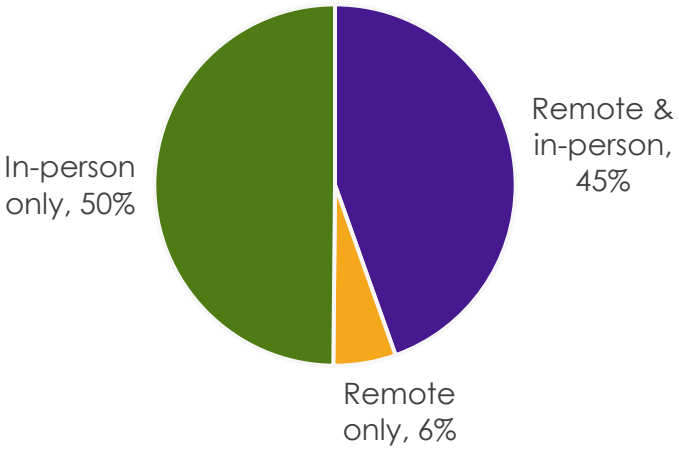
Remote caregiving

Half of caregiving survey respondents indicated they are providing remote caregiving (defined in the survey question as: check-in phone call, video chat, text

[viii] https://www.aging.senate.gov/hearings/modern-scams-how-scammers-are-using-artificial-intelligence-and-how-we-can-fight-back

or voice message, bill-paying, home monitoring via in-home camera, scheduling appointments, etc.) (Figure 21). In addition, many participants in the listening sessions and focus groups revealed that they help with online healthcare, socializing, and ordering delivered goods, and similar internet-based activities for their care recipient.

Figure 21 Half of caregivers provide care in-person only, and half use remote options, n=374.



Telehealth

The rise of telehealth services during the pandemic was clearly a benefit to many older people, their families, and the caregivers. Telehealth offers ready access to health and support services when transportation, geographic distance, illness or disability, or time posed a constraint. Many service providers have made telehealth access a permanent feature in response to the demand. Because, according to many participants, telehealth is often the antidote to transportation barriers, expanding telehealth services and expanding their scope and accessibility will be important to aging Mainers.

Feeling respected

A substantial majority of older people feel respected at their age. Nearly 66% responded Strongly agree or Agree to the question "At my current age I feel that other people respect me." Only 7% responded *Disagree* or *Strongly disagree*. Interestingly, over one-quarter (28%) responded *Neither agree nor disagree,* which could indicate uncertainty or hesitation about this issue. Internalized ageism is often unconscious and not recognized given the ubiquity of ageism in society.[ix]

Solo aging

While only one participant mentioned the specific issue of *solo aging*, it is apparent from the listening session conversations that many older people in Maine are aging without a support network of adult children and close friends, putting them at physical and emotional risk. The issue is receiving increased attention in the research community[x] and should be an area of focus in future State Plans on Aging. *Learning to Be Old*[xi] may be necessary to equip all of us with the necessary mindset, values, and resources to be able to age safely and without fear.

Many older people living alone are worried about the things they may not be able to do by themselves in the future; "I live in the woods about three miles from the center of [name of town] on a quarter mile driveway, which was great when I was younger. Now that I'm alone, I get concerned about transportation."

[ix] Steward A. Toward interventions to reduce internalized ageism. *J Hum Behav Soc Environ*. 2022;32(3):336-355. doi: 10.1080/10911359.2021.1898516

[x] An entire 2023 issue of the journal Generations was devoted to solo aging.

[xi] Cruikshank, M. (2013). Learning to be old: Gender, culture, and aging. Rowman & Littlefield Publishers.

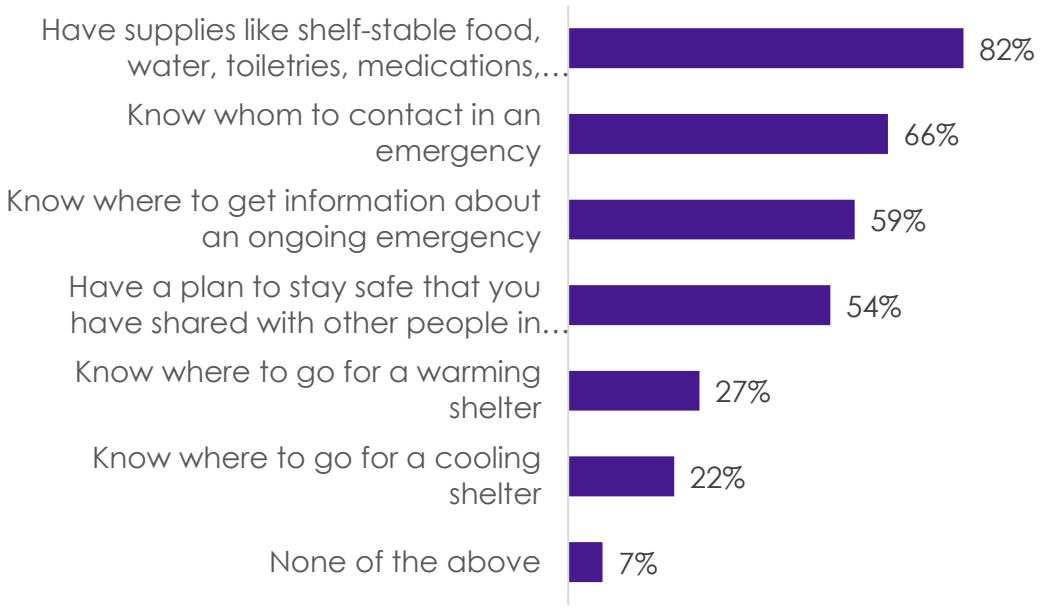
As noted below, LGBTQ+ older people, particularly those living in rural communities expressed that "it is more difficult being alone and uncoupled while aging." Some older people living alone with disabilities cannot always use, for instance, the means of communication that most others are using. "Being a widow, being alone, and being deaf, I can't just pick up the phone call 911." Another expressed concern about people stopping at her house because she lives alone and on a major road in her town.

Climate concerns and preparedness

Only a handful of listening session participants raised the specific issue of climate change as an aging concern, though concerns about weather, snow, and being unable to adequately heat one's home in severely cold weather were raised by many others.

The survey asked a single question about preparedness for a health or environmental emergency. Most respondents (82%, 2,454) have access to shelf-stable food, water, and similar necessities, but a third or more may not know who to contact in the event of an emergency or where to get information about an ongoing emergency (Figure 22). Even fewer, 27% and 22% respectively, know where to go for warming and cooling shelters, and 7% (213) responded, None of the above. Maine's County Emergency Management Agencies have been promoting heating and cooling shelters for people of all ages. Responses to this question in future surveys may offer insight into the effectiveness of information dissemination on these programs.

Figure 22 Most older adults have emergency supplies, n=3,005.



Emotional content

During all of the needs assessment conversations the project team was acutely aware of how much emotion was expressed when people were talking. While it was difficult to fully capture this in the data collection notes, a few insights are notable.

Many older people expressed extraordinary gratitude for the programs and program staff when commenting about assistance they'd received. The same was true when commenting about the meaningful relationships they developed with program staff and clinicians. Alongside the gratitude, however, many older people expressed raw fear and anger about current and likely future situations that would be beyond their control: fear of not having financial resources, fear of not being able to get or afford care (of any sort), fear of being taken advantage of. Because older people gravitate towards those they trust, they often are less willing to take risks, instead choosing to do without.

Of concern was a pervasive resignation to the status quo; that circumstances would not likely improve. This may reflect the ability of older people to understand and accept the realities of aging, but it may also reflect the accompanying internalized ageism and fatalism of a society that devalues aging. As noted above, strength-based approaches and the intentional adoption of narratives of resilience and progress can help counteract long-standing and widespread systemic and institutional ageism.

Part Four: Special Populations

The ACL guidance for State Plans on Aging provides requirements and recommendations for continued inclusion and to advance support around equity in state plans. The Older Americans Act has provisions around determining services needed and evaluating programs for specific older adults including Native Americans, Asian-Pacific American, Native American, Hispanic, and African American older individuals, and older lesbian, gay, bisexual, and transgender (LGBTQ+) persons. The provisions align with the Biden-Harris administration's Executive Orders #13985 and #14091 to advance racial equity and support for underserved communities through the federal government.[xii]

This section describes findings from focus groups and key informant interviews with representatives of underserved or underrepresented populations in Maine. We have noted that specific source in each section below. Our findings include relevant information from listening sessions and surveys.

Maine Tribes

A limitation of this State Plan on Aging Needs Assessment is that we were unable to engage with members of the Wabanaki Confederacy: the Penobscot, Passamaquoddy, Maliseet, and Mi'kmaq peoples. We did not receive a response to repeated outreach efforts to multiple key informants in August through October 2023. However, through working with Maine Council on Aging (MCOA) and their contacts with tribal members, we learned that some tribal elders chose

[xii] Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government and Executive Order On Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government .

not to speak with us about their experiences because they had nothing positive to share.

This finding speaks to the lack of trust between Maine's tribes and the State our own lack of connection with Tribal Councils. Future needs assessments should consider having a longer time to develop relationships and open dialogs with Tribal Councils so they can decide whether and how to participate in the needs assessment and State planning process.

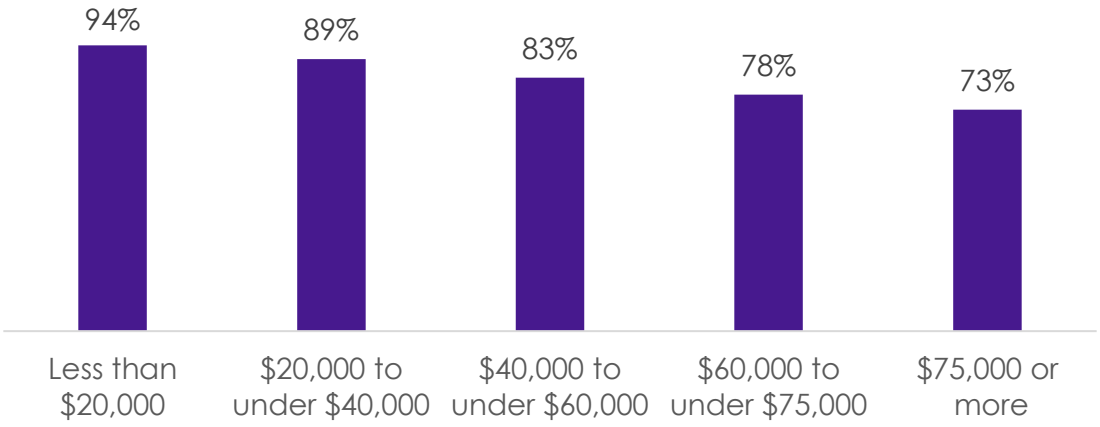
Low-income Older People

Source: Focus Group

The focus group of older adults with limited financial resources living in southern, central, and northern Maine offered a window into the challenges of aging on limited income. As expected, low-income older Mainers feel they are barely getting by. “Well, financially, I feel like I'm treading water. I live as cheaply as I can to pay the oil for my unit.” Those who find and qualify for grants and subsidies feel grateful for those opportunities. “It's always like you’re walking a tightrope. I am fortunate that I have just been approved for an RDA roadway development loan for my roof which is sadly in need of desperate repair and that has been very helpful. It is something that more people should be aware of that's available. I found it through to a backdoor.”

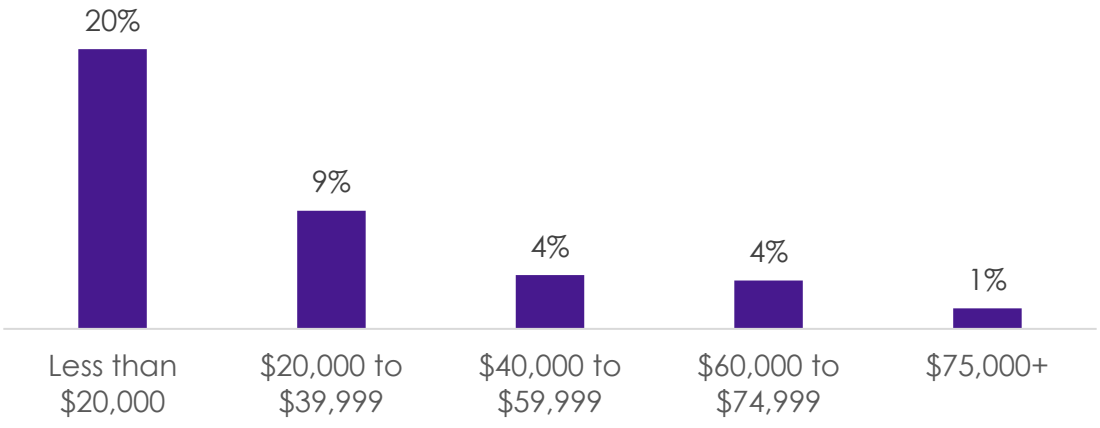
Ninety-four percent of survey respondents with incomes below $20,000 said they needed help in the past six months, compared to 73% of those with incomes above $75,000 (Figure 23).

Figure 23 **Nearly all low-income older adults said they needed help** in the last 6 months, n=2,653.



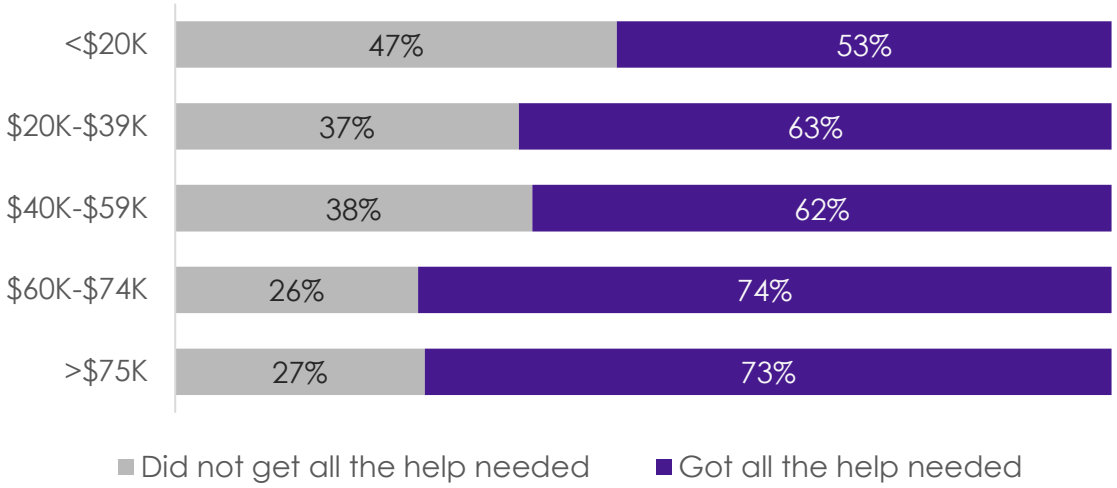
The need for help varied by income with larger proportions of people with lower incomes needing help. For example, 20% of people with income below $20,000 said they needed help with transportation in the past six months compared to only 1% of those with incomes of $75,000 or more (Figure 24).

Figure 24 **Twenty percent of low-income older adults needed help with transportation** in the past six months compared to just 1% of high-income older adults, n=2,692.



Just over half (53%) of people with incomes under $20,000 said they got all the help they needed compared to almost three-quarters (73%) of those with incomes over $60,000 (Figure 25).

Figure 25 Just over half of low-income older adults got all the help they needed, n=828.



Black and African Americans

Source: Focus group

In collaboration from CCCS and the MCOA, we spoke with a group of U.S.-born Black and African Americans about their experiences as older adults and caregivers. Five were older adults, three were caregivers and all lived in the greater Portland area.

Throughout the conversation, participants raised similar themes as in the listening sessions, surveys, and other focus groups including worries about transportation, housing costs and home repairs, food, socialization, caregiving, and safety.

Health

Focus group participants said they felt their doctors and other providers were knowledgeable and respected them. However, they also raised issues of ageism in healthcare saying that sometimes it seems that providers are reluctant to provide treatment options because they are "probably not going to be here much longer." Participants described providers assuming a 90-year-old might be near the end of life without considering that their close family members lived into their 100's. Ageism contributes to older adults feeling that no one cares about them or their needs.

Navigation

Caregivers voiced significant frustrations with accessing and navigating different services for their family members. They wanted a single source of information about available public and private pay services that included eligibility criteria so that they could understand what services their parents might receive. Instead, they must call different agencies or look at website after website to learn about services, sometimes receiving conflicting information. Different application forms and processes are overwhelming and sometimes humiliating to have to repeatedly prove their family members are eligible and in need of services.

Caregiving

Echoing findings from other discussions and the surveys, caregivers said it has been very difficult to find in-home help with homemaking and other care, and that it is hard to know if they are trustworthy. The high cost of these services quickly depletes their family members' savings and publicly funded options are difficult to access.

LGBTQ+ Older People

Source: Focus groups (2)

We spoke with two groups of LGBTQ+ older adults, an in-person focus group of nine participants ages 50-81 from the greater Portland area and a virtual focus group of seven participants (ages 62-74) from Aroostook, Hancock, Penobscot, Somerset, and Washington Counties. Both groups described the same types of needs and priorities described earlier in this report including frustrations with wait times for healthcare and the lack of geriatricians in Maine, worries about transportation now and in the future, the high cost of fresh fruits and vegetables, and housing costs and repairs.

Health

Participants in both groups said they did not have any issues with disclosing being gay in the healthcare system. One rural participant noted that when medical providers ask about sexual orientation, it seems like a "check the box" process rather than an attempt to engage on relevant health issues. The participant wished providers would follow up with a question like, "Is there anything about your being a lesbian that you think would be helpful for me to know, in terms of providing care?"

Socialization

In the Portland group, participants said that there seemed to be more LGBTQ+ groups for gay men than lesbians, although a gay man also said he had difficulty making connections just for socializing. Rural participants said that social groups had faded over time and that there are fewer Pride Events in rural towns. They also said they didn't feel that community and aging organizations reached out to the LGBTQ+ community to include them in activities or support them. They said they had done so much organizing and advocating for themselves and the

LGBTQ+ community during the HIV/AIDS crisis, and they wish others would step up to do the same now.

A transgender woman in the rural group described the challenges of going out in public as a trans individual, “I've developed a bit of a shell, because I have been out quite a lot. But you have to have that hardshell. You're going to have to deal with people staring at you.”

Participants suggested that AAAs could help support those who want to start LGBTQ+ groups in rural areas and that Equality Maine could provider more programming for women.

Caregiving

A participant in the rural focus group made the point that LGBTQ+ people are less likely to have children than the general population. This has implications for the role that family caregivers play in the long-term services and supports system of care. Children, often daughters, take on caregiving for their aging parents. LGBTQ+ older adults may not have this resource and need to rely on other more distant relatives, friends, or paid support.

Safety

Participants in both groups said they feel safer as LGBTQ+ now compared to when they were younger. However, participants described worries about being LGBTQ+ and “coming out” again in a nursing or assisted living facility and how they would be received. A rural participant said pride flags had been stolen from their yard. Others said the current political climate seems to have given permission to people to act on their homophobia and racism. They worried that living far from neighbors made them more vulnerable if someone were to attack them, “My nice neighbors may not be able to protect me from somebody who's

just decided that 'There's a rainbow flag here. Let's go get that old lady.' They can't protect me."

Asian Older People

Source: Focus group

With assistance from CCCS, MCOA, and Khmer Maine, we convened a focus group of thirteen Khmer older adults in Portland ranging in age from 64 to 77. An interpreter was used to translate the questions and answers for the group. Below are some key findings from the conversation.

Health

Most participants were very pleased with the healthcare they received and felt welcomed and respected by their providers. All participants said their health status was "so-so."

Family life

All participants said they were living with their children, and in keeping with Cambodian culture, their children were taking care of them. They reported that their children did all the food shopping. They do not care for American food and miss certain foods from their home country that they cannot get here, including mustard greens and winter melon.

Transportation

Participants' adult children did most of the driving for them, although some were worried about being able to get around in the future. Some were concerned about learning to drive on their own or use public transportation because they cannot communicate or read and navigate road signs or transit directions in English.

One participant said changes in his daughter's life could impact her ability to drive him, and he was trying to learn to drive himself.

Lack of transportation also gets in the way of participants' ability socialize with friends and attend church services on a regular basis. They said they would use public transportation if the bus schedules and routes were printed in Cambodian.

Citizenship and Work

Four participants were U.S. citizens. Several others wanted to become citizens but had difficulty reading or understanding English. Citizenship impacts these older adults' ability to qualify for Social Security. Although several participants were of "retirement" age, they continued to have to work. Five of the participants said they still worked, two on a farm, two at a lobster company, and one sews for a Maine company.

Unhoused Older People

Source: Key informant interviews

Homelessness and housing insecurity is a growing concern across the State. The recent increases in home prices and rents have put older adults on fixed incomes at risk of not being able to afford housing that meets their needs. Key informant interviews with homeless services providers and legal advocates described particular challenges of finding housing for older adults who have experienced evictions and who need some level of service or support. Older adults with mental health and substance use challenges are at heightened risk of becoming or remaining unhoused. Many assisted living facilities require tenants to be sober, which can be problematic for people with active substance use disorder. Prohibitions on smoking can also be a barrier for some older adults needing housing with services.

Health

Homelessness and unstable housing impact all aspects of an individual's life. Key informants said older adults who are homeless are at heightened risk of developing health crises as they do not have a regular source of care. Without a way to store needed medications, food, and clothing and lacking transportation to primary, specialist, and mental healthcare appointments, older adults who are homeless often end up in crisis, needing emergency department care.

Housing Data

MaineHousing, the Maine State Housing Authority, is implementing a statewide strategy to address homelessness. It established nine Homeless Response Service Hubs throughout the state, each with a Hub Service Coordinator. The strategy envisions mobilizing community resources to address the most pressing needs identified through real-time data collection on those experiencing homelessness in the Homeless Management Information System (HMIS). From July 1, 2022 through June 30, 2023, over 500 adults over age 62 sought and received services[xiii] across the nine Hubs (Figure 26). This is likely an undercount of older adults who experienced homelessness in FY23 as it includes only those who contacted a service Hub and provided age information. It does not include data from victim service provider shelters as they are prohibited from entering data into the HMIS.

[xiii] Street Outreach, Shelter, Safe Haven, and Transitional Housing, the programs that meet the HUD definition of literal homelessness.

Figure 26 Older adults served by Homeless Response Service Hubs, FY23

Hub and County/Towns Served	People 62+ Served
1 York	41
2 Cumberland	234*
3 Midcoast: Sagadahoc, Knox, Lincoln, Waldo, and towns of Brunswick and Harpswell	14
4 Androscoggin	20
5 Western: Oxford, Franklin, and towns of Livermore and Livermore Falls	6
6 Central: Somerset and Kennebec	86
7 Penquis: Penobscot and Piscataquis	80
8 Downeast: Washington and Hancock	13
9 Aroostook	15
Total	**509**

*Includes people who received transitional housing vouchers. Hub 2 administers the program for the entire state. Voucher recipients may be located in other counties.
Source: MaineHousing Homeless Management Information System

In September 2023, a key informant from Preble Street in Portland, a hub program serving vulnerable and underserved residents of Portland, said they had served 112 people over age 60 in the previous twelve months. Of those, eighty-eight were between 62 and 71 years old, twenty-two were between 72 and 81, and two were over 82 years old.

Housing instability

A key informant with York County Community Action Program said it was not uncommon for housing insecure or homeless older adults to receive a monthly Social Security check, spend the money on a few nights in a motel, and then stay with friends or sleep in their car until they received their next check. As described in other sections of this report, applying for subsidized housing is complicated, requiring forms and documents to be submitted, sometimes electronically or by mail. If an older adult does not have a stable address, phone, or internet access, the challenge can be insurmountable without assistance from a case manager.

Safety

Safety among Maine's homeless and housing insecure older adults can be precarious, and exposure to the elements and street crime pose an obvious threat. Another often less visible threat is elder abuse perpetrated by family and others. When an older adult is evicted or is experiencing homelessness, the crisis may lead them to rely other others who do not have the best intentions, resulting in abuse, neglect, and exploitation.

Older Refugees and/or Asylees

Source: Key informant interview

As expected, older refugees have a difficult time "accessing mainstream aging services" because of the language barrier. While local refugee support agencies are working to partner with AAAs and others to increase visibility, access, and cultural appropriateness of services (e.g., food, socialization, rituals), there is much more to do. "We partnered in that way where I could bring the clients and the language access—the interpretation and translation… And our hope is that can continue to grow and expand our capacity with the Area Agencies on Aging." "[Some] municipalities have trips they take with older people, maybe out to

lunch, and our folks aren't able to access those. Maybe if there was a scholarship or a fee waiver for some of those events they would join in if it was culturally appropriate."

Health

Refugees often do not understand, for instance, the limitations of our healthcare system (e.g., no home visits), or our safety regulations (e.g., no open flames), or our food storage practices, and this unfamiliarity sometimes does not stand them in good stead with neighbors, property owners and property managers, or with impatient staff.

Food and Nutrition

Older men who come to this country without their families are often at high risk for poor nutrition since they are unaccustomed to not having a woman to cook meals. "Not having a woman to cook for them is culturally not something they've done and so often they are trying to find somebody to have dinner with to go over somebody's house. And they are often food insecure." Cooking classes or drop-in places with prepared meals would, according to key informants, help support refugee men. Refugee men are also at risk of feeling loss of power and identity in their displacement to a country that does not recognize or value their previous experience, expertise, or status. Even though there are resettlement programs that help train refugees, older refugees sometimes can no longer work due to health or other circumstances.

Technology and Communication

Older refugees typically cannot afford computers, but they are often quite adept at using cell phone apps, such as *WhatsApp* or *Viber*, to communicate for free with relatives and friends here in the U.S. and in other places in the world. Agencies leverage this skillset by communicating via text and by using short

YouTube videos to provide information and educational content. Refugees' comfort level using texting platforms allows them to stay in close contact with providers who are willing to adapt to a text-based relationship.

New Mainers

Source: Focus groups (2)

We heard from older Somali and Sudanese New Mainers and older people from several French and Portuguese-speaking African countries in two separate focus groups.

Health

Older people in both groups expressed that while they were mostly treated well by individual providers, particularly women providers, they had difficulty navigating our complex healthcare systems in general but also because of language and cultural challenges. Having family and caregivers who spoke English was an important part of getting the care they need for themselves or loved ones. A few mentioned they received more attentive care at the community health clinics, where they have developed relationships, than at the large provider practices. Several reported long wait times in the ED and, like many older Mainers across the state, long delays for appointments with specialists, calling "again and again". Others reported providers dismissing their health concerns, including pain-related concerns.

Transportation

Very few of the New Mainers drive and those that do only drive to places they know well. Transportation is a major issue for this group, leaving them to rely on family or friends, expensive Uber options, or public transit which does not reach those who live outside the main service area. These obstacles sometimes lead to

missed health appointments or the inability to participate socially. When public transportation is used, participants experienced long wait times between buses. Cost and the lack of translated signs and instructions are also barriers to wider use of public transportation.

Socialization

Participants in both focus groups confirmed the existence of strong ties to their cultural community and frequent gatherings that support these bonds. As noted, there are definite challenges with transportation to many social events. A few expressed the need for free, affordable, and available spaces to gather and that organizing an event was sometimes difficult. Several older people expressed interest in intergenerational cultural events so that younger and older New Mainers can be together for cooking, storytelling, and communing.

Safety

Participants in both groups confirmed that they feel physically safe in their homes and neighborhoods. As with many older people, several also expressed deep concern about the level of scamming, one noting that it interfered with the care of her husband because she was wary of phone calls and texts.

AAAs

Of note, none of the participants in either group were aware of the programs and services offered by the AAAs in their area.

Older People with Intellectual and Developmental Disabilities

Source: Key informant interview

Health

Advances in healthcare and supportive services in recent decades has resulted in increasing numbers of older adults with Intellectual and Developmental Disabilities (IDD), many of whom are living with parents who are very old and less able to fully meet their needs, much less their older adult children. “So many people with intellectual and developmental disabilities were expected to die. They weren't expected to make old age. So, this is a relatively new phenomenon when you look at the field of medicine.” In addition, there are virtually no physicians who provide specialty care to aging patients with IDD, and specialists in other disciplines, gastroenterology for instance, are not equipped to understand the needs of older patients with IDD who may need routine preventive case such as colonoscopies. There are provider training needs so that these older patients can be best served. The Maine Developmental Disability Council is working on this.

Housing

There are three distinct groups of older adults with IDD, based on the services they receive: 1) people who live in group homes; 2) adults who do not access IDD services but instead obtain services geared toward older adults and adults with physical disabilities such as Assisted Living; and 3) older adults living with their older parents. Many older adults with IDD who are living with aging parents are very worried about what will happen to them when their parents die. It is not clear what housing opportunities are available for them.

Lack of trust

There is a historic lack of trust between people with IDD and their families and the medical and social service systems. Also, some older families tend to isolate and refuse services because they "do not trust the system." Maine's history of institutionalizing people with IDD at the Pineland Center[xiv] continues to have a lasting impact on the individuals who experienced the segregation and mistreatment and their aging parents. Many older parents of adults with IDD raised their children during the era when "refrigerator mothers" were blamed for their child's IDD, and families internalized this blame. Planning support for these families, especially those who have stayed away from formal supports, such as MaineCare Home and Community-Based Services, out of a lack of trust, would be helpful.

COVID-19

COVID-19 felt very threatening for people with IDD as they had poorer health outcomes than the general population. Although people with IDD living in group homes were restricted from seeing family, they were still at risk of contracting the virus from workers. Advocates were frustrated with the lack of data collection on people with IDD throughout the pandemic.

AAAs

Few older people with IDD or their families know about the AAA services, but when they do, "they are never turned away." Volunteering opportunities at the AAAs for people with IDD offers important socialization and engagement. "For a

[xiv] The Pineland Center in New Gloucester was an institutional facility for people with IDD that operated between 1908 and 1996. It was the subject of a class action lawsuit in the 1970's for alleged abuses of residents. For more information, see shadowsofpineland.org.

person with a disability, bringing the food to another person and building relationships and creating a meaningful community - that's incredibly valuable. If I could get more AAAs to integrate people with IDD that way, that would be amazing." Transportation support is sorely needed. "People with IDD are often not included in information about local volunteer driving programs."

Older Islanders

Source: Key informant interview

Transportation

Transportation on and off Maine's islands is weather dependent and expensive. An airplane service recently increased their fares substantially, leaving many islanders without a way to fly on or off island. Some islands are served by the State ferry system, and costs have been increasing over the past couple of years. The system has become less reliable due to shortages of captains and staff, and ferries have been cancelled. While there may be multiple ferries to and from an island in the summer during tourism season, in the fall, winter, and spring, for the fifteen islands with year-round populations, there may be only one trip on and one trip off. In these cases, a trip to the mainland for an appointment could require an overnight stay.

Health and Caregiving

Healthcare is limited on many of Maine's islands, especially specialist and dental care. A key informant said the extra days of travel that might be required to see an eye doctor or dentist or have a preventive screening such as a colonoscopy can sometimes deter people from getting needed care, "Those kinds of things are really at the bottom of the list."

For older islanders with chronic and healthcare and assistance needs, formal service provider options are limited. Mainland provider organizations may include island communities in their service areas, but functionally, they do not have a way to get their services to the islands. To remain at home, some older adults rely on friends and neighbors to help, but as their needs become increasingly complex, they may have to leave their island communities for care on the mainland. A key informant gave an example of a person who needed hospice care, "When the hospice care became such that their community could no longer provide it for them, they made the very hard decision to leave their island to die. Even though that was not their wish, they didn't want to be a burden on their community." Islands with assisted living-type care homes provide additional options for older adults needing care to age in place, but not every year-round island has one.

Resiliency and Community

A common theme in our Maine islanders conversation was resilience. To live year-round on an island off the coast of Maine takes effort, grit, and resilience. Islanders must be self-sufficient because there is no quick trip to a big-box store for supplies. However, when someone is in need, neighbors and communities work together to help them. "One of the really wonderful things about these small communities is even if there is tension or conflict between people, no one's going to let anyone suffer. Those things kind of go out the window, when there's someone who's aging… and they need some support, the community is going to support them."

Food and Nutrition

Access to fresh, nutritious food can be very limited on islands. Stores are small, often the size of a convenience store on the mainland and may not be open year-round. What they offer may be limited and the costs of getting the food to the

island is passed on to the consumer, sometimes doubling or tripling the price. Amazon, Misfits Market, and other mail order services have improved islander access to food because they come through the U.S. Postal Service – if the mailboats and planes are able to travel.

Aging Population

Like the rest of Maine, the year-round island populations are aging. Island schools are shrinking as families want their children to be in mainland schools. With faster fishing boats and changes in the industry, younger fishing families head to the mainland in the winter. Without younger community members available, there are fewer people stepping into the roles of government and infrastructure maintenance in wintertime to run the libraries, plow the streets, run the power company, or maintain the airstrips. A key informant said older adults are saying, "'We can't do it anymore,' 'I'm 80 years old, I don't want to plow the streets any longer,' or 'I can't plow the streets any longer.'" They are wondering how they will be able to stay on their islands without help from younger people.

Kinship Caregivers

Source: Key informant interview

The acute challenges of older people caring for young relatives such as grandchildren or grandnieces or nephews are mostly invisible. They often must shoulder the emotional burden of the death, incarceration, or incapacity of their own adult child or children while providing hands-on care for very small children, many of whom exhibit behaviors consistent with grief, abandonment, or drug or alcohol-related spectrum disorders. In addition, because they are older, they are managing their own health, financial, housing, or social worries.

The care of young children is often thrust upon grandparents on short notice, and they must scurry to find items such as car seats, clothing, and furnishings, in addition to planning for larger housing or roomier cars in situations where several children are delivered into the care of relatives. Grandparents must also connect with childcare, elementary or high school, and consider the important social needs of young children, the landscape of which has entirely shifted to social media in the intervening decades since grandparents were parents themselves. They need information and resources for quickly making homes safe for small children, such as child-proofing cabinets, medications, electrical outlets, stairs, or other home hazards.

Health

Kinship caregivers are also concerned about revealing and attending to their own health issues for fear they will be judged by state or community workers or worse: found not competent or capable of caring for their young relatives. “If they've ever had counseling, or would like to have counseling, they fear that they will be judged as not competent to care for the children, if they disclose that.” The result is that caregivers do not receive the help, support, or treatment they need for their own wellbeing which, in turn, impacts the wellbeing of their grandchildren.

Financial and Emotional Support

Kinship caregivers need ongoing financial and emotional support and must be quickly and reliably connected to local services according to the needs of the children now in their charge.

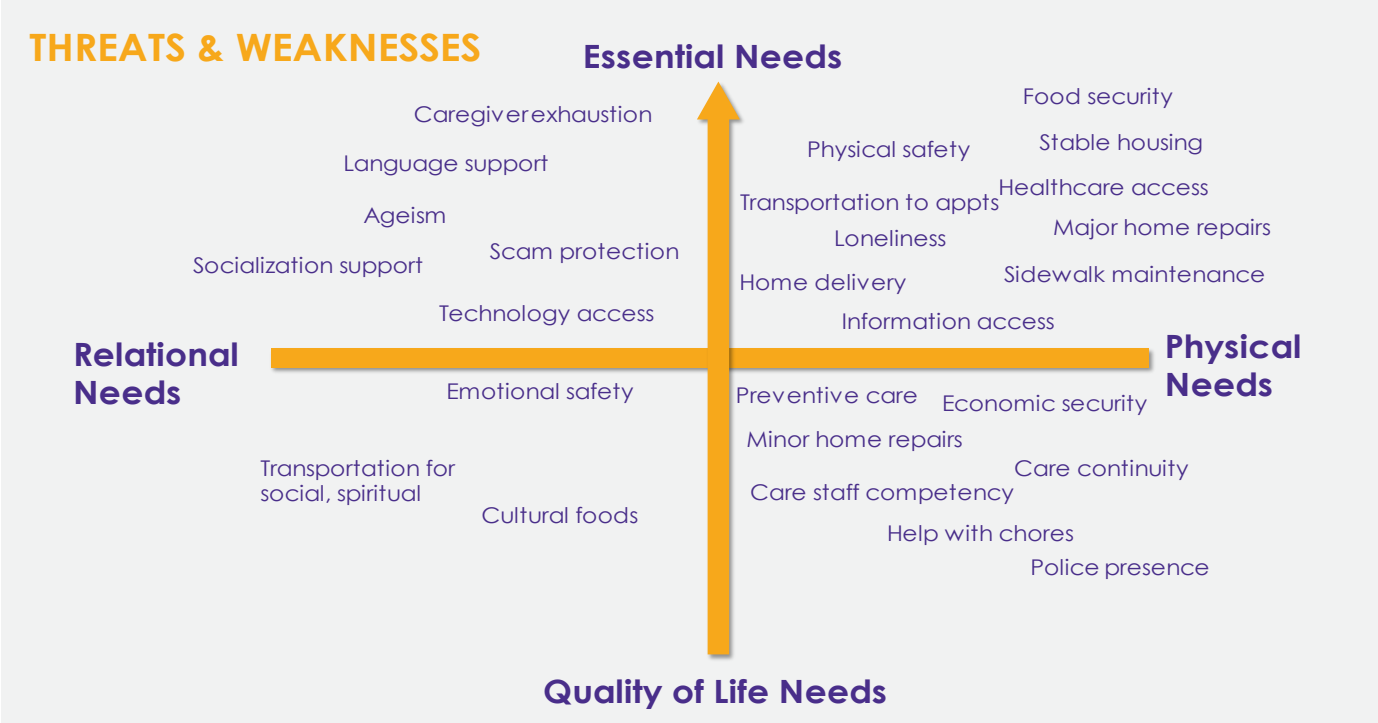
Part Five: Strategic Approach

Mapping the Strengths, Weaknesses, Opportunities, and Threats (SWOT) domains onto strengths and needs canvases presents one way to organize the volume of data collected in this needs assessment. While the placement of need-related themes along a *critical* to *quality-of-life* continuum and along a *relational* to *physical* continuum is moderately subjective, it provides an opportunity to brainstorm and create strategies that address either (or both) broad and/or specific needs. Additionally, it will generate new questions and discussion about strategies targeted at sub-populations, geographic regions, or service sectors, as well as discussions of leveraging trends, partnerships, available expertise, emerging science, or public or private funding opportunities.

- What strategies will most effectively and cost-effectively prevent the most harm?
- Are there any available "shelf-ready" interventions that might address current needs?
- How can we expand current strengths so they reach more people in ways that serve individual or population needs?
- What is the best way to balance strategies for physical needs and those for relational needs?
- What are the next steps for leveraging opportunities or for adopting suggestions offered by participants in the needs assessment?
- Should strategies be spread across the canvas or concentrated in certain quadrants?

The project team offers the following two strategy canvases for preliminary consideration, one of threats and weaknesses, and the other of strengths and opportunities. Both canvases reflect the voices of older people across Maine, their fears and frustrations, and their gratitude, hopes, and suggestions. Based on those voices, we suggest a few preliminary inquiries for further discussion:

Figure 27 Strategy Canvase



Part Six: Comparison with 2019

This needs assessment followed the same format and used the types of data gathering formats and survey questions as the 2019 needs assessment to allow for cross-year comparisons. This section provides high-level comparisons of this year's key findings to 2019 where possible. However, changes in the survey methodologies may limit the comparability of survey results.

Comparison of Key Take-Aways for Older People 55+

The 2019 statewide 55+ survey was conducted using a sample of email addresses (n=40,000) with phone follow up and by mail (n=5,000). Two-thirds of the responses came via the email addresses and phone follow-up. Therefore, it was not primarily a random sample. The 2023 survey was conducted using a random sample of mail address (n=15,000) and online links distributed on the OADS listserv, AAAs, and age-friendly and town websites. The majority, of the responses (82%) came from the random sample. Again, these methodologic differences may account for some of the differences in results between the two surveys.

Health

Access to specialty care was noted by rural participants in 2019, but not nearly to the extent that we heard this year; there no references to access to primary care or disrupted relationships with primary care providers in 2019 as there was in 2023. This seems due to the pandemic and the severe healthcare labor shortages in its wake.

Housing

The unaffordability of housing repairs as a precursor to health and safety harms is a returning theme this year. Older people and key informants in both 2019 and 2023 noted the importance of supporting older homeowners in maintaining their homes for safety, comfort, and service access. What is new this year is the frequent and distressing calls for available workers, especially those who can be trusted to do the work competently. In 2019, 7% of survey respondents reported that their home does not meet their current needs. That percentage jumped to 16% of respondents this year.

Food & Nutrition

Unsurprisingly, in 2019 we also noted the "complex relationship" of food and nutrition with access to other essential needs such as transportation and healthcare. While more fresh foods are available from food pantries, home delivery (e.g., Misfits, Amazon), and donations from large retailers (e.g., Trader Joe's), food insecurity continues to be an issue for Maine's low-income older people, particularly those in rural areas without transportation options. Interestingly, 8% of survey respondents in 2019 indicated they do not usually have enough to eat versus 5% in 2023.

Transportation

In 2019 we identified transportation as a "gateway" to better health and quality of life. This year we heard repeatedly that lack of transportation options—and the resulting isolation and lack of access—precipitates food insecurity, missed health appointments, and social disconnection. Maine clearly continues to struggle with offering a sufficient variety of accessible and affordable transportation options to allow most older people full and personalized access to essential and important needs. In 2019, 5% of survey respondents reported they need help finding or arranging transportation versus 4% in 2023. However, listening to the day-to-day

experiences of older people around Maine provides a highly nuanced and interrelated needs-based picture of the transportation services gaps around the state.

Safety

Comments about physical safety in 2019 were similar to this year's: few older people (but not none) are concerned about crime, and their worries instead center around maintaining stable housing and repairing their current housing. This year, however, the hyper-focus— across needs assessment conversations—on the safety risks of scamming was new. This is an emerging and important area to address as older Mainers across demographics identify scamming and potential financial loss as problematic.

Socialization

The conversations about socialization had a markedly different feel this year due to the state and national focus on social needs coming out of the pandemic. Older people and service providers are more attuned to social needs, and to discussing the greater variety of socializing options available to many, notably those who can socialize online by choice or necessity. In 2019, we primarily heard about the isolation of the "oldest-old" who rarely left the house and older people living in the most rural areas of the state. We learned this year that socializing online became easier for many people during and since the pandemic.

Caregiving

The 2019 caregiving survey was implemented online. Online links were pushed out through the OADS listserv, by AAAs, and through other aging services agencies targeting people who were caregivers. Therefore, it was not a random sample. Three caregiving questions were also included in the 2019 statewide survey around the type of person cared for, the assistance provided by the

caregiver, and the top needs of the caregiver. As noted above, the 2019 55+ survey respondents were not primarily a random sample.

In contrast, all 2023 caregiving survey questions were included in the statewide 55+ survey as well as mailed to a random sample of adults 45-54 in all Maine counties. Both surveys had online links included in the mailed survey, and flyers for both were pushed out via OADS listserv, AAAs, and age-friendly community and town websites. As noted above, most survey responses (82%) were submitted through the mail or through the online link within the mailed survey.

The 2019 survey used a broad definition of caregiving and did not exclude those who were paid to provide care to a family member or friend. The 2019 survey results showed that 13% of caregivers provided care to four or more people. These respondents may have been working or caregiving in supported housing such as assisted living or residential care facilities. In contrast, only 3% of the 2023 survey respondents reported providing care for four or more people.

While many of the survey results are similar across the years, there are some marked differences that may be an artifact of the different survey samples.

Caregiving assistance

Across conversations and represented in the 2023 survey responses, caregivers continue to provide many types of assistance to their loved ones such as transportation, talking with healthcare professionals, daily household tasks, and food or meal preparation.

Caregiver burden

Measures of caregiver emotional, physical, and financial stress in the 2019 results appear quite a bit higher than in the 2023 results. Care should be taken when comparing the two surveys. As noted earlier, the previous caregiving survey was targeted through OADS, AAAs, and other community partners that service older adults and caregivers. This could reflect differences in the survey samples, with

the 2019 sample having already reached “Somewhat” and “Very Much” levels of emotional, physical, and financial stress and having reached out to OADS, AAAs, and other agencies for assistance. A related finding is that 31% of 2023 respondents indicated they did not need any help as a caregiver compared to 19% in 2019, indicating a lower level of caregiver need in the 2023 survey sample.

Caregiver information and navigation

Like 2019, listening session and focus group caregiving participants in 2023 described significant stress and frustration with managing and navigating the service system for their family members. A higher percentage of caregivers in the 2023 survey said they were not getting all the help they needed because they did not know who to ask: 43% in 2023 compared to 26% in 2019. This could reflect differences in the samples due to differences in survey implementation methodology.

Part Seven: Summary Survey Results

Statewide Aging Survey Summary

Demographics

We received 3,094 completed surveys. Results were weighted using the American Community Survey 5-Year Estimates from 2017-2021. The weighted gender distribution was based on the dichotomous sex categories provided by the Census. The survey included additional categories for those who felt they did not fit into these categories. The first four figures below show the unweighted and weighted results for county, age, gender, and income. All other results presented in this report reflect the weighted data. Differences in sample sizes (n) indicate that not every respondent answered every question.

Figure 28 Distribution of unweighted and weighted responses by County, n=3,094

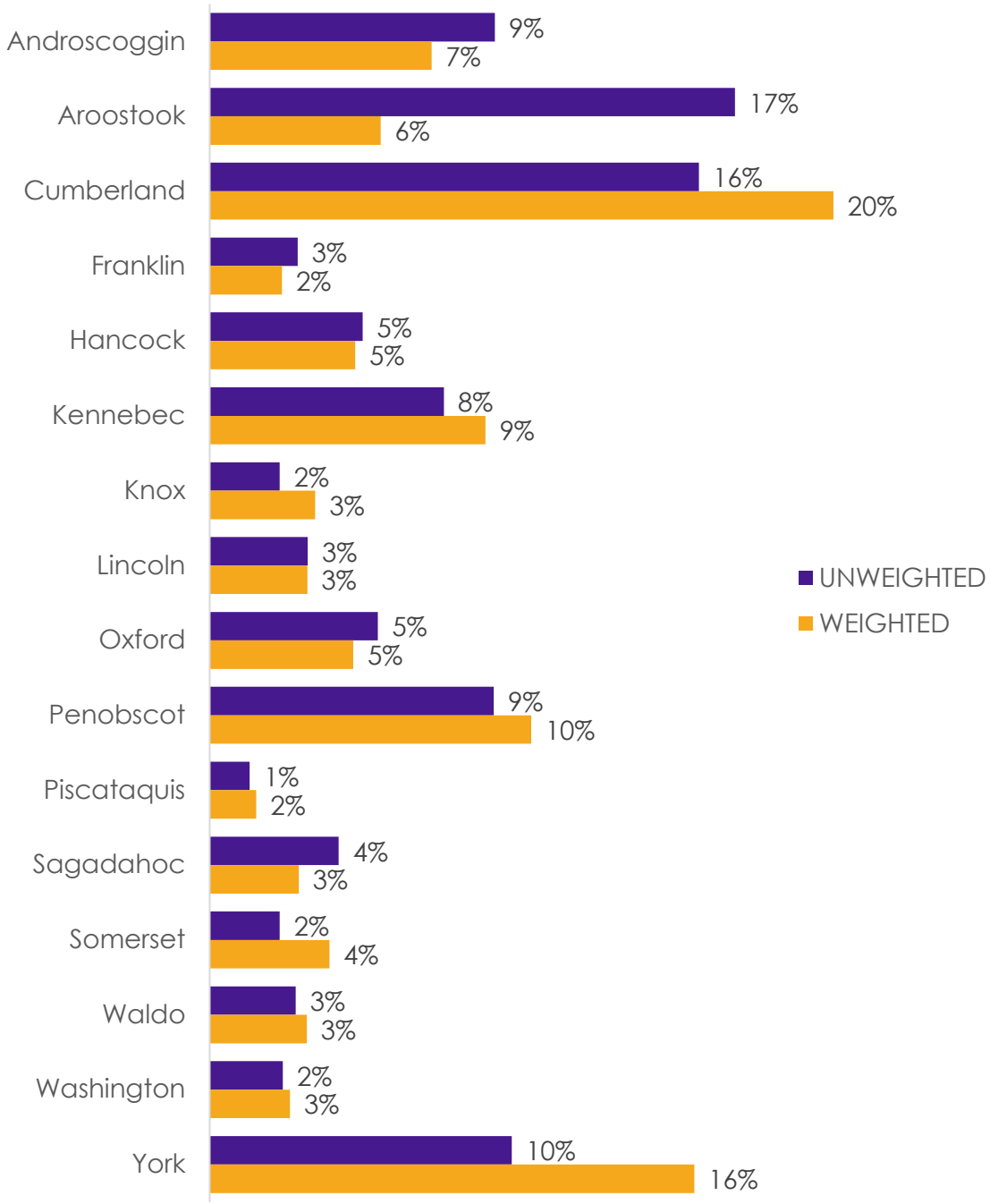


Figure 29 Distribution of unweighted and weighted responses by age, n=3,094

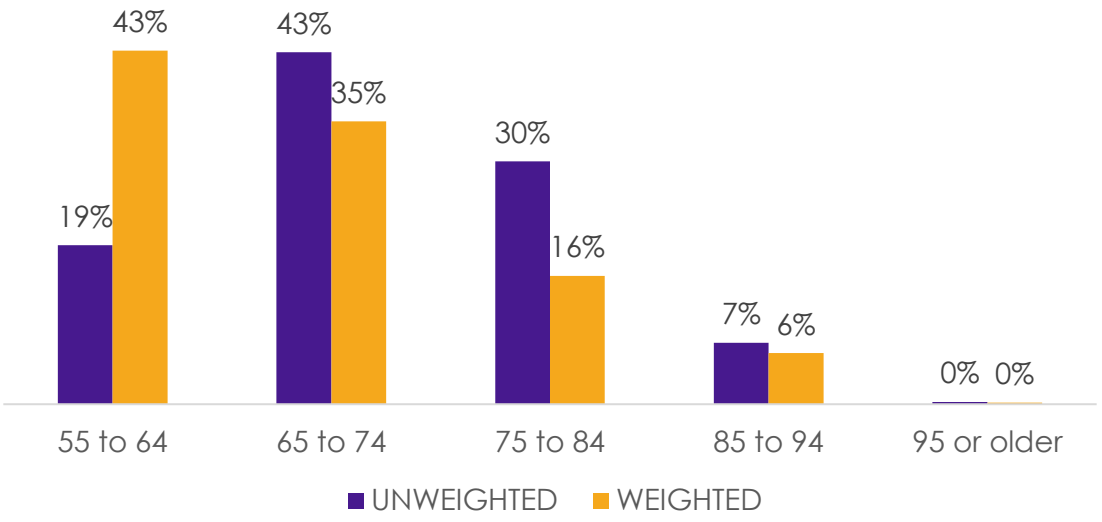


Figure 30 Distribution of unweighted and weighted responses by gender, n=3,094

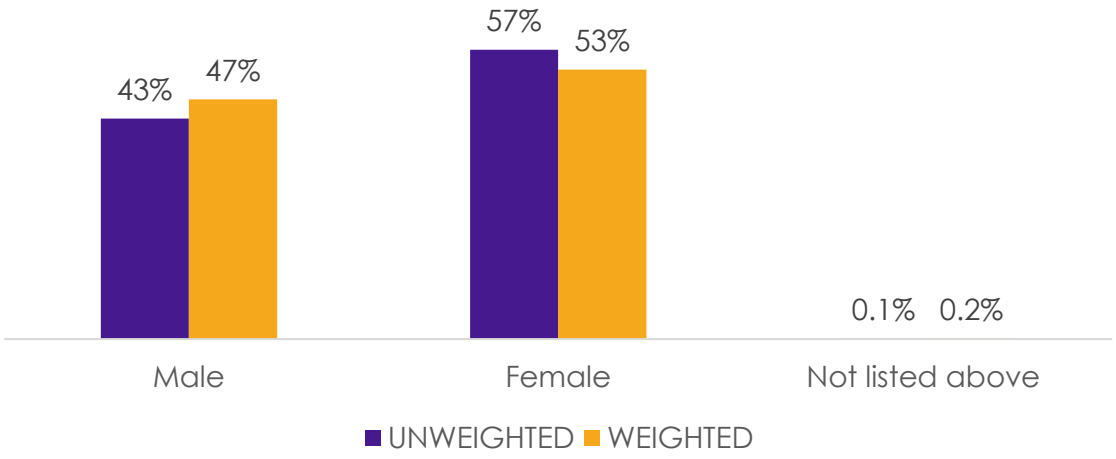
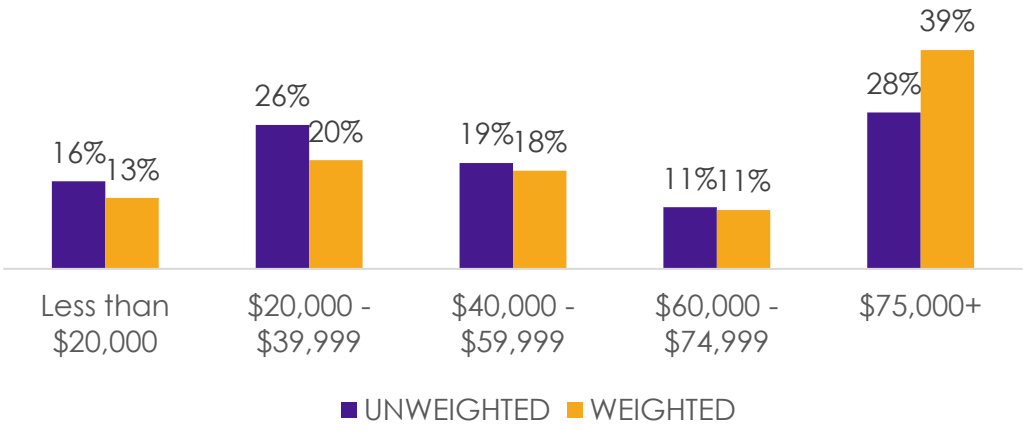
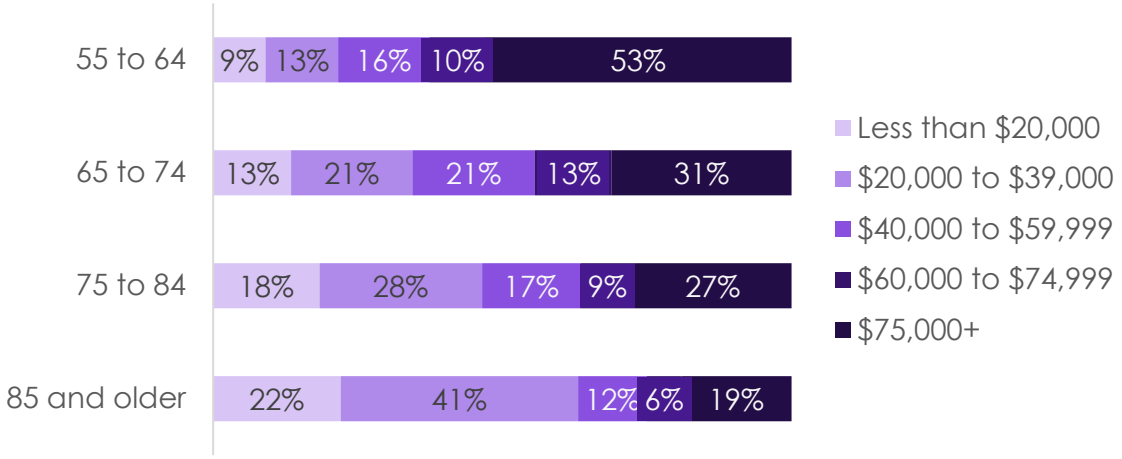


Figure 31 Distribution of unweighted and weighted responses by income



There was notable variation in income by age group, with older age groups having lower incomes compared to younger age groups (Figure 32). There were differences in income by gender, with a higher percentage of women having income less than $40,000 and a lower percentage of women having income of $75,000 or more as compared to men. There were no gender differences for people with incomes between $40,000 and $74,999.

Figure 32 Income decreases with advancing age, n=2,812



Most respondents identified as white (97%) and spoke English as their primary language (99%). Most respondents indicated a heterosexual sexual orientation (94%).

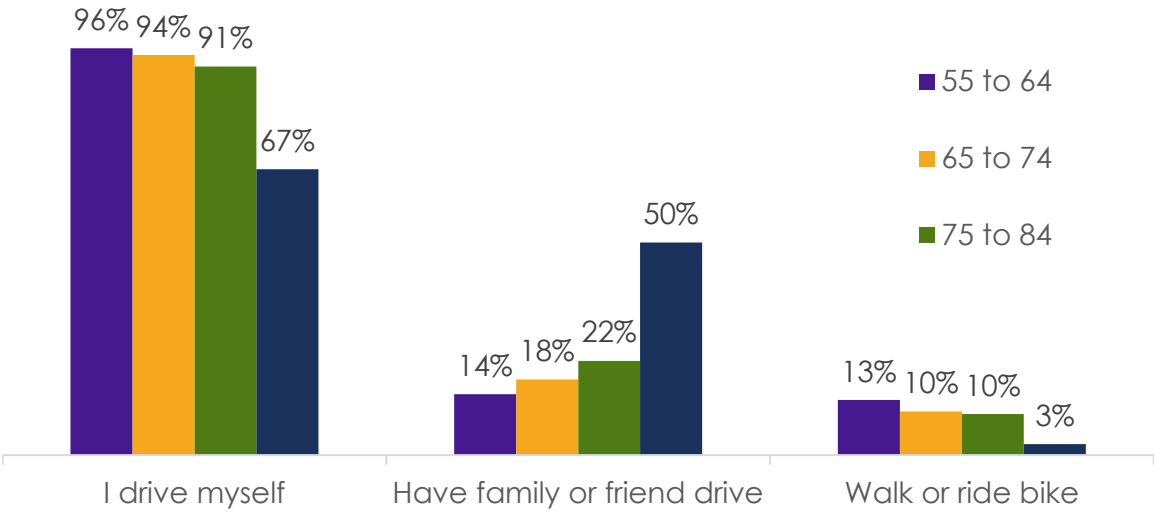
Thirty-one percent of respondents lived alone, and 60% lived with a spouse or domestic partner. The was gender variation in living along with a higher percentage of women living alone (39%) compared to men (21%). Fifty-six percent of survey respondents have an education level of college degree or higher and 21% have a high school diploma/GED or lower level of education.

Transportation

Most survey respondents (93%) drive themselves to the places they need to go. Other methods for getting around include family or friends driving, walking, and biking. Only 3% of respondents reported using public transportation. The survey responses confirm that there is considerable diversity among older people in how they travel. For instance, among those ages 85 and older, only 67% reported driving themselves, while 50% rely on family or friends for transportation (respondents could check more than one option). This contrasts with the

responses of the 55 to 64 age group 96% of whom drive themselves and 13% walk or bike (Figure 33).

Figure 33 Age variation in how people get around to the places they need to go, n=3,059



There were county differences in respondents' use of public transportation and those who walk or ride a bike. In Cumberland County, 19% of respondents said they walk or bike, while in Somerset County, only 3% do. In Sagadahoc County, 8% use public transportation, whereas in Washington, Somerset, and Kennebec counties, 0% reported using public transportation (Figure 34).

Figure 34 Walking or biking and taking public transportation varied by county.

County	Walk or bike	Take public or regional
Androscoggin	9%	3%
Aroostook	5%	3%
Cumberland	19%	4%

County	Walk or bike	Take public or regional
Franklin	11%	1%
Hancock	14%	4%
Kennebec	5%	0%
Knox	17%	1%
Lincoln	6%	1%
Oxford	8%	1%
Penobscot	12%	2%
Piscataquis	6%	2%
Sagadahoc	16%	8%
Somerset	3%	0%
Waldo	8%	3%
Washington	5%	0%
York	9%	3%

While 95% of respondents indicated they can find or arrange transportation without help, for those who face transportation challenges, the majority cited as reasons for needing help the absence of transportation services in their area, a lack of available drivers, or financial constraints preventing them from accessing the transportation they need.

Housing

Eighty-seven percent of respondents own their own home, 10% rent, and 2% live with family or a friend. Most (84%) said that their current home meets their needs, and 16% said it does not meet their needs, providing reasons such as the inability to afford needed repairs, difficulty heating or cooling the home

comfortably, excessive upkeep requirements, and the need for physical home modifications. Almost half of all respondents said they would not have other housing options if they lost their current housing and 12% expressed a fear of losing their housing.

Food & Nutrition

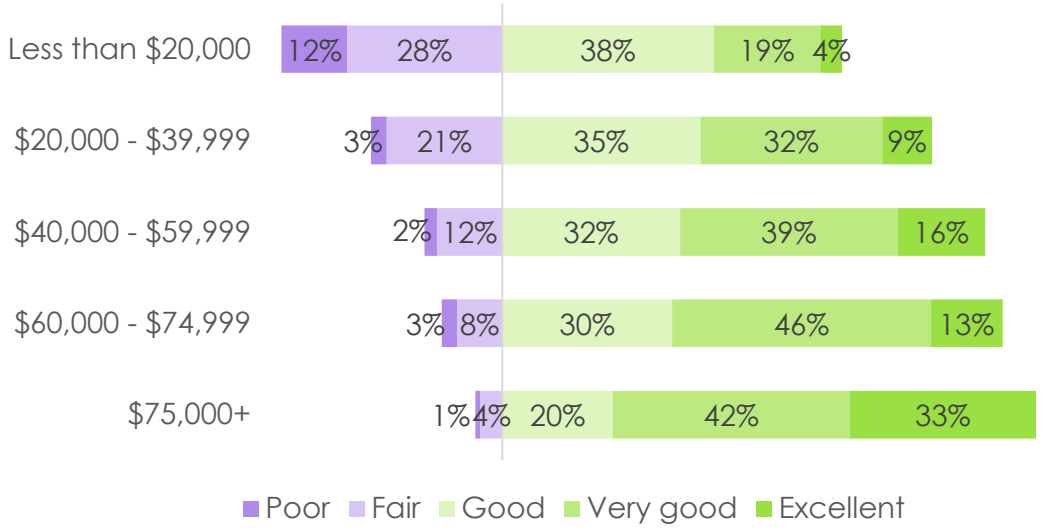
Most survey participants stated they have enough money to buy the food they need. However, 5% indicated that they do not have enough money to purchase the necessary food. Eleven percent of respondents use food assistance programs like SNAP to supplement their food purchases, and 5% of participants stated they sometimes or frequently eat at community meal sites for their main meals. Of those who reported not using community meal sites, 12% may need that service but have reasons preventing them from participating.

Four percent of participants report having difficulty preparing their own meals. However, only 2% of respondents indicated participation in Meals on Wheels. A small percentage of respondents also mentioned they do not have access to foods important to their ethnicity or culture (5%) or lack access to food that meets their dietary needs (3%).

Health

Over half (56%) of respondents stated they were in Very Good or Excellent health. Although only 15% said their health was either Fair or Poor, this varied by income. Forty percent of individuals with incomes less than $20,000 said their health status as either Fair or Poor compared to only 5% of individuals with incomes of $75,000 or more (Figure 35).

Figure 35 Respondents with lower incomes have poorer health status, n=2,791.



Respondents reported various health concerns including:

- 23% had concerns about their own memory,
- 19% had fallen within the last 6 months.
- 12% of said they have tooth or mouth problems that affect their ability to eat.

Some (25%) said they were *Somewhat* or *Very Interested* in a free or low-cost workshop or class to learn about how to keep themselves healthy.

Social isolation and loneliness

As noted earlier in this report, social isolation and loneliness often have a significant impact on health and wellbeing. Nearly three-quarters of respondents said they *Never* or *Hardly Ever* felt lonely or disconnected from other people. However, feeling lonely and disconnected varied by age and income with older people and those with less income experiencing these feelings more often (Figure 36 and 37).

Figure 36 Over one-third of adults 85+ feel lonely sometimes, often, or always, n=3,067.

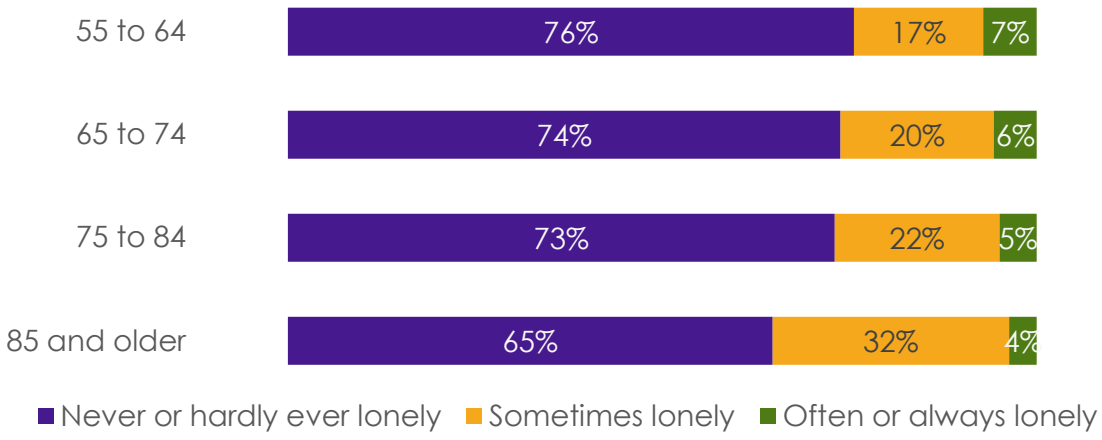
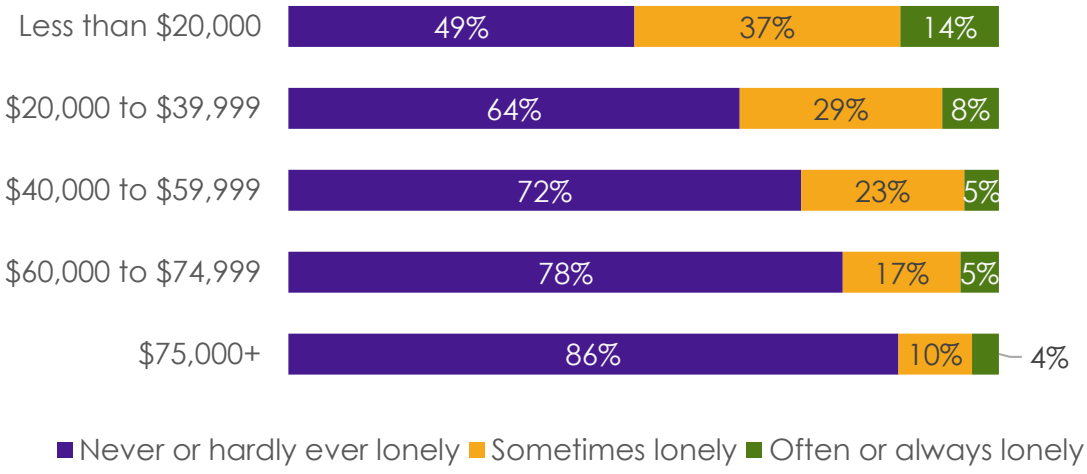


Figure 37: Over half of low-income adults feel lonely sometimes, often, or always, n=2,786.



Need help with daily tasks

About 10% of respondents said they have difficulty with some tasks such as household chores, personal care activities or managing their medications. Of those who have difficulty, only 32% indicated they are receiving in-home help from another person or outside organization. The most common reason was they could not afford help (36%), they did not know how to get help (28%) or there was no help available (11%).

Employment and Volunteering

More than half of all respondents stated they were retired, 27% work full time, and 12% work part time. We asked respondents if their work status had been impacted by caregiving, personal health, workplace attitudes, financial concerns, and other factors. Fifty percent said their health status and 19% said caregiving had played a role in their current work status.

Over one-third of respondents reported they volunteer regularly and 40% reported they volunteered regularly at some point during the last four years. Of those who currently volunteer regularly, two-thirds said they volunteer 1-10 hours per week and one-third volunteer more than 10 hours per week. Types of volunteer programs included, among others, religious/spiritual, social and human services, education, hunger and food security, civic, advocacy, and arts and culture.

COVID-19

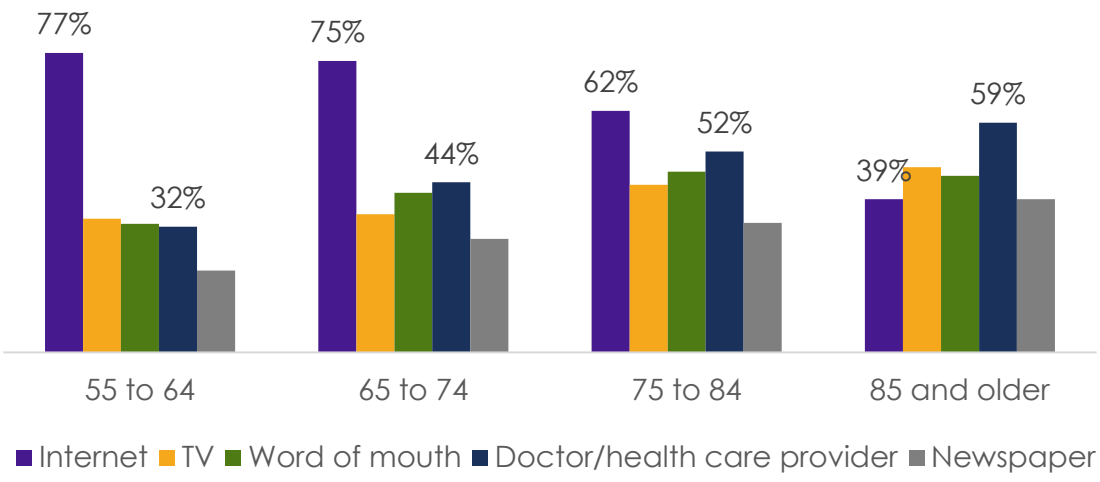
Nearly half of survey participants stated that social gatherings (29%) or feeling socially connected to others (19%) had become more challenging due to the COVID-19 pandemic. Additional challenges that emerged since the COVID-19 pandemic included difficulties in staying active, attending religious activities, and taking care of their health. Notably, survey respondents indicated that some

services are easier to access since the pandemic including telehealth (70%), online worship or religious services (32%), and virtual classes (21%).

Information

One-quarter of survey participants said it was somewhat difficult or very difficult to get information on services and programs for older adults. Most people said they find out about these services on the internet, but 8% of participants said they do not access the internet. Other ways older people get information includes from their doctor, word of mouth, and from the radio or TV. The ways that people get information about services varies by age (Figure 38).

Figure 38: Best ways to get information about available services for older adults by age.



Although 79% said they needed help with some services in the last 6 months, most participants said they do not call or look online for organizations that might offer services including Area Agencies on Aging, Maine 211, Legal Services for the Elderly, or Long-Term Care Ombudsman Program.

Community

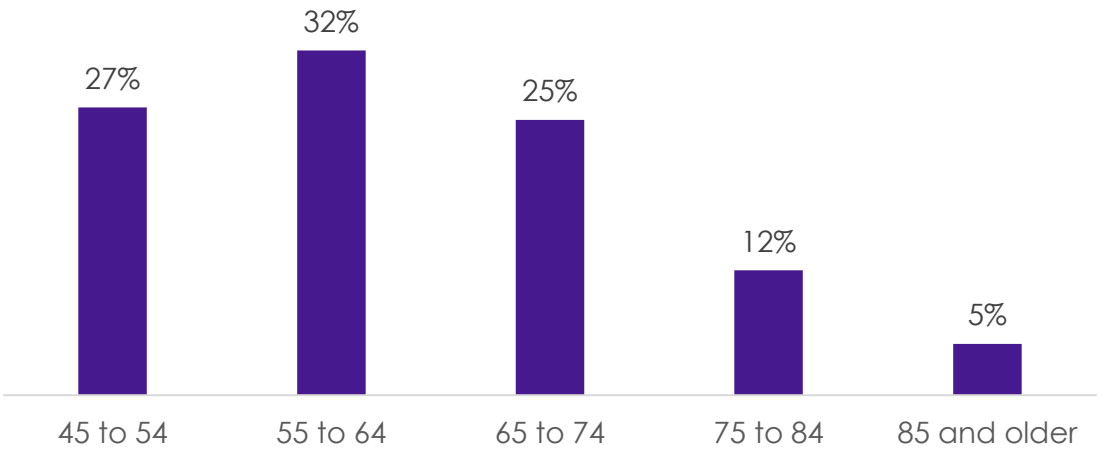
Nearly three-quarters of respondents rated their community as a *Good*, *Very Good*, or *Excellent* place for people to live as they age. Among those who did not rate their community positively, 21% of respondents rated their community *Fair* or *Poor* and 6% said they were *Unsure*. Two-thirds of respondents said they feel respected by other people at their current age, while 28% expressed a neutral stance, neither agreeing nor disagreeing with this statement.

Statewide Caregiving Survey Summary

Caregiver and Care Recipient Profiles

A total of 627 survey respondents ages 45 years and older indicated they provide help or care to one or more people ages 60 or older. Of these, slightly over half of the respondents identified as women (52%) and 48% as men.[xv] While survey respondents ranged in age, almost three-quarters (74%) were 55 years of age or older and 27% were 45-54 (Figure 39).

Figure 39 Age distribution of respondents ages 45 and older, n=627.

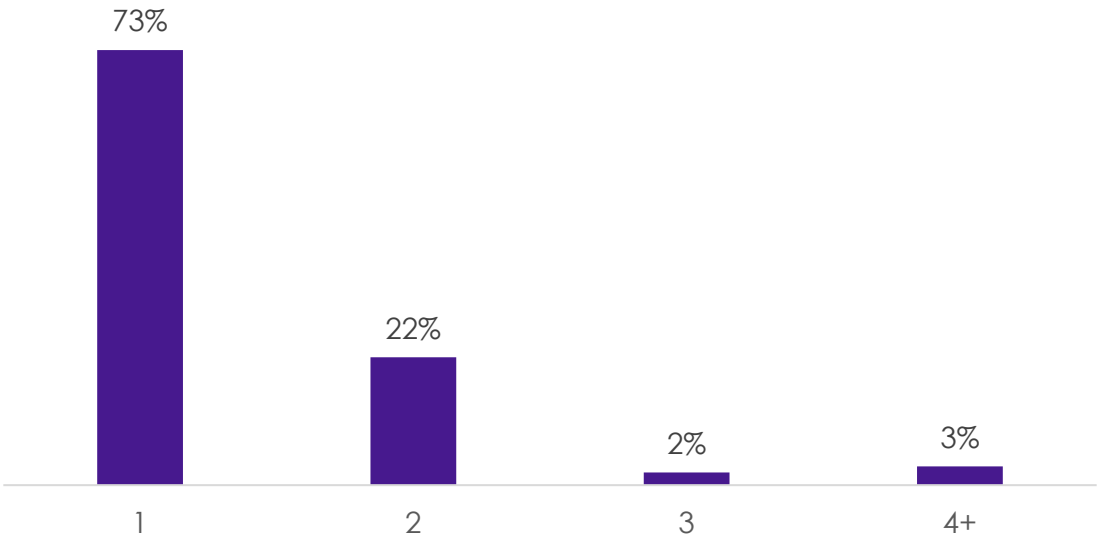


Most caregivers provide in-person care. Half of respondents provide only in-person care, and 44% provide a combination of in-person and remote care. Six percent exclusively provide remote care. Remote care is defined as check-in phone call, video chat, text or voice message, bill-paying, home monitoring via in-home camera, scheduling appointments, etc.

[xv] Additional categories were available in the survey.

The average age of caregiver respondents' care recipients was 76 years old. Eighty-five percent of caregivers provide care to an individual 65 years or older and 88% provide care for an individual 60 year or older. Thirteen percent care for an individual under the age of 60 with a disability, 4% provide care for a grandchild or other relative under the age of 18, and 4% care for an adult under the age of 60 who has Alzheimer's or other related dementia.[xvi] Twenty-seven percent indicated they provide care for two or more people (Figure 40).

Figure 40 How many people do you care for? n=612



Many caregivers (63%) provide care to an adult family member, including biological, adopted, step, in-law or chosen family member. Another 25% of respondents care for their spouse or partner.

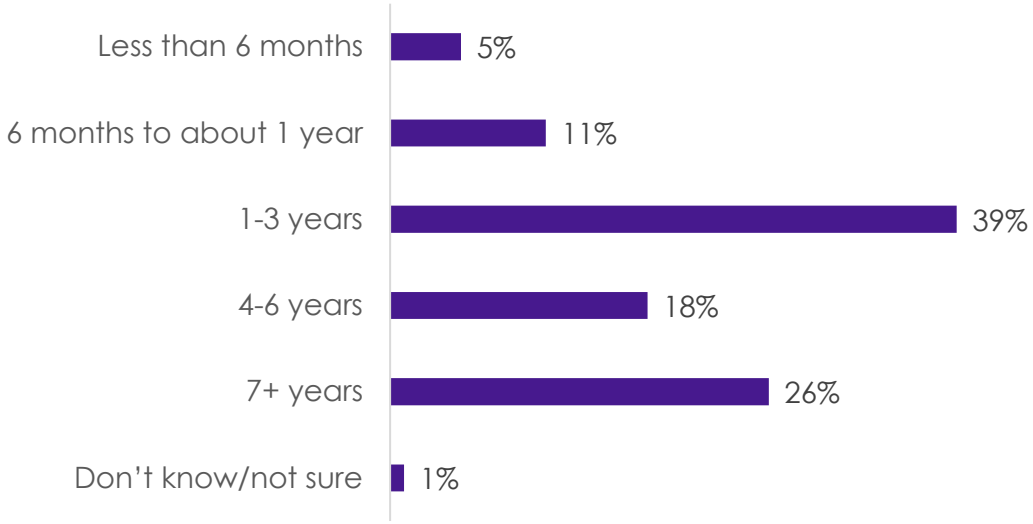
[xvi] Respondents ages 45-54 met survey inclusion criteria if they provided care to an adult over age or an adult under age 60 who has a diagnosis of Alzheimer's disease or related dementia (ADRD). The survey did not include younger caregivers caring for younger adults without ADRD or caring for children.

Forty percent of caregivers live in the same home as the care recipient, and 34% live less than twenty minutes away. Most care recipients (82%) either own their home or live in an apartment, while the remaining 18% live in an assisted living facility, nursing home or other type of supported housing.

Time spent caregiving

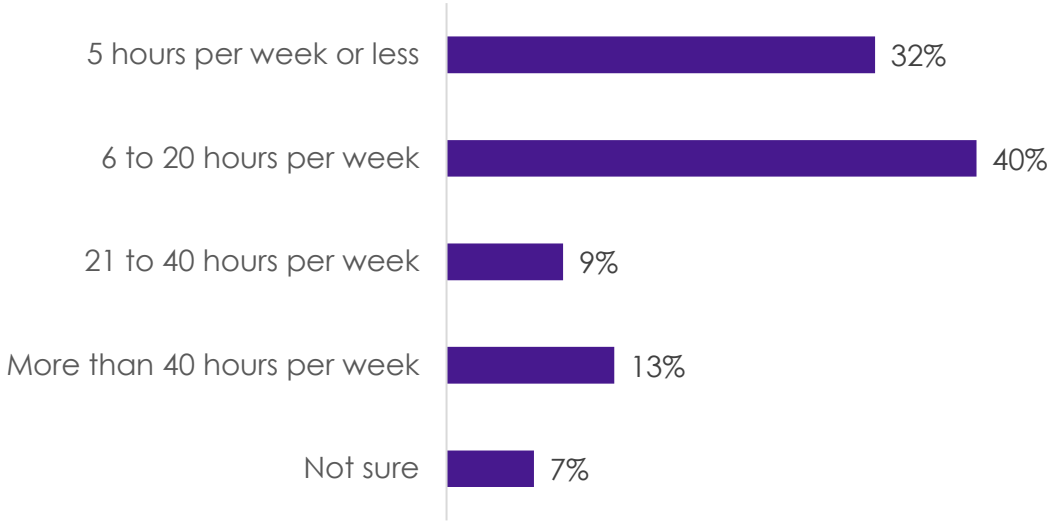
Most respondents have been providing care for over a year with just over a quarter providing care for 7 years or more (Figure 41).

Figure 41: How long have you been providing care to this person? n=623



Fifty-seven percent of caregivers visit their care recipient more than once a week. Forty percent of caregivers provide between six and twenty hours of care per week and 32% provide five or less hours (Figure 42).

Figure 42 How much time do you typically spend each week helping this person? n=611



Types of care provided

Caregivers provide myriad types of assistance to their family members. Transportation and talking with healthcare professionals and other service providers are the top types of care, along with household tasks, regular check-ins, and meal or food preparation (Figure 43).

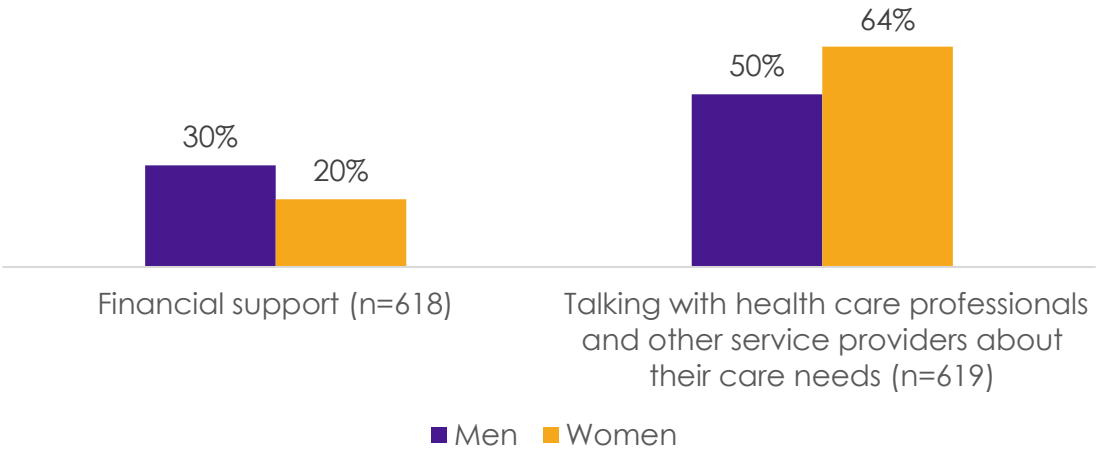
Figure 43: Types of care and assistance provided by caregivers, n=624.

Type of care provided by caregivers	Percent
Transportation	62%
Talking with healthcare professionals, social services agencies, and	58%
Daily household tasks	56%

Type of care provided by caregivers	Percent
Daily or frequent check-in by	56%
Food or meal preparation	53%
Companionship or supervision	52%
Financial management	43%
Help with medications	37%
Financial support	25%
Help with personal care such as bathing, dressing, using the toilet	17%
Medical care	11%
Other	7%
Education	3%
Childcare	1%

There are noteworthy gender differences in a few types of care provided. Men are more likely to provide financial support, and women are more likely to talk with health care professionals or other service providers (Figure 44).

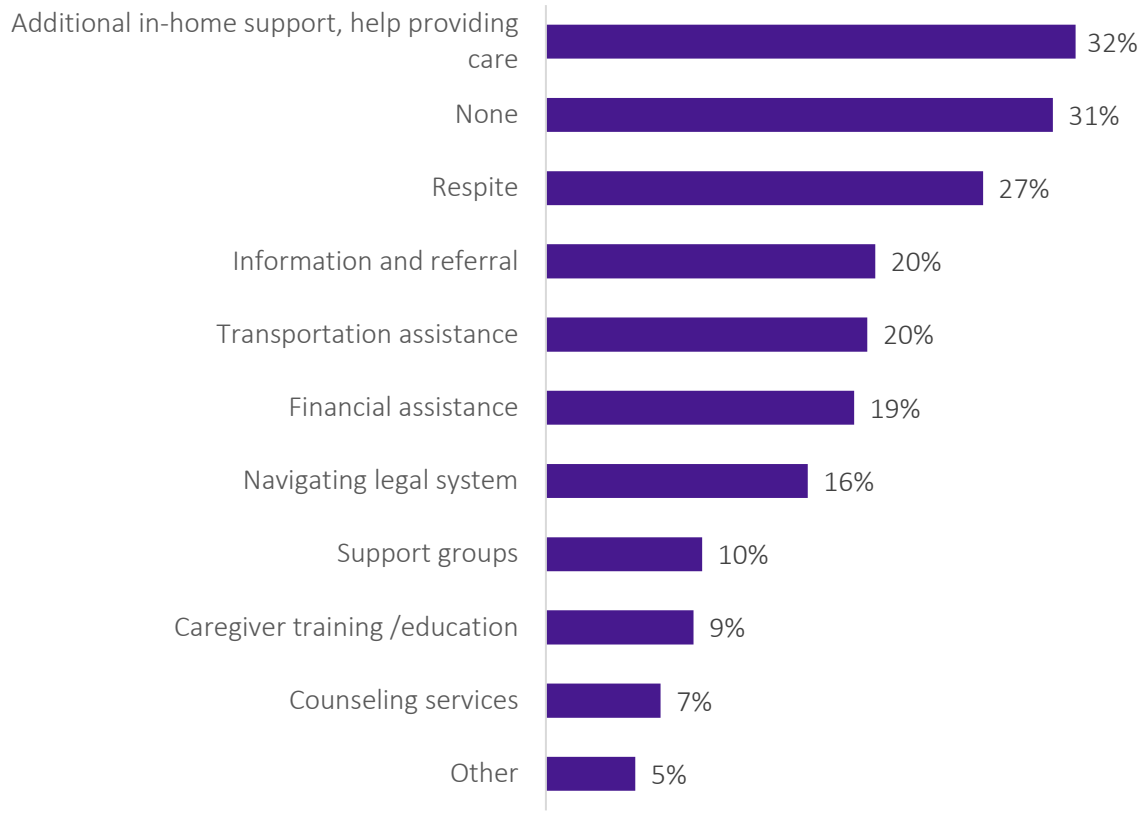
Figure 44 More men provide financial assistance, and more women talk with health care and other service professionals.



Assistance for caregivers

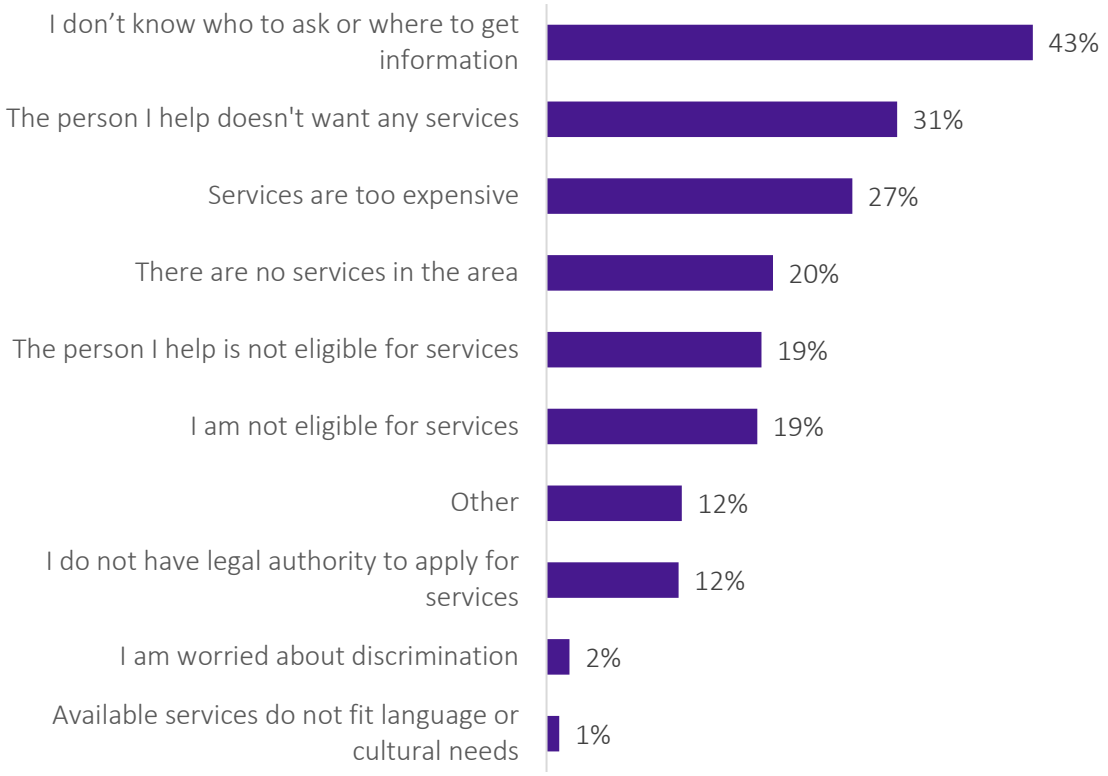
While nearly one-third of caregivers said they did not need any of the caregiver support services that AAA and other agencies provide, others said they needed additional in-home support, respite services, help with getting information and referrals to services, and assistance with transportation (Figure 45).

Figure 45 Top caregiver needs include additional home support, respite, and information and referral, n=600.



Thirty-seven percent of caregivers responded they were not receiving the help they need as a caregiver, and another 21% were not sure. Forty-three percent of respondents said they weren't getting help because they didn't know who to ask or where to get information, 31% said the person who is receiving care doesn't want any services, and 27% said the services are too expensive (Figure 46)

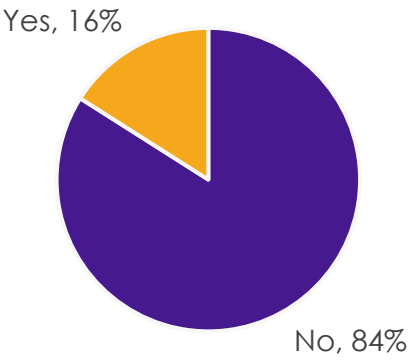
Figure 46 If you are not getting help, why not? n=321



Caregiver Employment Status

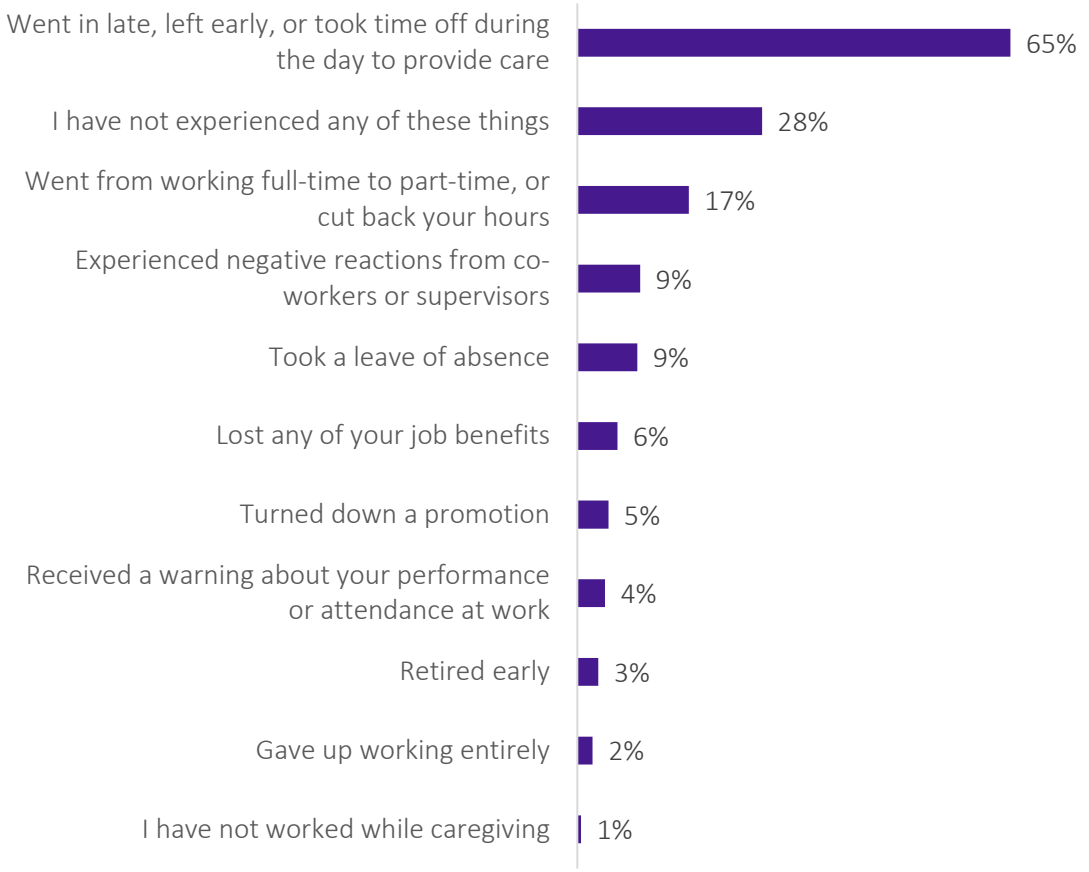
Well over half (57%) of caregivers were employed, at any time, during the past six months while they were providing care. The survey also asked whether caregivers had had to leave their job because of providing care and 17% said yes (Figure 47).

Figure 47 Sixteen percent of caregivers left a job as a result of being a caregiver, n=339



Caregivers indicated that over the past six months, caregiving responsibilities impacted their employment in a variety of different ways. The most common was going to work late, leaving early, or taking time off during their day to provide care (65%). Another 17% indicated they went from working full-time to part-time or cut back their hours (Figure 48).

Figure 48 As a result of caregiving, did you ever experience any of these things at work? n=340



Caregiver Strain

Caregivers can experience stress or strain in various ways while providing care for others, including physical, emotional, and financial strain. When asked about their experience, 74% indicated they *Somewhat* or *Very Much* experience emotional strain. Nearly 50% indicated they *Somewhat* or *Very Much* experience physical strain, while 40% experience *Somewhat* or *Very Much* financial stress (Figures 49-51).

Figure 49: How much of a physical strain would you say that caregiving is? n=621.

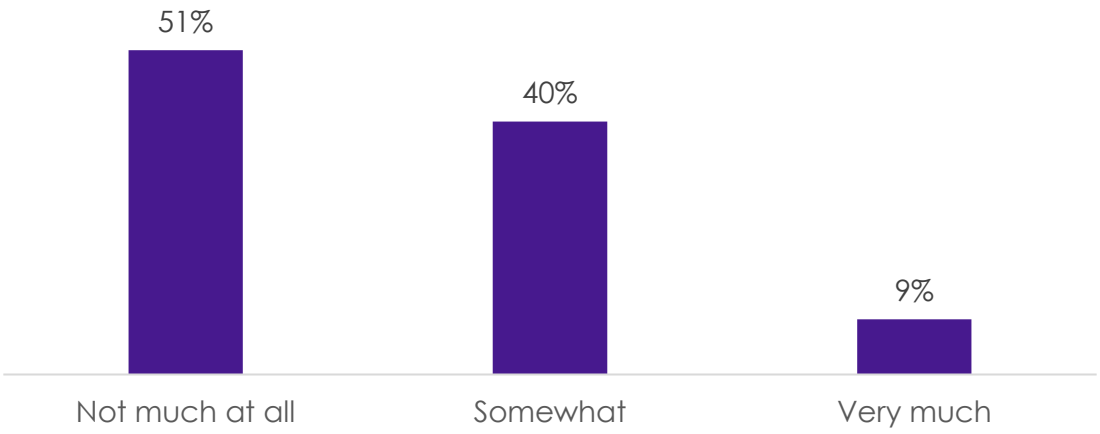


Figure 50: How emotionally stressful would you say that caregiving is? n=623

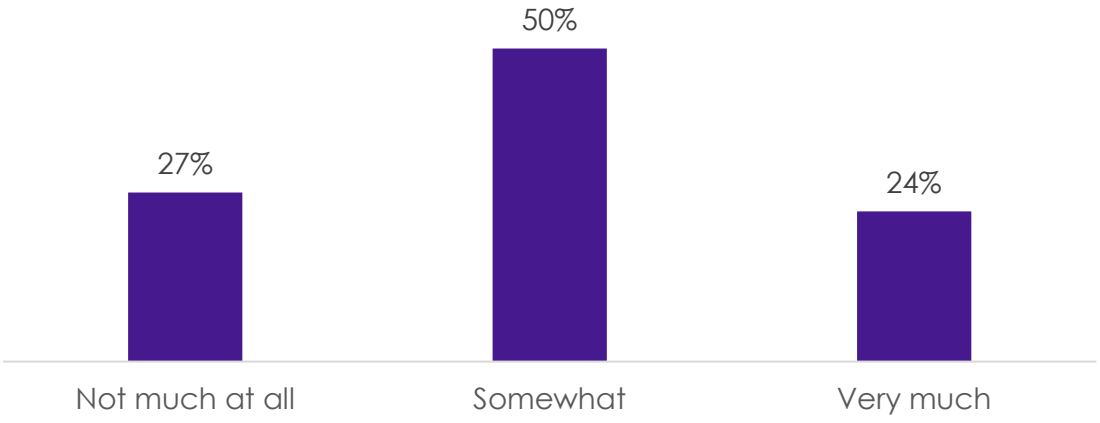
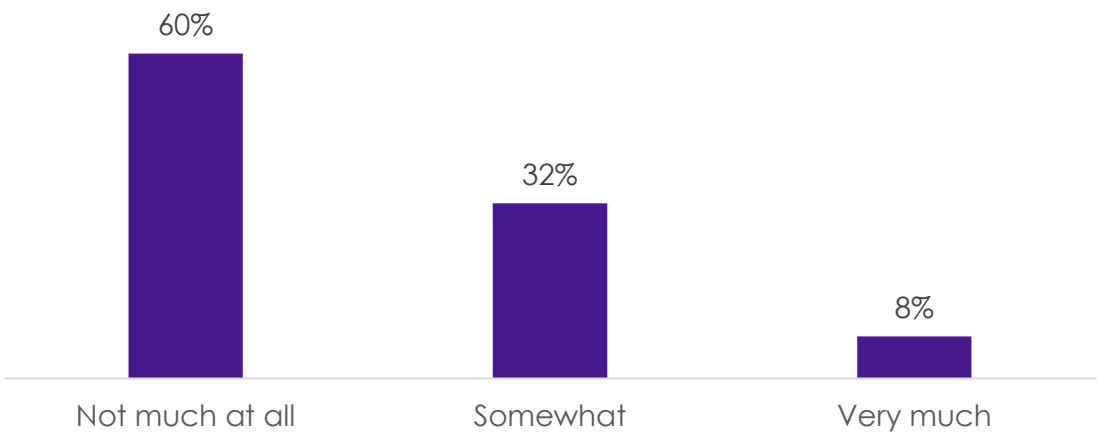
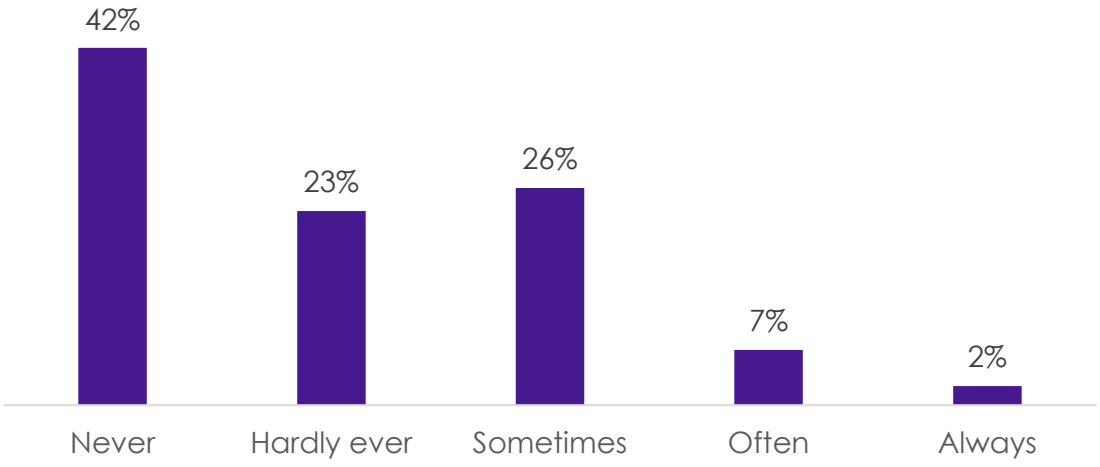


Figure 51: How much of a financial strain would you say that caregiving is? n=625



When asked if they experience loneliness or disconnection from others due to their caregiving responsibilities, 65% said they never or hardly ever felt this way. However, 26% said that they feel lonely and disconnected *Sometimes* and 9% said they *Often* or *Always* feel that way (Figure 52).

Figure 52: In the last 6 months, how often have you felt lonely and/or disconnected from other people due to caregiving? n=623



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By Domain

Healthcare: Access

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Healthcare: Falls

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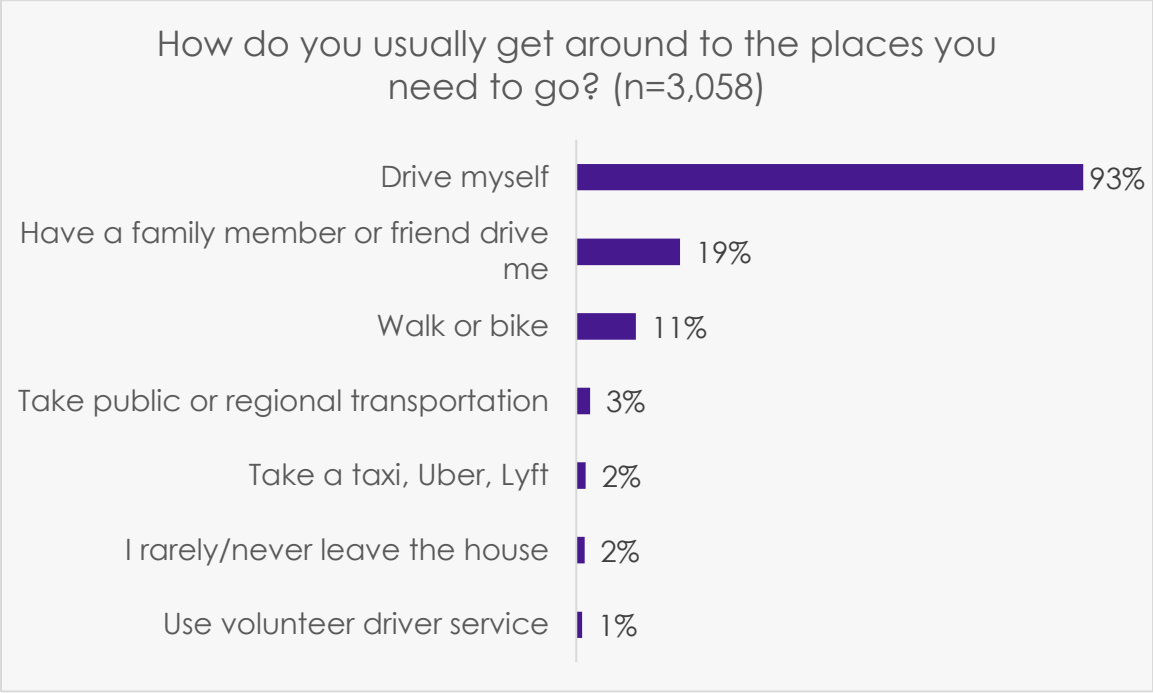
Appendix A: Statewide 55+ Survey

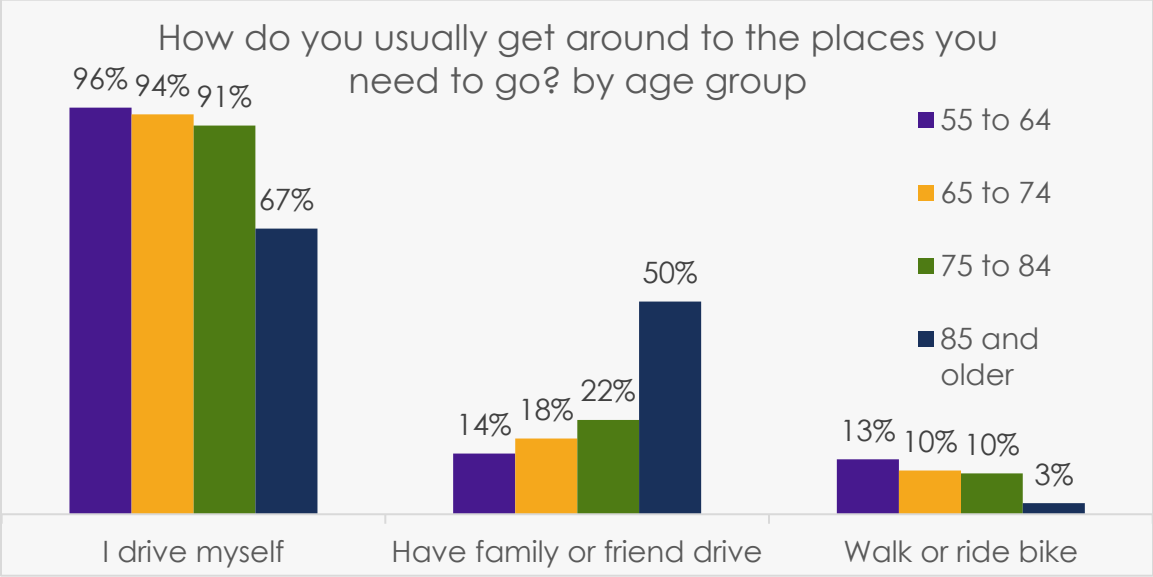
Complete Results

Transportation

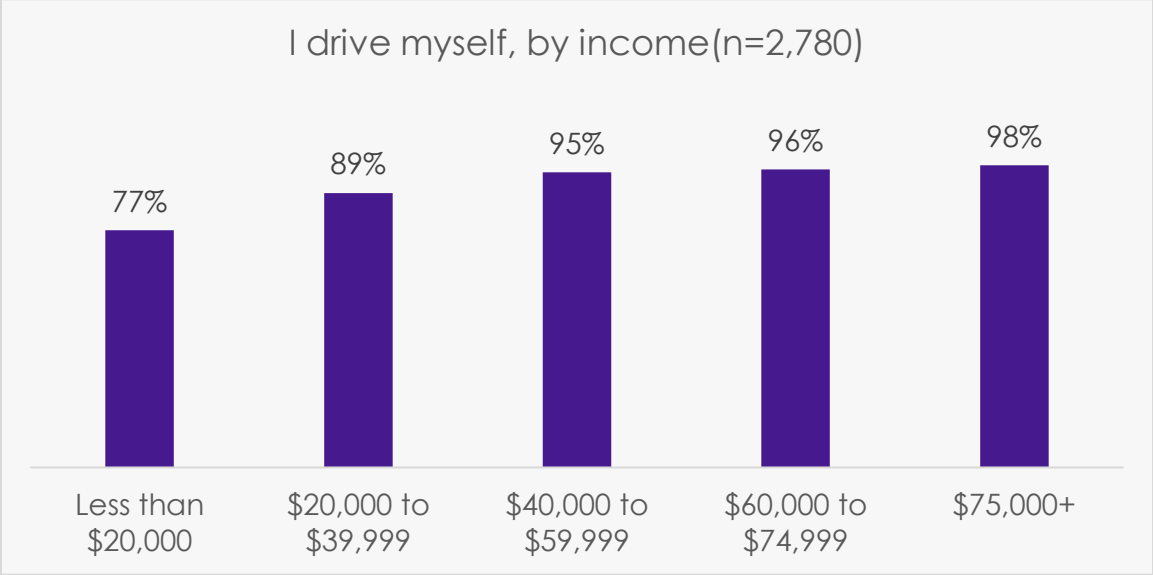
Q1:

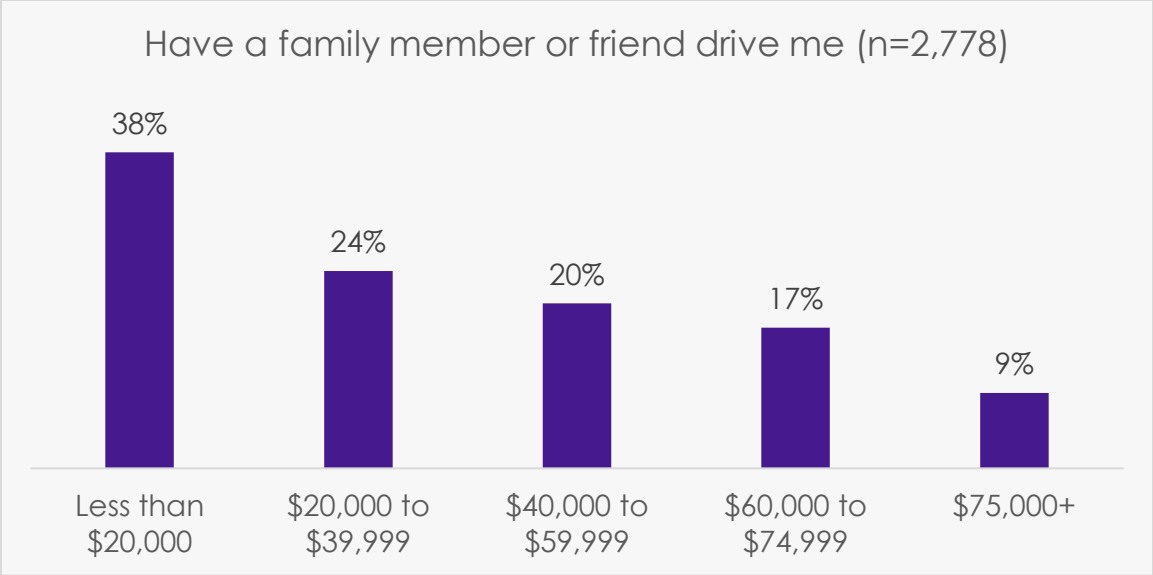


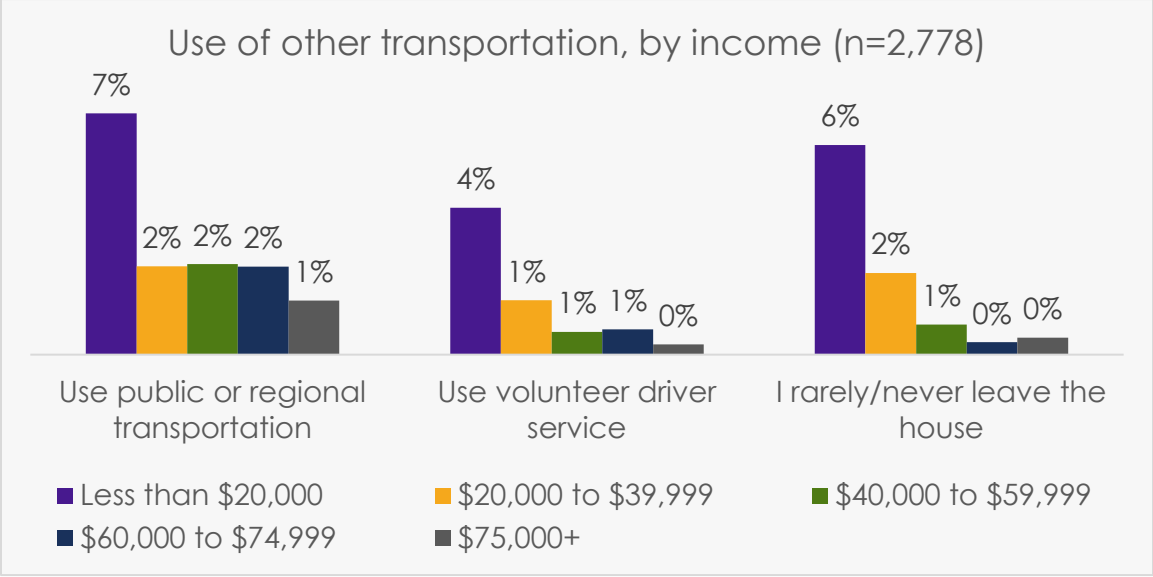
Additional crosstabulations around transportation



There was notable income variation in driving self, having family or friends drive, using other transportation options, or rarely leaving the house.




Have a family member or friend drive me (n=2,778)
38%
24%
20%
17%
9%
Less than $20,000
$20,000 to $39,999
$40,000 to $59,999
$60,000 to $74,999
$75,000+

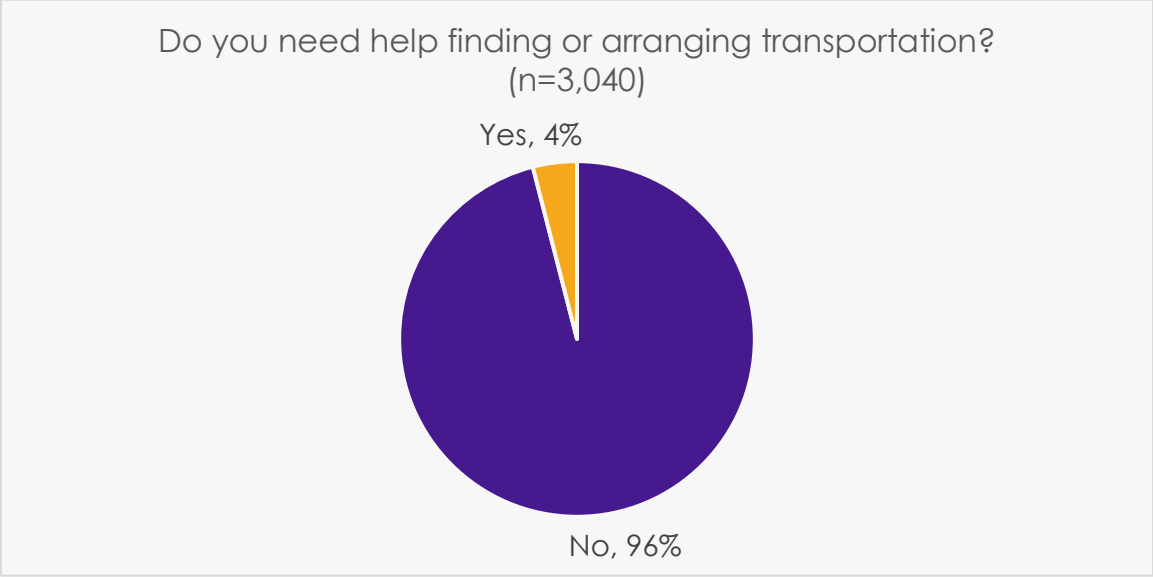

Use of other transportation, by income (n=2,778)
7%
2%
2%
2%
1%
4%
1%
1%
1%
0%
6%
2%
1%
0%
0%
Use public or regional transportation
Use volunteer driver service
I rarely/never leave the house
Less than $20,000
$20,000 to $39,999
$40,000 to $59,999
$60,000 to $74,999
$75,000+

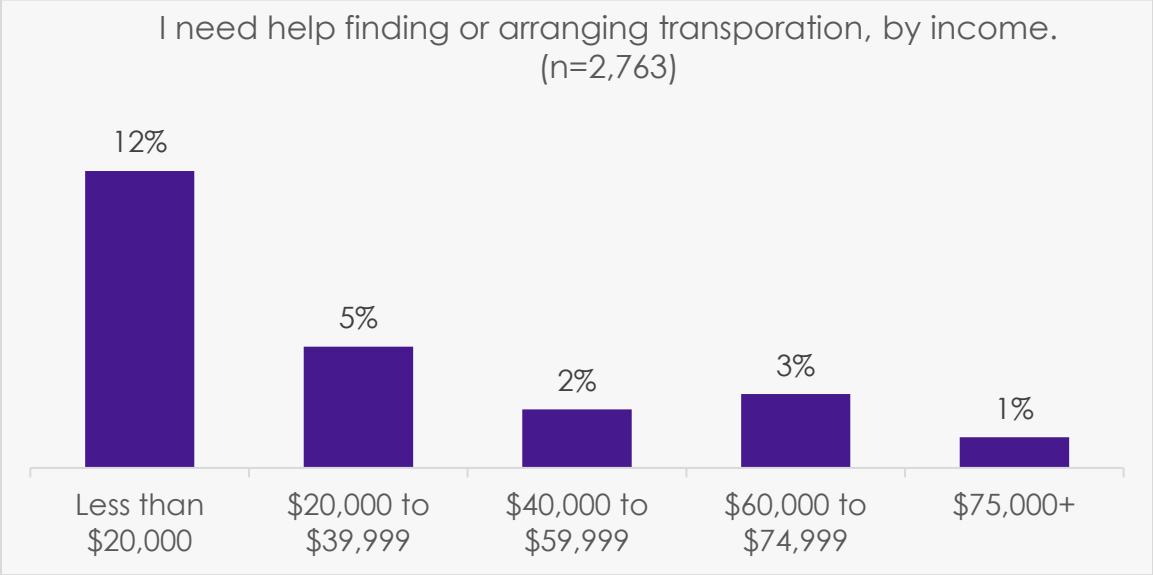
There was notable county variation in alternative methods of getting around, across all ages.

Table 1: Alternative Transportation by County

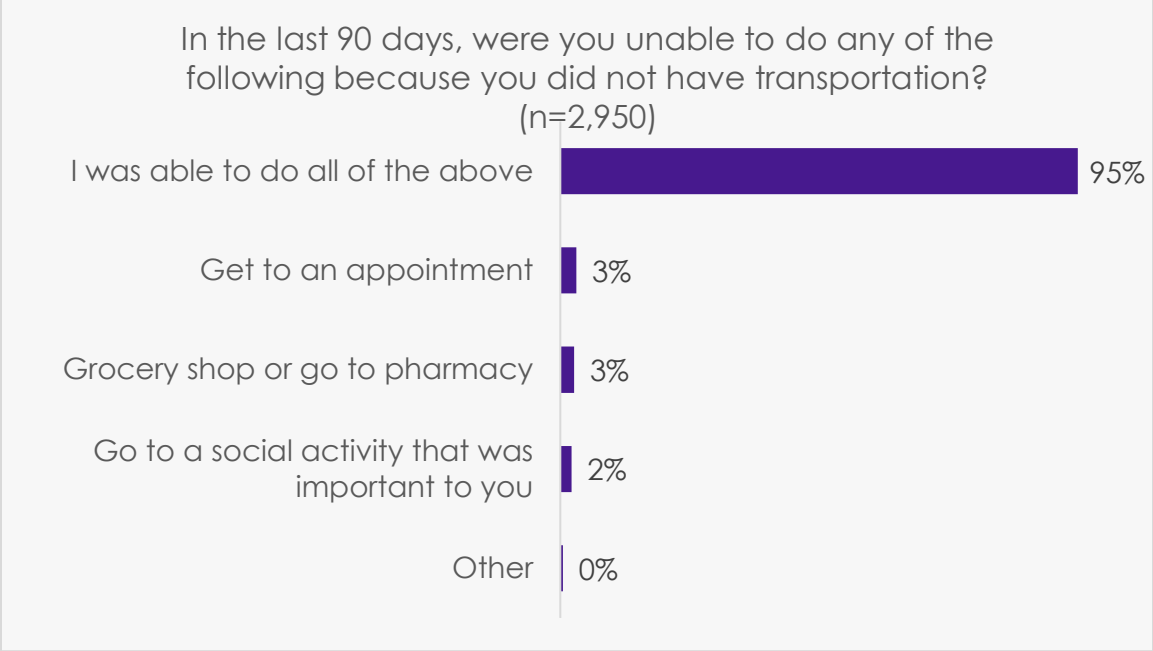
County	Walk or bike	Take public or regional transportation
Androscoggin	9%	3%
Aroostook	5%	3%
Cumberland	19%	4%
Franklin	11%	1%
Hancock	14%	4%
Kennebec	5%	0%
Knox	17%	1%
Lincoln	6%	1%
Oxford	8%	1%
Penobscot	12%	2%
Piscataquis	6%	2%
Sagadahoc	16%	8%
Somerset	3%	0%
Waldo	8%	3%
Washington	5%	0%
York	9%	3%

Q2:


Do you need help finding or arranging transportation?
(n=3,040)
Yes, 4%
No, 96%


I need help finding or arranging transporation, by income.
(n=2,763)
12%
5%
2%
3%
1%
Less than $20,000
$20,000 to $39,999
$40,000 to $59,999
$60,000 to $74,999
$75,000+

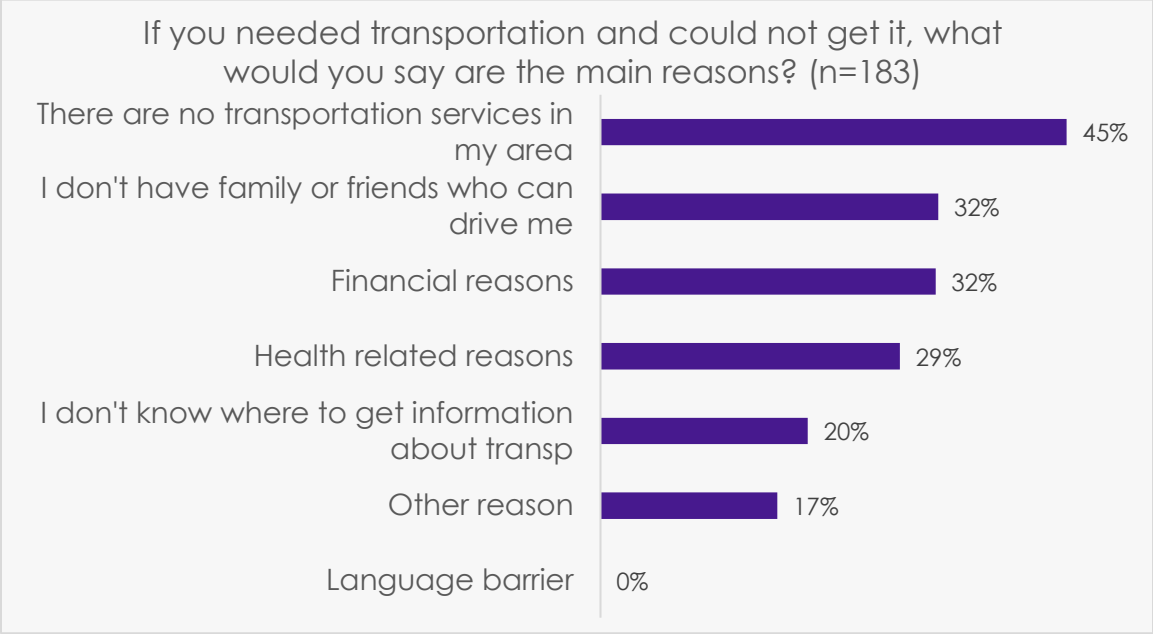
Q3:


In the last 90 days, were you unable to do any of the following because you did not have transportation? (n=2,950)
I was able to do all of the above
95%
Get to an appointment
3%
Grocery shop or go to pharmacy
3%
Go to a social activity that was important to you
2%
Other
0%


I was able to go to appointments, shopping, social events, and other, by income (n=2,681)
82%
95%
96%
96%
Less than $20,000
$20,000 - $39,999
$40,000 - $59,999
$60,000 - $74,999

Q3. Other responses: When asked "Were you unable to drive to appointments, go to the grocery store or social activities?" respondents shared they were unable to either drive at night or use public transportation. Few mentioned they were unable to go to work, and therefore lost employment, or visit the local mall, picnic area, and library.

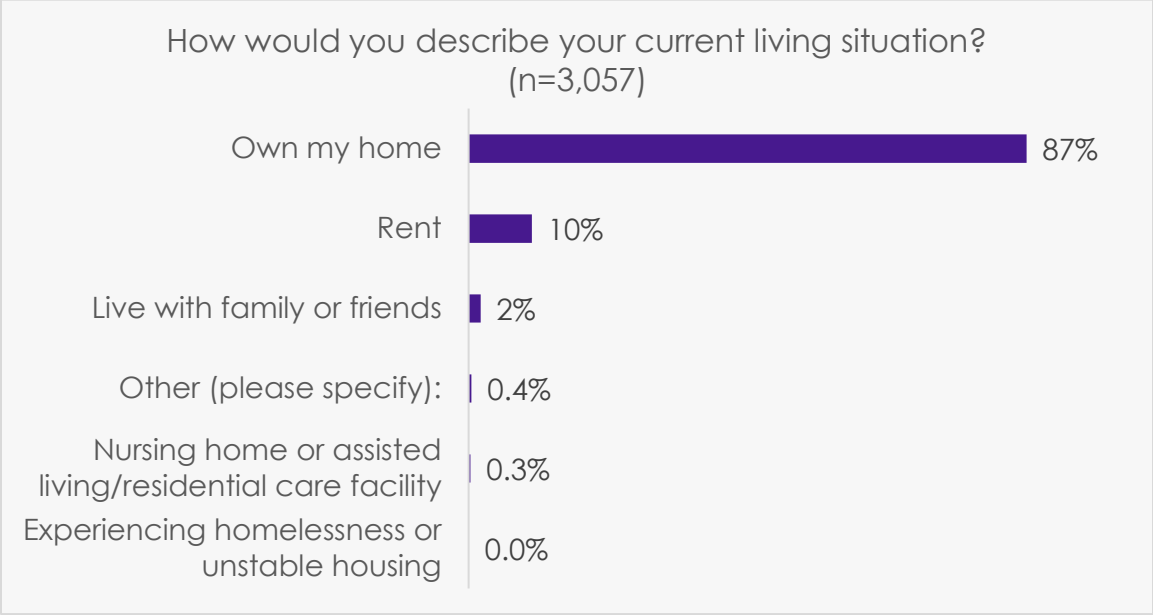
Q4:



Q4. Other responses: Respondents shared that one of the primary reasons they were unable to access transportation was due to cost, for example only having one car per household, fuel prices being too high, or their vehicle is unreliable. The majority mentioned there are barriers to obtaining reliable transportation. Though they do have friends and family available to help, they aren't always available when the respondent needs help. In addition, if the respondent may have physical disabilities and that not all vehicles are able to transport them. Public transportation also poses access problems, as the transportation is not available in some areas, does not accommodate wheelchairs or is just "inadequate." However, some mention they do participate in home delivery services.

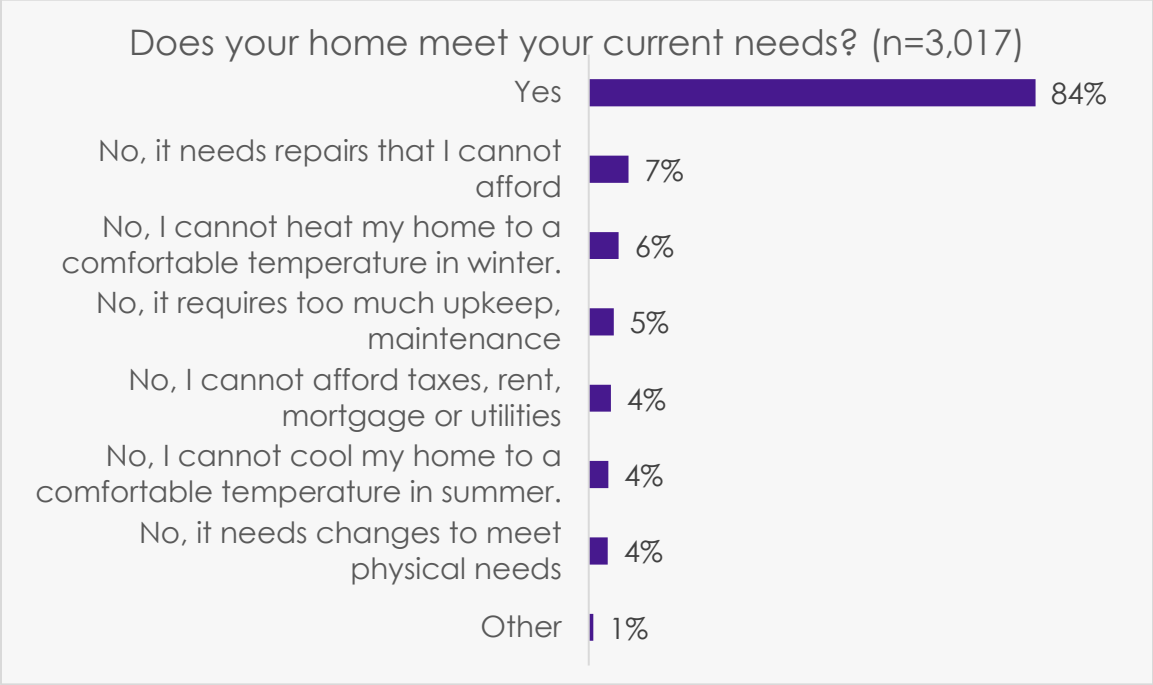
Housing

Q5:



Q5. Other responses: When asked "how would you describe your current living situation," respondents shared that they live in an independent living community, co-op, or retirement community. Few shared that their partner owned the home they reside in.

Q6:



Q6. Other responses: When asked "does your home meet your current needs" respondents shared they have trouble finding safe, reliable, and affordable trades people to help them with home repairs. Few mentioned they do not feel safe, the surrounding area is too loud, their driveway is too long, or their house is too large, has unsafe water, or radon problems.

Q7:

Question	Yes	No
Q7: Do you have any fear of losing your housing for any reason? (n=3,051)	12%	**88%**

Q7: Reasons for fear of losing housing: Respondents who said they feared losing their housing were asked to specify why. The most common responses centered on the cost of living followed by concerns around taxes and home maintenance or repairs.

Q8:

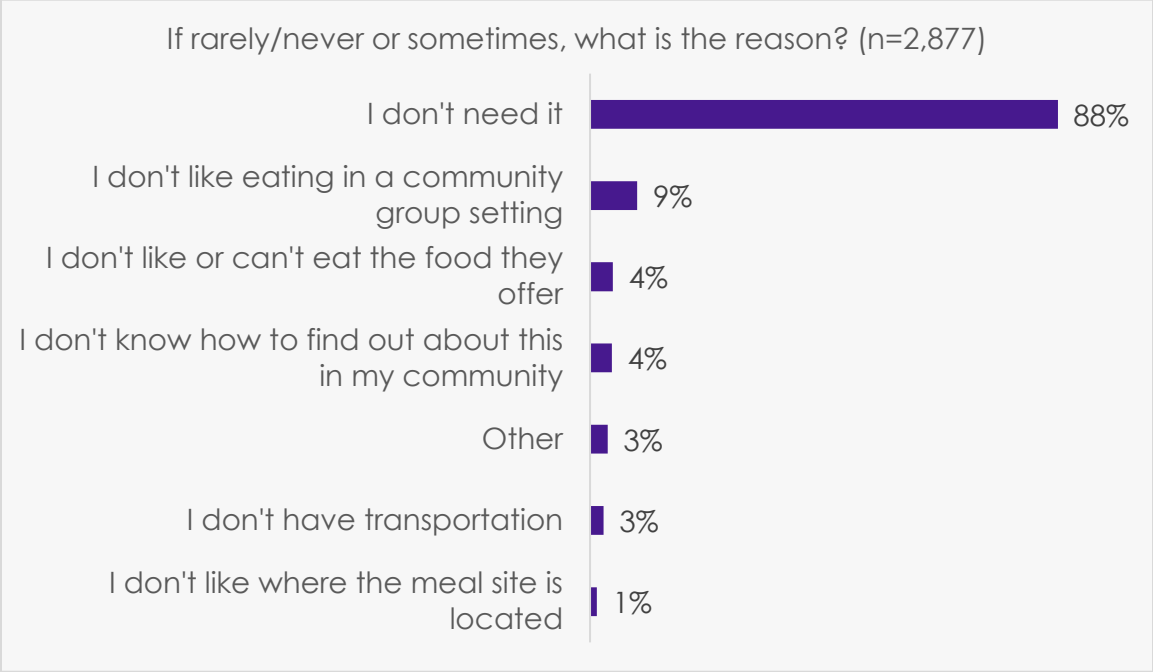
Question	Yes	No
Q8: Would you have other housing options if you lost your current housing? (n=2,965)	**51%**	49%

Food and Nutrition

Question	Yes	No
Q9: Do you usually have enough money to buy the food you need? (n=3,073)	**95%**	4%
Q10: Do you use food pantries or participate in a food assistance program (such as SNAP)? (n=3,073)	11%	**89%**

Q11:

Q12:



Q12. Other responses: When asked "How often do you eat at a community meal site?" respondents who selected "rarely/never" shared they are unable to participate due to either medical or dietary restrictions or feeling unsafe attending due to fears of the COVID-19 virus. Some indicated that their community does not offer community dining opportunities, or they are unable to participate when offered, some mentioned they couldn't afford the nominal fee some community meal sites charge. Others said others have greater needs for the meals. Respondents also shared they do not participate in community meals because they enjoy cooking at home, prefer to be alone, or just do not want to.

Q13:

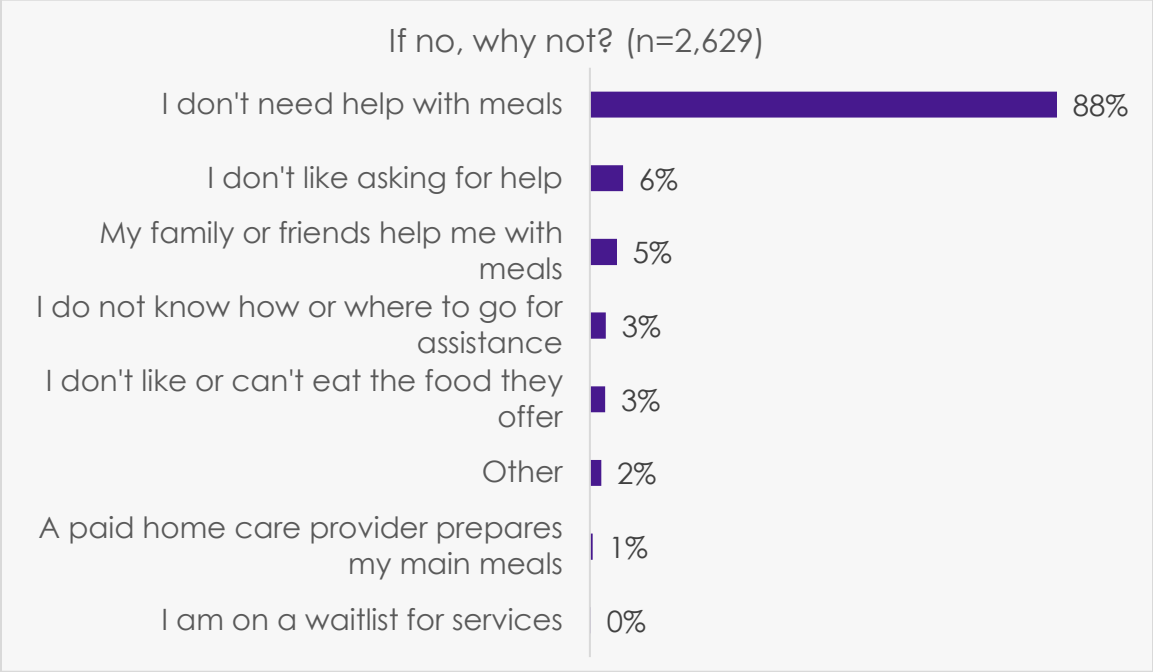
Question	Yes	No
Q13: Do you have difficulty preparing or cooking your main meals? (3,067)	4%	**96%**
Q14: Do you have access to foods that are important to your ethnicity or culture? (n=2,995)	**95%**	5%
Q15: Do you have access to foods that meet your dietary requirements? (n=3,070)	**97%**	3%

Q15. Other responses: When survey participants were asked if they if they have access to foods that meet their dietary requirements, respondents who indicated "no" shared that healthy foods, including fruits and vegetables, were either too expensive or not available in their area.

Q16:

Question	Yes	No
Q16: Do you participate in a home delivered meal program (Meals on Wheels)? (n=3,071)	2%	**98%**

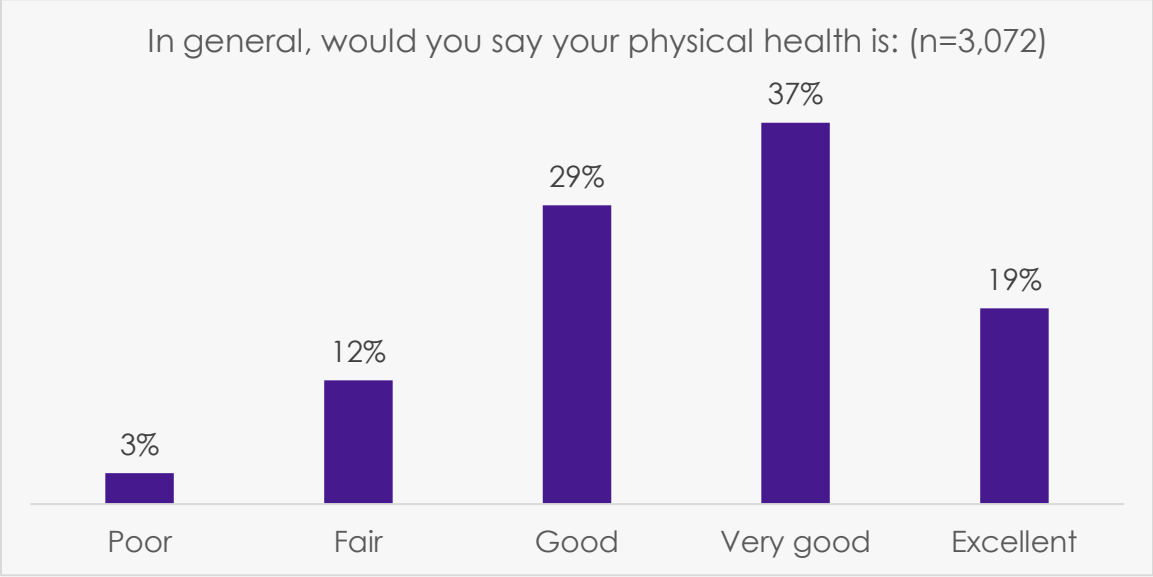
Q17:

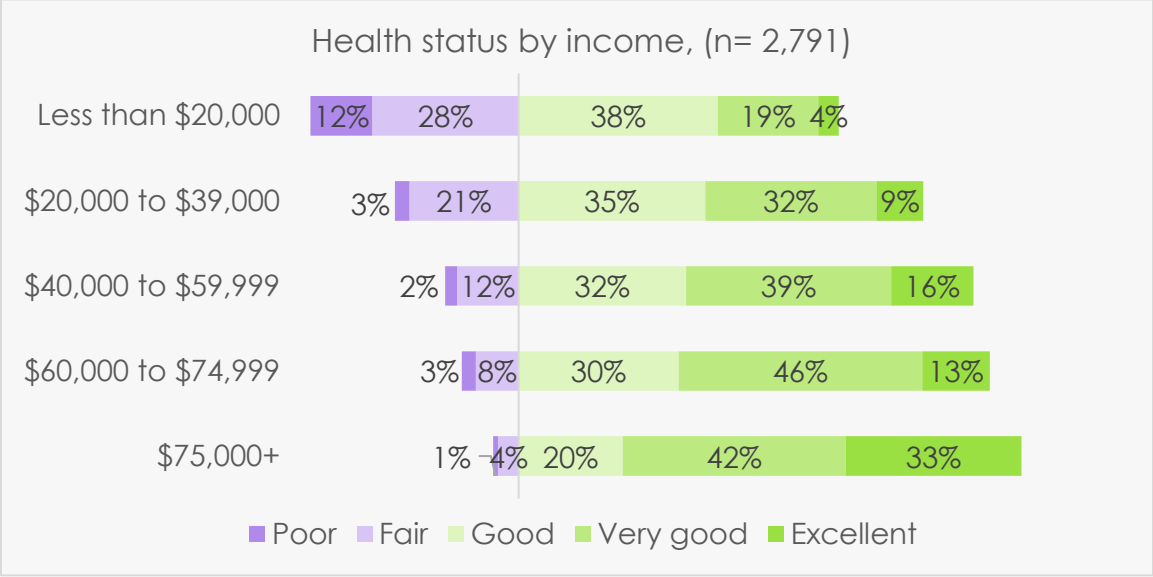


Q17. Other responses: Other reasons for not participating in a meal delivery service included scheduling conflicts, unavailability in their area, age restrictions, income level restrictions, dietary preferences, ability to manage meals on their own, and some individuals indicated they felt others needed it more or that they did not need this kind of service.

Health

Q18:

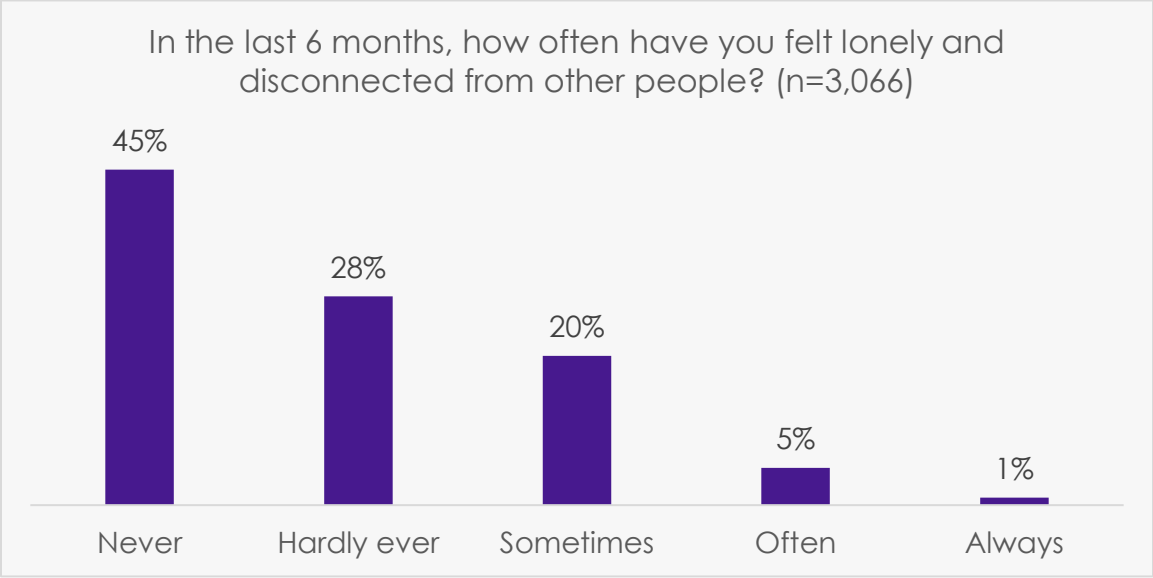

In general, would you say your physical health is: (n=3,072)
3%
12%
29%
37%
19%
Poor
Fair
Good
Very good
Excellent

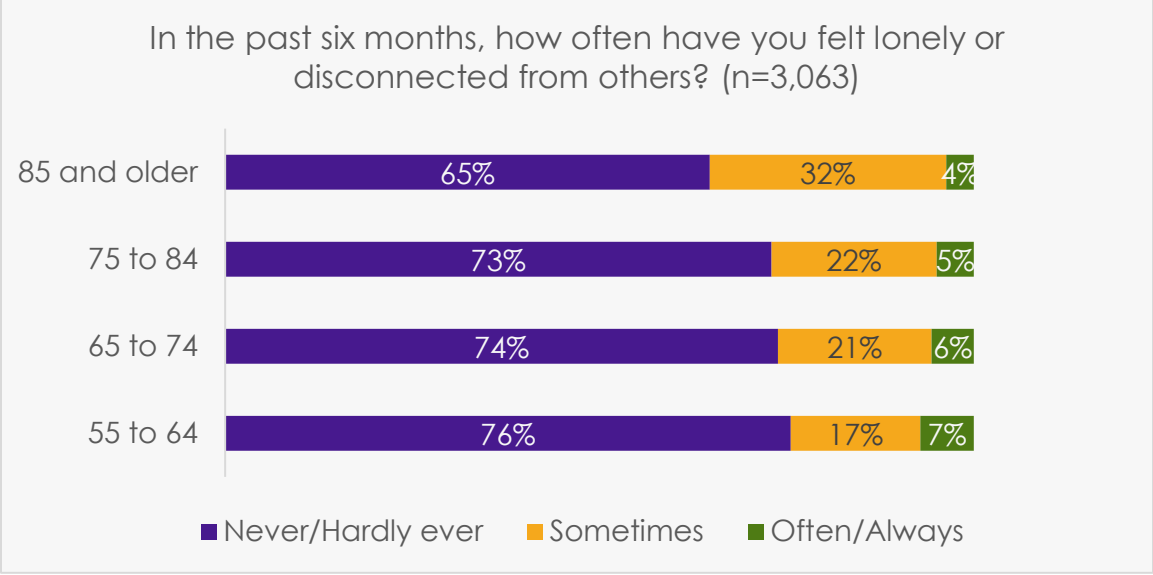

Health status by income, (n= 2,791)
Less than $20,000
12%
28%
38%
19%
4%
$20,000 to $39,000
3%
21%
35%
32%
9%
$40,000 to $59,999
2%
12%
32%
39%
16%
$60,000 to $74,999
3%
8%
30%
46%
13%
$75,000+
1%
4%
20%
42%
33%
Poor
Fair
Good
Very good
Excellent

Q19:

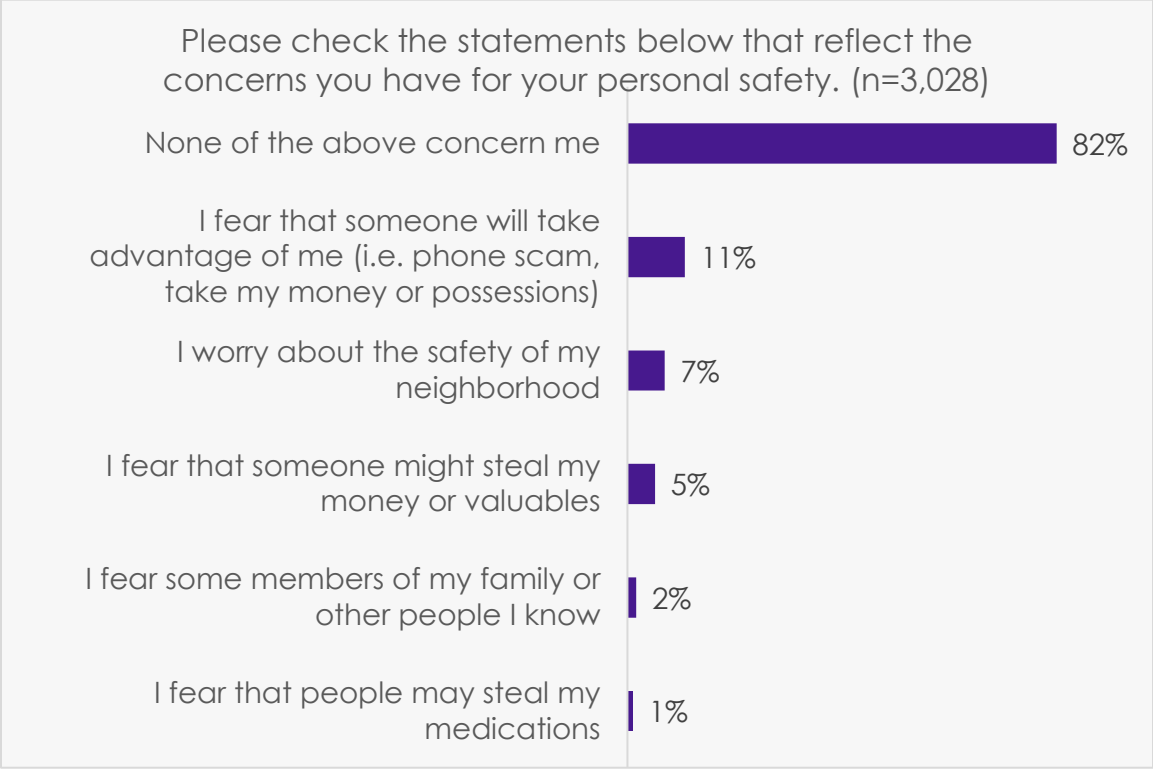
Question	Yes	No
Q19: Do you have concerns about your own memory? (n=3,061)	23%	**77%**

Q20:





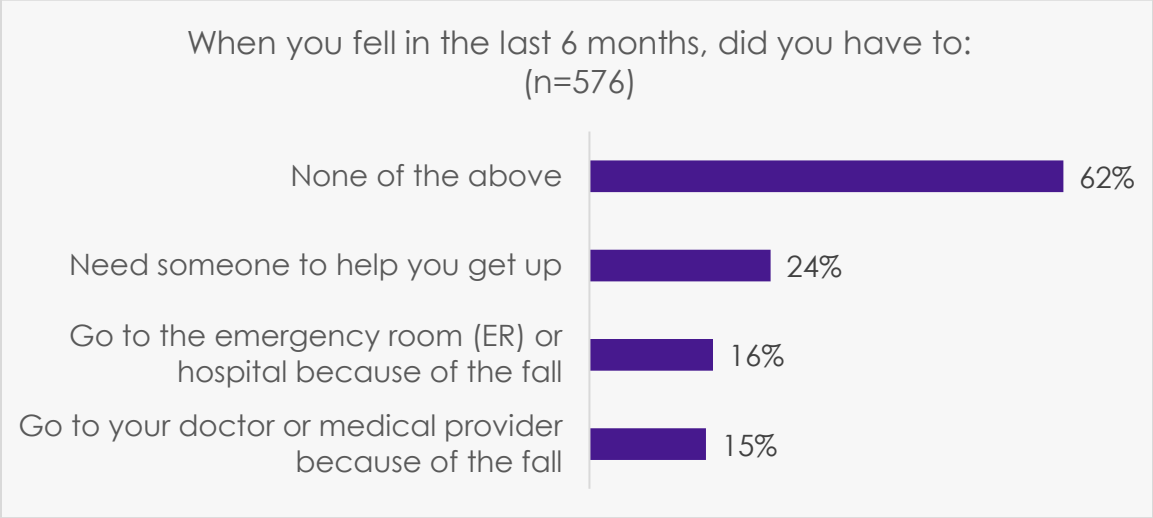
Q21:



Q22:

Question	Yes	No
Q22: Have you fallen in the last 6 months? (n=3,062)	19%	**81%**

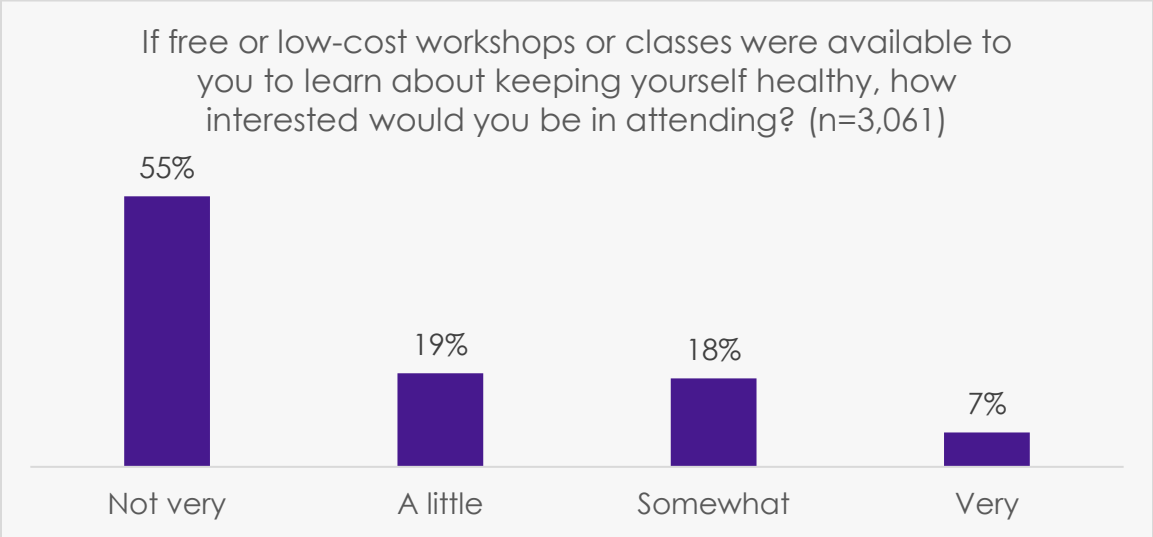
Q23:



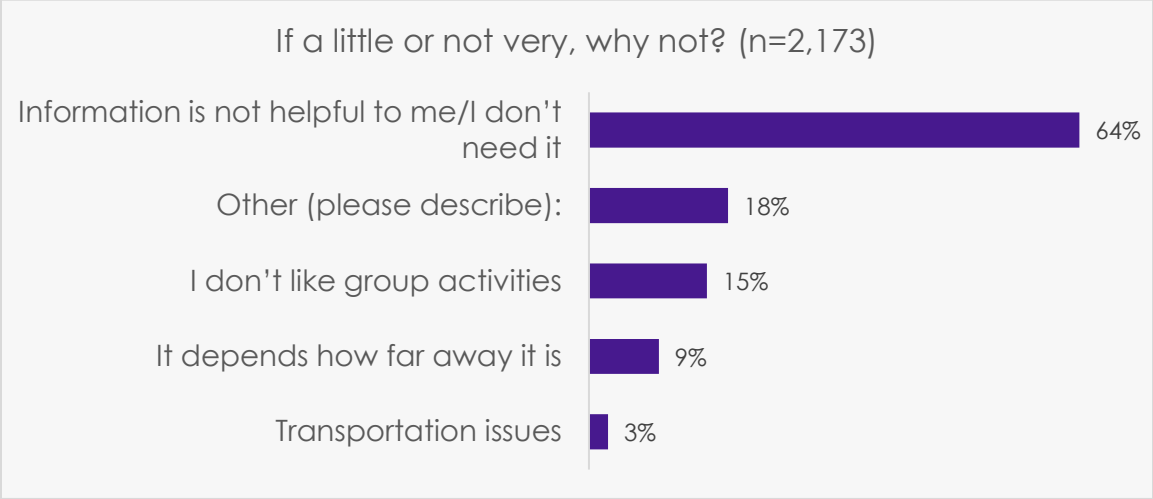
Q24:

Question	Yes	No
Q24: Do you have tooth or mouth problems that make it hard for you to eat? (n=3,070)	12%	**88%**

Q25:



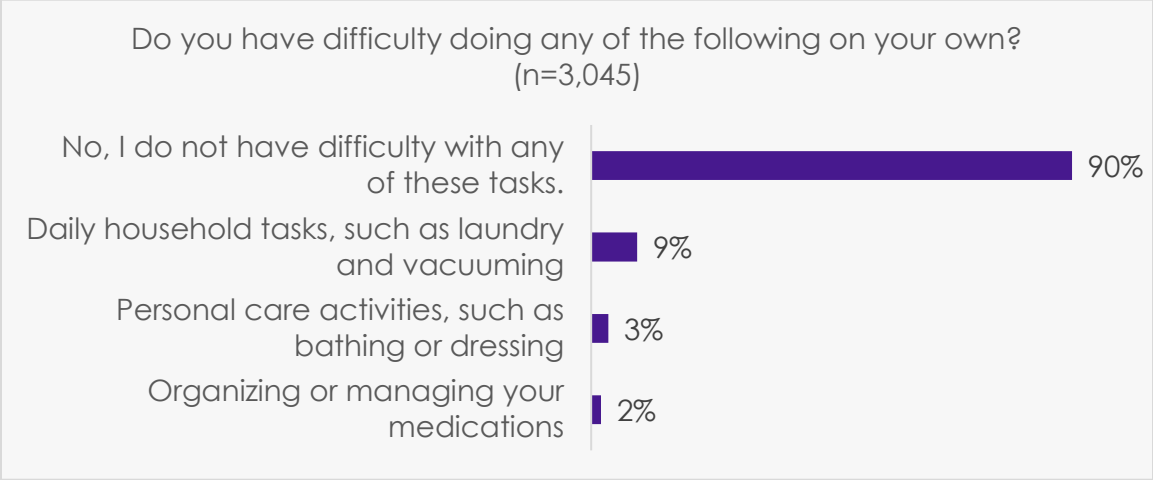
Q26:



Q26. Other responses: When asked, "If free or low-cost workshops or classes about keeping yourself healthy were available, would you be interested?" respondents who said "a little" or "not very" mentioned factors including scheduling conflicts such as work schedules, health conditions, language barriers, or that they do not need these classes and/or can find the information on their own elsewhere. Scheduling conflicts were the most common response. Others said it would depend on the subject being taught.

Q27:

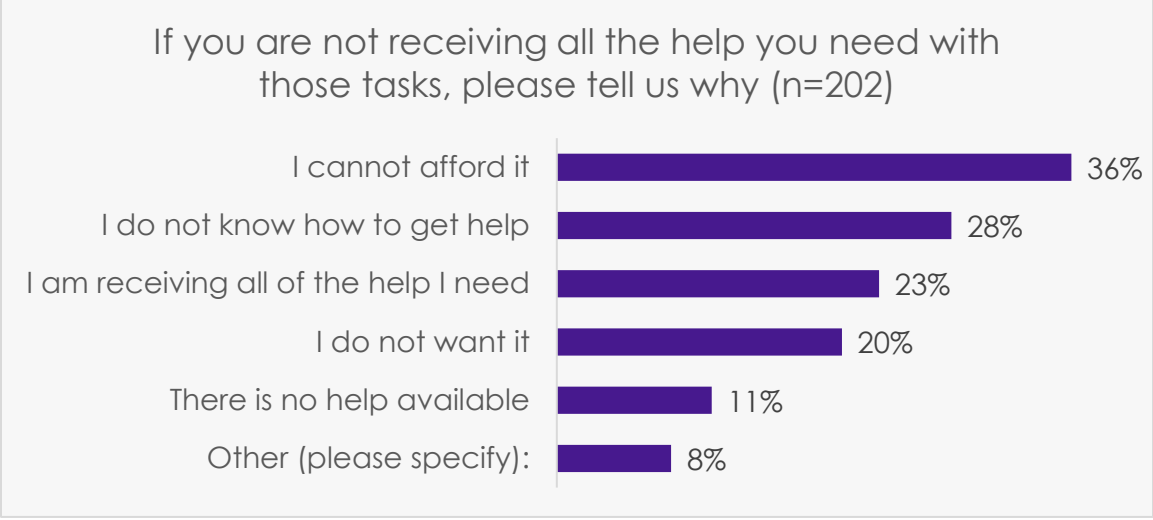
Q28:



Q29:

Question	Yes	No
Q29: Are you currently receiving in-home help with any of those tasks from another person or outside	32%	**68%**

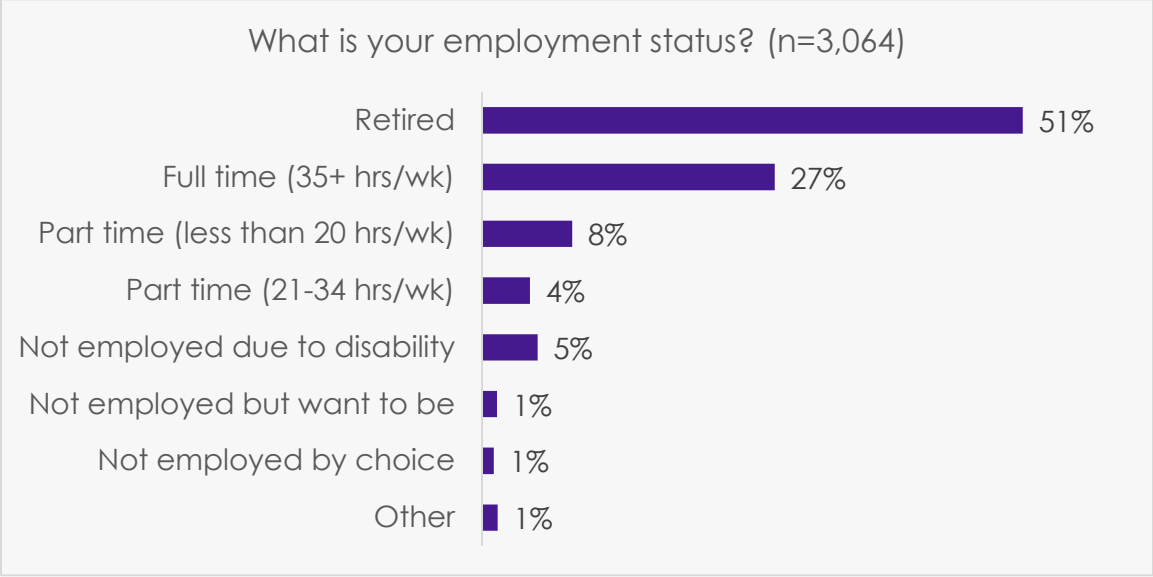
Q30:



Q30. Other responses: Respondents who indicated they were not receiving in-home help with tasks from another person or outside organization gave different reasons. The most common was a lack of trust of someone coming into their home and issues with privacy. Other responses included financial issues with health insurance, family, not wanting to ask for help, and receiving poor service in the past.

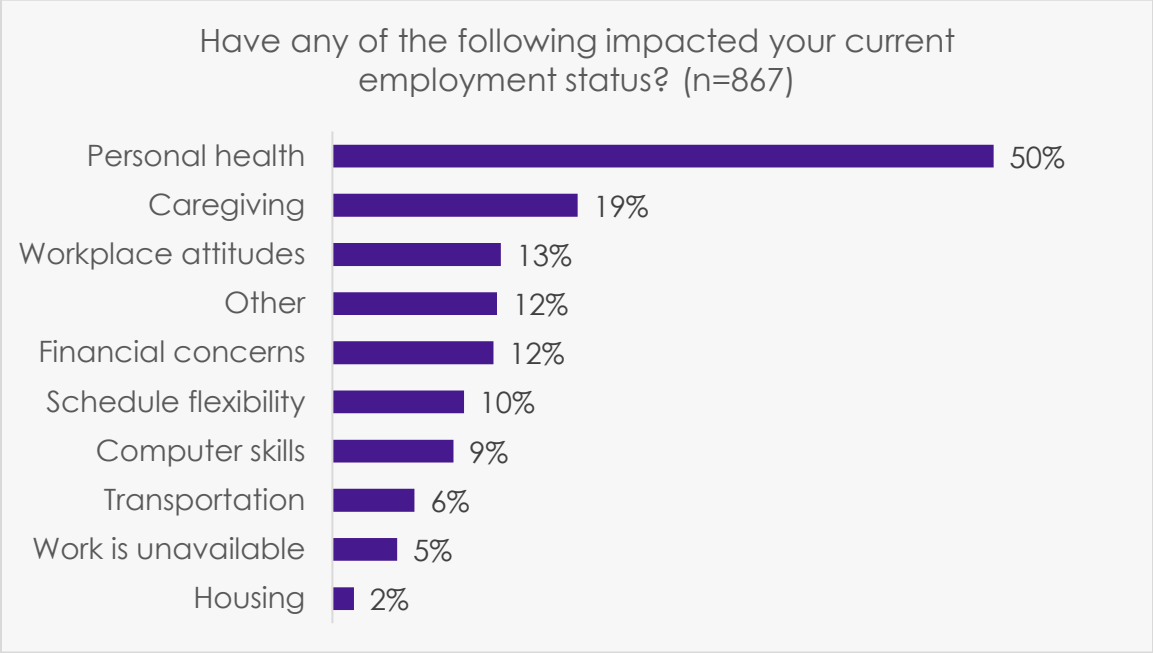
Employment and Volunteering

Q31:



Q31. Other responses: Other forms of employment included self-employed as artists, farmers, business owners, etc. Others indicated they were seasonally employed, retired but working part time or seasonally, caregivers who were not able to work, disabled, on medical leave, or working per diem.

Q32:

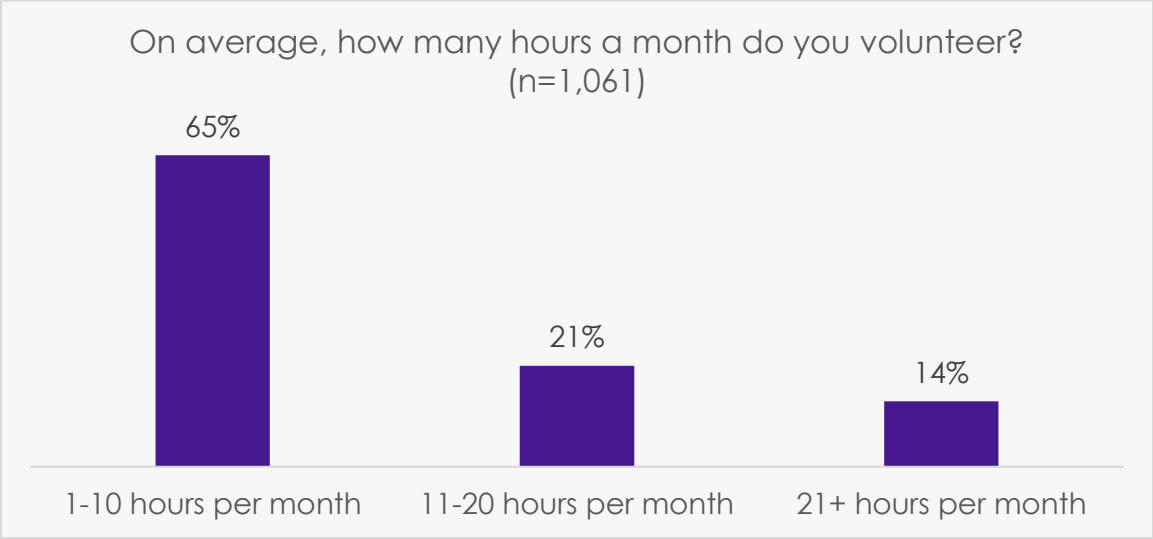


Q32. Other responses: When asked what impacted their current employment status, respondents indicated other factors that impacted their employment status including they retired, COVID-19, losing their jobs, health issues, that they did not need to work, or they only work when work is available (seasonal). A few said age discrimination impacted their employment status.

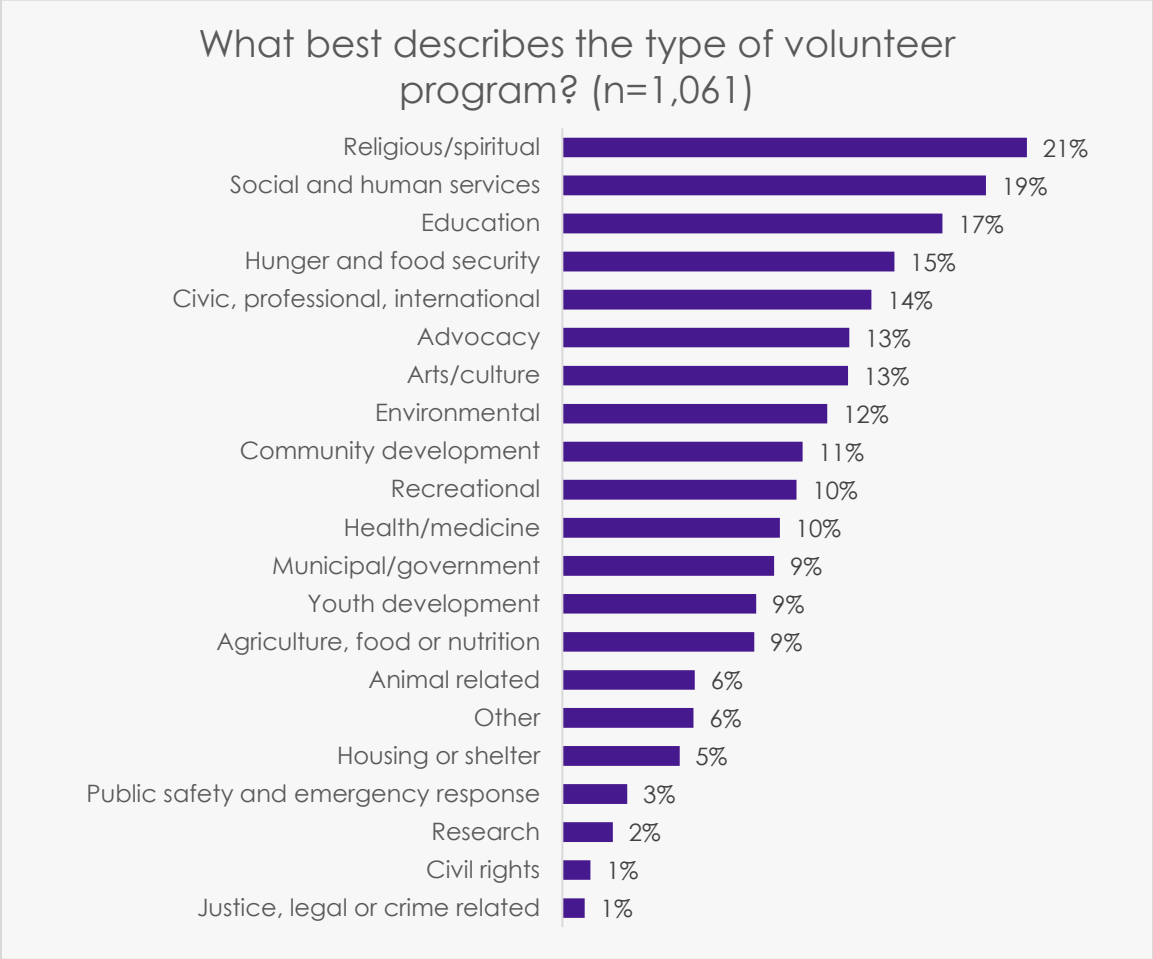
Q33:

Question	Yes	No
Q33: Do you currently do volunteer activities? (n=3,052) organization?	35%	**65%**

Q34:



Q35:

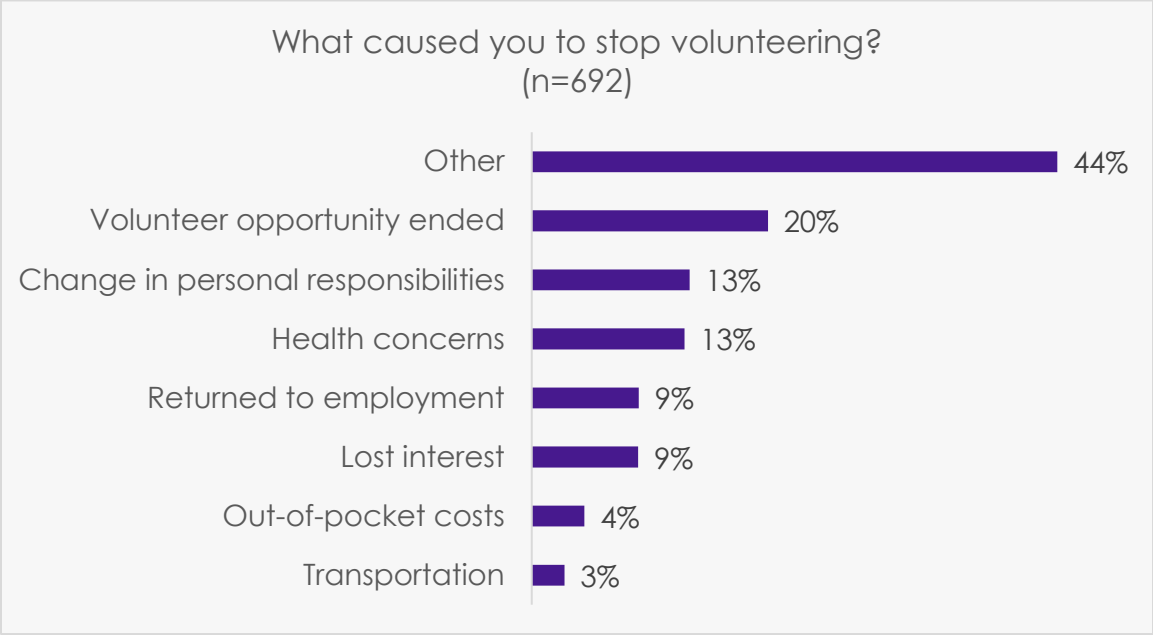


Q35. Other responses: Additional types of volunteer activities described by respondents included tax/financial preparation, thrift store, helping veterans or age friendly neighborhoods, outdoor maintenance, and healthcare or food preparation. Some respondents volunteer for a political party, condo association and serving on a board.

Q36:

Question	Yes	No
Q36: Did you volunteer on a regular basis anytime during the past 4 years? (n=2,961)	42%	**58%**

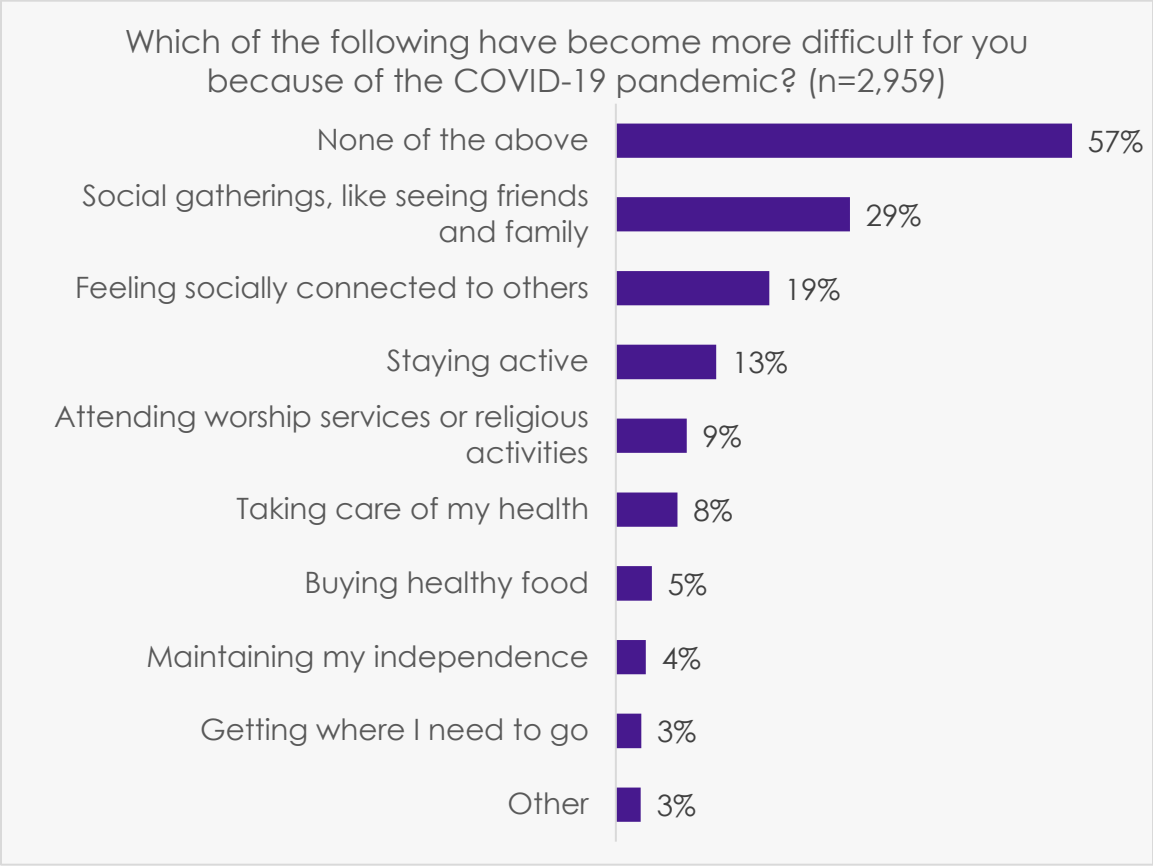
Q37:



Q37. Other responses: COVID-19 was the most common reason people stopped volunteering, others said they had moved to a new area, had cognitive or physical challenges, and a few said it was too time consuming.

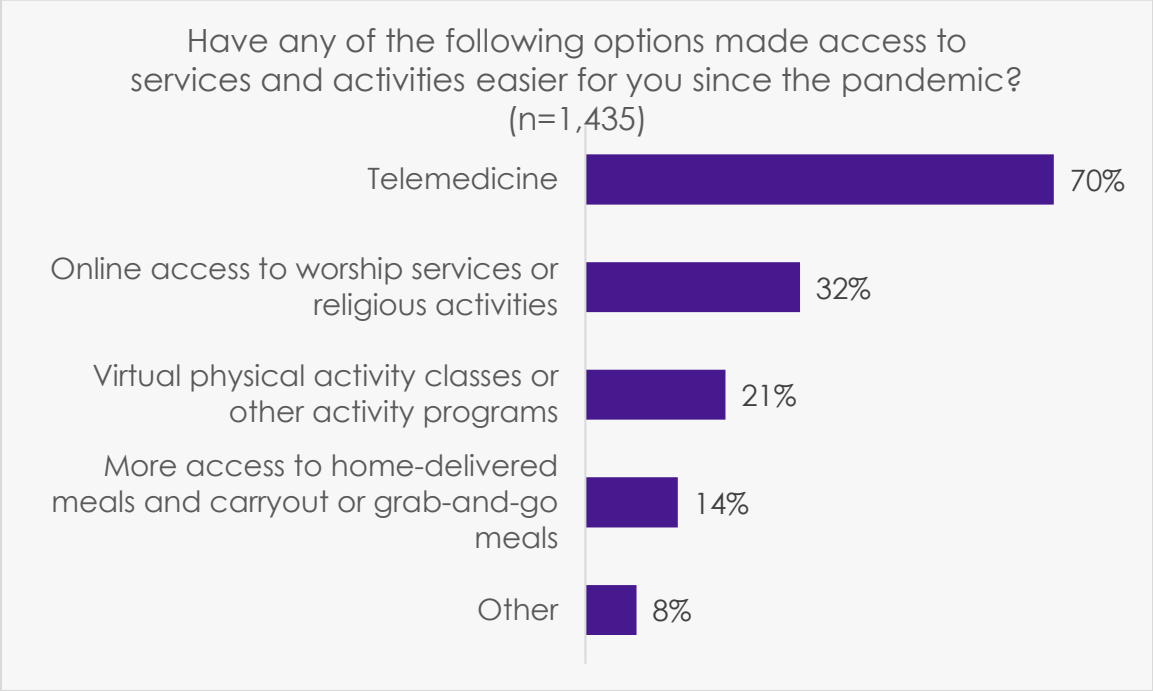
COVID-19

Q38:



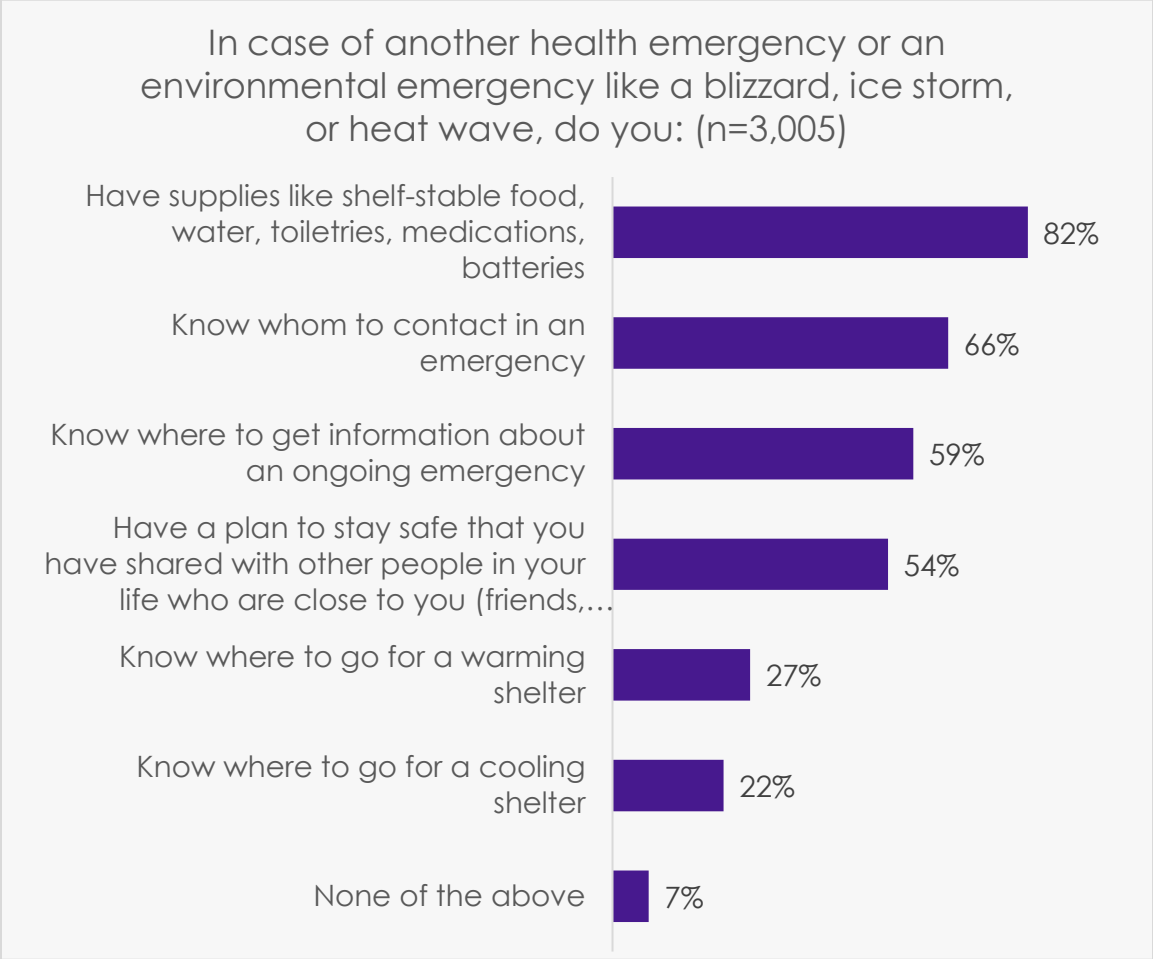
Q38. Other responses: Respondents shared that traveling or attending social activities, volunteering or working, and shopping or dining out have become more difficult since the pandemic.

Q39:



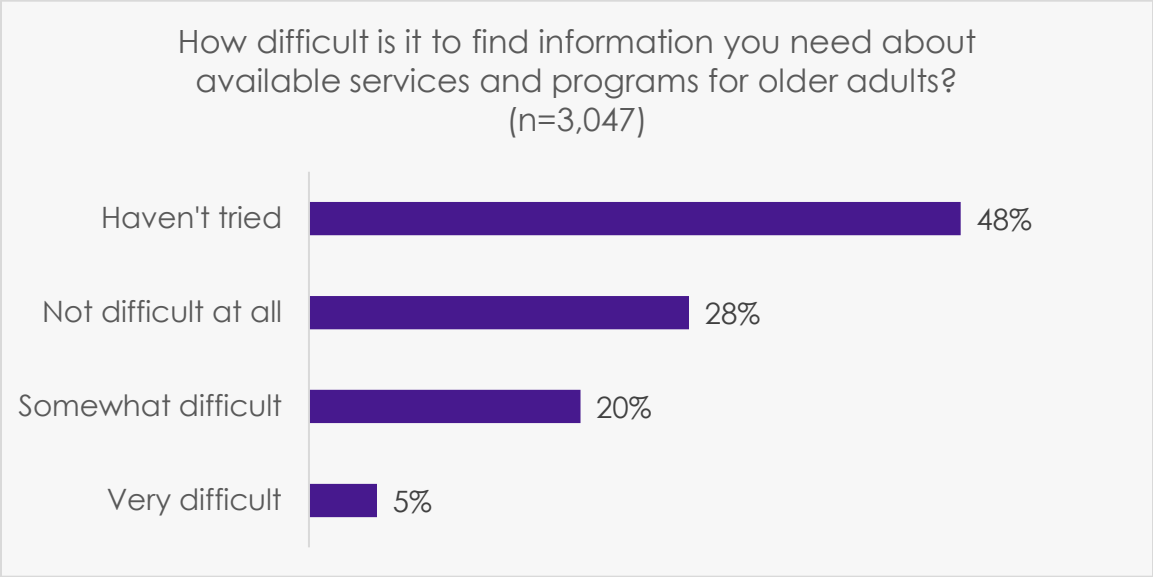
Q39. Other responses: Respondents said that technology, Zoom, and virtual gatherings made social activities, volunteering, and working much easier. Others said on-line ordering and curbside pickup at stores connecting to medical and mental health services is easier.

Q40:

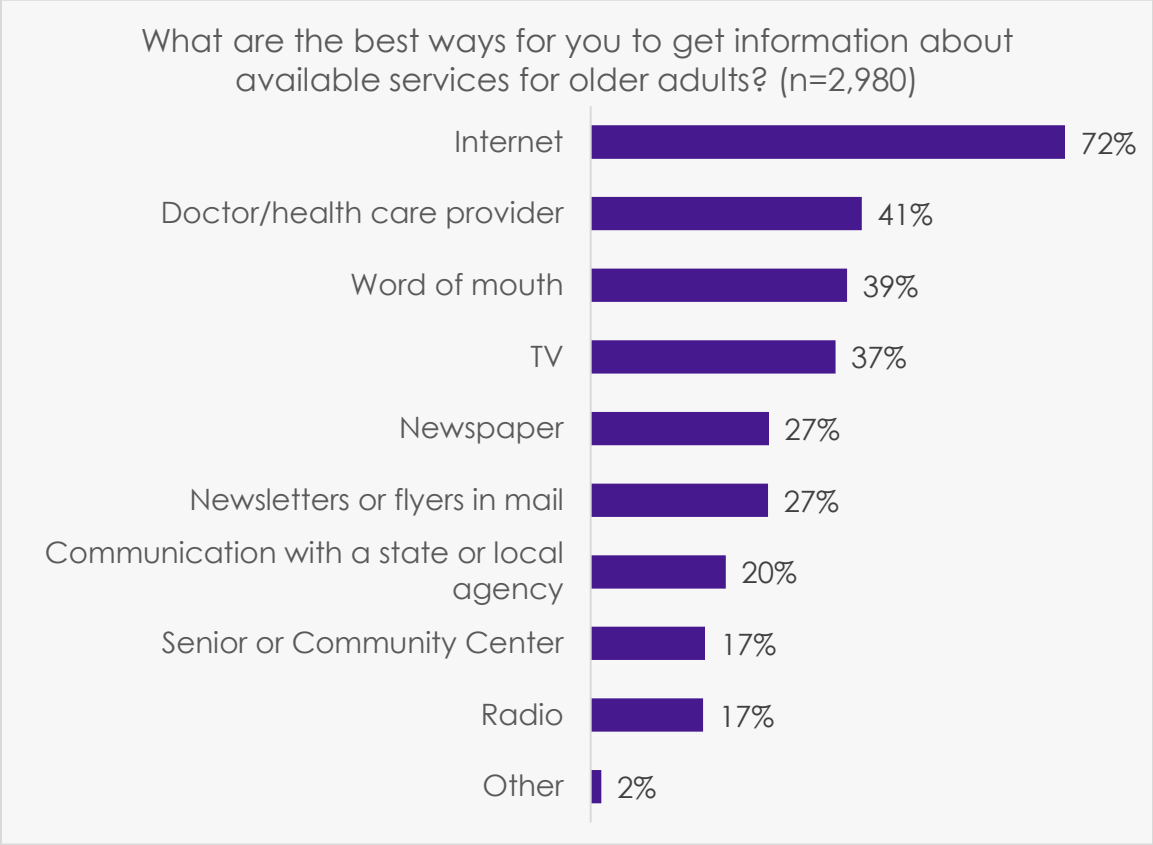

In case of another health emergency or an environmental emergency like a blizzard, ice storm, or heat wave, do you: (n=3,005)
Have supplies like shelf-stable food, water, toiletries, medications, batteries
82%
Know whom to contact in an emergency
66%
Know where to get information about an ongoing emergency
59%
Have a plan to stay safe that you have shared with other people in your life who are close to you (friends,…
54%
Know where to go for a warming shelter
27%
Know where to go for a cooling shelter
22%
None of the above
7%

Information

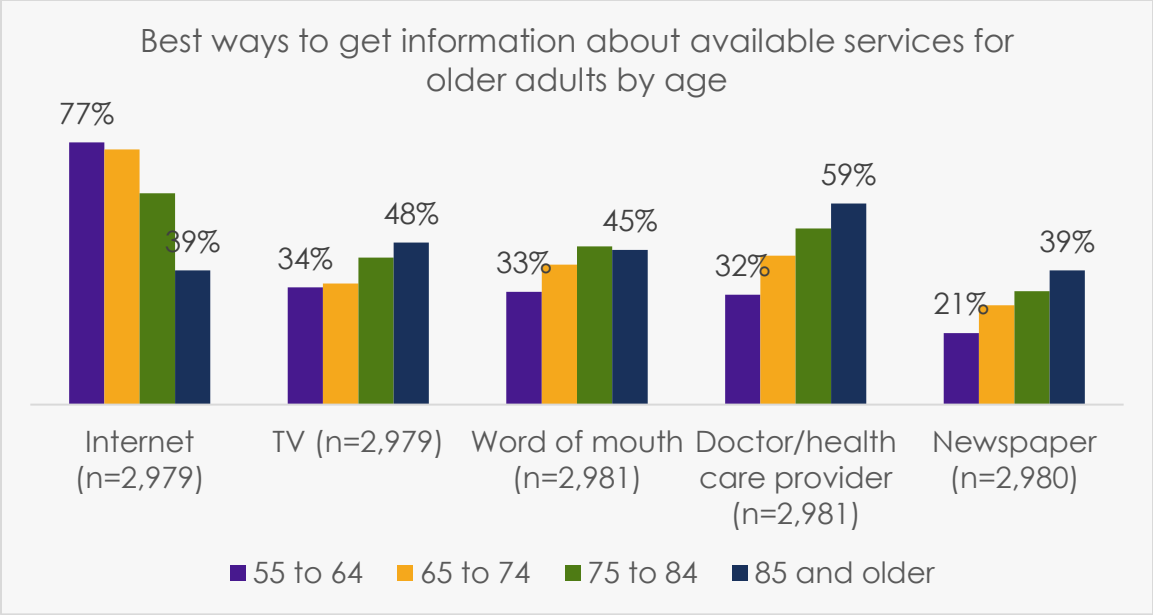
Q41:

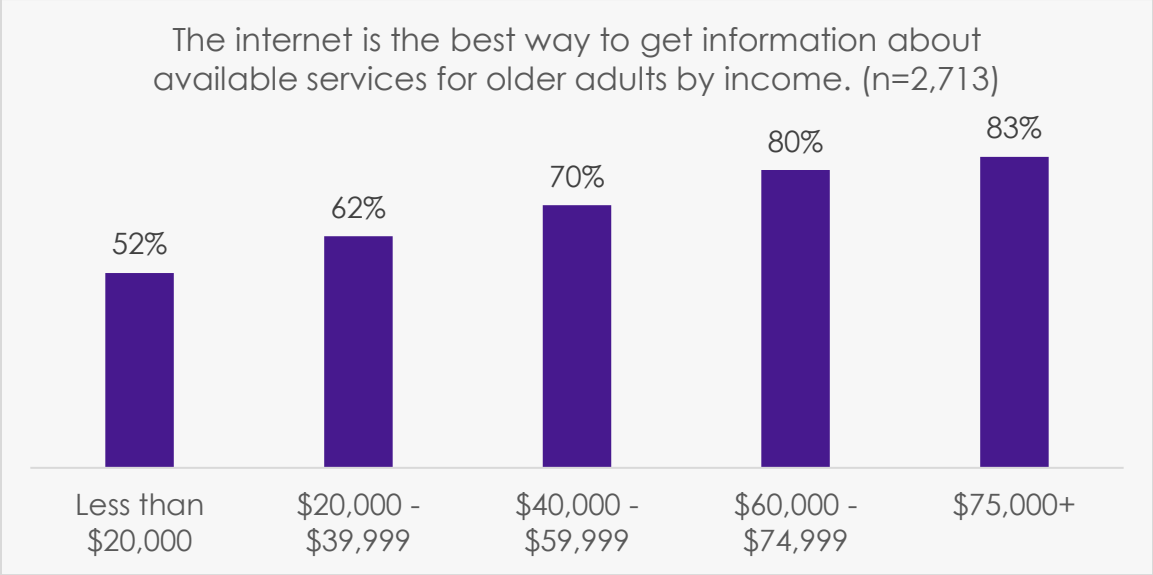


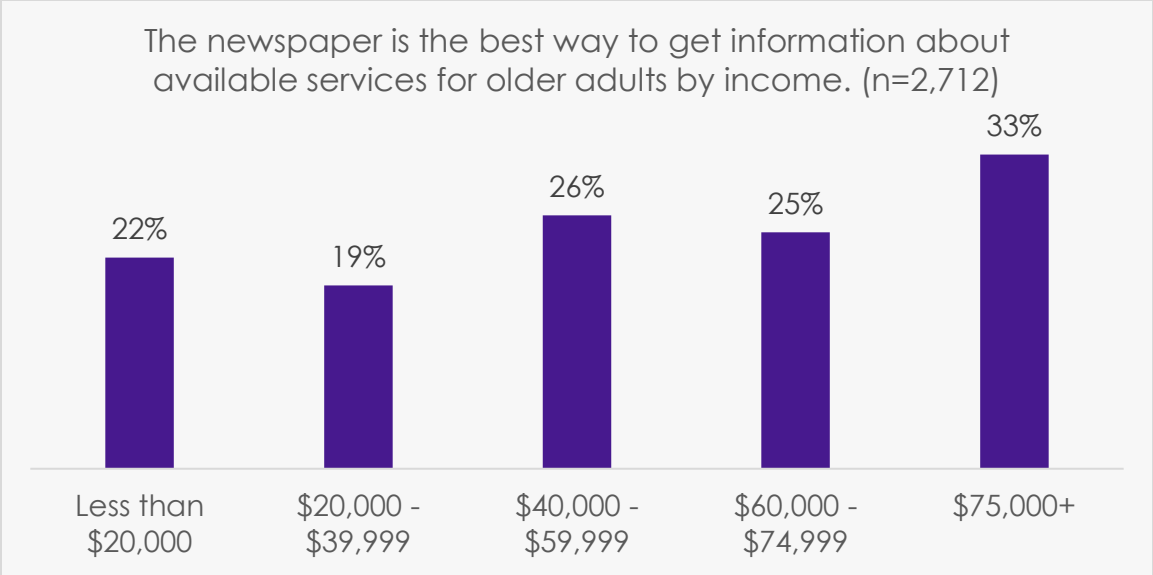
Q42:



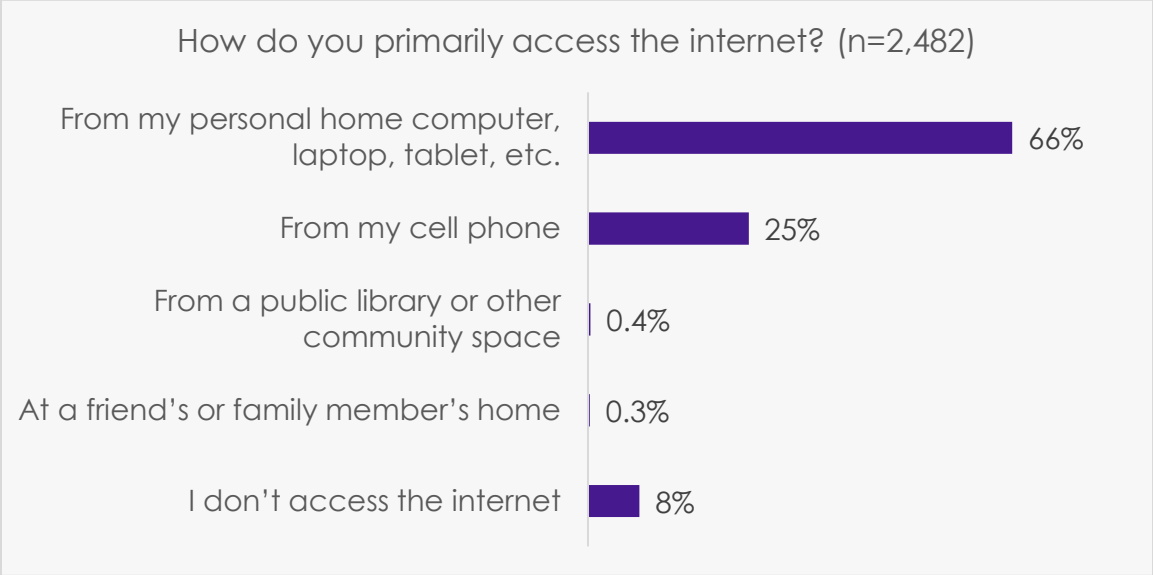
Q42. Other responses: Respondents also shared they get emergency information from AARP, local community library, church, their retirement home, and grocery stores. Few mentioned their local Area Agency on Aging as a resource.


Best ways to get information about available services for older adults by age
77%
39%
34%
48%
33%
45%
32%
59%
21%
39%
Internet (n=2,979)
TV (n=2,979)
Word of mouth (n=2,981)
Doctor/health care provider (n=2,981)
Newspaper (n=2,980)
55 to 64
65 to 74
75 to 84
85 and older

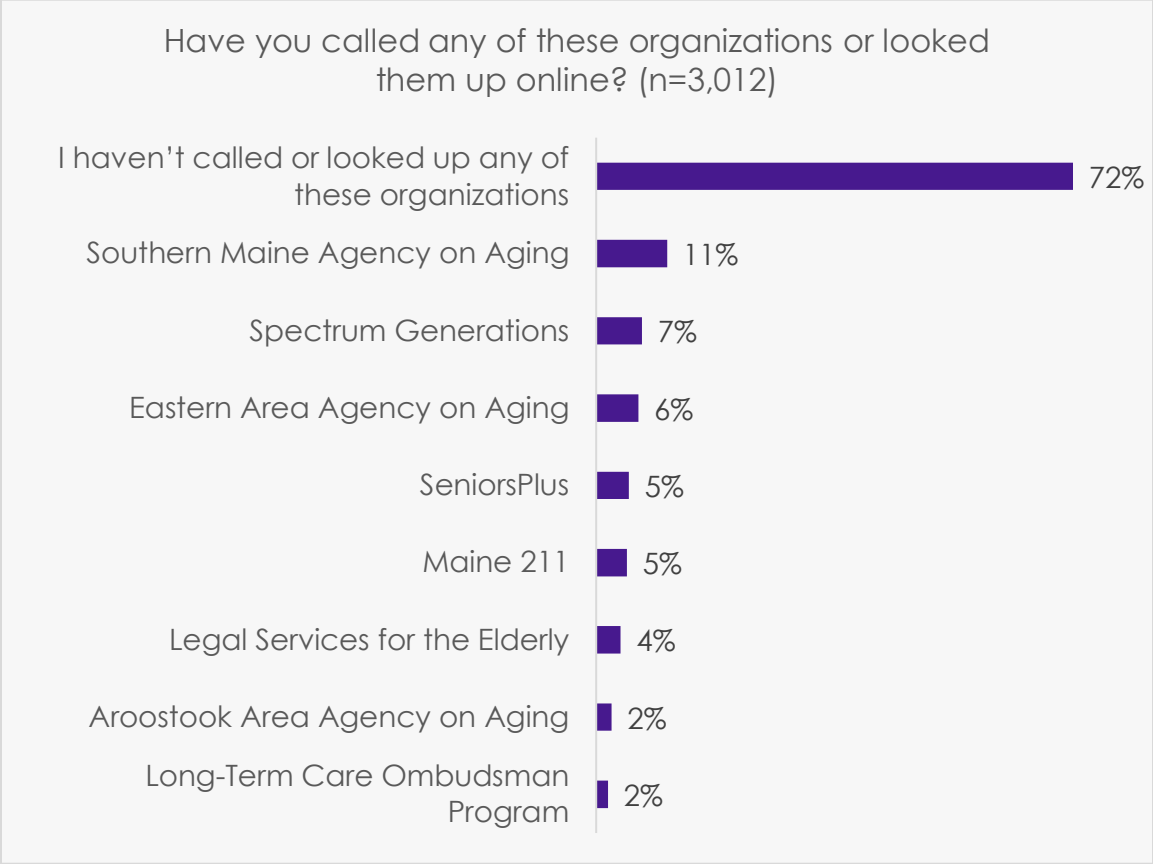

The internet is the best way to get information about available services for older adults by income. (n=2,713)
52%
62%
70%
80%
83%
Less than $20,000
$20,000 - $39,999
$40,000 - $59,999
$60,000 - $74,999
$75,000+


The newspaper is the best way to get information about available services for older adults by income. (n=2,712)
22%
19%
26%
25%
33%
Less than $20,000
$20,000 - $39,999
$40,000 - $59,999
$60,000 - $74,999
$75,000+

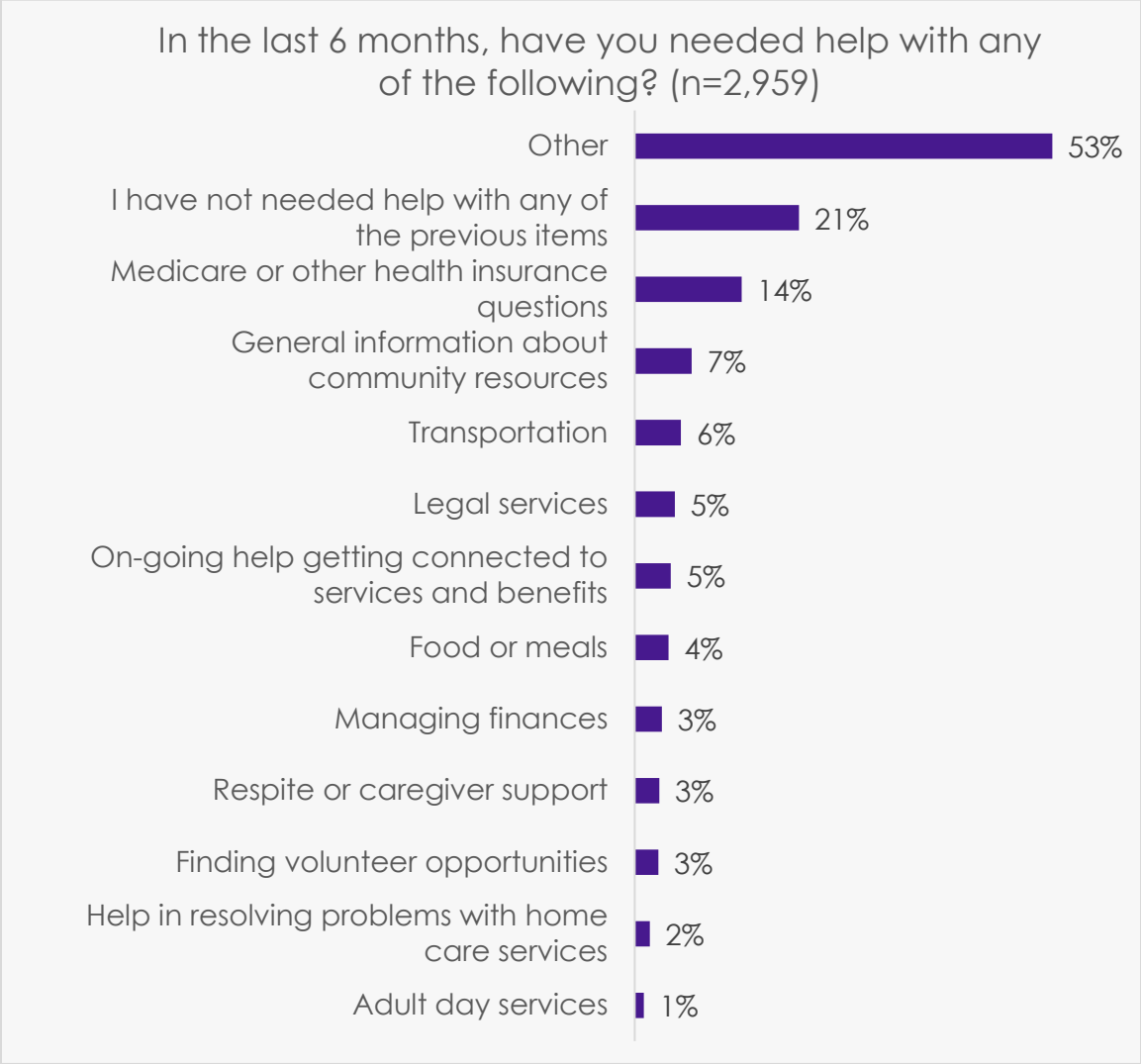
Q43:


How do you primarily access the internet? (n=2,482)
From my personal home computer, laptop, tablet, etc.
66%
From my cell phone
25%
From a public library or other community space
0.4%
At a friend's or family member's home
0.3%
I don't access the internet
8%

Q44:


Have you called any of these organizations or looked them up online? (n=3,012)
I haven't called or looked up any of these organizations
72%
Southern Maine Agency on Aging
11%
Spectrum Generations
7%
Eastern Area Agency on Aging
6%
SeniorsPlus
5%
Maine 211
5%
Legal Services for the Elderly
4%
Aroostook Area Agency on Aging
2%
Long-Term Care Ombudsman Program
2%

Q45:

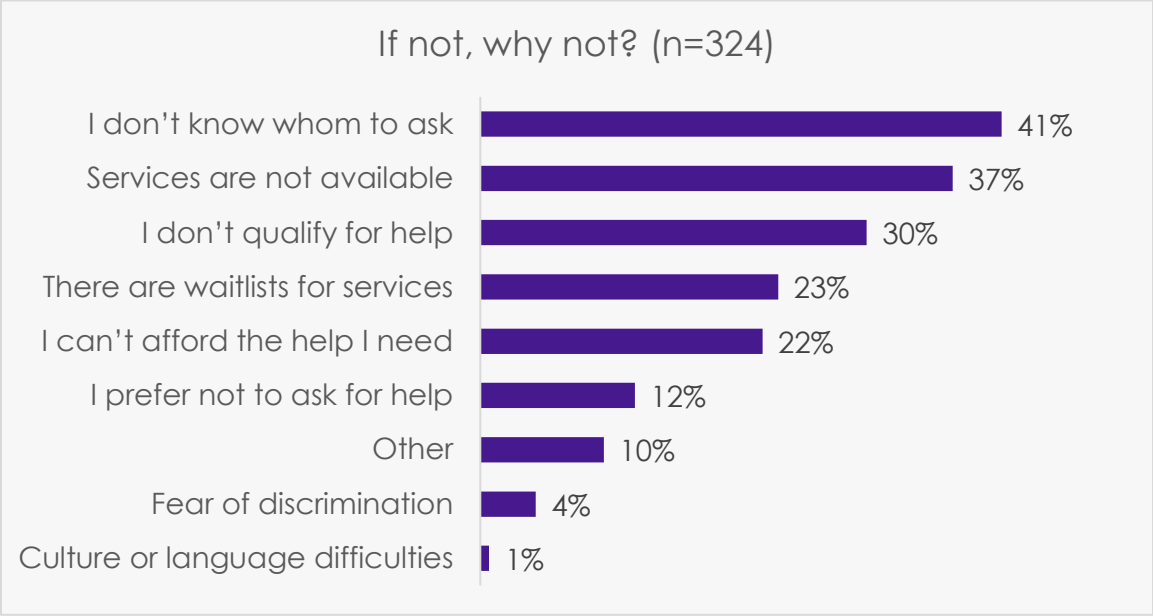


Q45. Other responses: Respondents also shared they needed help with home improvements/maintenance, financial matters, locating exercise programs, and medical support.

Q46:

Question	Yes	No
Q46: Did you get all the help you needed? (n=912)	**65%**	35%

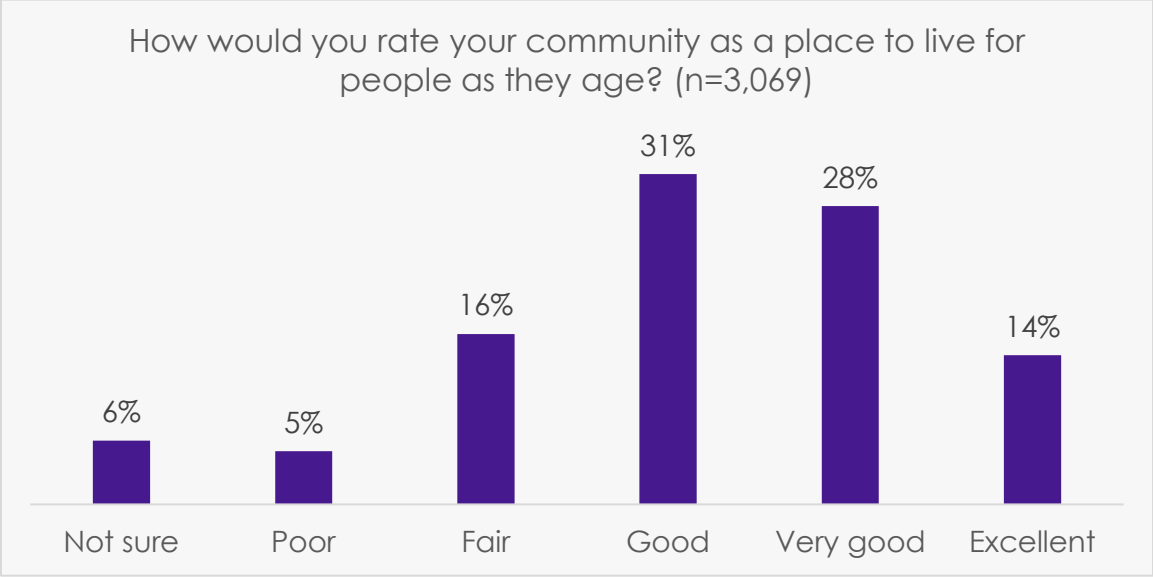
Q47:



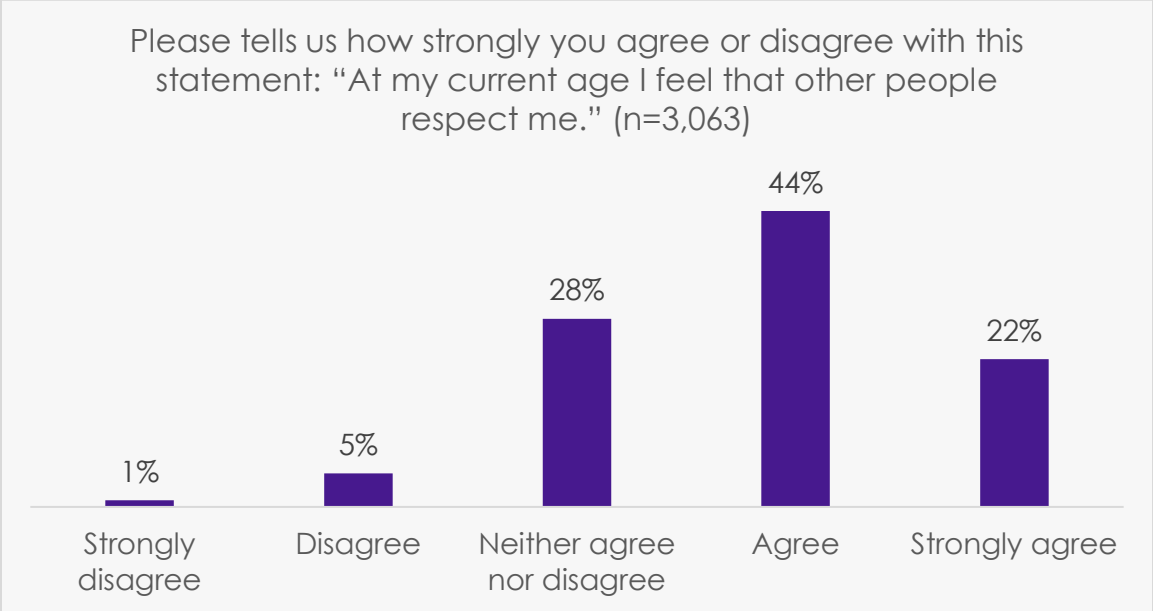
Q47. Other responses: Respondents also shared they did not receive the help they needed because there was a lack of support and/or response from the agency they reached out to. Others said they had not reached out yet.

Community

Q48:

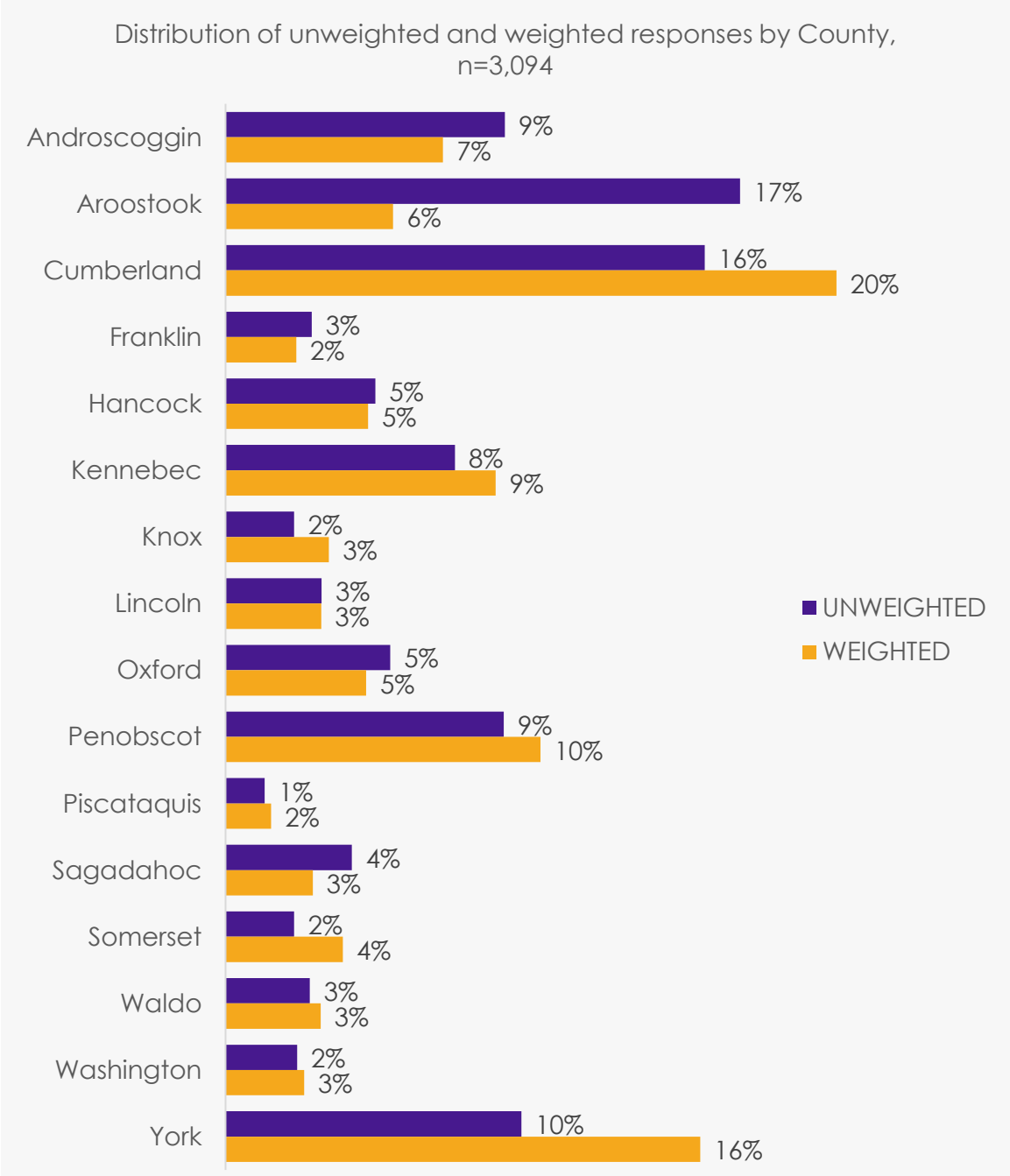


Q49:

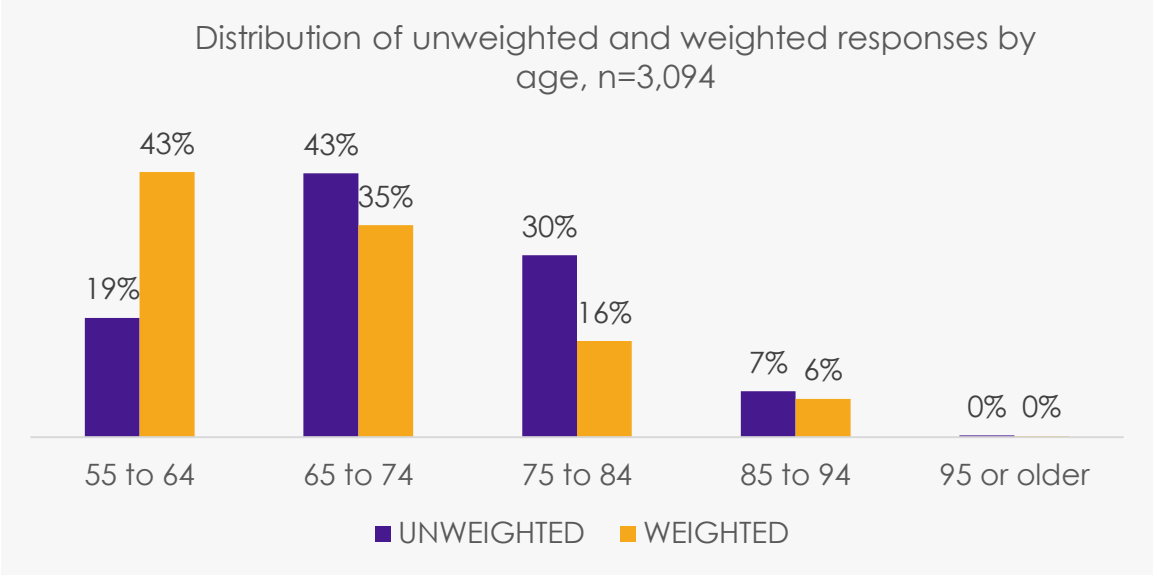


Demographics

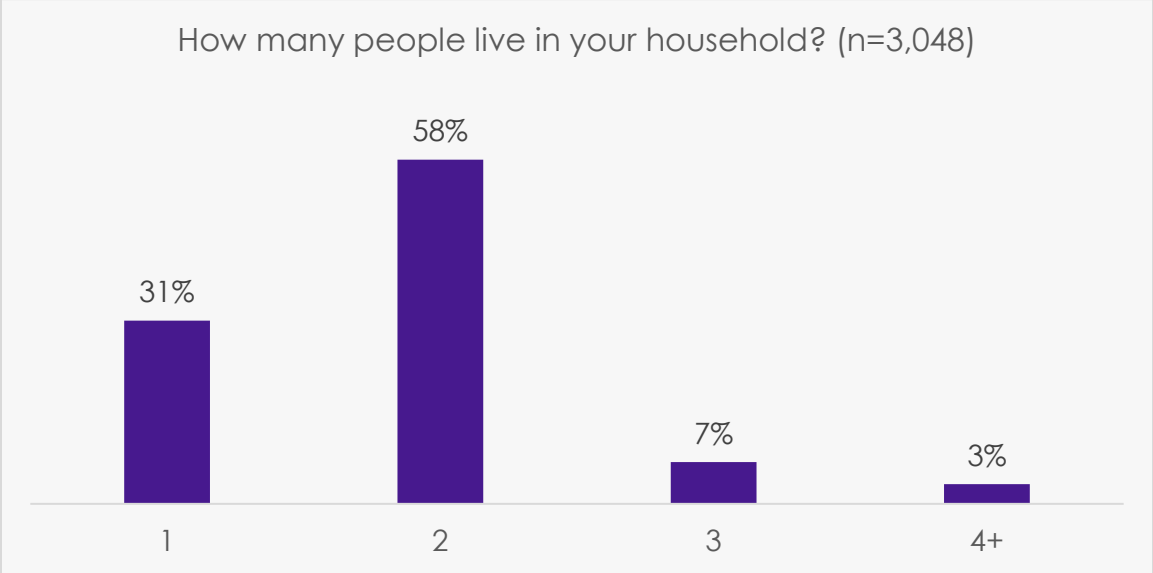
Q51



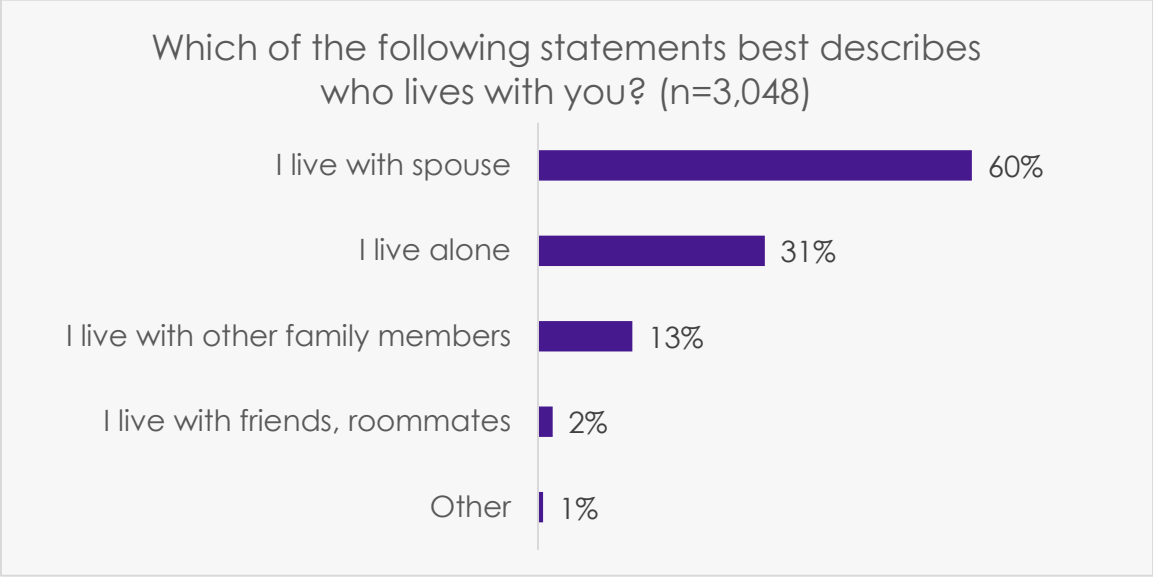
Q52


Distribution of unweighted and weighted responses by age, n=3,094
43%
43%
35%
30%
19%
16%
7%
6%
0%
0%
55 to 64
65 to 74
75 to 84
85 to 94
95 or older
UNWEIGHTED
WEIGHTED

Q53:


How many people live in your household? (n=3,048)
58%
31%
7%
3%
1
2
3
4+

Q54:



Q55:

Question	White	Other than White alone
Q55: Please specify your race/ethnicity. (n=2,976)	**97%**	3%

Q56:

Race other than White alone	Percent of survey respondents
Multiracial	0.7%
Asian/Pacific Islander	0.6%
Native American or Alaska Native	0.5%
Black or African American	0.3%
Other	0.7%

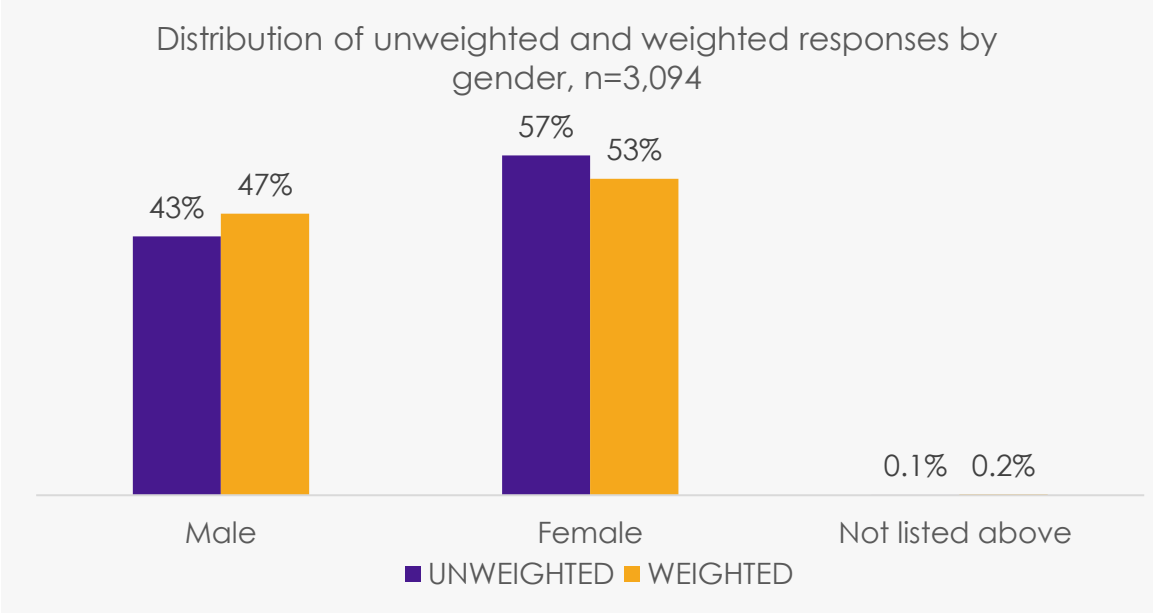
Q57:

Question	Yes	No
Q57: Is English your primary or preferred language? (n=3,064)	**99%**	1%

Q58: If no, what is your primary language? (n=16)

Language	Percent
French	**78%**
German	10%
English and French	7%
Cantonese	5%

Q59:



Q60:

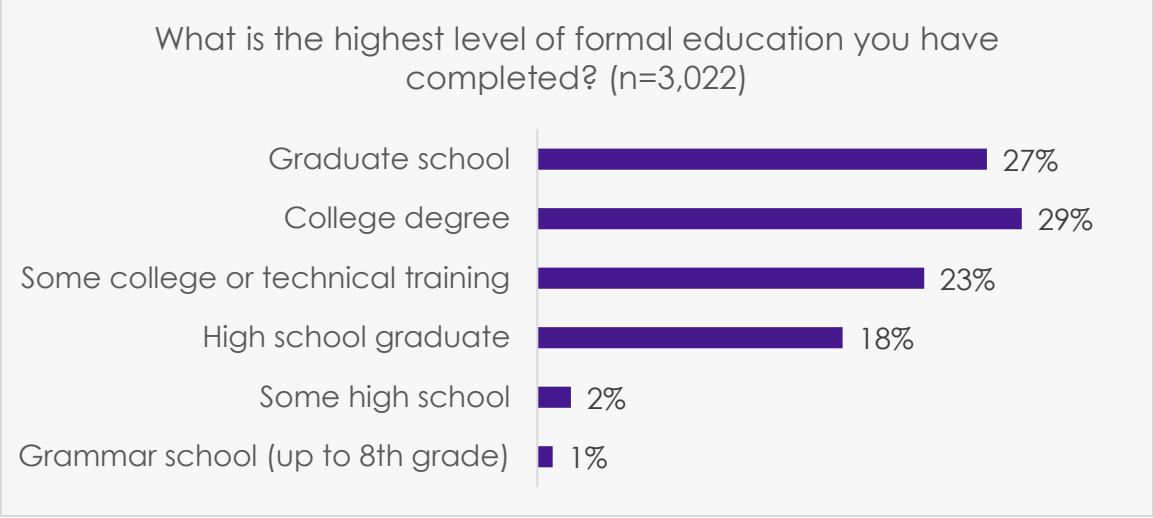
Question	Female	Male	Nonbinary	Not listed
Q60: What is your current gender identity? (n=2,989)	**53%**	47%	0.2%	0.1%

	Cisgender	Not cisgender
Analysis of question about sex at birth compared to current gender identity (n=2,988)	**99%**	1%

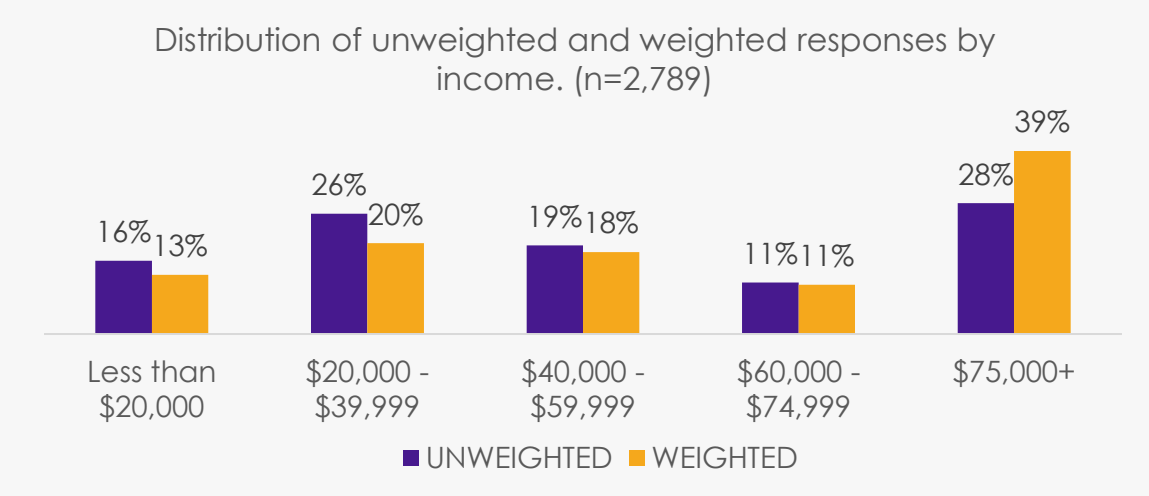
Q61:

Question	Straight, not gay or lesbian	Gay or lesbian	Bisexual	Not sure	Not listed
Q61: Do you think of yourself as: (n=2,960)	**94%**	3%	1%	1%	0%

Q62:



Q63

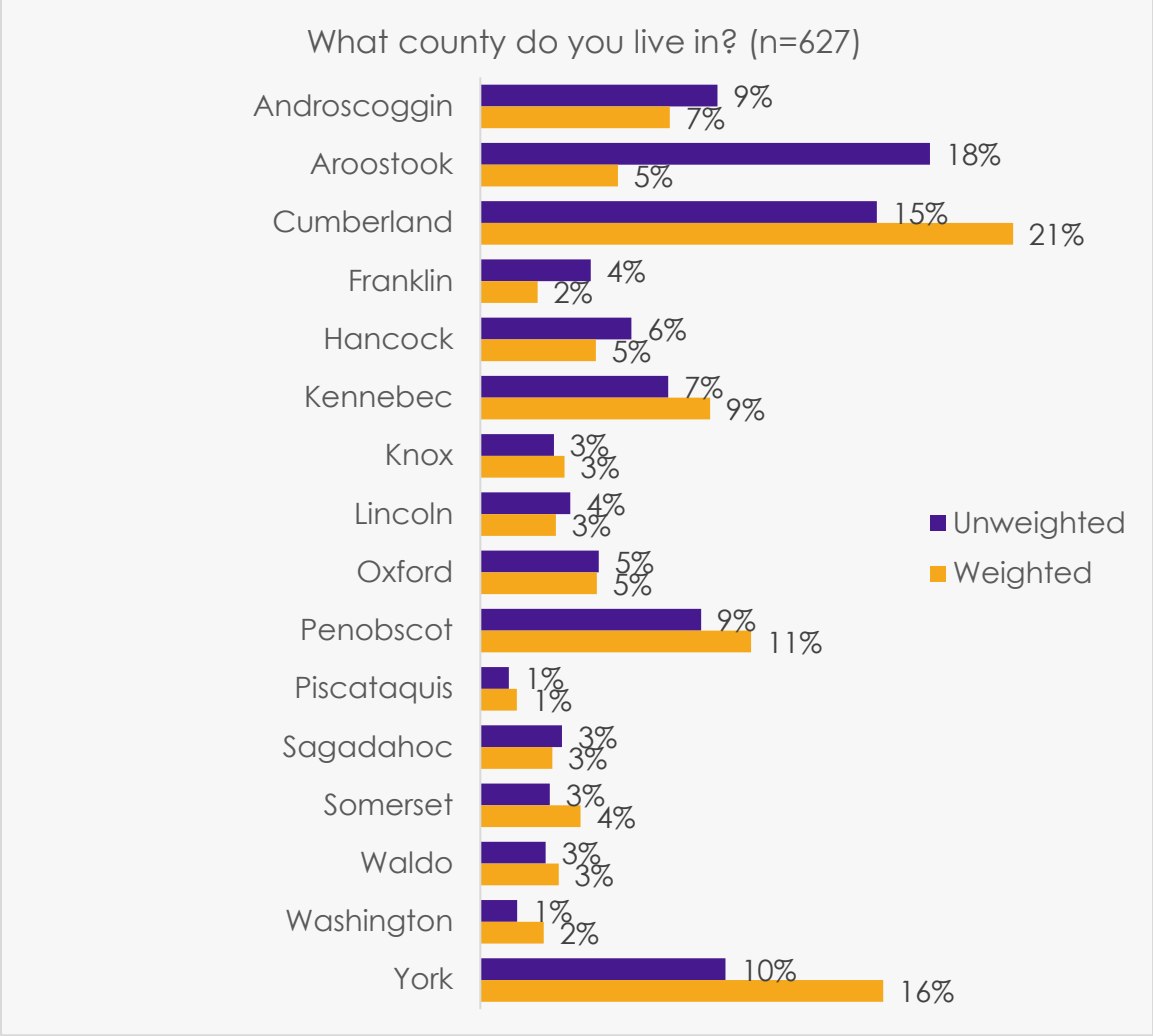

Distribution of unweighted and weighted responses by income. (n=2,789)
16%
13%
26%
20%
19%
18%
11%
11%
28%
39%
Less than $20,000
$20,000 - $39,999
$40,000 - $59,999
$60,000 - $74,999
$75,000+
UNWEIGHTED
WEIGHTED

Appendix B: Statewide Caregiving Survey

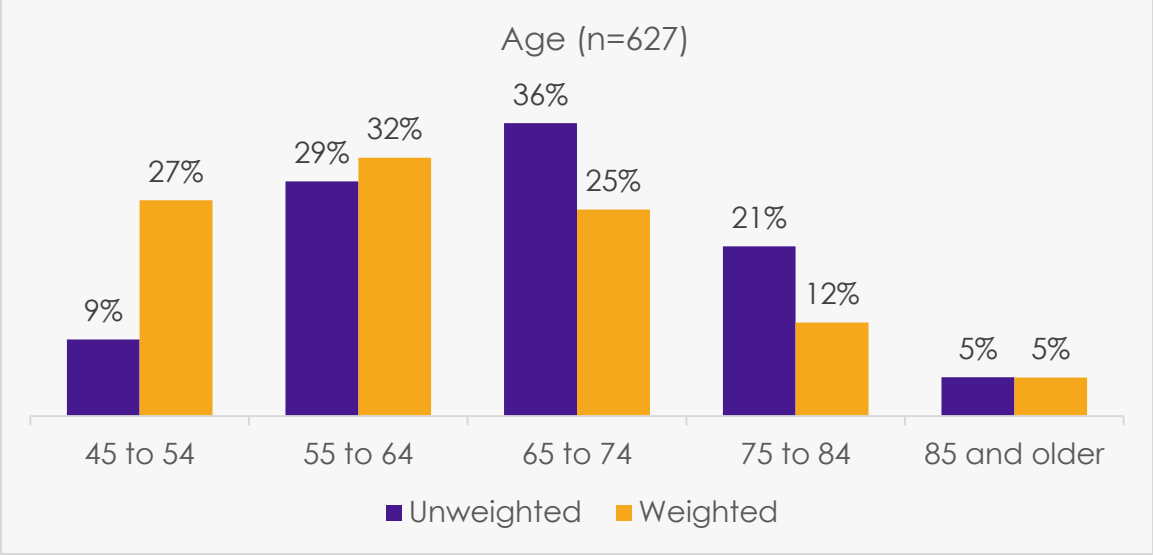
Complete Results

Demographics

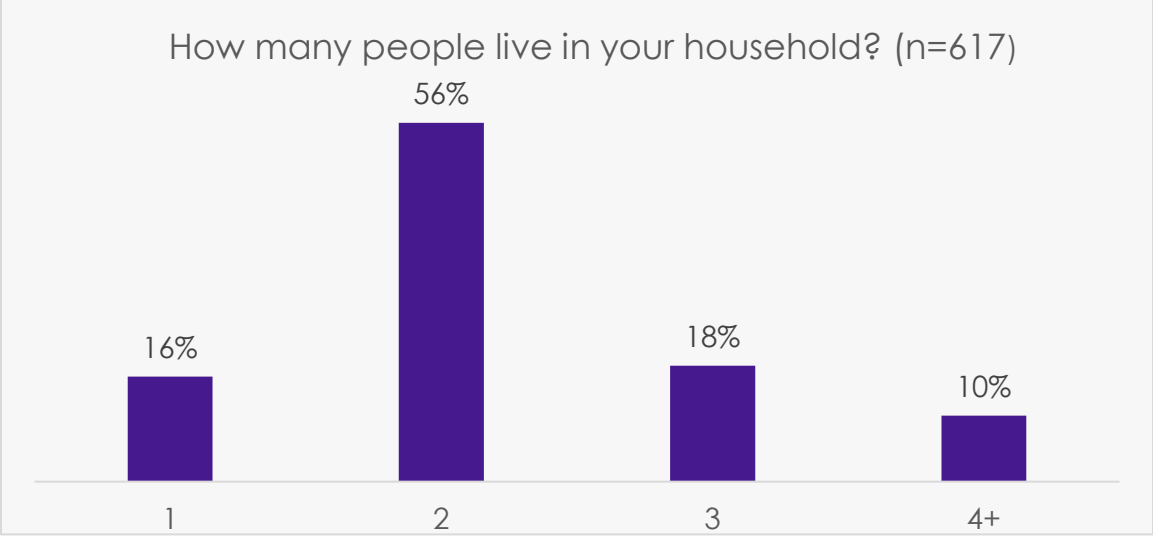
Q1:



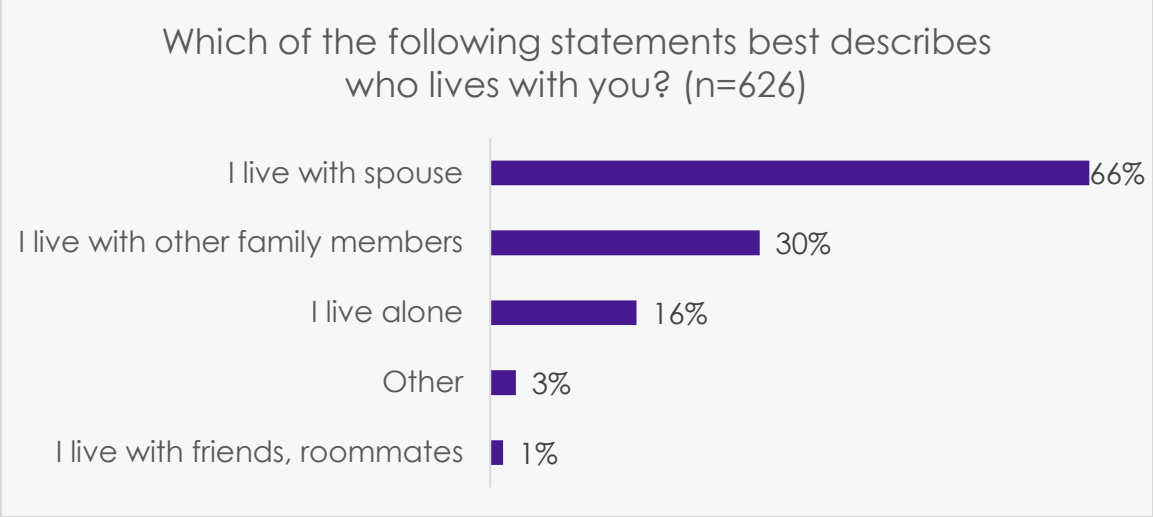
Q2:


Age (n=627)
9%
27%
29%
32%
36%
25%
21%
12%
5%
5%
45 to 54
55 to 64
65 to 74
75 to 84
85 and older
Unweighted
Weighted

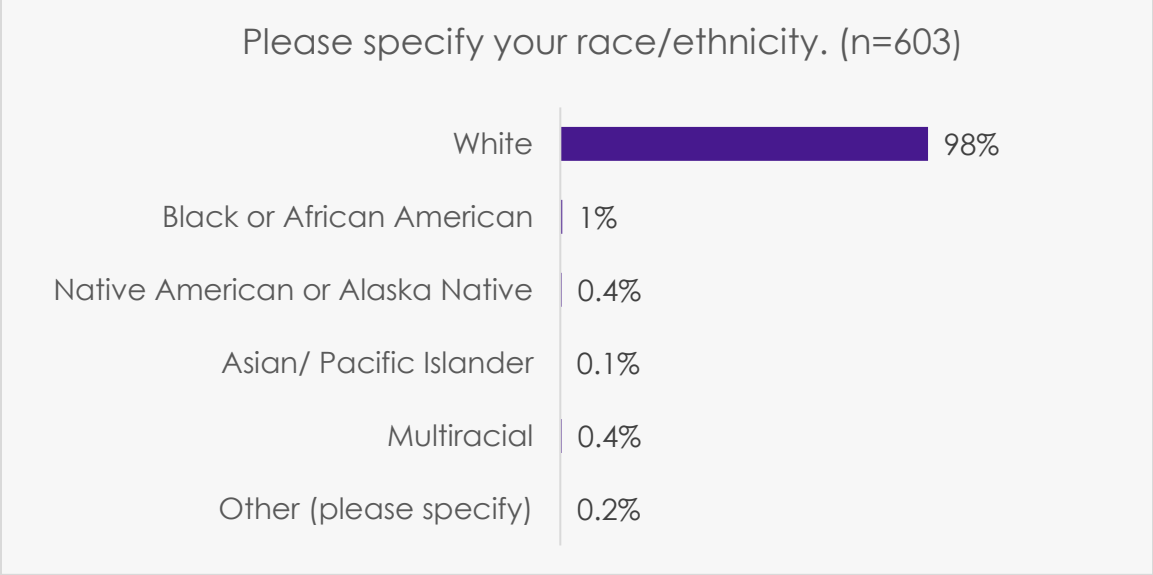
Q3:


How many people live in your household? (n=617)
16%
56%
18%
10%
1
2
3
4+

Q4:



Q5:



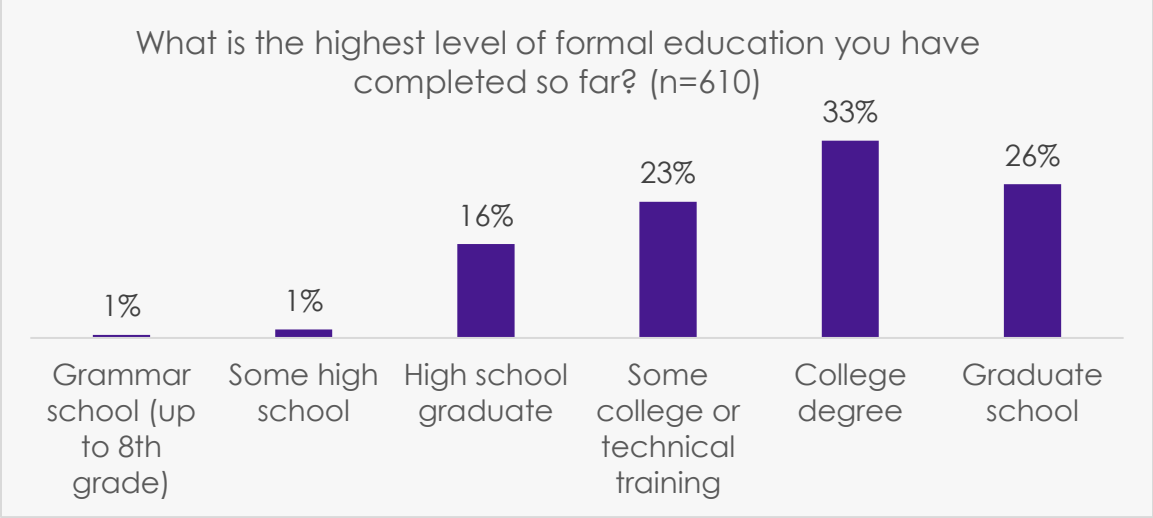
Q10:

Question	Female	Male	Not listed
Q10: What is your current gender identity? (n=612)	**52%**	48%	0.04%

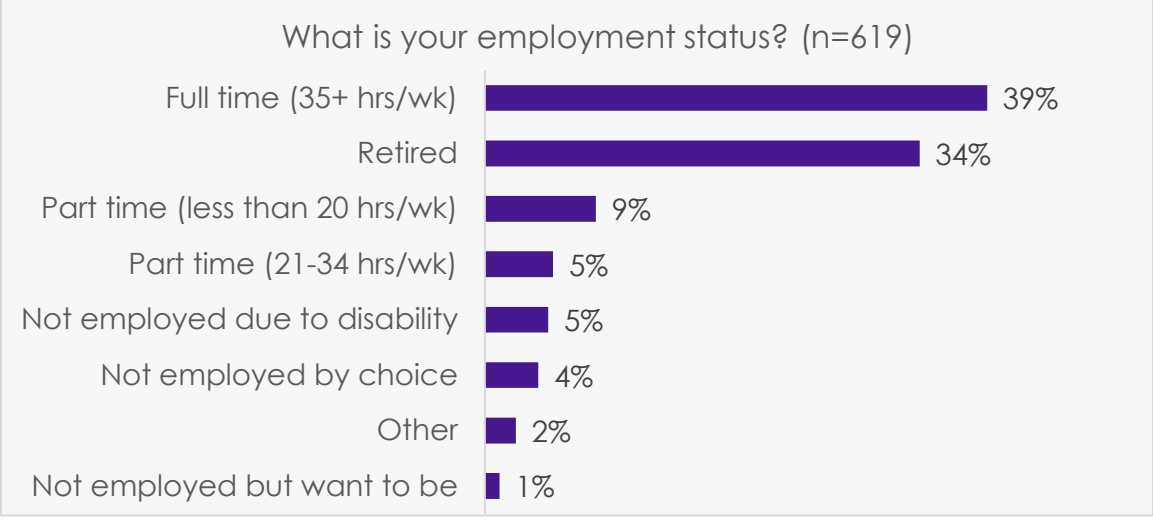
Q11:

Question	Straight, not gay or lesbian	Gay or lesbian	Bisexual	Not sure	Not listed
Q11: Do you think of yourself as: (n=609)	**94%**	3%	2%	0.5%	0.1%

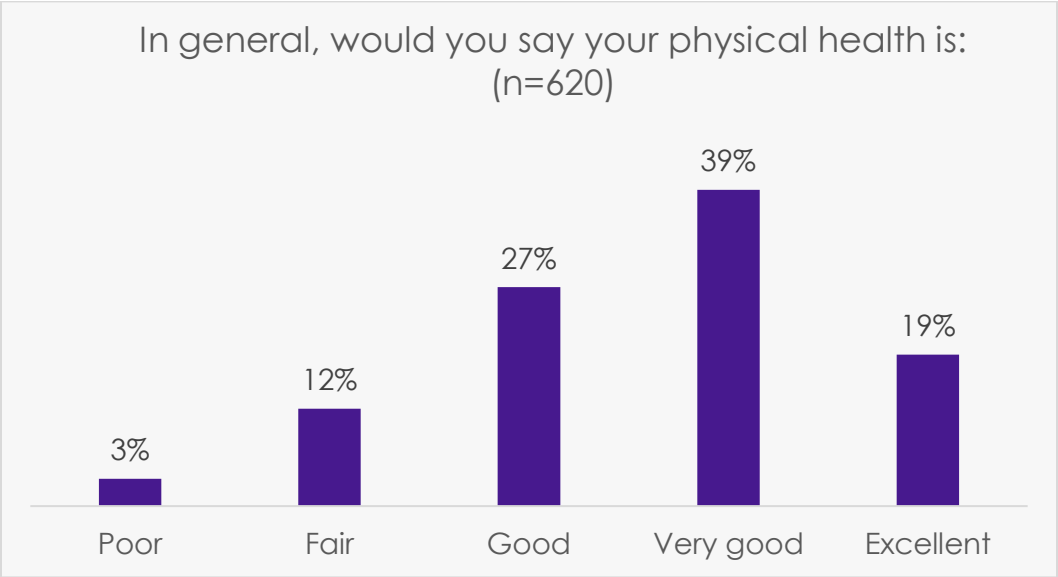
Q12:



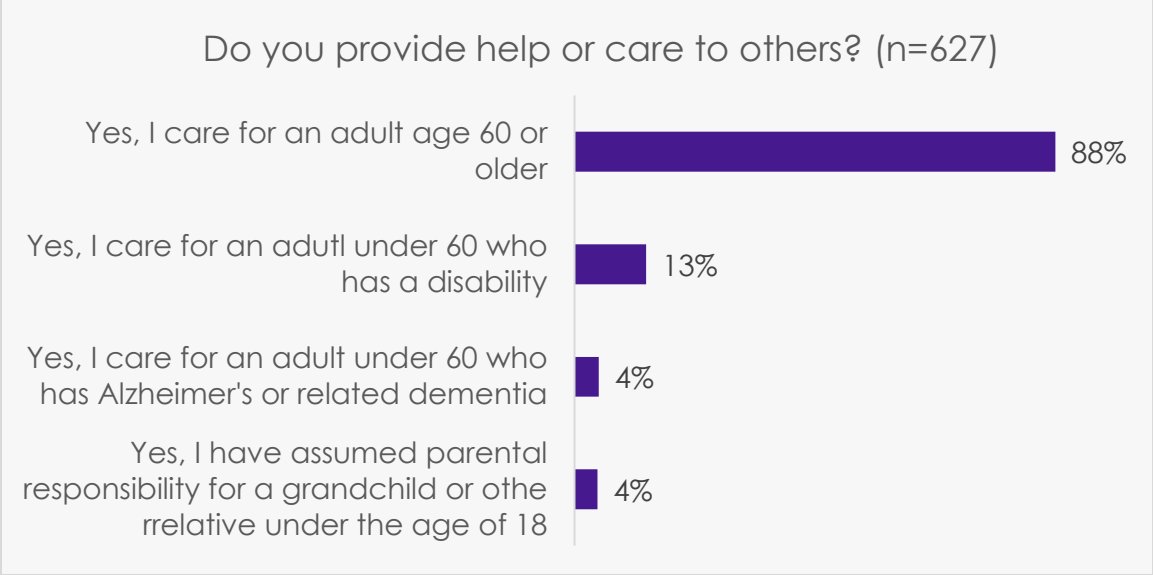
Q13:



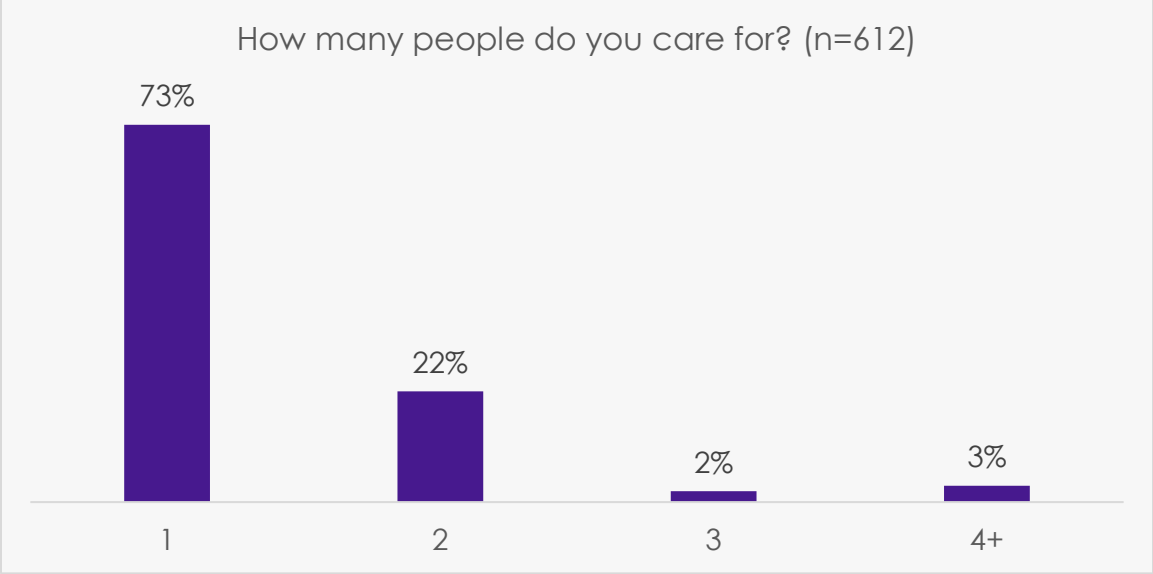
Q15:


In general, would you say your physical health is: (n=620)
3%
12%
27%
39%
19%
Poor
Fair
Good
Very good
Excellent

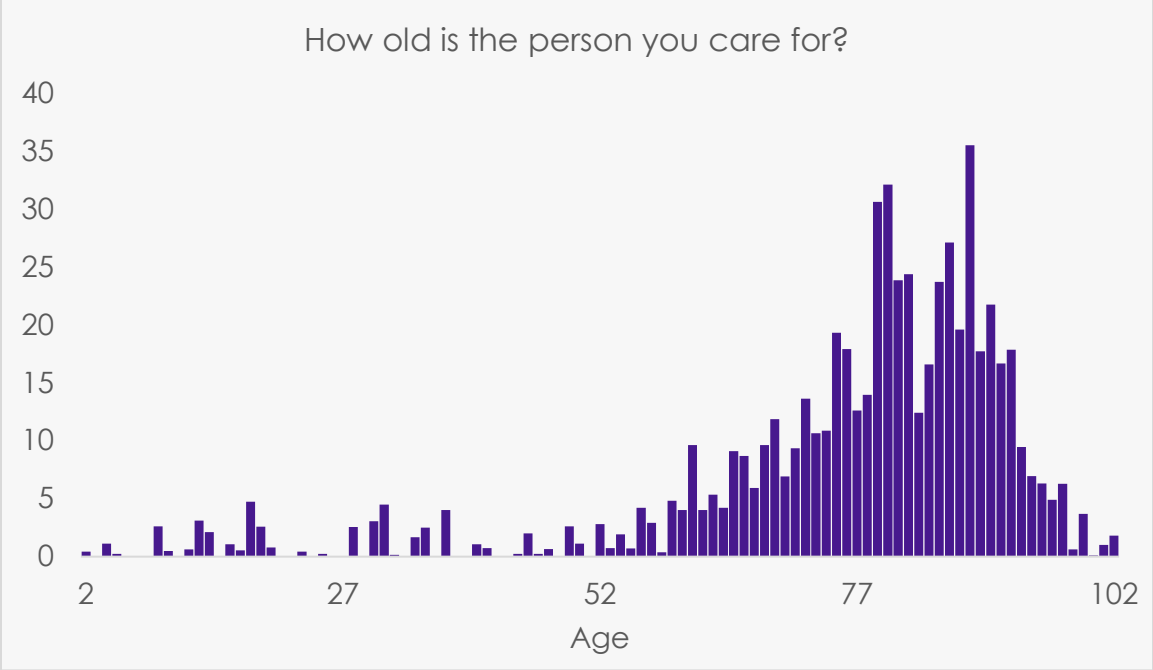
Caregiving



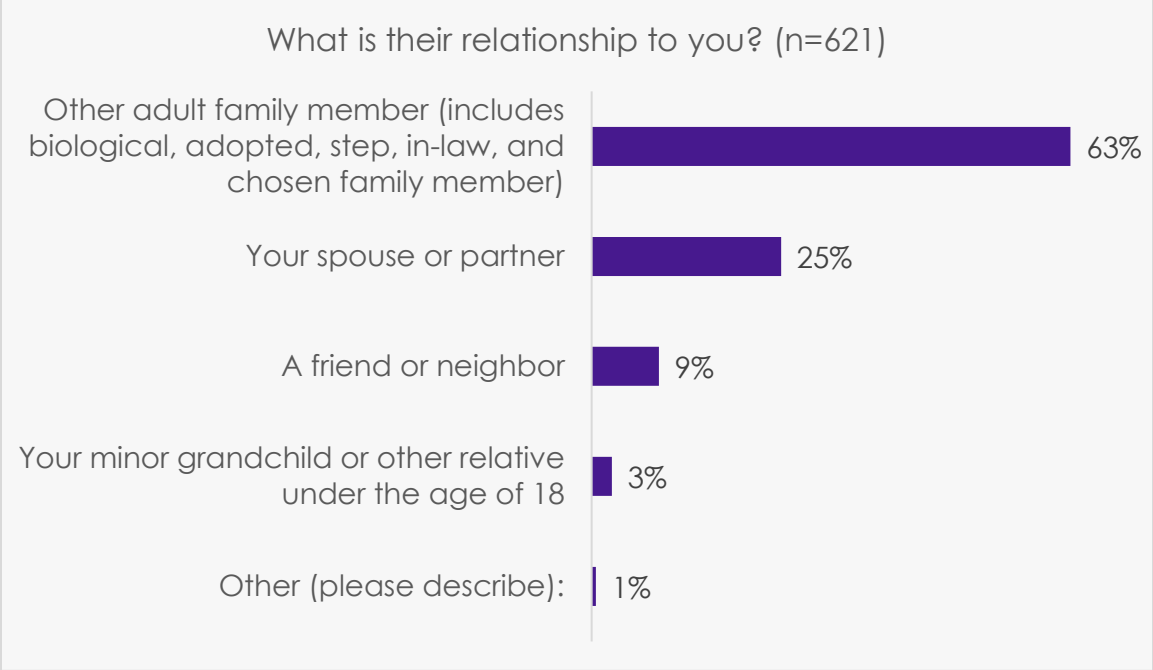
Q16:



Q17:

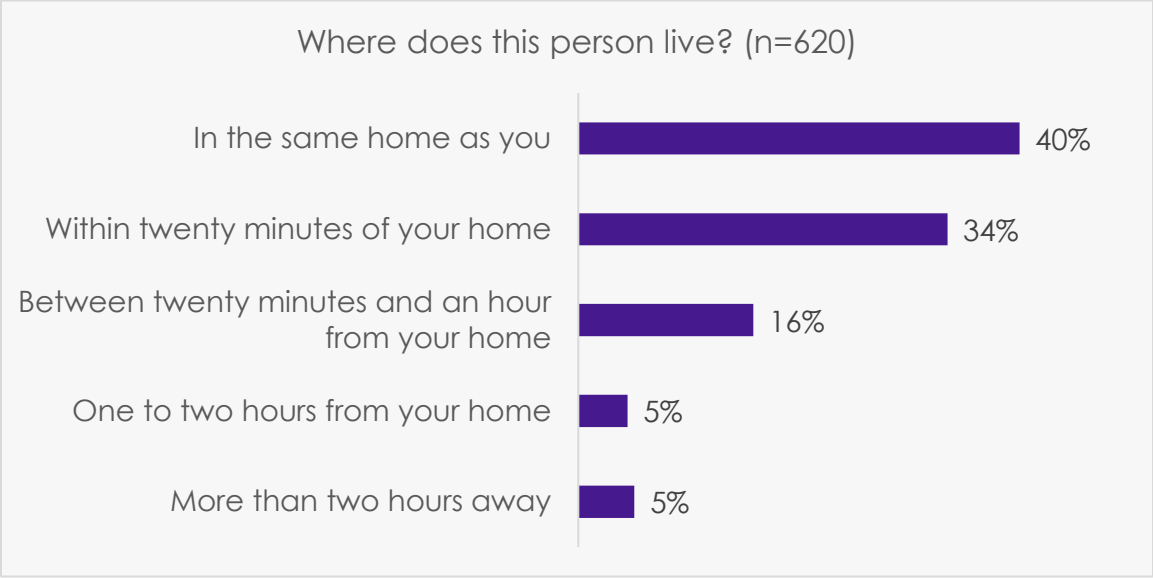

How old is the person you care for?
40
35
30
25
20
15
10
5
0
2
27
52
77
102
Age

Q18:

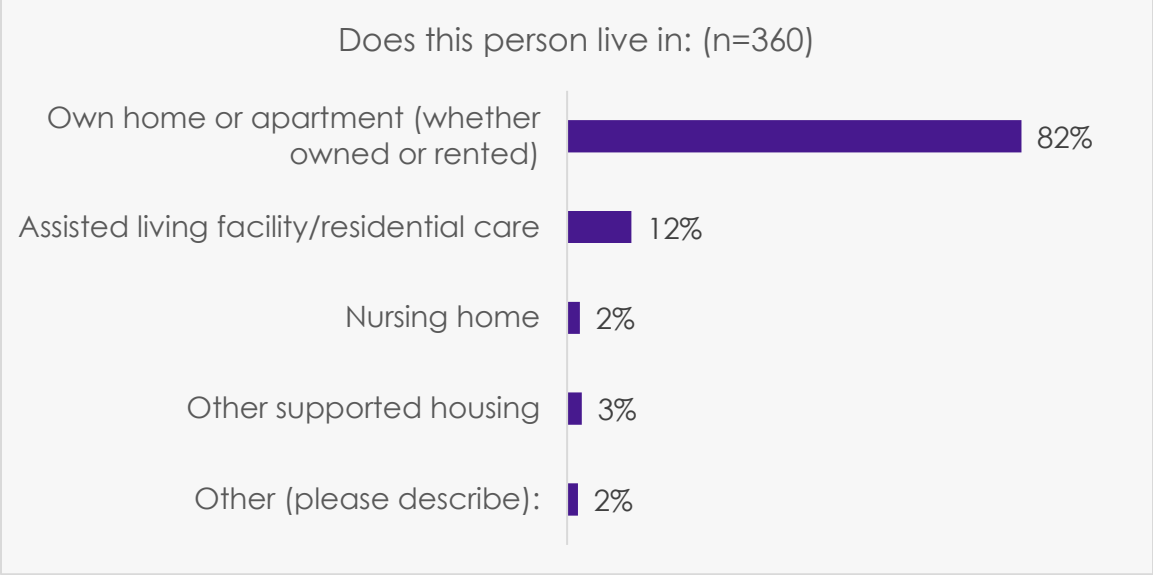

What is their relationship to you? (n=621)
Other adult family member (includes biological, adopted, step, in-law, and chosen family member)
63%
Your spouse or partner
25%
A friend or neighbor
9%
Your minor grandchild or other relative under the age of 18
3%
Other (please describe):
1%

Q18. Other responses: Other types of relationships included a roommate, acquaintance, an ex-spouse.

Q19:

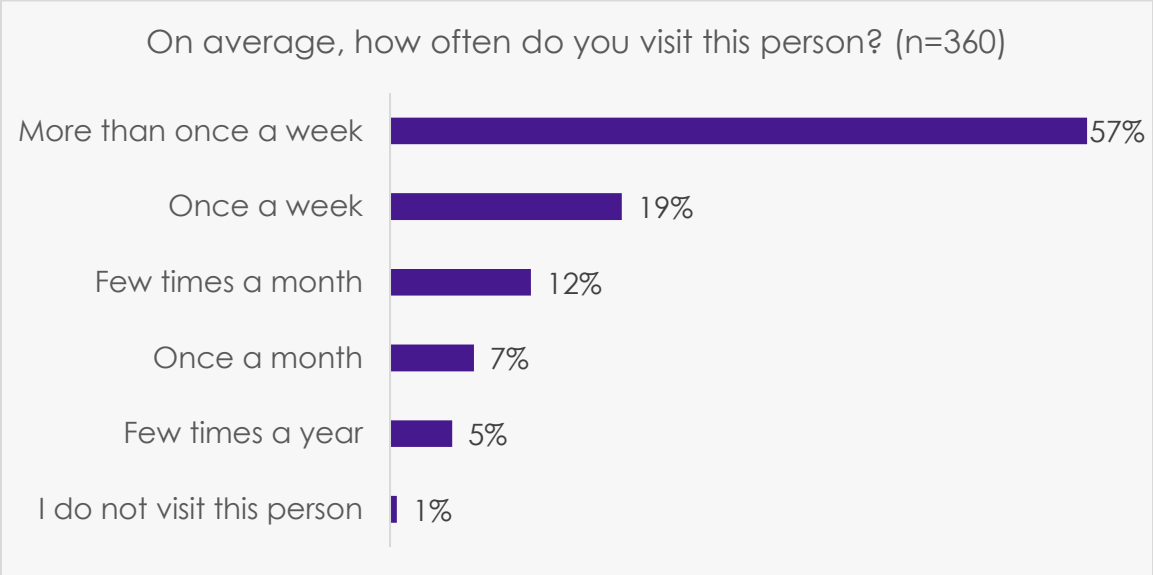


Q20:

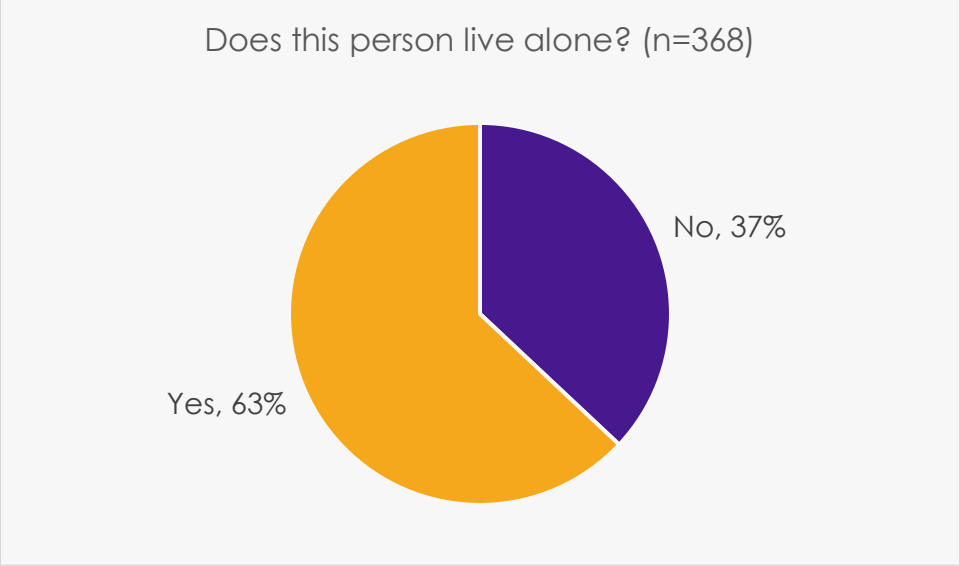


Q20. Other responses: Other living arrangements included with another family member, in an independent living facility, or with unstable housing.

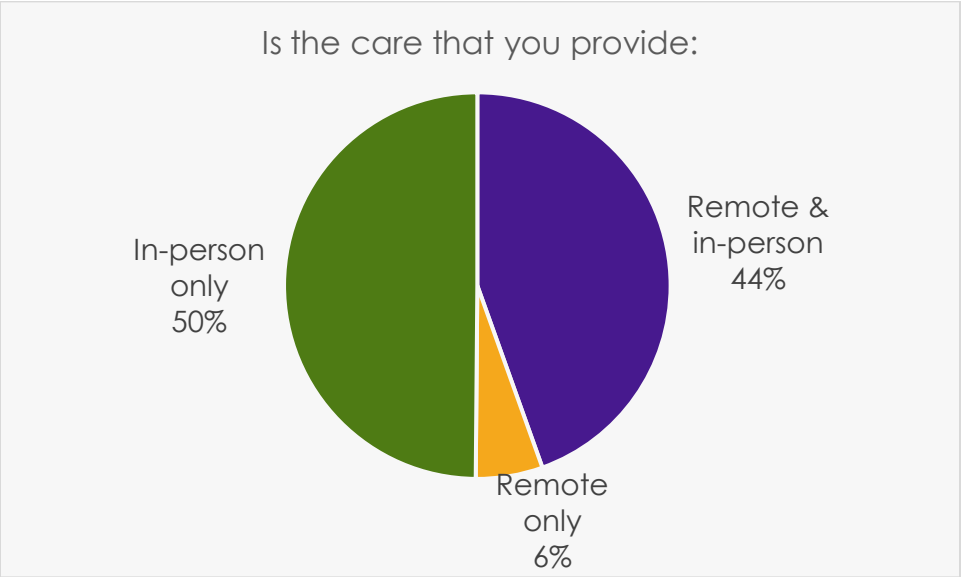
Q21:



Q22:

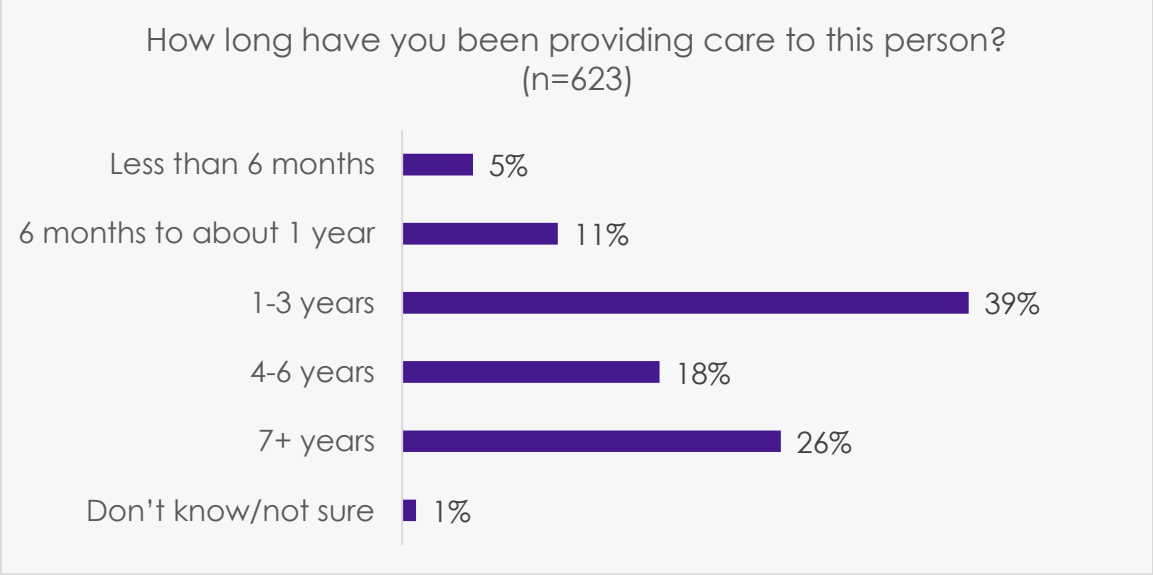


Q23:

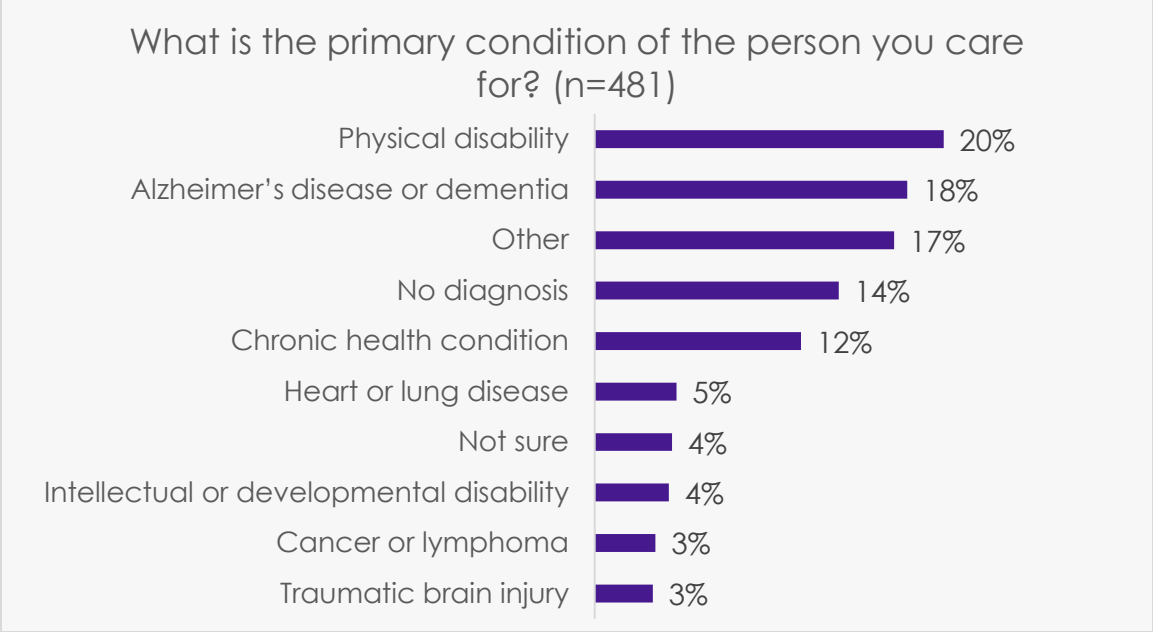


Q23. Respondents described providing different types of care including checking-in with their care recipient via telephone, text, or video chat.

Q24:

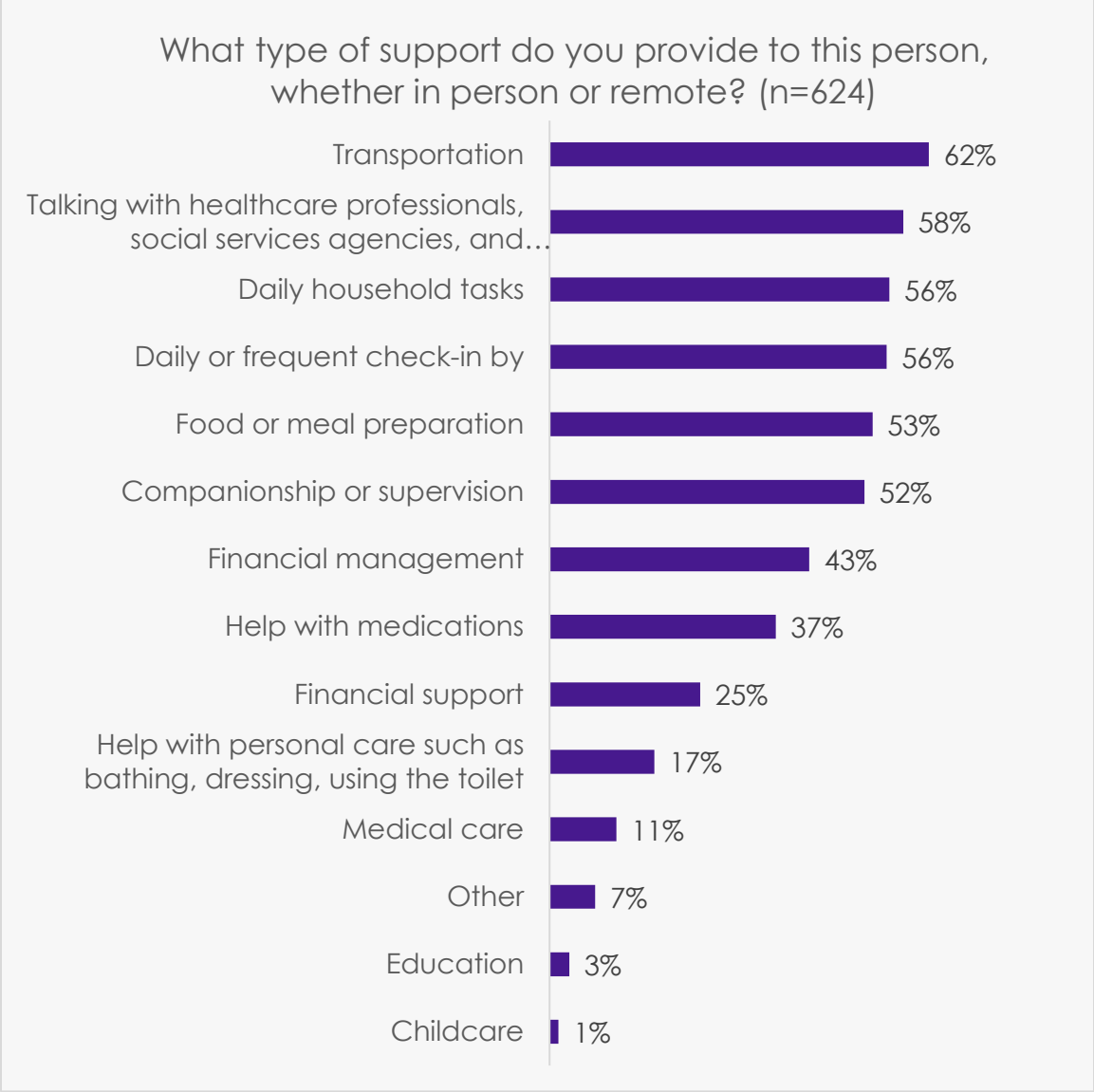


Q26:



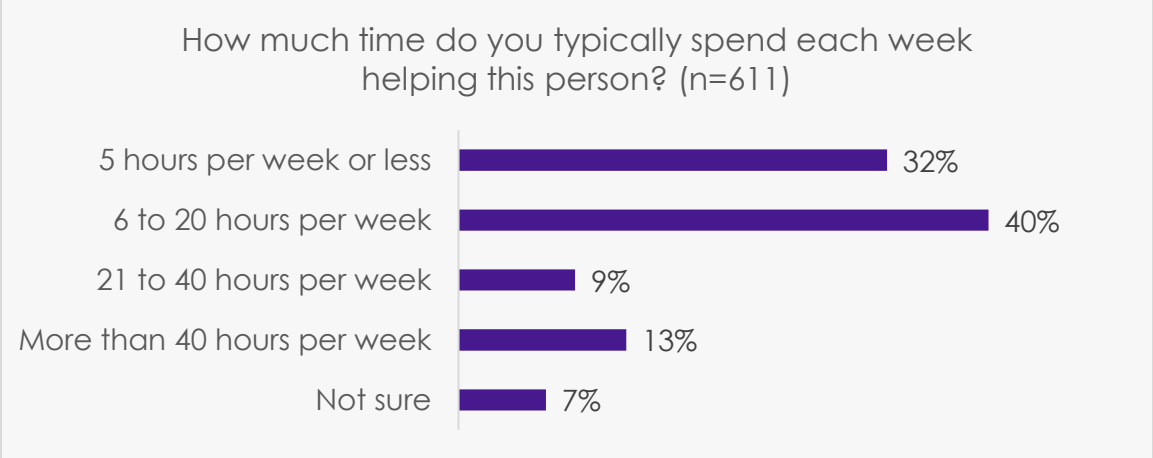
Q26. Other responses: Other types of medical conditions included age related diseases, mental health, and hearing or vision issues. Several respondents mentioned Parkinson's disease, autoimmune disorders, and neurological conditions.

Q27:

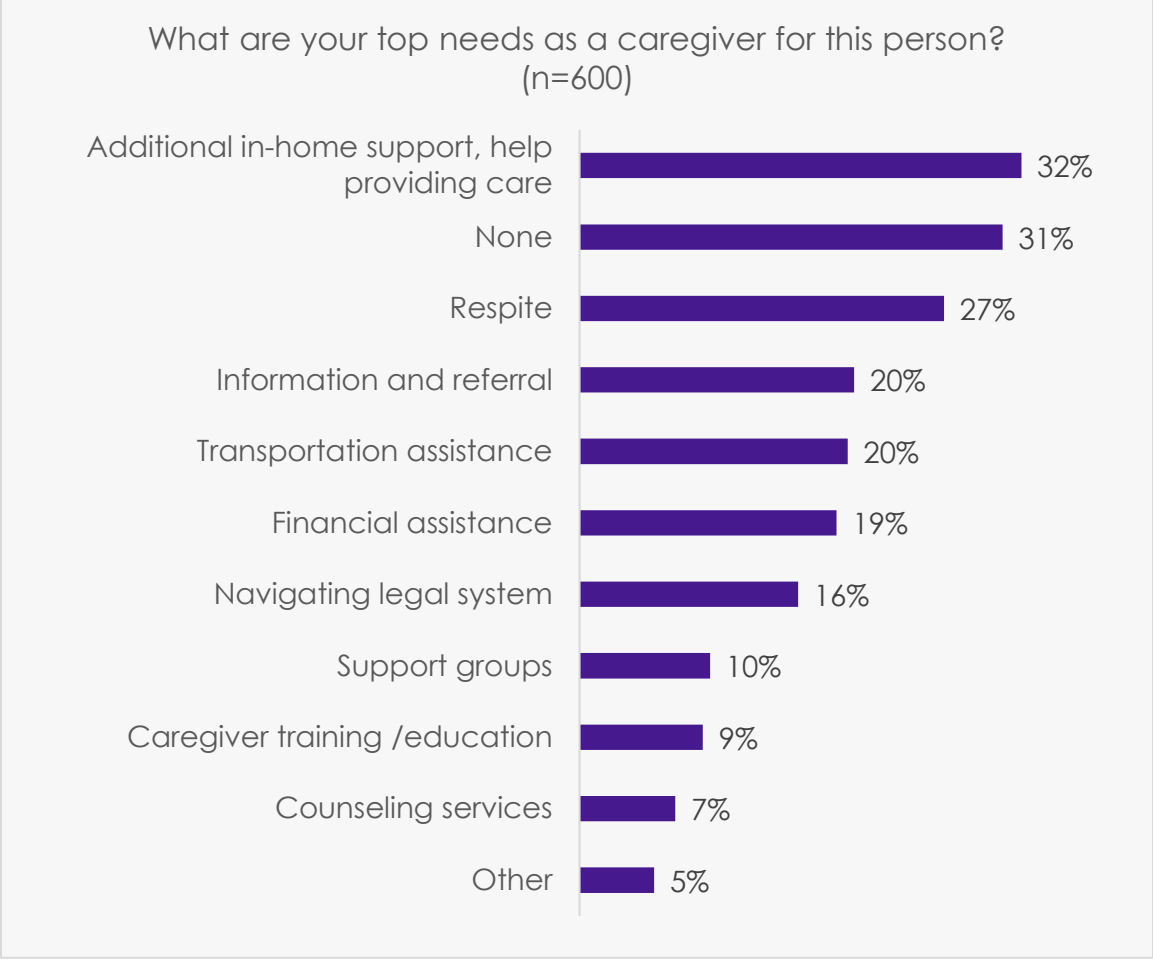


Q27. Other responses: Caregivers said they provide a variety of supports, many indicating they "just help when needed." Others said they provide housing, help with home repairs, maintenance, or cleaning. Several mentioned providing emotional or respite support to either the care recipient or primary caregiver. Few mentioned helping with medical decisions, including going to appointments, managing insurance policies, and overseeing nursing home care.

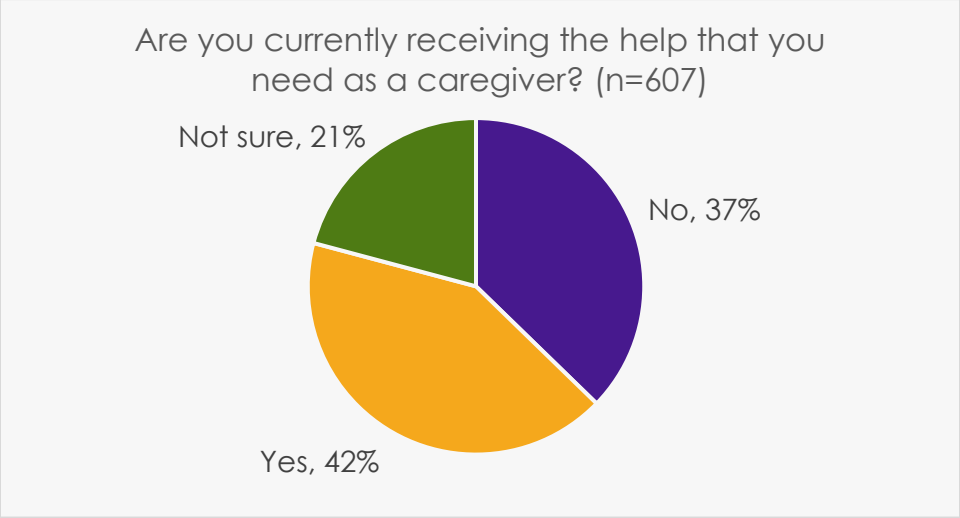
Q28:


How much time do you typically spend each week helping this person? (n=611)
5 hours per week or less
32%
6 to 20 hours per week
40%
21 to 40 hours per week
9%
More than 40 hours per week
13%
Not sure
7%

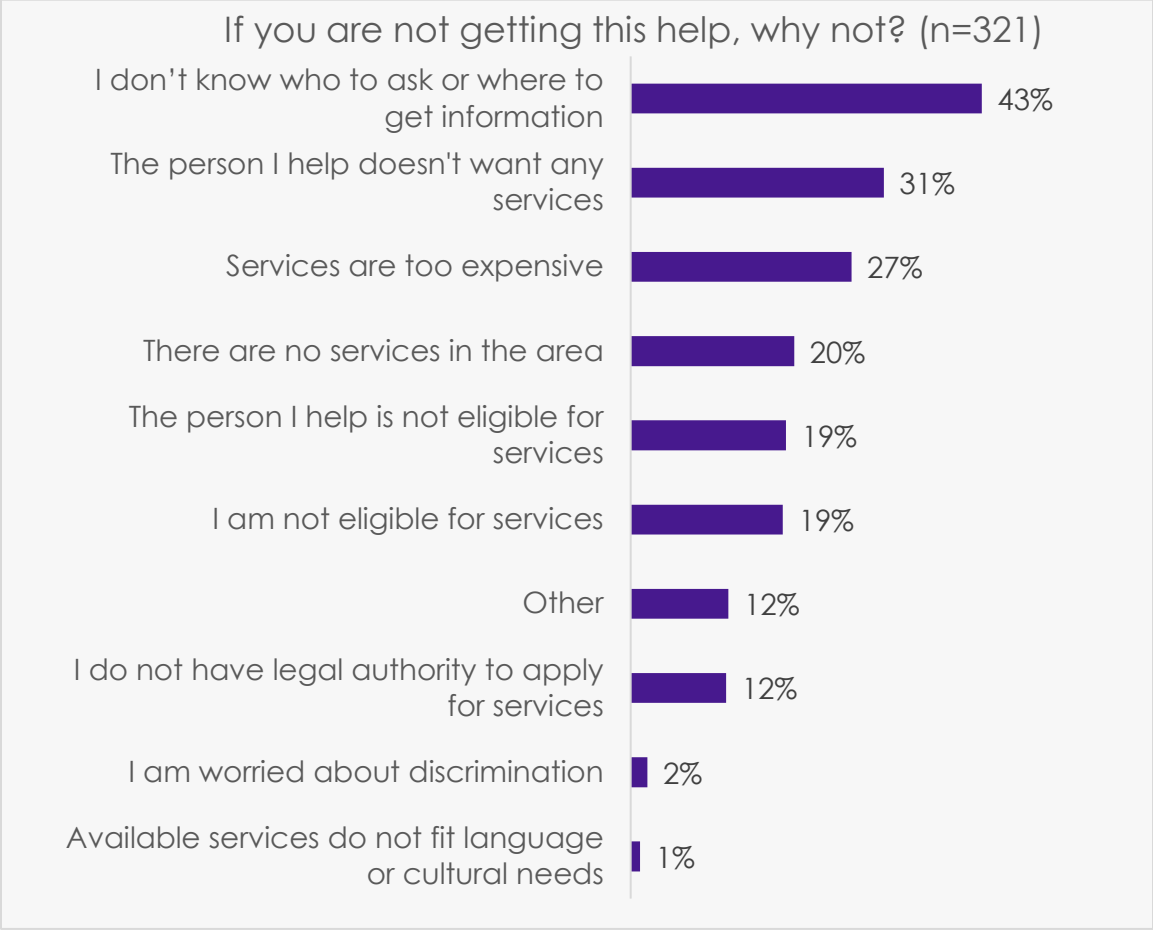
Q29:


What are your top needs as a caregiver for this person? (n=600)
Additional in-home support, help providing care
32%
None
31%
Respite
27%
Information and referral
20%
Transportation assistance
20%
Financial assistance
19%
Navigating legal system
16%
Support groups
10%
Caregiver training /education
9%
Counseling services
7%
Other
5%

Q30:


Are you currently receiving the help that you need as a caregiver? (n=607)
Not sure, 21%
No, 37%
Yes, 42%

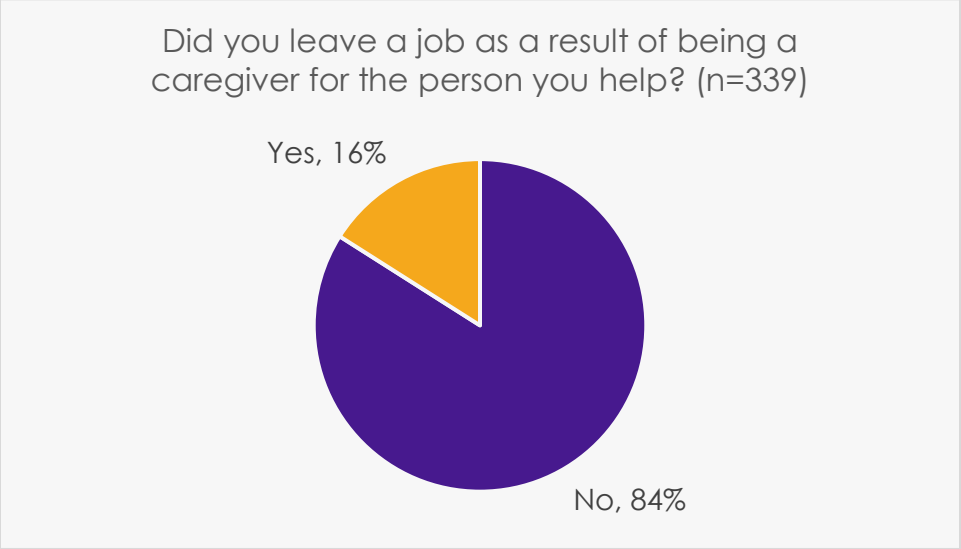
Q31:



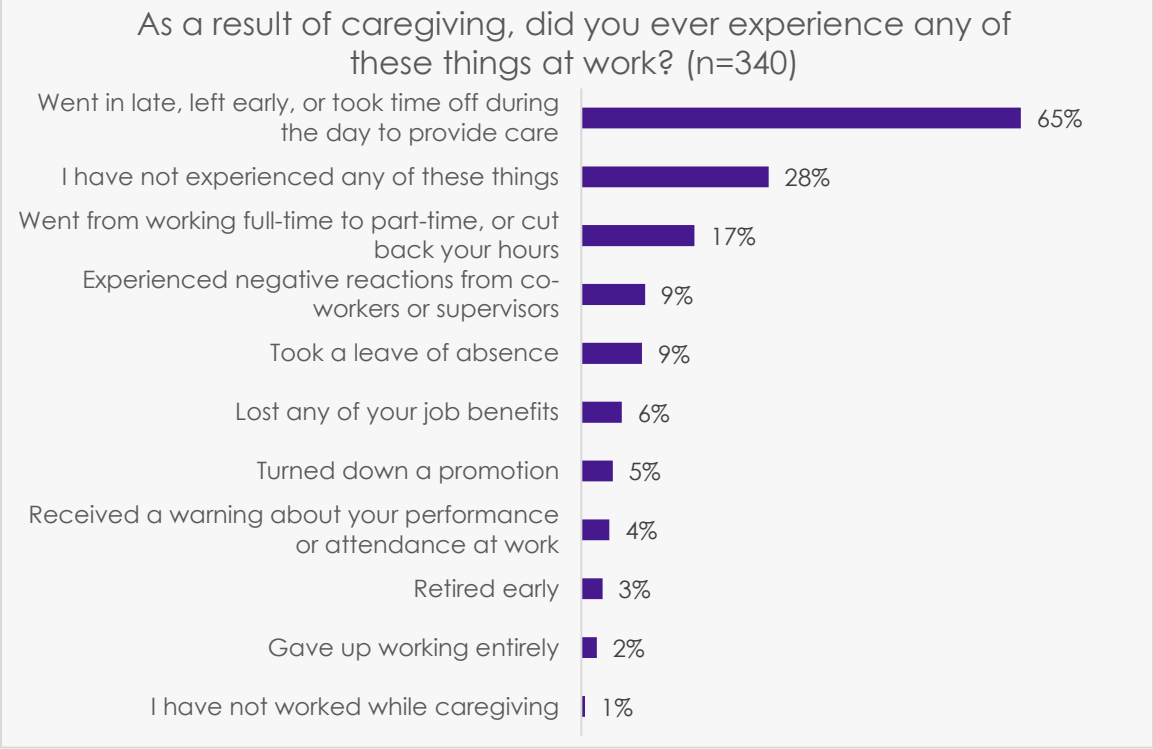
Q31: Other responses: Additional reasons for caregivers not receiving the help they needed included needing additional services or information or needing help from other either trained professionals or family members.

Caregiving and Working

Q33:

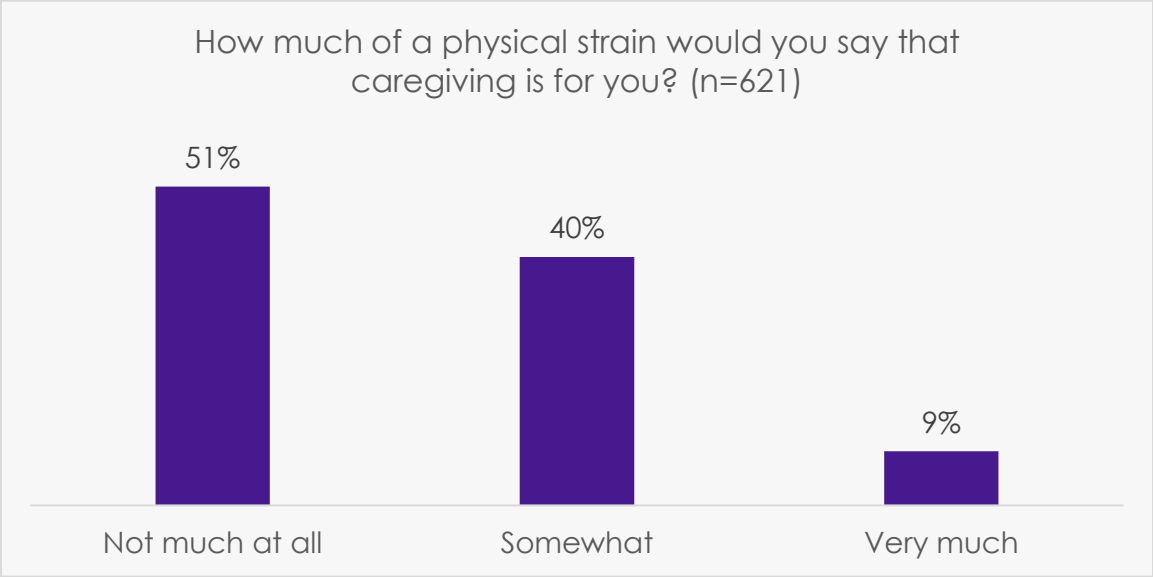


Q34:

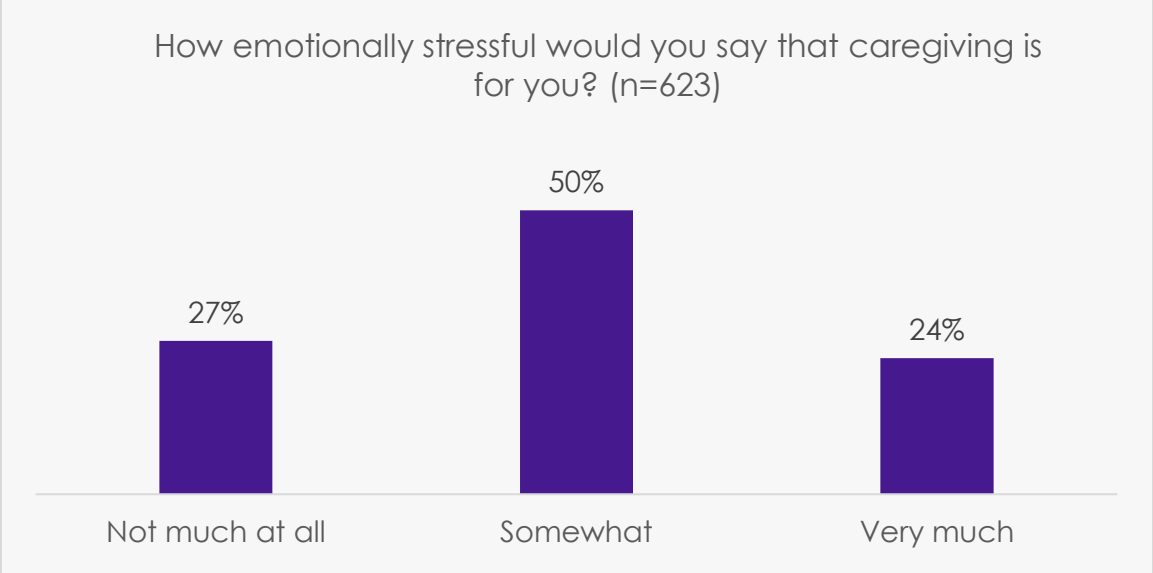


Caregiving and Stress

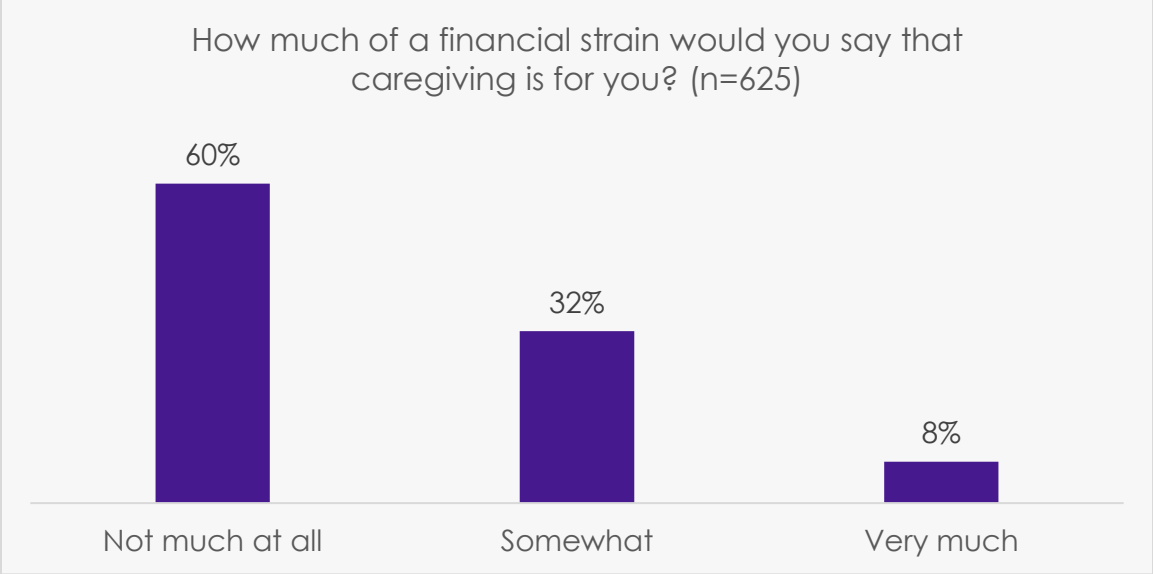
Q35:



Q36:



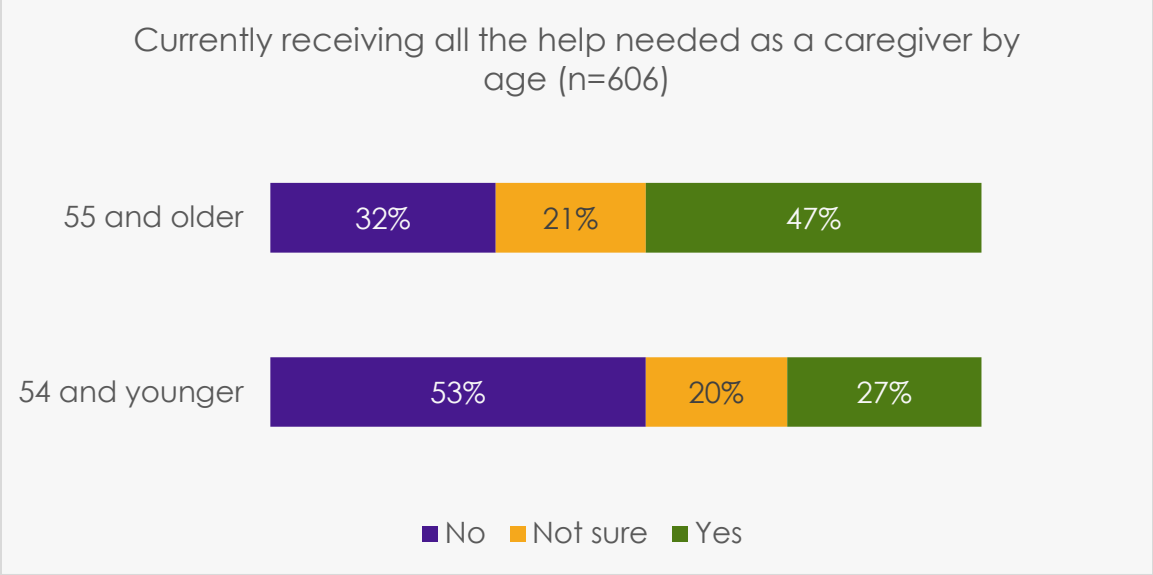
Q37:

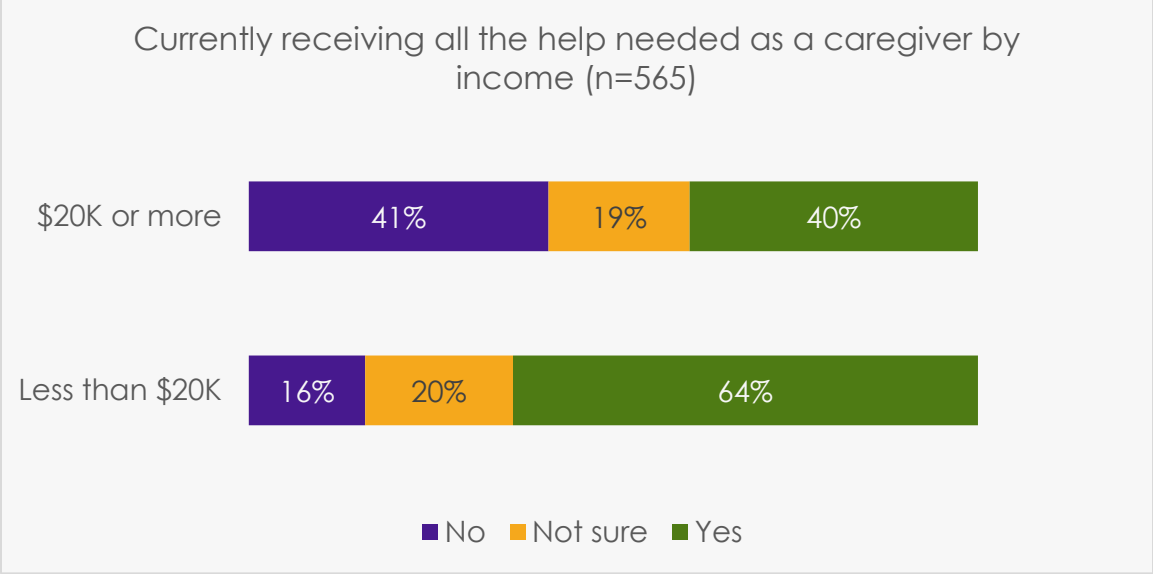

How much of a financial strain would you say that caregiving is for you? (n=625)
60%
32%
8%
Not much at all
Somewhat
Very much

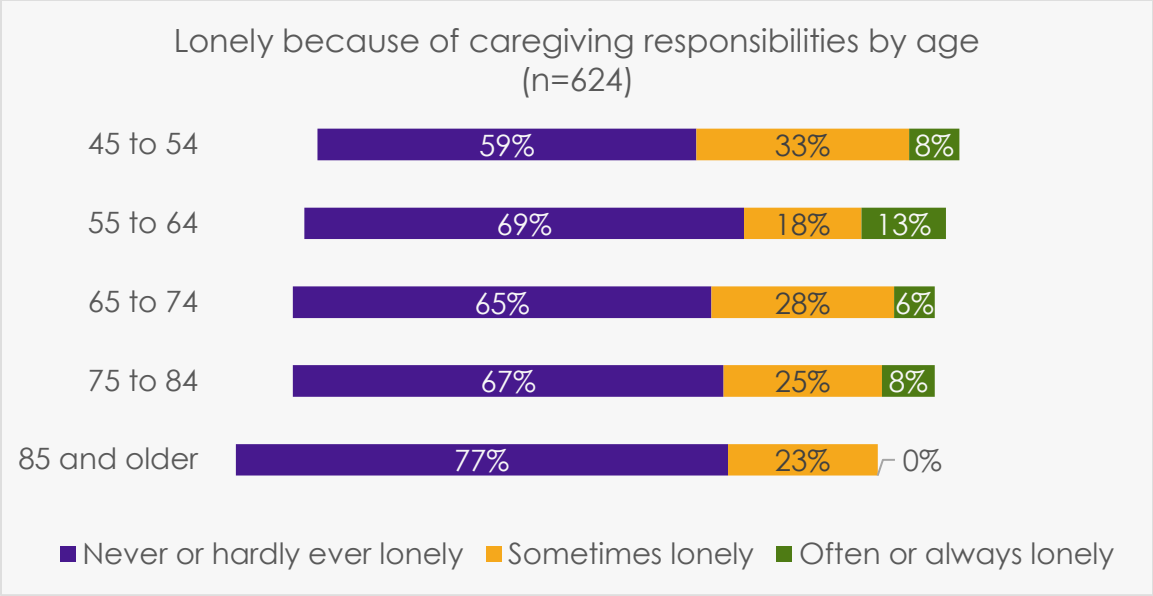
Q38:

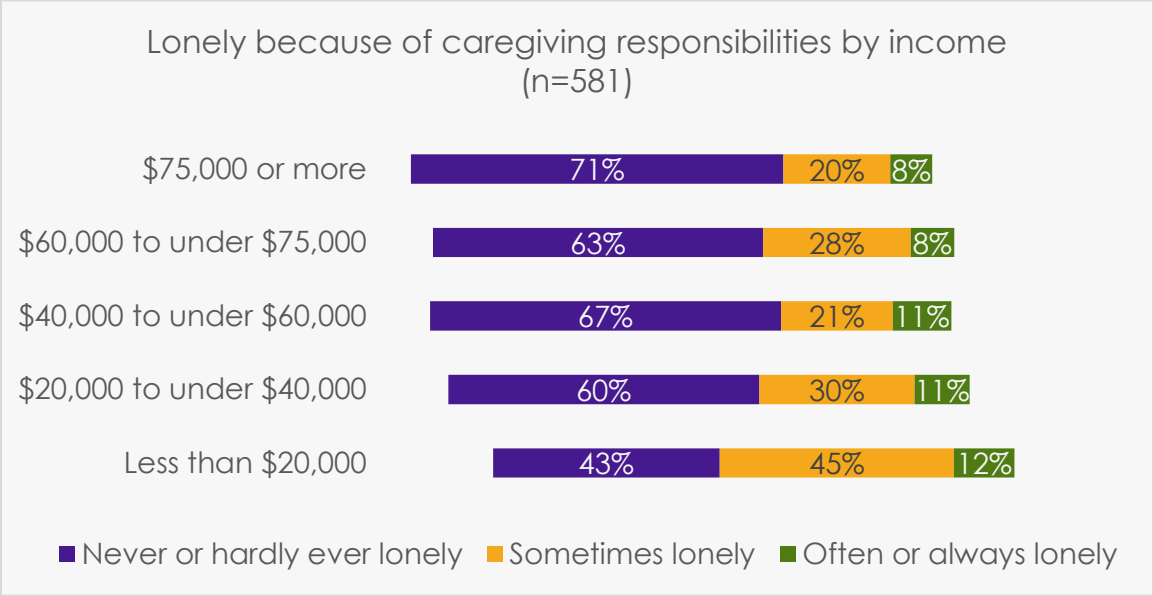

In the last 6 months, how often have you felt lonely and/or disconnected from other people because of your caregiving responsibilities? (n=623)
42%
23%
26%
7%
2%
Never
Hardly ever
Sometimes
Often
Always

Crosstabs


Currently receiving all the help needed as a caregiver by age (n=606)
55 and older
32%
21%
47%
54 and younger
53%
20%
27%
No
Not sure
Yes


Currently receiving all the help needed as a caregiver by income (n=565)
$20K or more
41%
19%
40%
Less than $20K
16%
20%
64%
No
Not sure
Yes


Lonely because of caregiving responsibilities by age
(n=624)
45 to 54
59%
33%
8%
55 to 64
69%
18%
13%
65 to 74
65%
28%
6%
75 to 84
67%
25%
8%
85 and older
77%
23%
0%
Never or hardly ever lonely
Sometimes lonely
Often or always lonely


Lonely because of caregiving responsibilities by income
(n=581)
$75,000 or more
71%
20%
8%
$60,000 to under $75,000
63%
28%
8%
$40,000 to under $60,000
67%
21%
11%
$20,000 to under $40,000
60%
30%
11%
Less than $20,000
43%
45%
12%
Never or hardly ever lonely
Sometimes lonely
Often or always lonely

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