MAINE STATE PLAN ON AGING: NEEDS ASSESSMENT

Summary of Findings

March 2020
Maine State Plan on Aging: Needs Assessment
Summary of Finding

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Members of the State Plan on Aging Advisory Committee provided guidance and helped shape key areas for discussion and inquiry. Members also helped publicize the surveys, listening sessions, and focus groups through their networks, providing a trusted source of information. In particular, we would like to recognize staff from Maine’s five Area Agencies on Aging (AAAs) for supporting this broad outreach effort. In addition to assisting with securing many of the site locations, AAA representatives hosted and attended listening sessions in their respective region. They were instrumental in distributing the caregiver survey link as well as information about the listening sessions and focus groups and were integral to helping get the word out.

This project would not have been possible without the funding and support through Maine’s Office of Aging and Disability Services (OADS). In particular, we would like to thank the leadership and vision provided by Karen Mason and James Moorhead who oversaw this project, attended the community listening sessions, and introduced the Older Americans Act and the State Plan on Aging. Their presence assured participants that the voices of older Mainers would be heard as part of this planning process.

The Maine Health Access Foundation (MeHAF) supported this effort in multiple ways including providing additional funding for the focus groups allowing us to better understand the needs of some under-served populations.

We also want to acknowledge Jeremy Zuckero, a USM graduate assistant, for his contributions over the fall of 2019.

Most importantly, we extend our deepest appreciation to the many older adults and caregivers who took their time to share their experiences, candor and insights with us. This has been a rich experience because of their participation and we hope the results presented here illuminate efforts to support aging comfortably in our homes and communities.

State Plan Advisory Committee members:

- Adam Lacher, Alzheimer’s Association Maine Chapter
- Betsy Sawyer-Manter, SeniorsPlus
- Brenda Gallant, Maine Long-Term Care Ombudsman Program
- Dyan Walsh, Eastern Area Agency on Aging
- Fatuma Hussein, Immigration Resource Center of Maine
- Gerry Queally, Spectrum Generations
- Jaye Martin, Maine Legal Services for the Elderly
- Jessica Maurer, Maine Council on Aging
- John Hennessey, SAGE Maine of Equality Maine
- Joy Barresi Saucier, Aroostook Agency on Aging
• Megan Walton, Southern Maine Agency on Aging
• Ruta Kadonoff, Maine Health Access Foundation
INTRODUCTION AND PURPOSE

The Department of Health and Human Services’ Office of Aging and Disability Services (OADS) partnered with the Muskie School of Public Service 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 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 Maine State Plan on Aging for the years 2020-2024 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 report summarizes findings across five data collection strategies that include surveys, listening sessions, focus groups, and key informant interviews. Each section includes the methodology, findings, and key take-aways. Section 4 focuses on findings related to caregivers across all study components. Section 7 highlights common themes heard throughout this needs assessment.
BACKGROUND

Maine’s Office of Aging and Disability Services (OADS) is the federally designated State Unit on Aging (SUA). 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)\(^1\) 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 nutrition services and programs; health promotion and disease prevention; information, referral and assistance; and family caregiver support. OAA services also support advocacy and legal assistance services.\(^2\) 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 the years 2020-2024. 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 timeframe. The AAA plans set forth goals and objectives for the coordination of services and supports within their geographic service area.

To help inform the development of the State Plan on Aging, OADS partnered with the Muskie School of Public Service 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 three times in July and August of 2019. 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, community listening sessions, special population focus groups, and key informant interviews. This report includes the results from all of the data collection activities conducted as part of this needs assessment.

1 The five AAAs serving Maine are Aroostook Agency on Aging, Eastern Area Agency on Aging, SeniorsPlus, Spectrum Generations, and Southern Maine Agency on Aging. A map of the five AAA service areas can be accessed at: http://www.maine4a.org/service.html

2 This includes services provided by Legal Services for the Elderly (LSE) and the Maine Long-Term Care Ombudsman Program (LTCOP).
KEY DEMOGRAPHICS AND TRENDS

The following figures provide contextual information about Maine’s older adult population and projected trends. Much of the information shown comes from the United States Census Bureau American Community Survey (ACS) 5-year estimates, the ACS 1-year estimates, and Woods and Poole Economics, Inc. population projections. The sources of information are included on each figure.

Like the rest of the nation, Maine’s older adult population is expected to continue to grow as a percentage of total population. However, Maine’s older adult population is likely to grow at a much faster rate, comprising nearly 30% of the total population by 2040 compared to 20% nationwide (Figure 1).

Figure 1 Historical and Projected Trends in the Percentage of Population 65 and Older, Maine, New England, and the United States, 2000-2040

2017 Woods and Poole Economics, Inc., “2017 New England State Profile: State and County Projections to 2050”. 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 Muskie School at USM.

3 For additional information on Maine’s older adult population, see the following publication: Snow KI, et al., Adults Using Long Term Services and Supports: Population and Service Use Trends in Maine, SFY 2016. Portland, ME: University of Southern Maine, Muskie School of Public Service; 2018. This publication can be accessed at: https://digitalcommons.usm.maine.edu/aging/110/
Figure 2 shows the historical and projected median age in Maine, New England, and the United States. By 2040, half of Maine’s population is projected to be over 47 years old.

**Figure 2 Historical and Projected Trends in the Median Age, Maine, New England and the United States, 2000-2040**

<table>
<thead>
<tr>
<th>Year</th>
<th>United States</th>
<th>New England</th>
<th>Maine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Census 2000</td>
<td>35</td>
<td>37</td>
<td>39</td>
</tr>
<tr>
<td>Census 2010</td>
<td>37</td>
<td>40</td>
<td>43</td>
</tr>
<tr>
<td>2020 (est.)</td>
<td>38</td>
<td>41</td>
<td>46</td>
</tr>
<tr>
<td>2030 (est.)</td>
<td>39</td>
<td>42</td>
<td>47</td>
</tr>
<tr>
<td>2040 (est.)</td>
<td>40</td>
<td>43</td>
<td>47</td>
</tr>
</tbody>
</table>

*2017 Woods and Poole Economics, Inc., “2017 New England State Profile: State and County Projections to 2050”. 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 Muskie School at USM.*
The projected dependency ratio shown in Figure 3 indicates that by 2040, there will be only two working age persons (age 20-64) per one person age 65 and older. This compares to 4.1 working age persons per one person age 65 and older in 2000. This lower dependency ratio has significant implications for the availability of a workforce in Maine to serve an aging population.

**Figure 3  Historical and Projected Dependency Ratio-- Number of Working Age Persons (20-64) per One Person Age 65+, 2000-2040**

![Dependency Ratio Graph]

2017 Woods and Poole Economics, Inc., “2017 New England State Profile: State and County Projections to 2050”. 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 Muskie School at USM.
In 2017, forty-three percent of Maine households had one or more members who are 60 years or older. This varied at the county level with Androscoggin County having the lowest percentage at 37% and Lincoln County the highest at 53% (Figure 4).

**Figure 4  Percentage of Maine Households with One or More Members 60+, 2017**

<table>
<thead>
<tr>
<th>County</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maine average</td>
<td>43%</td>
</tr>
<tr>
<td>Androscoggin</td>
<td>37%</td>
</tr>
<tr>
<td>Aroostook</td>
<td>46%</td>
</tr>
<tr>
<td>Cumberland</td>
<td>39%</td>
</tr>
<tr>
<td>Franklin</td>
<td>46%</td>
</tr>
<tr>
<td>Hancock</td>
<td>48%</td>
</tr>
<tr>
<td>Kennebec</td>
<td>43%</td>
</tr>
<tr>
<td>Knox</td>
<td>51%</td>
</tr>
<tr>
<td>Lincoln</td>
<td>53%</td>
</tr>
<tr>
<td>Oxford</td>
<td>48%</td>
</tr>
<tr>
<td>Penobscot</td>
<td>40%</td>
</tr>
<tr>
<td>Piscataquis</td>
<td>52%</td>
</tr>
<tr>
<td>Sagadahoc</td>
<td>42%</td>
</tr>
<tr>
<td>Somerset</td>
<td>44%</td>
</tr>
<tr>
<td>Waldo</td>
<td>45%</td>
</tr>
<tr>
<td>Washington</td>
<td>48%</td>
</tr>
<tr>
<td>York</td>
<td>42%</td>
</tr>
</tbody>
</table>

Maine’s older adults vary widely in level of family income by age group. Figure 5 shows that younger age groups (55-74 years) are more likely than the oldest age group (75+ years) to have incomes 300%+ of the federal poverty level (FPL). In 2017, there was an estimated 42,036 older adults age 55+ with incomes below the FPL, about nine percent of the total population age 55+. The FPL varies by household size and by age of householder under or over age 65. The 2017 FPL for 2-person households where one householder was 65+ was $14,828.4

Figure 5  Family Income as a Percent of the Federal Poverty Level (FPL) by Age Group and Income Categories, 2017

![Chart showing family income as a percent of the Federal Poverty Level (FPL) by age group and income categories, 2017](chart.png)


Food Stamps and SNAP benefits that help with food insecurity are available to households that meet eligibility requirements. Figure 6 shows that in 2017 thirty-four percent of Maine households receiving Food Stamps/SNAP had at least one member age 60+. Knox County had the lowest percentage (28%) while Lincoln County had the highest percentage (44%) of households receiving Food Stamps/SNAP with at least one member age 60+.

**Figure 6  Percentage of Maine Households Receiving Food Stamps/SNAP with at Least One Member Age 60+, 2017**

![Bar chart showing the percentage of Maine households receiving Food Stamps/SNAP with at least one member age 60+ for different counties.]

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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. The 2017 ACS data shows that among Maine grandparents living with their own grandchildren, nine percent were responsible for caring for their grandchildren and also had a disability themselves (Figure 7). The needs of these grandparents may straddle two systems, one supporting older adults and one supporting children.

**Figure 7  Maine Grandparents Living with Own Grandchildren by Disability and Responsibility Status, 2017**

<table>
<thead>
<tr>
<th></th>
<th>Responsible for own grandchildren</th>
<th>Not responsible for own grandchildren</th>
</tr>
</thead>
<tbody>
<tr>
<td>With any disability</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>N = est. 5,462</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With no disability</td>
<td>27%</td>
<td>45%</td>
</tr>
<tr>
<td>N = est. 13,699</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

U.S. Census Bureau (2018). *Disability status of grandparents living with own grandchildren under 18 years by responsibility for grandchildren and age of grandparent, 2017 American Community Survey 5-year estimates.* Retrieved from [https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_5YR_B10052&prodType=table](https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_5YR_B10052&prodType=table)
Older adults often live in family households, but not always. Figure 8 shows that in 2017, an estimated twenty-seven percent of older adults in Maine lived alone. Older adults who live alone may have greater needs for formal long term services and supports (LTSS) than those who live with spouses, partners, or other family members.

**Figure 8  Living Arrangements of Maine Adults Age 65+ in 2017**

![Diagram showing living arrangements of Maine adults age 65+ in 2017.]

The percentage of older adults with disabilities tends to increase with age. The following three figures show the percentage of older adults by age group with different types of disabilities, those with one disability or two or more, and the percentage of older adults with an independent living difficulty (Figures 9, 10, and 11 respectively).

Figure 9  Percentage of Maine Older Adults with Disabilities by Type and Age Group, 2017

Figure 10  Maine Older Adults with One or More Disabilities by Age Group, 2017

![Bar chart showing percentage of Maine Older Adults with one or more disabilities by age group, 2017.](image)


Figure 11  Percentage of Maine Older Adults with an Independent Living Difficulty by Sex and Age Group, 2017

![Bar chart showing percentage of Maine Older Adults with an independent living difficulty by sex and age group, 2017.](image)

SECTION 1 – STUDY COMPONENTS OVERVIEW

The full statewide needs assessment was envisioned as a broad study comprising mixed methods data collection through survey instruments, 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. While most study components are reported on separately in this report, certain sections of the report include cross-analysis across study components.

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 and perhaps one-on-one interviews and may require additional partnerships outside of the aging network in order 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 currently data is lacking for many sectors. For this reason, questions on sexual orientation and gender identity were included in both the statewide and caregiver surveys.

Each of the data collection methods is briefly summarized below.

Statewide Survey

In conjunction with the USM Survey Research Center (SRC), project staff conducted a statewide survey by mail, on-line, and by telephone for adults age 55 and older. Primary topic areas included:

- Transportation
- Housing
- Food and nutrition
- Caregiving
- Information and referral
- Community assets

Listening Sessions

Eight regional listening sessions were conducted across the state. Locations included small rural towns as well as Maine’s larger cities. The sessions were designed to hear in greater detail about community assets and the needs of older adults and caregivers.

Caregiver Survey

An on-line caregiver survey was disseminated to solicit feedback from adults of any age who are

5 The age eligibility for this survey of 55 years of age or older was decided in conjunction with the Advisory Committee. While the OAA generally serves adults age 60 and older, the intent was to include individuals who would meet or be close to meeting that eligibility during the period of the State Plan on Aging for 2020-2024.
caregivers of older adults or adults with disabilities and older adults caring for a minor grandchild or other family member in the place of a parent (kinship care).

**Key Informant Interviews**

Three group interviews were conducted with health and social service providers from three of Maine’s tribes to better understand whether and to what extent older tribal members were accessing Maine’s Area Agencies on Aging (AAAs). Tribal key informants could also offer general information about the needs of tribal elders aging in place on or off tribal lands.

**Focus Groups**

Through separate funding from the Maine Health Access Foundation (MeHAf), the Muskie School conducted three focus groups with individuals whose voices otherwise might not be fully heard in the more conventional needs assessment efforts due to language or cultural differences, geography, population size, or other barriers to participation. This project complemented the broader needs assessment funded by OADS. Focus groups included older adults who self-identified as LGBT⁶; older adults who are refugees or immigrants (“New Mainers”); and older adults providing kinship care.

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⁶ While recognizing that individual preferences vary, the term “LGBT” is being used in this report instead of “LGBTQ” consistent with guidance provided in the following report: *Inclusive Questions for Older Adults: A Practical Guide to Collecting Data in Sexual Orientation and Gender Identity* (National Resource Center on LGBT Aging & Services and Advocacy for LBTG Elders (SAGE), 2016).
SECTION 2 – STATEWIDE SURVEY RESULTS

This chapter summarizes the methodology and the overall statewide results of the survey that was conducted of adults age 55 or older. A detailed description of the methodology as well as a complete analysis of survey results is included in Appendix C. The results included in Appendix C are presented at the statewide level as well as regionally by the five service areas of the Area Agencies on Aging (AAAs).

Methodology

In order to identify potential participants for this statewide survey who met the criteria of being age 55 or older, the Survey Research Center (SRC) purchased two separate sample lists. The first list, obtained from Exact Data, contained the email addresses of approximately 79,000 Maine residents ages 55 and older. In addition to email addresses, each record included age, county, income level, and in some cases, telephone number of residents. Beginning on October 3, 2019, emails were sent by the SRC in several batches. Age, county, and income details were used to randomly select email addresses from sample groups with low response rates for each subsequent batch. This sample received an advance email invitation to participate in the survey from the Office of Aging and Disability Services (OADS), followed in a few days by an emailed link to the survey. Approximately 40,000 emails were sent to potential respondents, and a total of 1,500 surveys were completed online. Approximately 18.5% were undeliverable and 2.5% opted out.

Non-respondents for whom a telephone number was available were called and asked to complete the survey over the phone. This resulted in an additional 388 completed surveys.

The second sample list was obtained from Dynata Inc. and contained mailing addresses of 5,000 Maine residents located in areas identified as being more likely to contain a high proportion of older adults. This sample received a survey booklet along with an explanatory cover letter from OADS. Recipients were asked to complete the survey if they met eligibility requirements and to return it in the postage paid envelope. The surveys were mailed out on November 13, 2019. A total of 9% were undeliverable. A total of 934 mailed surveys were completed and returned, resulting in a grand total of 2,822 completed surveys.

Software programs used for data collection and analysis included SNAP, Remark, SPSS, SAS, and Nvivo software.

Limitations

In the interest of time and budgetary constraints, this survey was conducted using non-probability sampling. While efforts were made to ensure that respondent traits matched the population of interest as closely as possible (through weighting), bias may nevertheless be present. In addition, it may have excluded persons who had difficulty accessing the internet, had vision or reading difficulties, or limited English proficiency. Future surveys could benefit from in-person outreach to gather information from people who do not have regular internet access, have vision or reading difficulties, have limited English proficiency, or who have cognitive impairments that make survey participation difficult.
Findings

Demographics

Respondents to the survey represented every county in Maine, with over half (57%) coming from Cumberland, York, Penobscot, and Kennebec counties. Forty-five percent of respondents were age 55 to 64, thirty-two percent were age 65 to 74, and twenty-two percent were age 75 or older. The majority (58%) live in households of two people. Ninety-nine percent of respondents identified as white.

Overall, the majority of survey respondents were well educated with over half of respondents having at least a college degree (54%). Fifty-three percent were fully retired, while forty-six percent were working either part time or full time. There was wide variation in income among respondents with nineteen percent having an annual household income of less than $20,000, and twenty-one percent having incomes between $20,000 and $40,000. Seventeen percent had incomes between $40,000 and $60,000, and forty-three percent had incomes over $60,000. Income level varied by age; this finding is described below under Cross Tabulations.

Transportation

The vast majority of respondents (92%) usually drive themselves to get around to the places they need to go, although 5% need help finding or arranging transportation. Among respondents who have difficulty meeting their needs for transportation (N=157), nearly half (45%) said that a primary cause was the lack of transportation services in their area. Other reasons included financial reasons, not having friends or family to help, and not having information about services in their area.

Housing

The majority of respondents (77%) own their own home while nineteen percent rent their home. While most respondents said their home meets their current needs (93%), seven percent said that it does not, citing the need for unaffordable repairs, modifications to meet physical needs, too much upkeep, unaffordable taxes, rent, mortgage, or utilities, and difficulty heating the home to a comfortable temperature.

Food & Nutrition

Most survey respondents (92%) said they usually have enough money to buy the food they need. Twelve percent said they use food pantries or participated in food assistance programs such as SNAP. Most respondents (95%) rarely or never eat at community meal sites for their main meals, mostly because they do not need to. Other reasons for rarely or never eating at community meal sites included not liking to eat in a community group setting, not knowing about the services, and not having transportation to get to the meal site. Only seven percent of respondents said they participate in a home delivered meal program such as Meals on Wheels.
Health Status

Twenty percent of respondents said they were in fair or poor health while eighty percent said they were in good, very good, or excellent health. Twenty-six percent said they had concerns about their own memory and twenty percent said they had concerns about someone they care for. Regarding social isolation and loneliness, thirty percent of respondents said they felt lonely and disconnected from other people either sometimes or often. Twenty-two percent reported having fallen within the last six months, and forty percent of those respondents said they needed help getting up, medical attention, or emergency room treatment as a result of the fall.

Caregiving

Nearly eighty percent (78%) of respondents said they do not provide caregiving supports to others. Among those who are caregivers, the most common supports they provide are transportation, meal preparation, daily household tasks, and financial management. The caregiving respondents indicated they needed respite services, help with providing care, assistance with transportation, and information and referral help to find needed services.

Information & Services

Twenty-six percent of respondents said it was either somewhat difficult or very difficult to find information they needed about available services and programs for older adults and their caregivers. Perhaps an artifact of the administration of the survey, most respondents (70%) said they get information from the internet. Other common sources of information cited were doctors or other health care providers, word of mouth, television, and newspapers. Seventy-five percent of respondents said they primarily access the internet on their home computers while seven percent said they do not access the internet at all.

Seventy percent of respondents said they had not called or looked up online any of the Area Agencies on Aging, Maine 211, Maine Legal Services for the Elderly, or the Long-Term Care Ombudsman Program. While sixty-eight percent of respondents said they did not need any information or services in the last six months, seventeen percent of respondents said they had needed help with Medicare or other health insurance questions; eight percent said they needed general information about community resources; and seven percent needed help with transportation. Among those who said they needed help, forty-four percent said they did not get all the help they needed. Many of these respondents cited the following reasons for not getting the help they needed: not knowing who to ask; not able to afford the needed help; services are unavailable; not qualifying for help; and waitlists for services.

Community

While the majority of respondents (70%) said their communities were either good, very good, or excellent places to live for people as they age, twenty-four percent rated their communities as fair or poor. Seven percent of respondents were unsure, perhaps reflecting a lack of knowledge of both needs and available resources.
Cross Tabulations

When analyzing survey data, performing cross tabulations illuminates relationships between variables. The following highlights how age, income, caregiving status, and health status might influence survey responses. While conclusions cannot be drawn about causality, these variables appear to impact how people responded to some of the survey questions. The charts below show the stronger relationships in the data.

Figure 12  Income by Age

There were more younger respondents with high incomes compared to the older groups which were more balanced across the income ranges. This distribution could help explain some of the findings below, such as the falls within the last six months and concerns about memory.
Figure 13  Fell within the last 6 months by income

Fell within the last 6 months by income

Income is negatively correlated with falls. While one out of every three adults from the lowest income bracket fell within the last six months, only 1 out of every 10 from the highest income bracket did so.
Figure 14  Concern about one’s own memory by age group

About one out of every five adults ages 55 to 74 say they have concern about their memory. For adults 75 and older the proportion is higher—one out of every three. These differences persist when controlling for income.

Figure 15  Concern about one’s own memory by income

Income is negatively correlated with concern for one’s memory. One out of every five respondents from the highest income bracket reported feeling concern for their memory while one of out every three respondents from the lowest income bracket reported the same. These differences persist when controlling for age.
Younger respondents (55 to 64 and 65 to 74 years of age) were more likely to say the internet is a good way to obtain information (75% and 71%, respectively) compared to those 75 and older (at 57%).

The proportion of those who said the newspaper is a good way to obtain information increased with age; 22% of those 55 to 64 years of age said so, compared to 30% of those 65 to 74 years of age, and 36% of those 75 years of age and older.
At 50%, younger adults (ages 55 to 64) were less likely to report having received all the help needed compared to older adults (ages 65 to 74 and 75 and older), at 61% and 64%, respectively.

Income was positively correlated with receiving all the help needed; 44% of those in the lowest income bracket reported receiving all the help needed compared to 76% from the highest income bracket.
Those whose caretaking did not include a person with a disability age 18-59 were more likely to report having received all the help they needed compared to those whose caretaking did include a person with a disability age 18-59.
At 34%, younger adults (ages 55 to 64) were more likely to report having felt lonely and disconnected in the last six months than older adults (ages 65 to 74 and 75 and older) at 26% and 25%, respectively.

A strong correlation exists between health status and loneliness and disconnection. While 9% of those in excellent health reported having felt lonely and disconnected, 68% of those in poor health reported the same.
Income is positively correlated with good health. While 54% of those in the lowest income bracket reported being in good, very good, or excellent health, 94% of those from the highest income bracket reported the same.

**Open-ended Responses Summary Findings**

When asked the open-ended question, “What would make aging in your home or community better or easier for you?” a total of 1,177 respondents shared their thoughts. These responses included individuals residing in all five of the AAA service areas:

- Aroostook Agency on Aging service area: 172 responses
- Eastern Area Agency on Aging service area: 250 responses
- SeniorsPlus service area: 222 responses
- Southern Maine Agency on Aging service area: 276 responses
- Spectrum Generations service area: 257 responses

The most commonly referenced topic in the responses related to housing. A significant number of respondents across the state described the need for more affordable and accessible housing. Respondents also indicated needing assistance with home maintenance services, including household chores, snow removal, and lawn care. Others noted the need for home modifications to create a safer space. These modifications included adding outside ramps, removing stairs or adding chair lifts, as well as relocating bedrooms, bathrooms, and laundry rooms to the first floor. Some respondents indicated they were considering relocating to housing that was more affordable, closer to town, in a warmer climate, or closer to services. Respondents noted the need for more assisted living services or nursing facilities, especially in their local communities.
The second highest number of responses concerned transportation services. Transportation issues were raised by many survey participants in both rural and urban regions of the state. Respondents spoke of the need for low or no cost, safe, reliable public or private transportation to medical appointments, grocery / department stores, libraries, churches, and other social gatherings. Many respondents indicated that their communities could benefit by making improvements to create a safer environment. Examples included safer sidewalks, adding walking and bike paths, better road maintenance, more street lights, and increased law enforcement presence. Several mentioned the need for a local community or senior centers where people can gather for social interaction, avoid isolation, increase physical activity, attend classes, gather information and resources, and learn more about local services.

A number of responses referenced health care themes. Some respondents expressed concerns about distances to medical provider and specialized medical care facilities, including qualified doctors and specialists. Some respondents noted they were in need of better medical insurance, decreased insurance premiums, and lower prescription drug costs.

Caregiving, including informal, professional, volunteerism, and respite, was noted several times. Some survey participants mentioned the need for in-home services from caregivers and volunteers ranging from family, friends, neighbors, home health aides, personal care attendants and nurses to allow people to remain in their home longer.

Some respondents referenced the need for help with meal preparation, nutrition counseling, and issues of food insecurity.

It is worth noting that when asked would make aging in your home or community better or easier, some survey respondents had not considered this question before. These individuals mentioned they “don’t know”, were “unsure”, it “wasn’t applicable,” had “no idea”, or “hadn’t thought about it.” Others responded that they were doing well therefore “didn’t need any help.” A few expressed themes of pride and independence in that they were able to do everything themselves and did not want help from other people.

Key Take-Aways

Given the relative younger age of most older adults who responded to the survey (45% between the ages of 55 -64; 32% between the ages 65-74), it is unsurprising that the majority of survey respondents indicated they were financially secure, healthy, and did not have many unmet needs. Even with this, there were areas of note: one-fifth to nearly one-third of respondents reported falling in the last six months, having concerns about their own memory, or sometimes or often feeling lonely or disconnected. A significant proportion (24%) also rated their communities as only fair or poor places to live for people as they age.

This report focuses attention on the smaller percentage of older Mainers who identify needs because this population is particularly relevant to the delivery of community services and supports under the
OAA.\textsuperscript{7} Twelve percent rely on food pantries or participate in SNAP; five percent indicated a need for information about transportation options. Almost a quarter (24\%) of respondents are caregivers. The concerns respondents raised about housing and transportation in the open-ended questions show how intertwined these basic necessities are to older adults’ health care and socialization needs, especially for those who are isolated by geography, poverty, or poor health. Cross tabulations of survey data suggest correlations between income, health status and age which reflect on service needs. For example, while younger older adults may be comfortable using the internet to find information on available services, older groups may not either have access to the technology or the ability to effectively use it to locate the services and supports they need to age comfortably at home.

Given that over the ten-year period from 2017 to 2027, the 75 to 84 year old age group is projected to increase by seventy-three percent and by eighteen percent for adults age 85 and older, these needs will only increase over time. A significant number of respondents indicated that they have not thought about what they need to age comfortably in their homes and communities. Seventy percent of respondents indicated they have not called or looked up an Area Agency on Aging, which shows the opportunity for public education about aging resources.

\footnote{In part, the OAA requires states to target services to older individuals with greatest social and economic needs, older adults with limited English proficiency, and those at risk of institutional placement. This includes a focus on low-income minority individuals, and older individuals residing in rural areas.}
SECTION 3 – LISTENTING SESSION RESULTS

Introduction

The Muskie School facilitated eight community listening sessions held across the State in October 2019 in eight locations. Proposed sites were based on demographic information at the county level that reflected key focus areas under the OAA while also ensuring coverage across the five service areas of the AAAs. Final site selection was discussed and determined in collaboration with the State Plan Advisory Committee. While the listening sessions were intended as regional forums, the site selection included small rural towns as well as Maine’s larger cities. Listening sessions were held in the following locations: Ashland, Waldoboro, Brewer, Waterville, Machias, Lewiston, Wilton, and Portland.

All listening sessions were held in the month of October 2019. For dates, times and specific locations, please reference the Listening Session Flyer in Appendix D.

Table 1 provides listening session attendee information. Local AAA staff or volunteers attended each regional listening session. Table 2 represents a snapshot of the counties in which listening sessions were held. As these were regional sessions, the location of the session does not necessarily correlate with the residency of the participants.

A separate listening session was facilitated by James Moorhead from OADS in September 2019 as part of the 2019 Wisdom Summit hosted by the Maine Council on Aging. Information captured from that session is included in Appendix K.
### Table 1

Number of Listening Sessions Attendees

<table>
<thead>
<tr>
<th>Session*</th>
<th>Total attendees</th>
<th>Under 55</th>
<th>55-64</th>
<th>65-74</th>
<th>75-84</th>
<th>Over 85</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ashland</td>
<td>12</td>
<td>1</td>
<td>3</td>
<td>6</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Waldoboro</td>
<td>11</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Brewer</td>
<td>14</td>
<td>5</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Waterville</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Machias</td>
<td>14*</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Lewiston</td>
<td>23</td>
<td>9</td>
<td>4</td>
<td>7</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Wilton</td>
<td>12</td>
<td>2</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Portland</td>
<td>60**</td>
<td>31</td>
<td>9</td>
<td>13</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Totals</td>
<td>151</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Some Attendees did not share their age

**Attendees included social work students, approximately 20%
Table 2
Listening Session County Demographics

<table>
<thead>
<tr>
<th>County</th>
<th>Total Pop.</th>
<th>% age 65+</th>
<th>% Rural</th>
<th>% below poverty</th>
<th>% food insecure</th>
<th>% living alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Androscoggin</td>
<td>107,393</td>
<td>17.1</td>
<td>43</td>
<td>11</td>
<td>16</td>
<td>11</td>
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<tr>
<td>Aroostook</td>
<td>70,005</td>
<td>23.4</td>
<td>80</td>
<td>13</td>
<td>17</td>
<td>15</td>
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<tr>
<td>Cumberland</td>
<td>286,119</td>
<td>18.1</td>
<td>36</td>
<td>8</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>Franklin</td>
<td>30,402</td>
<td>21.7</td>
<td>83</td>
<td>9</td>
<td>14</td>
<td>11</td>
</tr>
<tr>
<td>Kennebec</td>
<td>121,112</td>
<td>18.9</td>
<td>63</td>
<td>9</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>Lincoln</td>
<td>34,156</td>
<td>28.1</td>
<td>100</td>
<td>8</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Penobscot</td>
<td>153,437</td>
<td>18.1</td>
<td>58</td>
<td>11</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>Washington</td>
<td>32,191</td>
<td>24.0</td>
<td>92</td>
<td>13</td>
<td>17</td>
<td>15</td>
</tr>
</tbody>
</table>

Methodology

The protocol used to conduct each listening session was standardized across sessions according to the following categories of questions: assets, needs, barriers, information, and magic wand. Within each of these question categories, listening session participants were asked a series of related questions accompanied by “prompts” to help them think about the issues most relevant to them. While quotes have been included in this section, listening sessions were not transcribed; a minimum of two notetakers participated at each session.

While listening session facilitators closely followed the question categories, they exercised discretion regarding the exact use and wording of question prompts, depending on audience engagement and preliminary question responses. The listening session protocol was followed in each session but effort was made to allow natural-flowing participant discussion, thereby reducing inhibitions to

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8 Griffin E, Gattine E. Charting a Pathway Forward: Redesigning and Realigning Supports and Services for Maine’s Older Adults. Portland, ME: University of Southern Maine, Muskie School of Public Service; September 2017.
speaking up. On occasion, comments categorized as needs were raised under barriers or some other section, or vice versa. For fidelity to the process, we have largely grouped comments in the section in which they were raised. However, to accurately report on the extent of similar or numerous comments on a single issue, and for ease of understanding, some participant remarks have been re-categorized for this summary.

Listening session findings are summarized below according to the order of the question categories presented in the listening sessions and according to the primary themes of participant responses across all sessions that inform on core objectives of the OAA. Lesser themes are also noted if facilitators and note takers observed general assent in the group (e.g., nodding heads, etc.), if it was similarly raised in another listening session, or expressed with particular emphasis.

We also provided each participant with a note card at the start of the session to share thoughts they did not have an opportunity to express during the session or to emphasize certain points. We have incorporated these written comments into the relevant sections below.

**Assets**

**Community Characteristics**

We began the listening sessions by asking participants about things they love about their communities, including any supports and services they felt were working well. Listening session participants actively shared the positive aspects of their respective communities. Across both urban and rural areas, participants described the sense of community they feel in their particular towns or neighborhoods. Many participants said that churches, community centers, town offices, local Senior Colleges, and Area Agencies on Aging helped to make their towns great places to live. These elements of infrastructure appear to provide a sense of town pride and belonging and opportunities for both volunteering and finding assistance. One participant described Maine as “a handshake state” and “a big small town” where connections and conversation make a difference in people getting the help they need.

Across the state, many participants described a love of the outdoors and being physically active. Maine’s natural beauty from the coast to the lakes and mountains provide opportunities for hiking, swimming, and other recreational activities that participants value. Town parks, hiking trails, opportunities for exercising at local school gyms, and YMCA facilities were often named as assets of participants’ communities. One participant described moving away from Maine several times, but, “the pace of life here, the people, and the natural beauty always calls me back”.

Participants in the more urban sessions described their love of cultural opportunities and variety of things to do in their cities. They appreciate their museums and restaurants as well as the diversity of their communities. The availability of resources such as SAGE Maine for older LGBT adults was mentioned several times by participants in Brewer and Portland.
In the rural sessions, participants described loving the calm, small town character of their communities. As one participant said, “Small community means you have ‘your people’ who you know. If you need a service, you think of a person, not a company.” While they acknowledged that they can be isolated, participants valued the privacy and quiet of their rural towns.

**Opportunities to Socialize**

Socialization is very important to older adults in Maine. Across the state, listening session participants described local community centers, libraries, churches, and the YMCA as offering opportunities to socialize. Brewer, Lewiston, and Portland participants mentioned art walks, SAGE Maine, mall walks, and grocery shopping as social activities. Participants in the more rural areas said they socialize at church-sponsored community meals, the American Legion and VFW halls, and local restaurants. A participant from the Wilton session described annual dinner-dances to raise funds for community services such as the fire department or library as popular opportunities to socialize. One participant in the Ashland session illustrated the tight-knit nature of small Maine towns saying that a group of farmers used to meet at a restaurant to chat, and when the restaurant closed down, they moved their group to a gas station where the owner gave them a room to use for their gatherings.

Volunteer opportunities were often described in terms of providing services to people in need and as social activities. Participants said that senior companion and volunteer transportation programs often have staff meetings for volunteers to come together and exchange ideas over coffee. Senior companions visit isolated older adults in many communities, checking on their well-being. Some participants described volunteering at a food pantry as a source of socialization.

Activities sponsored by businesses or private organizations are also available throughout the state. The SilverSneakers exercise program sponsored by Medicare insurance plans was mentioned by participants in the Wilton session. Participants in the Waterville session said that Beano games sponsored by the Elks club are very popular in the area. One participant noted the importance of a local music program for older adults that allowed for socialization and contributed to a sense of community.
Needs

This section focused on input from participants about their needs related to aging comfortably in their homes and communities. The questions in this section cast a wide net but also inquired about specific needs such as feelings of safety and security, both at home and around the community; the reasons older people move out of their homes; and the observed social needs of people who are the most isolated or lonely.

Listening session participants across the state were remarkably consistent in what they identified as necessary for remaining in their homes and communities as they age. Housing, transportation, food, and the need for caregivers were repeatedly mentioned, often with frustration given the extent of need and the lack of available resources.

Housing

Interestingly, but not surprisingly, nearly all of the listening session locations mentioned the need for more housing options for middle income older people. While wealthy seniors had their choice of settings, and low-income seniors could avail themselves of subsidized housing, participants felt that middle-income older people often could not afford expensive repairs to their older homes and had few other options. Several individuals noted the desire for types of communal housing that allowed for independence and socialization with other people, such as housing models available “in the Netherlands. We should not have to go out of the country for other types of housing options.” Others mentioned small clustered housing with easy proximity to services and shopping. Some participants specifically noted that they want to live in housing that is “well-designed and not a chicken coop”, a reference to a desire for modest design features and a place to sit outside - a small yard or garden space.

Several participants mentioned that the financial burdens – mortgage payments, real estate taxes, cost of repairs - is causing many older people to give up their homes. Older adults often cannot manage regular household chores including snow clearing, lawn care, raking, and trash removal and are unable to afford paying for routine home maintenance services. All listening session locations mentioned the need for reliable, affordable “handyman” services as necessary to support aging at home; one participant remarked, "How often can you ask your neighbor to help you out?"

Attendees mentioned that these housing issues become significant safety concerns when even small maintenance needs - such as repair of broken stairs or handrails - increase fall risk, prevent easy movement around or out of the house, or interfere with regular hygiene activities (e.g., bathroom access and safety).
Several participants mentioned that Maine’s older housing stock often requires expensive repairs to furnaces, chimneys, and septic systems. Some houses have water leaks and harmful mold that can only be remediated at significant cost. Participants also talked about the difficulties in retrofitting older homes, noting that bedrooms and bathrooms are often on the second floor. Small modifications were also needed, such as handrails and grab bars. Others noted that the inability to manage home repairs also prevents socialization. And while older Mainers generally do wish to remain in their homes, the frustrations repeatedly expressed in the listening sessions were that “there are no affordable options”. Older people in Maine might well accept moving out of their large, older homes if there were comfortable, affordable alternatives.

**Transportation**

As with housing, the lack of reliable, affordable transportation was raised repeatedly in every listening session. Transportation needs centered on several consistent deficits including 1) a lack of affordable or free services; 2) poor quality and reliability; 3) inaccessibility; and 4) the related issue of poor navigability due to non-existent or poor sidewalks and hazardous road conditions.

Participants in all communities emphasized the need for transportation as essential to remaining in their homes and communities as they age. “If you don’t have transportation, things snowball.”

Regarding availability, most sessions noted that while Logisticare was available for medical appointments for people who qualified, though it was described as not always reliable or expedient, there were insufficient public transportation options, particularly in rural communities, or volunteer transportation programs. While a few participants expressed appreciation and noted the importance of having transportation services covered through Medicaid, a number of participants complained about long wait times and missed appointments, and drivers who would not assist with transfers or were not knowledgeable about the needs of the person being transported.

Public transportation was a critical issue emphasized across all listening session locations. Where it is available - most notably Portland and Lewiston - it was inaccessible for many. For instance, it is not available evenings and weekends when people need or want to travel to outings or activities, nor does it cover all of the locations where older people wish to go. One Portland participant noted that once you arrive at your destination by public transportation, the sidewalks are so “terrible” for using a walker that they have to walk in the street, which is equally unsafe. Waldoboro participants also noted the need for sidewalks in their community. Portland participants mentioned that Amtrak should be available to more easily get to other parts of the state. Participants in the Wilton session noted the burden of relying on a set schedule and having to travel a long, predetermined route to arrive at one’s destination. This often results in spending many hours of travel and waiting time for just one appointment. They requested more on-demand transportation services which would give older riders more freedom and flexibility in their daily or weekly errands and social activities.

Portland listening session participants mentioned that free or low-cost transportation services are needed. A participant noted that Independent Transportation Network (ITN), a non-profit community-based transportation network for older adults, has a membership fee and operates in some southern Maine communities but not all. Attendees from other communities, including

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9 Logisticare is a transportation broker responsible for coordinating the delivery of non-emergency transportation services covered through MaineCare. While not the only transportation broker, it covers Androscoggin, Aroostook, Franklin, Hancock, Oxford, Washington and York counties, with partial coverage in Cumberland and Knox.
Machias and Waldoboro, noted the prohibitive expense of private cabs and the need for more volunteer drivers that could accommodate riders that had walkers, wheelchairs, and other assistive devices, as well as easily assist with managing those, often heavy and cumbersome, devices.

A noteworthy transportation sub-theme consistently raised in several listening sessions was the need for more broadly available information about existing transportation service. Several individuals stated that while some services are available, many older residents of these communities do not know about them. This suggests that for those communities where volunteer or affordable transportation services currently exist or will be established in the future, effort must be made to widely and regularly disseminate information about their availability.

**Food**

The poverty and lack of resources experienced by some older people was most obvious when the listening session discussions turned to food scarcity. While all communities applauded the availability of food pantries, community meal programs, and Meals on Wheels (MOW), there was worry about the accessibility of community food insecurity programs.

Four of the eight locations specifically mentioned the desire for more fresh produce and nutritious foods. These foods were not always available from food pantries and, when they were, they often could not be delivered to those who are unable to travel to pick them up. Some communities do have food delivery services, but not all. Where mobile services were available, there were insufficient volunteers to provide delivery to all who needed it. Machias specifically mentioned the need for food delivery: “there is nothing like that for rural areas; nothing for people who can afford food but cannot get to the grocery”.

A few participants in the Brewer session offered that they - and other older people they know - do not always have the energy to cook and would like more options for nutritious, high-quality prepared meals. Sometimes they rely on cereal or popcorn because they are too tired to cook and clean up, though they realize this is not the best option. Participants in the Wilton session indicated that if they had affordable help with chores, including cooking and cleaning, they would more likely be able to remain at home as they age. The need for homemaker services to help with these kinds of tasks, as well as other household chores, was mentioned across sessions.

**Caregiver Needs**

One of the listening session questions in the Needs discussions centered on family caregivers and direct care workers. Many participants in every session location discussed various aspects of the need for caregivers, but most often attendees requested opportunities for respite care. “Respite is very important…If [adult] children weren’t helping, then you could never leave.” There were several comments on the need for more adult day settings and services for the care of people with Alzheimer’s disease or other dementia. Most often, these comments were raised in the context of family caregivers needing a break from care. One participant noted that it was important to have choice for individuals and that adult day may not be a service that everyone wants.

The need for education and support groups, primarily on issues of Alzheimer’s and dementia caregiving, was also frequently mentioned, although participants in Brewer noted that even when there are available support groups, there is no one available to stay with the cared-for individual.
while the caregiver goes to the meeting. A participant in Lewiston commented that while they did not see the value of the caregiver support group “in the moment, in retrospect [they] found it very helpful”. Meditation was another activity valued by one caregiver. A Waldoboro participant noted that “caregiving is a community issue” and the training and education needs to “go beyond the individual”.

Ashland and Waldoboro attendees asked for information on trainings such as Savvy Caregiver and more information about palliative and hospice care. Attendees in the Wilton session requested more geriatric psychiatry services, primarily for medication expertise, perhaps delivered through Telehealth services. This participant reported that while a regional hospital is using psychiatric telehealth in its Emergency Department, older people may be uncomfortable with that interface.

Machias session participants also mentioned that some community members were not aware of their own forgetfulness and early cognitive declines, and the accompanying need for periodic care. These individuals were identified as needing considerable help and support to stay safely at home.

Across the state, session participants expressed worry and frustration over the lack of paid caregivers both in facilities and in-home settings. In the Portland session, a member of the palliative care and hospice caregiving community decried the lack of workers, describing the shortage as “critical, critical” and “severe”, resulting in many unstaffed hours. One participant noted there was an important need for male caregivers to join the workforce. In some communities, caregivers are simply unavailable in the quantities necessary to support aging at home, even for people with sufficient resources. Participants asked that caregivers themselves be provided “help and support”, and adequate pay, so they would come to Maine communities to work. Several others remarked that we should value the work of caregivers so that more of them would work in the field. Participants in Wilton requested more oversight of caregivers so the quality of their services was ensured.

**Isolation**

While there was a separate question in the Needs section about people who might be particularly isolated - about which there was general acknowledgment in both rural and urban areas- there was only occasional mention of social needs. One participant mentioned that social events are posted online, which makes them harder for some older people to find out about if there is no computer or no internet access. Lewiston participants expressed the need for telephone reassurance programs through the police or another local agency, so that someone was checking in on the most isolated residents. Others in Lewiston noted the difficulty of identifying those community members who are lonely or isolated, or at higher risk. Waldoboro participants commented that hearing and vision loss contribute to isolation and there is a need for lower cost hearing aids. Several participants in different sessions also talked about the important role pets played in helping to mitigate feelings of loneliness and isolation. One participant spoke to the need for low-cost pet care.

While concerns about isolation were not limited to rural areas, participants in rural sessions attributed isolation in part to geography. For example, Machias participants observed that “isolation is a problem -- everything is 25 miles away”. One attendee noted that other parts of the State were even more isolated because of geography, with one attendee describing the region north of Calais as the “Bermuda Triangle”.

Muskie School of Public Service, University of Southern Maine
Safety

When listening session participants were asked whether they feel safe in their communities and in their homes, their wide-ranging responses fell primarily in the categories identified below. Overall, however, there was no recurring safety theme - people felt unsafe about very different things - but there was greater urgency in the tone of these comments, given their safety-related nature.

Crime, Scams, Financial Literacy, Elder Abuse

Participants do worry - or know people who are worried - about crime. Waterville and Machias session participants mentioned the worry of homes being broken into to steal medications. Many more commented about financial scams and knew people who had been victimized, particularly those who are lonely or isolated. A Portland participant noted that more education about how to avoid scams is necessary, and another mentioned that there is financial exploitation from family members. One participant in Wilton noted that some health-related services peddled by insurers rise to the level of “medical exploitation” and is something older people must be on the lookout for.

Participants in Wilton and Waterville asked for more education and training programs on financial literacy, avoiding scams, and managing powers of attorney. They suggested that improving the financial literacy of older people would make it easier as older people “moved into retirement”. Waterville session attendees noted that older widows living alone are particularly concerned about scams; some older people are often unaware that someone is trying to scam them, and more training might help.

Attendees in several sessions mentioned concern about other types of elder abuse. One Portland participant noted that in their town “elder abuse is a huge problem”, though they are trying to be proactive and use different approaches to help victims. Another Portland attendee offered that elder abuse is under-reported and that adult “children abusing parents is a serious issue”. Others mentioned that LGBT older people may be particularly at risk, and that health care providers should receive more education about how best to respond to suspected abuse.

Transportation

Participants attending the Lewiston session emphasized the lack of safety of Logisticare’s services. Some of the vehicles appeared to be unsafe and drivers sometimes left riders in unsafe situations (e.g., “waiting outside for two hours”). An individual in the Waldoboro session noted unsafe road conditions and that drivers should be educated about how to drive more safely in communities with older residents: there are “no sidewalks on Route 1, no bike paths, no road shoulders”. One individual wanted to see mandatory training for drivers in first aid and cardiopulmonary resuscitation (CPR), particularly for those transporting individuals with chronic or life-threatening conditions.

Housing

Several attendees again commented on unsafe conditions occasioned by the inability to afford home renovations (e.g., installing a bathroom on the main floor), or home repairs (e.g., adding slip and fall protection), or regular home maintenance (e.g., snow removal). In the Waterville session, a participant lamented the lack of home repair programs and the recent termination of the local CAP
agency home repair program. A Waldoboro participant specifically noted the danger of, for instance, burning wood when other heating system upgrades are unaffordable. A participant in Waldoboro expressed concerns about fire with older structures, and with unsafe use of devices for heat in cold weather (e.g., ovens and hair dryers). A participant in Machias spoke about the need for generators, especially in winter.

Several participants in Lewiston noted the need for medical alert systems in case people fall and home telephone assurance programs (e.g., often offered through local police departments) for older people who are isolated. One Lewiston attendee talked about a community member who had died in their home and was not found for two weeks. A few participants, including caregivers and older adults, linked the lack of cell phone and internet access in parts of the state to safety. One participant noted that when electricity goes out, a cell phone may be the only means of communication to ask for help. Caregivers expressed frustration that they were unable to communicate effectively with older adults with only land line coverage and that assistive technologies that rely on internet access were not available as supports in areas with poor connectivity.
**Barriers**

This section sets forth the key barriers identified by participants attending the regional listening sessions impacting access to needed community services. It also includes participant feedback on ways to mitigate some of these barriers.

**Information and Referral**

The lack of a defined or centralized place for individuals to get information was a theme heard across the listening sessions. Several participants felt that older adults and caregivers do not know who to reach out to for help. As one person in Brewer said, “[s]ervices may exist and be available but people may not know.” Some attributed this to the lack of internet or the ability of some older adults to use a computer but participants also commented that people do not always know what to ask or where to look, even on the internet. One participant in Wilton noted, “I have all I can do to find information. I know how to use a computer and I still have problems.” Another in Waldoboro noted, “[t]he system is so used to being ‘tech-savvy’ and if you aren’t then you are left in the dark. You don’t have another place to go.” Some participants noted the important role that libraries play in helping older adults access the internet, and the need to have training and resources available to older adults in libraries and elsewhere on the use of computers and accessing the internet. A number of participants noted that people did not look for information until they needed it and that declines in health status or changes in circumstances can happen quickly, creating even greater difficulties. One participant noted that some people may only ask for help once, and if they do not get the right person or information, they are unlikely to ask again.

Participants noted that information is increasingly only available on the internet (for example, filling out or printing off applications) and that this creates barriers for older adults who do not have computers or may not know how to use them. Participants in Waldoboro noted that web pages are not designed with older adults in mind and seem to be increasingly difficult to navigate. Lack of broadband in some parts of the state was a consistent theme heard across sessions.

Many participants wanted to see more centralized systems for information and referral at local and state levels. The potential for county level coordination was discussed at the session in Machias. As one participant remarked, “[w]hile sports rivalries and the independence [of our towns] is wonderful, we need to start working together again.”

**Navigation Support and Advocacy**

Another theme heard across the sessions was that the current system of services is complicated (“fragmented,” “complex,” “siloed”), creating access barriers for older adults and their caregivers.
The biggest barrier was negotiating the maze of services and “nothing ties them together”. Participants in the Machias and Brewer session noted it was “a full time job to get services”. Participants in Brewer said that “people are falling through the cracks” and “getting lost in the system”. In Waldoboro, a participant remarked that people need help to know where to call or where to go (“What do I do?”). A participant in the Brewer session noted that when someone cannot get the information or help they need, they go to their police departments and they may not have the answers: this results in the person getting increasingly frustrated and isolated. Several participants said that some people who try to find services on their own just give up and go without. “Giving up” was a theme in several of the sessions.

In identifying specific barriers, one participant provided as an example that every service has its own application process and paperwork requirements. Participants also described long waiting periods on the phone, in some cases up to several hours. Limited minutes available for cell phones as well as health issues for participants on the phone discouraged people from staying on the line. Several participants felt that automated response systems, rather than a live person answering the phone, created barriers for older adults, especially those with vision issues who find it difficult to press in the account numbers or other requested information. One participant reported that people get so stressed, they would rather not reach out. A number of participants across sessions noted frustrations with accessing services through Maine DHHS, including long wait times for eligibility assessment, not being able to reach the right person to talk to (“having to go round and round”), and not having anyone call back. One participant in Lewiston expressed frustration that it sometimes requires a legislator to get involved just to have the system be responsive to members of the public (“Why does it take a legislator to call? Why can’t the same thing happen when the person in need calls for information or help?”).

Participants emphasized the importance of having someone to help navigate the system and noted access barriers were even greater for people who did not have some form of advocacy available. In some cases, legislators or other public officials filled this role. The role was often filled by a family member; a number of participants reported they were filling this role for a parent or other family member. Several participants emphasized that older adults who live alone or are homebound, individuals with Alzheimer’s disease or dementia, and those living with mental illness or trauma are at particular risk for being unable to get the help they need as they are less likely to reach out for help. Older adults who lose a spouse were also reported as being at high risk for “falling through the cracks”. A participant in the Ashland session noted that there are a lot of people in rural areas that do not have family nearby and have “no one to call, no one to advocate for them”. While some populations have care managers to assist them, older adults generally do not. A few participants felt that this coordination needed to happen at a local, rather than state, level. Participants in the Wilton session noted that training opportunities should include MaineCare eligibility navigation.

**Eligibility Barriers**

In discussing why older adults do not always get the services they need, a number of participants across the sessions identified financial eligibility criteria for programs as an access barrier for many older adults. A number of participants emphasized that eligibility is overly restrictive and that programs require older adults, including veterans, to have so little in income and assets that people do not have adequate resources to stay in their homes and afford their basic needs. A number of participants felt that many low and middle income older adults fell in a gap between qualifying for services and being able to afford services on their own. As one person in the Wilton session
described it: “there are systems in place but there is a significant portion of people who are just above the [eligibility] line but nowhere near what they need [for resources].”

Participants provided a number of examples of services where eligibility criteria was an issue for older adults, including MaineCare (inclusive of transportation services under MaineCare), housing, and heating and food assistance programs. One participant noted that internet services are expensive but important to have for safety and to mitigate isolation; they suggested that older adults be allowed to deduct these costs as part of determining eligibility for programs and services in recognition that that are needed services. Another participant noted, “seniors need computers”.

**Inadequate Accommodations/ADA**

Some participants reported accessibility barriers that prevent or discourage access to information and services. The following are examples provided by participants across the sessions:

- Food pantries, funeral homes, churches and other community buildings are not always physically accessible for individuals with disabilities
- Even if a building is accessible, the bathroom or other amenities may not be
- There is a lack of bilingual staff and information to assist people
- Information is not available for people who are illiterate or low-proficiency readers (“Everyone incorrectly assumes people can read. People who cannot read miss out on a lot of things.”)
- Getting information over the phone is difficult for people who are visually impaired or hard of hearing; it increases the risk of receiving incorrect information
- Drivers are not always able to help people who use walkers or wheelchairs
- Disability parking spaces do not provide enough room for people using wheelchairs or other assistive devices

One participant reported a number of barriers faced by Mainers who are deaf, including a lack of interpreters familiar with American Sign Language. In some cases, interpreters may be difficult to find and in others, organizations and providers do not understand the process and payment sources for these services. As an example, one participant reported identified a need for interpreters who know American Sign Language to help people with Medicare open enrollment. The participant also pointed out that being deaf limits opportunities for volunteering and participating in community gatherings and greatly increases feelings of isolation and loneliness (“So many barriers every day”).

**Provider Capacity and Quality**

Lack of transportation providers, affordable safe housing options, adult day services, and in-home supports were identified as key barriers to older adults being able to remain in their homes and communities. In some cases, services were available but not affordable; in others cases, services were not available at all, regardless of cost. A reoccurring theme across sessions was that since many needs are interconnected, the lack of capacity in one area causes issues across others.
Volunteer Networks

Several participants raised concerns about the stability of informal supports and community volunteer efforts to meet the needs of older adults. A participant in Lewiston noted that some people are afraid of getting involved and providing help or services to neighbors in their community because they are worried about liability issues. A number of attendees felt that shifting demographics are impacting the volunteer pool and there are fewer people available to volunteer. A few participants observed that older adults need to obtain paying jobs to supplement their incomes and cannot afford to work for free. Participants also expressed concern about “volunteer burn-out” as volunteers are being asked to do more and more, often with set schedules and hours.

Transportation

Not surprisingly, participants frequently raised the lack of adequate transportation providers as a key challenge for people being able to remain at home (“transportation is a huge beast”). While several participants in rural areas attributed challenges in accessing adequate transportation to the rurality of their communities, participants in more urban areas also identified barriers specific to transportation services. Participants in rural areas reported that available transportation - even for people able to pay - was hard to find, with limited if any public transportation available. Some noted that organizations were struggling to find volunteer drivers. Participants in the Lewiston session noted that while public transportation was available, bus service was not available on the weekends or in the evening, when older adults did not want to drive. One participant felt that people did not use transportation services because they did not know about available services or how to access them. Some participants expressed concern over what would happen when they could no longer drive (“they are going to have to pry those car keys out of my hand”). This was of particular concern in rural areas where people need to travel long distances to get services.

Another participant had difficulties using the transportation service because some of the vehicles were not easily accessible for people with physical disabilities. Some participants noted that drivers were not able to help passengers in and out of vehicles or help carry groceries for liability purposes. In all but one session, participants described limitations and quality issues with MaineCare transportation services. In addition to delays and other quality issues, participants described the need for advance notice, usually 48 hours, as a barrier to use.

Food and Nutrition

Participants reported several barriers in the area of nutrition and food. Participants noted that food pantries have limited hours, making access for those without transportation even more difficult. Participants also noted that not all food pantries delivered, even for people without transportation. In some cases, food pantries are not accessible for people with physical disabilities. Most locations expressed gratitude for Meals on Wheels (MOW) but voiced concern about continued wait lists in some areas (e.g., Waldoboro, Waterville) and, in a few locations, about the quality of the meals. Participants mentioned a dislike for the frozen meals and the abundance of starchy foods; one participant felt that the meals did not adequately meet individualized dietary needs. One participant noted that meals lacked nutrition labels, making it difficult for them to know whether the food met their dietary restrictions. Several people noted that some MOW recipients took the meals despite this because they did not want to waste them and others declined the meals because they did not like them even though they needed and wanted a meal. Some mentioned that the meals are “not what we
are used to”. One participant in the Ashland session believed that delivering frozen meals, and making less frequent deliveries, was causing people to stop their participation in the MOW program.

**Housing and Home Repair**

Several participants mentioned they were unable to find providers for home repair or home maintenance services, even if paying privately. One participant stressed the need for a list of vetted providers that people could rely on. Lack of affordable housing and available options led some older adults to “make do” or go without services rather than risk being placed in a facility. One participant also noted that some older adults are not able to move because there is a limited market for older homes, especially those in disrepair.

**Health Care**

A few participants, particularly in rural areas, also noted limited access to specialty care. One attendee noted the challenges of having to drive long distances to access dialysis services and the stress that added to the individuals receiving dialysis and their families. One session noted a lack of psychiatrists in the area (Wilton).

**Caregiver Services**

Participants described several barriers for caregivers, most notable the lack of in-home services due to shortages in the direct care workforce for both private pay and public programs. A number of participants attributed this to demographic shifts but many placed emphasis on inadequate reimbursement rates (“you get paid less than if you work at McDonald’s”); several emphasized that caregiving was not as valued as it should be. A number of participants felt that the lack of adult day services in their areas impeded older adults from being able to remain in their homes and forced families to consider facility placements. A few noted that even when services were available, they were not affordable and there was insufficient assistance to help with the cost. Several participants noted respite was difficult to find, particularly in rural areas.

While participants generally valued opportunities for participating in caregiver support groups or training opportunities, they also highlighted the inability of caregivers to leave the people they care for unattended (“Who is going to watch him while I’m away?”). Not everyone in the groups were aware that these services existed or how to find them.

A few listening session participants expressed concern that they cannot complain about caregiver behavior for fear that there is no one available to replace that person. This means that older people in the state may be tolerating substandard care because they feel they have no choice.

**Individual Traits and Personal Preferences**

Participants across the sessions strongly attributed traits of independence and pride to many older Mainers (“it’s the Maine way”). As one participant in the Machias session noted, “we’re a rugged bunch.” Fear of losing independence was commonly viewed as the biggest barrier to older adults getting services and led to people not self-identifying as needing help. As one participant remarked, losing independence and having to rely on someone else “goes against the grain”. Not wanting to admit needing help, a reluctance to accept “charity,” and not self-identifying as “poor” were also
referenced by participants. As one participant commented, “I'm too proud.” Another barrier to accessing services referenced in several sessions was the belief that “someone else needs this more than I do”.

Fear of losing independence also correlated with the fear of being moved out of their home or otherwise losing their ability to make decisions about their lives. For example, participants felt that an older adult might not tell anyone they fell for fear they will be moved to a nursing home. One participant described the reluctance of older adults to accept help as generational: while younger adults have a greater sense of entitlement and a willingness and trust to accept services, older adults feared loss in accepting services, including the potential for liens being placed on their homes. A number of participants described distrust of government interference in their lives; people would rather “go without” than take a chance on allowing people into their homes who might “take over”. This feedback was particularly heard in the rural listening sessions, where participants also expressed concerns about other people in town knowing their business and the perception that their private information might not remain confidential.

The lack of trust felt by many older people was mentioned in various contexts across most listening sessions, including the need for trustworthy sources of information. In order to feel comfortable using services, older people have to trust the service provider agencies and the staff and volunteers who work for them, otherwise, they will do without. A lack of trust interferes with individuals even using those services that are readily available in communities. Many older people “do not feel comfortable asking for help” and often will only do so if there are high levels of trust.

Several groups noted reluctance of people to self-report abuse, neglect or financial exploitation -- including being a victim of a scam - for similar reasons: lack of trust in the system, fear of losing independence, perceived stigma, and not wanting to admit to needing help.

**Discrimination**

Participants also described the stigma attached to getting older as a barrier to accepting services. One person noted that there is a fear on the part of the general public about what illness is and what it means. As an example, using the word “crazy” to refer to someone with dementia discourages people from seeking needed care because they fear being labelled. A few participants observed that because aging provokes such negative images, people do not like to think about getting older and wait until it is too late to make decisions and engage in advance planning. Participants in Waldoboro emphasized the need to change the public conversation about aging and address ageism directly by using more inclusive language and using care in how words are used.

Listening sessions in Portland mentioned that some caregivers, and service providers, discriminate against older adults who identify as LGBT. This creates reluctance to reach out for help or otherwise access services, particularly in the home. Participants in Brewer noted that living in congregate housing is not always welcoming to individuals who identify as LGBT; older people are sometimes forced to “go back in the closet” rather than risk discrimination.
Information Sources

How Do People Get Aging-Related Information?

Information cuts across all needs experienced by older adults and their caregivers. Listening session participants frequently reported not knowing where to get trusted, accurate, and accessible information on transportation, nutrition, housing, and direct care services. Participants described several different platforms for obtaining information: 1) in-person/phone; 2) print; and 3) digital.

In-person/Phone

Town Hall, libraries, food pantries, AAAs, fire departments, and community elder service navigators were identified most often as sources of information. In many instances, listening session participants described being able to call “a human,” “someone you know” at these community locations, while calling DHHS was described as difficult, time consuming, and confusing. However, participants noted that not all community offices or departments have the information needed. For example, one participant in Brewer said that people call law enforcement when they do not know who else to call, but law enforcement often does not have information about available services. An in-person opportunity mentioned by one participant was a local food pantry having a representative from Central Maine Power available to discuss getting assistance with utilities and fuel while another mentioned a community resource fair.

Print

Newspapers and newsletters were mentioned by many participants as useful and trusted sources of information. Free, local community newspapers were identified as good vehicles for disseminating information. Several participants favorably described community center and AAA newsletters as useful sources especially, about social opportunities. One participant noted that her AAA newsletter used to be widely available, but now it is harder to find and she has to look for it.

Digital

Participants mentioned two websites providing contact information for different types of service providers, 211maine.org (211) and AuntBertha.com. Sponsored by the United Ways of Maine, Maine DHHS, and the Opportunity Alliance, the 211 website provides referrals to a variety of social services. One participant referenced a national Aunt Bertha website, which provides similar contact information for service providers. While listening session participants mentioned 211 as a source of information, they had mixed reviews of its usefulness. Participants in Portland thought 211 was helpful while those in other sessions found the information difficult to navigate and outdated, especially in rural areas. Many participants had not heard of it before or did not use it.
More frequently mentioned digital information sources used by participants include Facebook and other social media, especially regarding social opportunities. Additionally, public service announcements on television and television monitors in doctors' offices that show information on services were noted as helpful sources of information. One participant described learning a lot about services from the TV monitor in the doctor’s waiting room, saying it was more helpful than the pamphlets that “no one looks at”.

**Magic Wand**

In an effort to get listening session participants to think expansively and freely about their needs and wants - beyond any perceived barriers to aging comfortably in their homes and communities - they were asked to consider what they would need or want if they had a magic wand that would deliver it for them.

While a few participants across the sessions were aspirational in their requests - climate change solutions, universal health care, valuing older people, and elimination of poverty - most responses mirrored the topics raised previously in the sessions. The magic wand question served to add emphasis to themes and topics mentioned earlier. This confirms that the listening session questions truly did get at the heart of what participants wished to talk about. There were no surprise issues raised in response to the magic wand question, though participants did weave together strands of previously mentioned themes. In the context of requesting information on what needs exist in Maine communities, one participant asked for more data reflecting the true number of Mainers living in poverty and in need.

**Transportation**

Participants in several sessions took the opportunity to stress the need for more public transportation options and more on demand transportation services, so that fewer people would feel isolated. To the extent that transportation services do exist, participants want and need easier access so individuals can obtain the full value of having those services in the community.

**Housing**

This issue resurfaced in the magic wand questions with an emphasis in two listening sessions on co-housing options; “homes where a group of people could live together.” A European model of co-housing where older and younger people live together was mentioned in Brewer and Machias. Others mentioned creating better quality housing and a desire for more housing options for people of all incomes.

**Food**

Attendees in Lewiston, Waldoboro, and Wilton again mentioned access to free food, focusing on the lowest income and most isolated members of the community. There should be no Meals on
Wheels waitlists, food pantries should expand their hours and deliver food to those who cannot pick it up, and communities could consider hosting free food events that would also serve as opportunities to socialize.

Service Navigation

Assistance in finding information about services and navigating service delivery was a common theme across the listening sessions and resurfaced in the magic wand discussions. Several participants noted the importance of community town offices and one person suggested that towns hire a staff member for the singular purpose of helping town residents figure out what they need and where they can get help. These “navigators” might also function as a central coordinator of social services, acting as both a referral source and more proactively for particular individuals who need greater assistance (e.g., those who are very isolated, have early stage memory loss, or are very low income). One Brewer participant noted that “coordinated care can improve care to individuals, but it also makes it more efficient for providers.” Listening session participants repeatedly noted the importance of town offices as a local point of contact for residents in need of something. Right now, community members feel that “systems are not structured or organized in a way that people can access them”; a “one-stop application” is needed. One participant wanted to see Medicare fund case management services similar to those funded by MaineCare for individuals with mental illness.

Companionship

Magic wand responses also circled back to the importance of being good neighbors to one another. Programs like Catholic Charities’ SEARCH and Senior Companion, as well as informal neighbor-helping-neighbor efforts help people stay in their homes longer. The theme of “it takes a village” was raised in several sessions with emphasis on cities and towns “increasing connectivity”, bringing people together, and reaching out with assistance if “someone is struggling.” One participant noted that local help reduces the burden on formal publicly financed services (i.e., “welfare”) and others noted that local churches could be more helpful here.

Other Noteworthy Mentions

- A Waldoboro participant mentioned updating zoning and planning ordinances to adapt to our changing demographic and our changing environment. It was suggested that the State Office of Planning be reinstated to support this effort.
- Wilton and Lewiston participants again raised the need for broadband in their communities, noting that aging baby boomers are tech savvy and rely heavily on internet access.
- Wait times for help from state agencies is extremely burdensome and individuals with cell phone minutes often use up available minutes waiting ‘on hold’. This generates mistrust: “people think the state is just waiting people out”.
- Some participants expressed interest in developing inter-generational programs and services, especially in the area of housing and as a way to enhance volunteer efforts.
Key Take-Aways

Participants

Most of the listening session participants were between the ages of 50 and 70 and very few attendees were over age 85. This may not represent the actual demographics of Maine communities, many of which are home to high percentages of people over 85 compared to other states. While many participants did speak to their own concerns about aging services, many more spoke about their own parents, friends, and neighbors who were even older and had aging-related challenges. This is evidence of the growth of “beanpole” families, where there are greater numbers of older people and fewer younger people. For purposes of the State Plan on Aging, it is a reminder that there are now significant numbers of two generations aging in communities. Baby Boomers, the Silent Generation, and even a few remaining Greatest Generation members have had very different life experiences and may hold vastly different views and expectations about aging services and supports. While some of these differences may fade over time (e.g., technological skills), it is more likely that with increases in life expectancy, we will face ever-increasing diversity in Maine’s older population.

Many of the comments at the listening sessions were couched in terms of aging “others” (e.g., my mother, my neighbor, the elderly), even when the speakers were themselves were likely over the age of 55 (the youngest Baby Boomers). This is consistent with principles of social science that recognize the human tendency to “otherize”; someone who is old is “anyone but me”. The concern for community services access is that aging Mainers who do not identify with the designation of old or aging may not avail themselves early on of services that would help and support them in remaining at home, putting themselves at risk for more serious or costly injury or health decline. Service messaging that is broadly inclusive and consistent with current and emerging reframing principles may improve access. Further, the dearth of listening session participants who are the “oldest old” also may indicate that messaging about available services is not reaching these individuals. Communities may need to take extra steps to identify the very old who are less likely to reach out on their own. Some listening session participants did note the need for advocacy on behalf of the most isolated and frail community members.

Many Issues Consistent Across the State

The listening sessions were scattered across the state in both urban and rural settings, and in small towns that bordered larger towns (e.g., Wilton, just outside of Farmington, Ashland, 30 miles east of Presque Isle). Despite the geographic and demographic differences, there was striking consistency on many of the concerns about transportation, housing, caregiving, food availability, isolation, and technology. For example, across the state and without regard to location, attendees expressed frustration about the lack of available transportation and worry about housing options for middle income people. Without fail, participants raised the dire need for caregivers and respite care, the need for home repair programs, and for greater access to better quality food (e.g., fresh produce) and more food home-delivery options. Trust in town offices as a source of information and the heavy reliance on community volunteer services also cut across state geography. It is noteworthy

that the tone of the comments was often similar across the state; there was much head-nodding in most sessions around many issues, concerns, and frustrations.

**Some Urban-Rural Differences**

Despite similarities in issues raised around the state, there were also many nuanced comments relating to specific community assets and needs. This was particularly noteworthy among the most rural and the more urban communities. Maine older adults value their sense of community, whether in an urban or rural setting. While some listening session participants prefer the diverse cultural activities in urban areas, others prefer the quiet calm of their rural communities. Regardless of the setting, participants did not want to have to move away from the surroundings they love.

Participants in both urban and rural areas shared many of the same frustrations with transportation and a lack of information and navigation assistance, although they may have varied causes. For example, both urban and rural participants described not being able to use public transportation, though for different reasons. In rural areas, public transportation options often do not exist, while in urban areas bus routes may not be located close enough to where older adults live, making access impossible.

Participants in both urban and rural areas noted that a lot of information about available services is online. However, both groups described a lack of uniform access to the internet, either because it was not available at all or because the cost of the service was prohibitive. Whichever the cause, the end result is that many older adults throughout the state do not have access to the information that they need.

**Interrelatedness of Needs**

Listening session participants noted the interrelated nature of needs. Transportation was most commonly identified as relating to other needs (e.g., healthcare appointments, social opportunities, community meals, food pantry access and routine errands). The lack of accurate, reliable information was also noted by participants. In some cases older adults may not know about available services which could support aging at home (e.g., home delivered meals, fuel assistance, respite services, caregiver training). Participants reported that older adults may not seek information or services until they are in dire situations (e.g., running out of fuel in winter, lack of food, etc.). Knowing who to call emerged as a top theme across the sessions. Navigation or “warm hand-offs” can serve to reduce the complexity of the delivery systems and also address inter-related needs of older Mainers, particularly if those systems are able to work across funding siloes and promote a person-centered approach to care.

**Trust**

Older adults’ levels of trust and mistrust - in people, in institutions, in service delivery - came up repeatedly in discussions in nearly every listening session. Participant comments reveal, and confirm, what is already widely known: high levels of trust facilitate civic participation and engagement and
contribute to increasing amounts of individual and community social capital. Conversely, lower levels of trust impede access to services and socializing, and erode quality of life. For the most part, older Mainers want to know and trust those who are providing information as well as individual services at home, such as food delivery staff, or volunteer drivers -- otherwise they are likely to not seek services or refuse the service, even when the need is great. Listening session participants frequently mentioned that older people rely on “word of mouth” information. When that information comes from a trusted source, the recipient will be more likely to use it.

Attendee comments indicate that older people do trust and rely on local institutions such as town officials, law enforcement, libraries, community centers, and well-established services such as Meals on Wheels. Some towns actively participate in supporting volunteer programs (e.g., Boothbay Harbor), and are a trusted source of essential information about local goods and services (e.g., Bucksport); these actions establish trust, facilitate access, and based on listening session feedback, are highly valued and appreciated by community residents.

**Caregiver Needs and Concerns**

Caregivers across the listening sessions voiced frustration that opportunities for respite that adult day programs could provide are not readily available. Some described a Catch-22 scenario of wanting to know how to be better caregivers or to find a support group but being unable to leave their loved one alone in order to attend a training or group.

Caregivers described having to rely on networks of volunteers in order to meet the needs of their loved ones because of severe workforce shortages or cost of services. However, many participants also said that these networks are being stretched too thin and that new, younger volunteers are not joining the ranks. Participants who are volunteers themselves said they were often asked to commit to certain periods of time rather than to volunteer on an ad hoc basis as networks try to maximize the available services.

The necessity of relying on volunteer networks presents an opportunity for communities and organizations to find ways of relieving the pressure felt by caregivers. Enhancing and supporting volunteer efforts especially during the critical shortage of direct service workers would enable caregivers to continue to meet the needs of their loved ones.

**Information Access (Service Delivery)**

Listening session participants described many different sources of information for aging services. There is no “one size fits all” approach that will reach all older adults and caregivers in need. Capitalizing on the strong relationships people have with their town offices could provide an opportunity to expand the reach of AAAs to share information about available services. Presenting information in a variety of formats such as in-person, printed materials, and digital formats is necessary to reach people with different technology experience, literacy levels, and communication styles. Often, participants described being able to locate contact information for a service agency,

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but they were not sure who to talk to or what to ask. Participants described the need for a navigator to guide them through obtaining services; it is not enough to provide a phone number. Additional outreach is needed for those who are unlikely or able to reach out themselves.
SECTION 4 – CAREGIVER SURVEY RESULTS

Background

Caregivers play a critical role in the provision of care to older adults and adults with disabilities. Many caregivers are older adults themselves. Older adults may be caring for a spouse, partner or an adult child with a disability, and in some cases, may be providing kinship care to a minor child.

The Older Americans Act (OAA) includes funding for family caregiver supports such as caregiver education and training, respite care, counseling and support groups, information and referral, help with accessing services, and other supplemental services. The OAA includes a focus on family caregivers who provide care to an adult with Alzheimer’s disease or related dementia.

This section primarily highlights key findings from the on-line caregiver survey, while also incorporating other relevant information on caregiver needs collected through the statewide survey of older adults, feedback received from caregivers as part of regional community listening sessions, and focus group findings. The complete analysis of results from the on-line Caregiver Survey is included in the Appendix H.

Data Sources

The Caregiver Survey: This survey was developed and reviewed with input from the State Plan on Aging Advisory Committee. It incorporates a broad definition of caregiving and did not exclude those who were paid to provide care to a family member or friend. It also did not exclude caregivers based on the type of setting in which the care recipient resided. A total of 444 caregivers completed the survey. Of those respondents, 168 people (39%) were caring for individuals with Alzheimer's disease or related dementia. Twenty-two older adults (less than one percent) provided kinship care.

The survey was limited to individuals able to complete the survey on-line; the survey was distributed primarily through organizations connected to the aging network. These survey results are not weighted. Key highlights of this survey are summarized in this section; the full survey and analysis of responses are included as part of the Appendix G and H.

Cross tabulations illuminate relationships between variables. This section includes cross tabulations based on length of time providing care, health status, and caring for individuals with Alzheimer’s disease or dementia that might impact survey responses. While we cannot draw conclusions about causality, these variables appear to impact how people responded to some of the survey questions.

Regional Listening Sessions: Eight regional listening sessions were held across the state in September 2019, all of which included individuals who identified as caregivers. Caregiving was one of the many domains covered as part of the protocol developed for the sessions.

Statewide Survey of Older Adults: In conjunction with the USM Survey Research Center, project staff conducted a state-wide survey by mail, on-line, and by telephone for adults 55 years of age or older. The survey asked questions in a number of domains, including one set of questions specific to

12 Because this section crosses study components, there may be some duplication with other sections of this report.

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older adults who were caregivers. Of the 2,191 individuals who completed the survey, sixteen percent identified as a caregiver of an adult age 60 or older. Four percent of respondents provided care to an adult with a disability between the ages of 18 and 59; and four percent of respondents provided care to a grandchild or other relative under the age of 18 (referred to as “kinship care”).

**Key Informant Interviews:** Key informant interviews were held with representatives from the Passamaquoddy Tribe, the Penobscot Nation, and the Houlton Band of Maliseets. Caregivers and their needs were among the topics discussed.

**Focus groups (separately funded by Maine Health Access Foundation):** Three focus groups were held with older adults, one of which was specific to older adults providing kinship care. The other two focus groups (older adults who identified as LGBT and older adults who were immigrants or refugees) included participants who were caregivers.

### Summary of Key Findings

#### Caregiver and Care Recipient Profiles

Well over three-quarters of the respondents to the on-line caregiver survey identified as female (86%). While caregivers responding to the caregiver survey ranged in age, it is evident that many older adults are caregivers. Almost three-quarters (73%) of respondents to the on-line caregiver survey were 55 years of age or older. Over a third (36%) were 65 of age or older. Because of the survey criteria, all respondents who identified as caregivers in the statewide survey of older adults were 55 years of age or older.

Participants in regional listening sessions who identified as caregivers ranged in age, with some adults caring for minor children as well as aging parents; one participant referred to themselves as being part of the “sandwich” generation. Several older adults were providing care to even older parents, reflecting the fact that we now have two generations aging in our communities. As part of the kinship care focus group, one participant was caring for an aging parent as well as school-aged grandchildren, highlighting the complexities of some caregiving relationships.

Eighty-three percent of respondents to the caregiver survey reported providing care to an individual 65 years of age or older; overall, the average age of the care recipient was 75 years old. Of the respondents to the statewide survey who identified as caregivers, almost three-quarters (73%) provided care to an individual age 60 or older. Others, including respondents to the state-wide survey and participants at the listening sessions and focus groups, were caring for a younger adult with disabilities or providing kinship care to a grandchild or other family relative under the age of eighteen.

The caregiver survey indicated that many caregivers (39%) were providing care to a parent/step-parent or in-law parent. Another twenty percent of respondents were caring for their spouse or partner. In terms of proximity, forty percent of all respondents to the caregiver survey lived in the same home as the care recipient. Another thirty-seven percent of caregivers lived less than twenty minutes away. Of the care recipients that did not live with their caregivers, fifty-one percent lived alone. For those care recipients with Alzheimer’s disease or dementia, the proportion living alone was thirty-three percent.
Caregiving Responsibilities

Most respondents to the caregiver survey reported providing frequent care over a period of years, highlighting the value of informal caregiving to our systems of care. Seventy-nine percent of the respondents reported providing care for a year or more. One quarter had been providing care for seven or more years. As noted above, forty percent of respondents to the caregiver survey reported sharing the same home as the adult they care for. Among caregivers who do not live with the adults they care for, eighty-five percent of caregivers visit at least once a week. Well over half (66%) of respondents to the caregiver survey visited more than once a week.

In terms of hours spent in caregiving activities, over forty percent (42%) of respondents to the caregiver survey reported providing over twenty hours of care per week. Over a quarter of respondents (26%) provided more than 40 hours of care weekly. For caregivers of individuals with Alzheimer’s or dementia, the percent of caregivers providing over 40 hours weekly increased to thirty-one percent.

**Figure 24** Online Caregiver Survey: If not living in your household, on average how often do you visit this person?

<table>
<thead>
<tr>
<th>More than once a week</th>
<th>66%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a week</td>
<td>19%</td>
</tr>
<tr>
<td>Few times a month</td>
<td>8%</td>
</tr>
<tr>
<td>Once a month</td>
<td>5%</td>
</tr>
<tr>
<td>Few times a year or less</td>
<td>2%</td>
</tr>
</tbody>
</table>
Respondents to the caregiver survey identified companionship, transportation, coordination with health care providers, homecare tasks, and financial management as the most common types of help provided. These responses are generally consistent with the most common responses received by caregivers as part of the statewide survey of older adults; differences between the two are likely due
to variations in the wording of the questions asked. Top responses in the statewide survey included transportation (65%); food or meal preparation (58%); daily household tasks (51%) and financial management (58%).

Of note, a significant proportion of respondents to both surveys reported providing personal care such as help with bathing, dressing and other hands-on help (51% of respondents in the caregiver survey and 25% in the statewide survey of older adults). More than half of respondents to the caregiver survey (59%) reported helping with medications; over a third of respondents to the statewide survey who identified as caregivers (39%) helped with this need.

Some respondents to both surveys provided additional detail in open-ended responses, including descriptions of the types of homemaker activities provided (e.g., laundry, grocery shopping, meal preparation, and errands) and mentioned coordinating care with family members as well as with health care providers. Other examples of help included:

- Doing home maintenance chores (e.g., yard work, snow removal, heavy chores)
- Providing emotional support
- Arranging and going on social outings and recreational activities
- Conducting daily check-ins
- Acting as guardian, conservator or power of attorney
- Accompanying friend or family member on walks and with exercise
- Advocacy for durable medical equipment and other needs
- Providing oversight and supervision
- Helping a friend or family member use a computer
- Helping with pet care

These findings were generally consistent with feedback received from participants who attended the regional listening sessions. Participants reported providing a range of support, including transportation, grocery shopping, recreational activities, providing personal care, and helping with home maintenance and repairs. Kinship caregivers reported providing some of the same types of assistance (for example, transportation and financial support), in addition to other types of supports reflecting the needs of minor children (for example, educational needs).

**Health Status of Caregiver**

Half of caregivers (50%) responding to the caregiver survey rated their health as very good or excellent, while fifteen percent rated their health as fair. Respondents providing care for a year or less were more likely to report excellent health (17%) than those caregiving for one to three years (10%); four to six years (6%); or seven or more years (10%).
The emotional strain of caregiving was evident in both the responses to the caregiver survey and in discussions with participants from the listening sessions and focus groups. Forty-four percent of respondents to the caregiver survey said that caregiving was very emotionally stressful for them, and many respondents added comments in the open-ended survey question to emphasize this point. The percent of participants reporting that caregiving was “very much” emotionally stressful was significantly higher than those reporting that caregiving was “very much” a physical strain (17%) or “very much” a financial strain (16%). Notably, fifty-four percent of respondents who were caregivers of those with Alzheimer’s disease or dementia reported that caregiving was “very much” emotionally stressful compared to thirty-nine percent of other caregivers.

The degree of physical strain reported by respondents to the caregiver survey tended to increase based on the length of time the caregivers had been providing care. For example, eleven percent of caregivers providing care for a year or less reported that caregiving was very much a strain; that number increased to fourteen percent for those providing care for one to six years and to twenty-six percent for caregivers with over seven years of caregiving responsibilities. Financial strain tended to increase as well over time, with thirteen percent of respondents reporting the strain as very much in the first year, increasing to fifteen percent for those caregiving one to six years and twenty-one percent of those providing care over seven years.

Forty-one percent of respondents to the caregiver survey noted that in the last six months, they sometimes felt lonely or disconnected from other people due to caregiving. While ten percent of caregivers providing care for a year or less reported always/often feeling lonely or disconnected, that number increased to nineteen percent for the group of caregivers providing care for seven or more years. The percent of caregivers who responded with often/always feeling lonely was slightly higher for those caregivers of individuals with Alzheimer’s disease or dementia than caregivers of individuals who did not have Alzheimer’s disease or dementia (18% versus 11%).

A number of caregivers in the listening sessions and those who participated in the focus groups sponsored by MeHAF vividly described feelings of isolation and loneliness that accompanied their
role as caregiver. For example, several participants in the focus group of kinship caregivers noted that kinship caregivers sometimes become estranged from other family members, no longer feel they fit with their own peer group, and are not included by or connected to younger parents. Participants in the LGBT focus group also noted that some LGBT adults are estranged from family members and that the risk of loneliness and isolation is exacerbated by fear of discrimination and safety concerns. Participants in the New Mainer group echoed feelings of isolation, often referencing communication and language barriers.

Figure 28  Online Caregiver Survey: How much of a physical strain would you say that caregiving is?
Figure 29 Online Caregiver Survey: How emotionally stressful would you say that caregiving is?

![Bar chart showing the distribution of responses to the question about emotional stressfulness of caregiving.]

Forty-three percent said that caregiving was not much of a financial strain, but sixteen percent said caregiving was very much of a financial strain.

Figure 30 Online Caregiver Survey: How much of a financial strain would you say that caregiving is?

![Bar chart showing the distribution of responses to the question about financial strain.]

Forty-three percent said that caregiving was not much of a financial strain, but sixteen percent said caregiving was very much of a financial strain.
Figure 31  Online Caregiver Survey: In the last 6 months, how often have you felt lonely and/or disconnected from other people due to caregiving?

Forty-one percent said that in the last six months, they sometimes felt lonely or disconnected from other people due to caregiving.

**Caregiver Employment Status**

Sixty-five percent of the respondents to the caregiver survey report being currently employed. Forty-five percent had full time employment while twenty percent were working part time. Similarly, many of the participants in the regional listening sessions and focus groups who identified as caregivers also worked. In some cases, participants reported working while caring for both children and aging parents.

Just over ten percent (11%) responding to the caregiver survey reported giving up work entirely because of their caregiving responsibilities. Fourteen percent reported taking a leave of absence and seven percent reported retiring early. Twenty-one percent of respondents went from working full-time to part-time, or cut back on hours. Over fifty-eight percent of respondents indicated they went to work late, left early, or took time off during the day to provide care.
Caregiver Needs

The most common caregiver need identified by respondents to the caregiver survey was for respite services. The need for respite increased based on the length of time caregivers reported providing care. For example, while twelve percent of caregivers providing care for under a year identified respite as a need, that proportion increased to thirty-three percent for those providing care between one and three years, and further increased to fifty-five percent for those providing care over three years. Likewise, respite was the top need identified by respondents to the statewide survey of older adults who were also caregivers, with thirty-six percent of caregivers identifying this as a need. Participants in regional listening sessions and focus groups echoed the need for respite, identifying it as a top need among caregivers.

While many of the response rates did not significantly differ for caregivers of individuals with Alzheimer’s disease or dementia, a higher percent of individuals caring for persons with Alzheimer’s disease or dementia reported going into work late, leaving early, or taking time off during the day to provide care (79% versus 48%). Similarly, a higher percent of caregivers providing care for people with Alzheimer’s disease or dementia reported cutting back on hours or transitioning from full time to part time employment (30% to 18%).

Figure 32 Online Caregiver Survey: As a result of caregiving, did you ever experience any of these things at work?

As a result of caregiving, did you ever experience any of these things at work? (N=348)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Went in late, left early, or took time off during the day to provide care</td>
<td>58%</td>
</tr>
<tr>
<td>Went from working full-time to part-time, or cut back your hours</td>
<td>21%</td>
</tr>
<tr>
<td>I have not experienced any of these things</td>
<td>20%</td>
</tr>
<tr>
<td>Experienced negative reactions from co-workers or supervisors</td>
<td>16%</td>
</tr>
<tr>
<td>Took a leave of absence</td>
<td>14%</td>
</tr>
<tr>
<td>I have not worked while caregiving</td>
<td>13%</td>
</tr>
<tr>
<td>Gave up working entirely</td>
<td>11%</td>
</tr>
<tr>
<td>Turned down a promotion</td>
<td>9%</td>
</tr>
<tr>
<td>Lost any of your job benefits</td>
<td>8%</td>
</tr>
<tr>
<td>Retired early</td>
<td>7%</td>
</tr>
<tr>
<td>Received a warning about your performance or attendance at work</td>
<td>5%</td>
</tr>
</tbody>
</table>

Participants in regional listening sessions and focus groups echoed the need for respite, identifying it as a top need among caregivers.
In separate but related comments, participants in the listening sessions mentioned the need for affordable and accessible adult day services for the care of people with Alzheimer’s disease or dementia. Several participants noted that these services provide respite for the caregiver while also providing socialization and other benefits to the care recipient. Of the respondents to the caregiver survey indicating adult day services as a need (25%), the response rate increased significantly (from 37% to 63%) for those caring for an adult with Alzheimer’s disease or dementia.

Table 3

<table>
<thead>
<tr>
<th>ONLINE CAREGIVER SURVEY: SERVICES NEEDED (N=411) (CHECK ALL THAT APPLY)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting respite services (where someone else helps short term to give you a break from providing care)</td>
<td>37%</td>
</tr>
<tr>
<td>A help line (or central place to call to find out what kind of help is available and where to get it)</td>
<td>34%</td>
</tr>
<tr>
<td>Someone to talk to or counseling services or support group</td>
<td>33%</td>
</tr>
<tr>
<td>Help with finding other paid or unpaid caregivers</td>
<td>32%</td>
</tr>
<tr>
<td>Help with finding services for the person I care for (transportation, fuel assistance, etc.)</td>
<td>29%</td>
</tr>
<tr>
<td>Online caregiver support resources</td>
<td>25%</td>
</tr>
<tr>
<td>Adult day services</td>
<td>25%</td>
</tr>
<tr>
<td>Medical alert/emergency response system for falls or other emergencies</td>
<td>22%</td>
</tr>
<tr>
<td>Free or low cost training classes about caregiving</td>
<td>21%</td>
</tr>
<tr>
<td>Help with finding a nursing home or assisted living services</td>
<td>16%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>15%</td>
</tr>
<tr>
<td>Help with living wills and advance directives</td>
<td>14%</td>
</tr>
<tr>
<td>Having non-English language caregiver materials</td>
<td>1%</td>
</tr>
</tbody>
</table>

Access to information was another frequently identified need in the caregiver survey. Thirty-four percent of caregiver survey respondents said having a centralized place for information would be helpful. This need was highest among caregivers providing less than one year of care (26%); the need was lowest for those providing care seven or more years (16%). Over twenty percent of respondents to the statewide survey who were caregivers identified a need for information and referral services.
Respondents to the caregiver survey identified counseling or a support group as the third highest need (33%). Several participants in the regional listening sessions and in the kinship care focus group noted that support groups provided emotional support and functioned as an information source. While participants generally valued opportunities for participating in caregiver support groups or training opportunities, they also highlighted the inability of caregivers to leave the people they care for unattended (“Who is going to watch him while I’m away?”) and stressed the need for local groups that minimized travel. Not everyone in the groups were aware that these services existed or how to find them. A smaller proportion of caregiver respondents (9%) identified support groups as a need in the statewide survey of older adults.

Approximately thirty percent of respondents to the caregiver survey said that assistance with finding services for the care recipient would be helpful, including help with finding in-home support. Respondents provided specific examples in the open-ended section of this question about the types of services they were seeking for the care recipient. These included homemaker services and other in-home supports (including comments about the need to increase worker reimbursement); reliable transportation services to adult day, medical appointments and shopping; housing; home modifications (e.g., ramps, lifts); friendly visitors or wellness checks; help with MaineCare applications; and assistance with accessing services through the Veteran’s Administration. Over thirty percent of the caregiver respondents to the statewide survey of older adults identified a need for additional in-home supports and help with providing care.

Several participants at the regional listening sessions expressed interest in having training opportunities available for caregivers on topics such as palliative and hospice care, as well as topics related to caring for an individual with Alzheimer’s disease. Lack of transportation and the inability to leave the person they were caring for were reported as barriers to accessing training opportunities. Twenty-one percent of respondents to the caregiver survey said that having free or low cost training classes would be helpful. Of those responding that training would be helpful on the survey, caregivers of individuals with Alzheimer’s disease or dementia were less likely than other caregivers to report this as helpful (43% versus 57%). Not surprisingly, those caregiving for a year or less reported the highest rate of interest (30%); those caregiving for seven or more years reported the lowest rate of interest (15%). Of those responding to the statewide survey of older adults, seven percent of caregivers identified caregiving training and education as a need.

A number of respondents added comments into the caregiver survey about their need for financial assistance to be able to afford to not work/miss work and provide care. Examples of other needs that caregiver provided in response to open-ended questions in both the caregiver survey and the statewide survey of older adults included:

- Help finding out what information is available, including LGBT specific resources
- Access to senior congregate meal programs
- Improved communication and coordination with health care providers; extended provider hours to help caregivers who work
- Help with communication and interpreter services
- Help with finding housing
- Support with becoming a guardian or conservator

Kinship caregiver input was gathered as part of the caregiver survey and the statewide survey of older adults, as well as through one of the focus groups sponsored by MeHAF. Kinship caregivers
generally indicated many of the same needs as other caregivers but had other needs as well reflecting their care of minor children. Kinship caregivers emphasized the need for respite as well as transportation, counseling, caregiver training, and financial support. Kinship caregivers reported wanting and needing information on a wide range of topics, including services for the child as well as other community resources relevant to their role as caregiver. This included the need for legal assistance and advocacy given the complexity of kinship care situations and help with navigating the educational system.

**Barriers**

Over half of caregivers (62%) responding to the caregiver survey are either not receiving the help they need or are unsure whether they are receiving the help they need as caregivers. Thirty-eight percent said they are receiving the help they need. Sixty-one percent of those who reported their needs were not being met reported caregiving as being “very much” an emotional strain. Over half (53%) of those respondents who were not sure whether their needs were being met reported caregiving as being “very much” an emotional strain.
Figure 33 Online Caregiver Survey: Are you currently receiving the help you need as a caregiver?

The percent of respondents who said they were unsure did not indicate a trend based on length of caregiving, other than for caregivers who provided care seven or more years who reported the lowest level of uncertainty (16%). This group also represented those with the highest reporting that their needs were not being met (45%). The fact that almost a quarter of all respondents were not able to identify whether their needs were being met was consistent with themes heard in listening sessions and focus groups; namely, some individuals did not always know what services were available, did not always know the right questions to ask, and in some cases, were too overwhelmed to focus on their own needs.

As barriers to help, respondents to the caregiver survey noted the high cost of services (35%) and having the care recipient not accepting other services (34%) as the most common responses. These themes were also common across regional listening sessions. For example, one participant noted that the person they were caring for did not meet eligibility for adult day services but also could not afford to pay for those services out of pocket. Participants across listening sessions noted that many older adults appeared to fall into an eligibility gap for many needed services and supports: while they were over income or asset limits for services, they also did not have the financial means to pay privately. Specific to accepting help, many listening session participants described the fiercely independent nature of Mainers. Fear of losing independence and control correlated in many cases to a lack of trust. For the most part, the listening sessions demonstrated that older adults need a sufficient level of trust with those providing information and services; otherwise, they are likely to not seek services or refuse the service even when the need is great. This finding from the listening sessions is consistent with the caregiver survey findings suggesting that a number of older adults accept the help and assistance of family members but choose to decline more formal supports and services.

Participants in listening sessions across the state—rural and urban—expressed concern and frustration about the lack of paid caregivers both in facilities and in-home settings. In some communities, caregivers are simply unavailable in the numbers necessary to support aging at home, even for people with sufficient resources. Several participants described the shortage as critical and severe, resulting in unstaffed hours. Participants asked that caregivers themselves be provided “help and support”, and adequate pay, so they would come to Maine communities to work. This concern
is reflected in the caregiver survey with thirty-two percent of respondents saying that they need help with finding other paid or unpaid caregivers.

Respondents provided the following reasons for not getting the help they needed in open-ended responses to the caregiver survey:

- In-home staff and nurses are not available (workforce shortages)
- Lack of affordable housing
- Care recipient is on a waitlist for services
- Lack of adult day services
- No support groups in the area
- No respite care available/having to manage paperwork for respite services
- The time commitment needed to find information and navigate services
- Support services are unreliable/quality issues with training

**Key Take-Aways**

Survey responses and other feedback gathered across the statewide needs assessment support what is already generally known; namely, caregivers provide tangible and significant contributions in helping older adults and adults with disabilities meet needs that might otherwise go unaddressed and provide significant supports to family members and friends living in the community. While some survey respondents and participants noted feelings of fulfillment, reward, and satisfaction in their caregiving role, they also noted the emotional, physical and financial toll of being a caregiver. Risk of isolation and loneliness is of particular concern for caregivers.

Caregivers across the surveys and sessions identified respite as a top need. For some, that meant adult day, for others an in-home worker. In the case of kinship caregivers, respite included childcare in and out of the home. The lack of direct care workers has exacerbated the need for respite, particularly for families who cannot find adequate in-home paid staff and rely on informal supports. The direct care worker shortage, and the lack of adequate reimbursement, were frequent refrains in the listening sessions and caregiver survey responses. Several participants felt that accessing respite was even greater in rural areas.

Caregivers described the need for other caregiving support such as support groups and training. While recognizing their value, several participants of listening sessions and focus groups emphasized various issues deterring their access to those supports. Many caregivers reported balancing work, family and caregiving. Related factors included lack of time, transportation issues, travel distance, and –importantly- not being able to leave their family member unattended. Many also described the cost of services as prohibitive.

Over a quarter of caregivers responding to the caregiver survey were not sure if they were receiving the help they needed. Participants of listening sessions and focus groups noted the complexities of navigating the system, finding trustworthy information, and the importance of having an effective advocate. As a few participants noted, it was not only about getting answers but also about how to ask the right questions. For kinship caregivers, participants noted the complexities of navigating two separate systems-one for older adults and one for children.
Of interest, over a third of those respondents to the caregiver survey reported they were not getting the help they needed because the care recipient did not want any services. This is consistent with the finding in listening sessions that many Mainers are independent by nature. For the most part, the listening sessions demonstrated that older adults need a sufficient level of trust with those providing information and services; otherwise, they are likely to not seek services or refuse the service even when the need is great. Providing outreach and information through a trusted source about available services in these cases could potentially benefit care recipients and care providers.
SECTION 5 – SUMMARY OF KEY INFORMANT INTERVIEWS WITH MAINE TRIBES

Introduction

There are four Native American tribes in Maine - the Houlton Band of Maliseets, the Aroostook Band of Micmacs, the Passamaquoddy and the Penobscot - and three reservations. One of the underlying goals of this part of the needs assessment study was to better understand whether and to what extent older tribal members were accessing Maine’s Area Agencies on Aging (AAAs). Tribal key informants could also offer general information about the needs of tribal elders aging in place on or off tribal lands.

Methods

Muskie School staff first reached out to Wabanaki Public Health to discuss the Statewide Needs Assessment study and obtain contact information for tribal Elder Services or Social Services staff in each of the Maine tribes. In an initial conference call with Wabanaki Public Health, staff suggested that we contact the tribes’ Health Service Directors. Invitations were sent to each health director to participate in a site visit or a Zoom conference call along with other tribal staff who would have information about the relationship with the AAA and the needs of tribal elders.

Three interviews were subsequently scheduled: 1) an in-person key informant interview with Penobscot Health Department and Elder Services staff; 2) a Zoom interview with Houlton Band of Maliseets Health Department staff and Elder Coordinator; and 3) a Zoom interview with the Interim Health Director at Pleasant Point, one of two Passamaquoddy reservations in Maine. All three tribes welcomed the opportunity to participate and freely shared information about current elder needs.

The interview protocol was divided in two sections: 1) the nature and extent of any relationship between the tribe and the AAA that might serve tribal elders; and 2) information on tribal elders themselves, including needs and barriers to services (See Appendix I for interview protocol).

Use of Area Agency on Aging Services

Overall, all key informants confirmed that there is little contact with or knowledge about the AAAs in the locations of the tribes’ reservations. While the key informants knew about the AAAs, and some referred small numbers of tribal elders for services, particularly homemaker, there was minimal contact. One tribe said few, if any, tribal elders were using AAA services because if they were, “we

13 The Penobscot Nation and the Aroostook Band of Micmacs receive their own allocation of OAA Title VI funds. The Passamaquoddy Pleasant Point also receives funding and the Houlton Band of Maliseets are a sub-grantee under that allocation.
14 Muskie staff confirmed with each tribe that the preferred term to refer to older tribal members is “tribal elders”. The term “community” generally refers to the community of native people, both on and off the reservation.
would know about it.” Despite this, each of the tribes expressed genuine willingness to establish a working relationship and learn more about how AAA services could be accessed to support tribal members living on and off the reservation.

In part, the challenge is geographic. For the Maliseets, the nearest AAA is almost an hour away and “transportation is a problem for many elders who must rely on others”. Others suggested that local contact information is lacking but acknowledged that it would be very helpful to have specific service details and the contact information for the AAA program staff for those services. Some key informants mentioned that the AAAs have indicated there is a lack of resources to send staff out to the reservations for outreach. During the interview, one key informant offered to send tribal staff to the AAA to help coordinate outreach and another offered to host a forum for AAA staff to explain available services and programs to tribal elders, their families and perhaps the larger community. Another suggested that AAA staff might offer an education program at a tribal elder gathering which would help build a relationship.

One key informant expressed a need for the Medicare counseling services given that several tribal elders had been contacted by Medicare Advantage plan salespeople who had provided confusing, possibly misleading information about health plans. This key informant suggested that the expertise of AAA counselors could be helpful in educating elders with accurate, current Medicare information. Transportation to the AAA office was cited as a barrier.

**Tribal Elder Information**

Key informants noted that given the lower life expectancy of many native people, the term “elder” generally refers to anyone 55 years or older.

**What is working well?**

Key informants mentioned a variety of things that are working well for tribal elders, primarily involving the tight knit, intergenerational, extended tribal families, and the respect accorded elders in Native American communities, particularly grandmothers. There are well-attended social events throughout the tribes and community members make sure that elders will get rides to traditional native ceremonies throughout the year.

In one tribe, the Chief has hired an elder advocate using tribal funds to check in on older tribal members and provide transportation and other needed services. Some have tribal funds (e.g., bingo revenue) that is used for tribal elder supports such as meal delivery or small cash vouchers. Other tribes mentioned improved caregiving resources, helpful MaineCare hotline, increased socialization at communal meal sites, and the engagement of elder “clubs” for trips, activities, and fundraising efforts.

The tribal health departments and their staff are central to the wellbeing of tribal elders. The health services staff are known and trusted sources of all types of information and referrals. Many staff have grown up on the reservation and have personally known the elder for many years. These close relationships support an increased level of access to information about specific elders’ needs. Key informants emphasized that when elders reach out for help, they are calling a person, not a position. The tribal health departments “have been around for a long time” - it is the clinic - and tribal
members trust the individuals who work there, many of whom have been in the same position for
decades. “It is such a small community, everyone knows one another”. Those tribes with an elder
coordinator reported being able to spend time with older tribal members and community health
nurses are doing home needs assessments and safety checks.

Notably, the key informants expressed few concerns about social isolation or loneliness, particularly
for those living on the reservation. The intergenerational nature of tribal families supports frequent
visits among extended family. Those few elders who self-isolate on the reservation were well known
in the community and health and social service staff reach out. Key informants noted that for those
living off the reservation, the primary cause of isolation was the lack of transportation and while
there is some transportation provided it does not match the needs.

**Tribal Elder Needs**

Key informants highlighted that most tribal elders on the reservation are living on a very limited
income and small social security amounts as a result of lower levels of steady employment during
their working years. Reduced income for elders contributes to needs spanning a wide spectrum from
housing to food security, to transportation and specialty health care.

Regarding housing, key informants confirmed that housing needs ranged from accessibility needs
such as ramps and grab bars to more extensive home repairs such as fall prevention measures and
seasonal weatherization. Often home improvement funding through mortgages or other loans is not
available for tribal elders. While some tribes have tribal resources for home repairs and upgrades, it
is not enough to meet all of the existing need. Key informants noted that the local CAP agencies do
offer some home repair services, but there is currently less program availability due to a closed local
office and weakening relationships between the tribe and the agency. Tribes have maintenance staff
to provide assistance for minor repairs to tribal elder housing on the reservation, but they do not
serve tribal members living off the reservation. One tribe has some newly completed elder housing
available, though key informants noted that even the tribal elders living there need periodic check-
ins from family or others to ensure their safety and comfort. One key informant noted, “Some
people do end up in nursing homes because there is no family to help out.” Another tribe expressed
a desire for an assisted living facility for elders who can still perform most daily tasks, but need some
additional help.

All tribes host communal meals with varying schedules and options for meal delivery; however, food
insecurity remains an issue across the tribes. One tribe has a congregate meal twice each week, but
on the other days there is only sandwich delivery. Some require “medical necessity” for home
delivered meals. The local food pantry often has “a mile long of cars waiting to get food. This is a
huge need.” Some tribal elders have transportation needs that are a barrier to accessing grocery
stores or food pantry resources. One key informant expressed frustration over the reduction in
congregate meal sites off the reservation, noting a challenge of finding volunteers. Another tribe,
however, is offering communal senior meals five days per week and reported good attendance
noting that the opportunity to socialize at these events supported elder wellbeing.

All expressed a significant tribal elder need for homemaker services such as cleaning, laundry, and
shopping. While some elders do have family available to help, not all have enough family to provide
consistent dependable assistance. For others, family members have moved away and so they must
depend on neighbors; this is more challenging for elders living off the reservation. One key
informant stated that tribal elders would want to hire another native person to provide various types of home-based care, but there are not enough people available to provide homecare even for those who have resources to pay privately.

For those elders who need specialty health services off the reservation, the “biggest barrier is transportation” which, in turn, leads to a lack of continuity in health care. In rural communities, there is heavy reliance on locum tenens physicians and tribal elders are seeing a new physician at every visit, another barrier to consistent and coordinated care. Specialty care often requires traveling long distance across rural parts of the state and reliable, affordable transportation options are unavailable.

**Safety and Trust**

All key informants stressed the challenge of a lack of cultural competence in the non-native provider community. They are, for instance, unaware of the trauma experiences of many native people and this is a barrier to building relationships outside of the tribal community. While some tribal members provide cultural competence training to health care workers, it is challenging to reach doctors and nurses. One key informant expressed that “no one is asking ‘what should we know about serving older tribal members?’” One representative mentioned that they would be willing to engage in experience-sharing as a way of educating non-native health care providers. Several key informants noted that some tribal elders are mistrustful of care and services from non-native providers and caregivers. Others are reluctant to ask for help now. Despite this, all key informants were clear about the desire for supportive relationships with aging service providers in locations around the reservations. One noted that “the care community feels the tribes take care of our own, but we are not able to do that with everyone”.

**Tribal Elder Caregiving**

Key informants all mentioned concerns about tribal elders caring for young family members. Increasing rates of opioid and substance use disorder have resulted in unmet needs of grandparents taking care of grandchildren and available resources are insufficient to meet the financial and emotional health needs of the grandparents. Tribal social service staff offer assistance to grandparents in applying for SNAP benefits or help with guardianship measures through the court system. Often grandparents are already struggling, especially financially, and it becomes a greater challenge to care for a young grandchild. Despite this, however, key informants stressed that “it is important to keep our kids here”; grandmothers do step up and they reach out for help within the community however, resources are limited.

Key informants noted that past trauma and discrimination have caused tribal elders to be very reluctant to “let go of kids for even respite care -- unless it is another family member.” There is a high value placed on raising children within the tribal communities. The consequence is that people are very cautious about asking for help and they avoid many outside services and supports as a result. Tribal health departments do some referrals for mental health counseling and coping with the stress of caring for young grandchildren.
**Key Take-Aways**

While each tribal entity is separate, this section summarizes common themes heard across the interviews with key stakeholders of three different tribes.

Generally, key informants reported that the tribes do not have relationships with AAAs but they would like to build one. Very few tribal elders know about or use the AAA programs and services and providing AAA contact and referral information to tribal health departments would be immediately beneficial, particularly about Medicare counseling. Key informants recognize the benefits of a closer AAA relationship and are amenable to discussing strategies to build stronger partnerships such as hosting AAA education sessions and finding tribal volunteers to work through the AAAs on outreach to tribal elders.

Each tribe provides somewhat different services and supports to tribal elders but all say they do not have the resources to meet the needs. Across the spectrum of needs - housing, food, transportation, and socialization - tribes are responding as best possible. Health departments, elder coordinators, and community health nursing are identifying and addressing needs, yet additional resources are needed to help more tribal elders age comfortably in their homes since elders’ resources are very limited.

Key informants consistently identified needs for homemaker services, housing, home repair, and communal or delivered meals. Many elders are relying on family and neighbors for help at home and intergenerational ties are strong. However, as family members move away, elders are increasingly without resources to fill gaps, particularly for tribal elders living off the reservation. The need outpaces the supply in all areas.

Key informants all stressed the need for cultural competence training for health and aging service providers. Past traumas and overt discrimination have resulted in tribal elders’ mistrust of services provided by non-native individuals.
SECTION 6 – FOCUS GROUPS

Background

The Maine Health Access Foundation (MeHAF) provided funding to the Muskie School of Public Service to facilitate three focus groups of older adults in Maine. This project is distinct from but complementary to information collected as part of the broader statewide needs assessment conducted by the Muskie School on behalf of Maine’s Office of Aging and Disability Services (OADS).

These focus groups were designed to collect feedback from older Mainers whose voices may otherwise be overshadowed in conventional needs assessment efforts due to language or cultural differences, geography, population size, or other barriers to participation. The State Plan Advisory Committee provided input into the composition of the focus groups for this project. Three populations were selected:

- Older adults who have assumed primary care in the place of a parent for a grandchild or other relative under the age of 18 (referred to as “kinship care”)
- Older adults who identify as LGBT
- Older adults who are refugees or immigrants (referred to as “New Mainers”)

This section provides an abbreviated summary of key findings.

Methods

The Muskie School utilized convenience sampling for the focus groups, relying primarily on trusted community partners to help with recruitment and publication of the groups. A total of 19 individuals participated across the three groups. Focus group facilitators obtained written consent from all participants. Participants received a $25.00 grocery store gift card as an acknowledgement of their participation. Sessions ranged from 90-120 minutes. The groups were held in Portland, Lewiston, and Augusta and took place in November-December 2019.

Since 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.

Findings

The following section provides brief highlights from the three separate focus groups. While similar key topics were discussed across the groups (e.g., community strengths, service needs, barriers in receiving help), each group was different and had individual areas of focus and discussion unique to that group.
Kinship Care Focus Group

For purposes of this report, kinship care refers to the care of minor children by a relative or close family friend, whether that care is provided as a foster parent, adoptive parent, legal guardian, or through a more informal arrangement. Families become kinship families due to a number of factors including child abuse and neglect, substance use, divorce, unemployment, deployment and others.

Participants emphasized that differences in the structure and formality of these caregiving arrangements directly influence legal responsibilities, eligibility for services, decision-making authority, and other aspects of the caregiving relationship. Participants also noted that older adults providing kinship care must navigate two typically siloed systems of care; namely, services that are part of the aging network as well as children’s services.

Because of their caregiving responsibilities, participants often spoke about the needs of the children for whom they were caring rather than focusing on their own needs or wants. A number of participants also described the isolation and loneliness felt by kinship caregivers. Factors that participants mentioned included estrangement from other family members, loss of contact and connectedness with peers while also not “fitting in” with younger parents, stigma\(^\text{15}\), and financial, physical and emotional stress.

Focus group participants identified a number of needs, including:

- Need for trusted source of information and referral services to help connect caregivers to available services for children they care for (e.g., subsidized childcare, MaineCare services)
- Individual and family counseling services
- Help with navigating education systems
- Legal advocacy
- Respite services both in-home and in other settings (e.g., after school care)
- Kinship care support groups
- Financial assistance
- Summer camp subsidies
- Help with home repair and modifications (including routine home repairs but also modifications required for approval as a foster parent)
- Training and education courses (e.g., parenting information, nutrition services)
- Coordinated transportation services that meet needs of older adults and children

Participants noted that the complexity of kinship care arrangements led to caregivers receiving confusing and sometimes inaccurate information. Because kinship older caregivers straddle two different service delivery systems—one for older adults and one for children—participants reported that advocacy services were generally not available for the types of issues for which they needed help. Some kinship caregivers are reluctant to engage DHHS for information for fear that government agencies will become overly involved and intrusive in their caregiving relationship to the detriment of the child. Participants generally voiced the need for an independent and unbiased ombudsman to assist kinship families.

\(^{15}\) Stigma relates to the perceptions of others that they must have failed in some way as parents themselves or they would not now be needing to take care of their grandchildren.
Participants described the emotional strain and stress that kinship caregivers often experience; they spoke of the need to make counseling services available to support the caregiver, the child/children, and in some cases, spouses or partners and other family members. Participants noted that children receiving kinship care have often experienced trauma; they emphasized the need for more trauma informed services and supports to better meet families’ needs.

**“New Mainers” Focus Group**

For purposes of this report, the term “New Mainer” is used to refer to older adults who are immigrants or refugees living in Maine. The focus group was conducted in two languages, French and Somali, with three interpreters present.

Participants in this group emphasized that immigration status shaped many of the experiences and responses that participants had around their needs and services. For example, immigration status influenced eligibility for MaineCare and access to a number of other services. Along with immigration status, language access issues directly influenced the services people had or could receive and contributed to feelings of isolation and other quality of life issues. Without interpreter services, participants did not know where or how to ask about services. Participants also noted the importance of having in-person interpreters that understood their language and culture, including the appropriate dialect. Participants in this group generally felt safe in their home and communities. While participants thought that some people may be reluctant to reach out and ask for help outside of their family and community, that theme was far outweighed by the sentiment that participants felt they did not even know what services existed and had no information about what to even ask.

While participants initially had difficulty responding to a question about service needs within the context of their own experiences and lives, several needs emerged over the course of discussion:

- The need for affordable and accessible transportation services
- Health care services, particularly for those without MaineCare coverage
- Interpreter services that meet language and communication need
- Food and nutrition assistance
- The need for trusted source of information and referral services through an entity such as an ethnic community based organization (ECBO) that understands participants’ needs, preferences, culture and language
- In-home services, including homemaker services
- Affordable housing
- Community based senior center where people could come together, socialize and eat a hot meal

Transportation issues were repeatedly raised throughout the session. Without transportation, participants described being unable to access other needed services (such as health care and grocery shopping) and feeling isolated and lonely without opportunities for social engagement.

Throughout the discussion, participants expressed a need for services that were trauma-informed and culturally appropriate for their needs. Participants noted that very few services were tailored to
the needs of older adults in their community and that many refugees had experienced significant trauma in their lives that adversely impacted physical and mental health.

LGBT Older Adult Focus Group

The focus group began with a discussion of preferred language and terminology regarding gender identity and sexual orientation. One participant noted that some older adults prefer LGBT to LGBTQ. Preferences varied even among the participants in the focus group; for purposes of this study, however, participants were agreeable to the use of the term LGBT.

While language and terminology used to describe sexual orientation and gender identity continues to change and evolve, participants emphasized the importance of communicating in a way that indicates inclusiveness of LGBT individuals. As one example, participants noted that many intake forms and questionnaires from service providers and health systems are written in a way that excludes LGBT individuals (for example, male/female gender categories). Participants emphasized that inclusive language helps build trust and mitigate fears about safety and discrimination.

Participants described how safety considerations and fear of discrimination underlie many aspects of everyday life. Generally, participants felt that safety and discrimination concerns were magnified for those who lived in more rural areas of the state. Participants reported concerns about LGBT older adults being isolated or lonely. While Portland offered opportunities for socialization, participants felt that there was less outreach and even fewer social opportunities in other parts of the state. Family estrangement, discrimination, harassment, and lack of a support network were some of the factors mentioned that increased risk.

Some of the needs identified by participants included:

- Information and referral services that are inclusive of individuals who identity as LGBT. Trust was identified as critical to ensure that individuals who identify as LGBT were comfortable disclosing information relevant to their needs (for example, disclosing medications indicating HIV status as part of Medicare Part D counseling).
- Culturally competent health care providers. Participants noted that LGBT people were not always comfortable disclosing their sexual orientation even to their health care providers. One participant noted that it is often up to the individual to raise issues of sexual orientation and if there is any level of discomfort, the person will likely omit that information which could negatively impact care.
- Behavioral health services; as one participant noted, LGBT adults are at higher risk of having substance use disorders (including alcohol).
- Chore services, home maintenance, and repair by trusted or vetted providers.
- Accessible transportation services.
- Food and meal services, including LGBT-friendly congregate meal sites.
- Affordable housing that meets the social and safety needs of older adults who identify as LGBT.
- Respite services for caregivers.

Participants felt that generally identifying as an older LGBT adult meant potentially experiencing additional access and service delivery barriers. Participants identified in-home care as a need but also emphasized the vulnerability and safety concerns that influence accessibility of this service for older
adults who identify as LGBT. Participants felt that concerns about safety and potential discrimination could translate into reluctance or hesitation about accepting services, particularly services that required people to come into their homes. Managing potentially harmful responses from service providers was considered an even greater concern for adults who are transgender, as well as individuals with HIV or Hepatitis C.

Participants repeatedly emphasized the need for training and education to promote inclusiveness and appropriate messaging and behaviors around sensitive issues for LGBT individuals. Several participants felt that the educational outreach needed to go beyond providers, noting that in facility or other types of congregate settings (e.g., adult day), residents and program participants do not always behave appropriately and that expectations needed to be set by providers to all residents or program participants.

**Key Take-Aways**

Though very different in many aspects, a number of common themes emerged across the three groups:

Information and assistance needs to come from a trusted source. For some, trust meant being able to have someone who understood a particular culture or language. For others, it meant a place that was free from discrimination, bias, or judgment. Participants felt if there was risk involved—though the nature of the risk could differ depending on the situation and the person—older adults would not reach out even if they need help. Trust also meant that participants wanted to be able to rely on the accuracy of the information provided. Participants also noted the need for navigation assistance, due in some cases to system complexities or nuances in legal status and responsibilities. It was also clear that trust starts with the very first contact, direct or indirect, and that any outreach that is conducted needs to be sensitive and inclusive of everyone the organization is trying to serve. Participants across groups noted that if an individual has a bad experience or does not feel comfortable, they might not take the risk of reaching out again.

Generally, participants appeared to express greater trust in local sources of information and organizations rather than statewide resources. This seemed to relate in part to participants’ acknowledgment that people’s needs and experiences differed depending on the region of the state and that services also varied by region. Importantly, local organizations may also facilitate the development of individual relationships. For example, participants said it was challenging at times to repeat the same information about themselves over again to different people; they also felt this led to a greater risk of receiving inaccurate information because the person did not know them and understand their situation.

Isolation and loneliness were key themes across all three groups and the need for targeted interventions specific to the different needs and barriers. Stigma, family estrangement, lack of peers, fear, bias (including ageism), and geographic location were mentioned as some of the contributing factors to isolation and loneliness. Examples of possible services that could help mitigate some of these situations varied but included: increased transportation services, respite services, support groups, creation of community centers or community gatherings that were culturally appropriate, and friendly visitor programs specific to different populations. Participants valued the importance of
peers or others that have shared experiences; in addition to emotional support, peers provide an avenue for sharing advice and information.

Participants shared the same needs as other older adults but participants across the three groups articulated a layered vulnerability or challenge to meeting their needs as older adults. For some participants, it was the added responsibility of caring for a minor child in addition to their own needs or the needs of other aging family members. For others, that added layer included navigating a different culture and system of care where language created communication barriers. Additional factors overlying daily needs included fear of discrimination, stigma, and concerns for safety.

Participants also emphasized the need to provide services in a manner appropriate to their different life experiences. Discussion around delivering culturally competent care as well as care that was trauma-informed (including educational services) was a theme across all groups. This points to the importance of engaging underserved populations in the design of services if those services are to meet their needs.

Importantly, participants across the groups stressed the danger of overly generalizing their responses to others within their “group”. For example, immigrant and refugee populations in Maine differ widely in language, culture, and background. Kinship caregivers may have different needs and experiences based on the formal or informal nature of the caregiving relationship among other factors. For LGBT older adults, the experiences of individuals who are transgender, as one example, may differ from those who identify as gay or lesbian. Participants also spoke about geography, noting that individuals in more rural areas of the state would likely report differently on community strengths, needs, barriers and safety. While individuals were comfortable representing themselves and their perspectives, they generally suggested additional discussion with others to gain a more representative sample of viewpoints.
SECTION 7 – RECURRING THEMES ACROSS STUDY COMPONENTS

Introduction

Each of the study components was designed to reach certain audiences and obtain specific information. While this section is not intended as a complete summary of all components, it is instructive to view themes across the study components to see which are recurring, what sub-themes are emphasized or feel urgent to which populations, or what nuance is buried in one study but emerges as noteworthy when viewed across collected data. The themes addressed in this section are those that surfaced in each study component, albeit in slightly different ways.

Transportation

The statewide survey respondents (aged 55 and older) were overwhelmingly (92%) driving themselves to the places they need to go. Despite this, the 4-5% of survey respondents that expressed transportation needs sounded very much like the listening session attendees: the lack of available, affordable transportation in communities was the principal barrier to accessing essential services such as food, medications, health care, and social activity for many older people, particularly the very old and those with physical or cognitive limitations. Nearly half (45%) of statewide survey respondents who identified transportation as a need indicated that there were no services in their area.

Many listening session attendees spoke on behalf of older family members or of neighbors and community members who could not be present at the session. Their views about the need in the community often represented those older individuals with the most significant vulnerabilities. For many in this population - likely the oldest-old and those with physical and cognitive limitations - the lack of affordable and flexible transportation options often means the difference between accessing basic needs or not. The lack of public or other affordable transportation options in many parts of Maine is also reflected in the on-line caregiver survey responses which confirm that many caregivers (85% of respondents) are providing transportation services to the individuals they care for. Focus group participants and tribal key informants also noted similar challenges resulting from a lack of available and affordable transportation.

Numerous open-ended responses to the statewide and caregiver surveys noted the need for more public or other transportation services. Some responses indicated a current need, but others expressed concern for when they may no longer be able to drive. This was echoed by participants across listening sessions, particularly in more rural areas. Across study components, we learn that the availability of transportation is one of a few “gateways” to better health and quality of life. Participants at listening sessions and focus groups emphasized the interrelatedness of needs; they emphasized the role of transportation in ensuring people get to medical appointments, food pantries, community meal sites, social activities, and routine errands such as grocery shopping or picking up prescription medications.
Some listening session attendees mentioned being unaware of information about transportation options. In those communities where programs and services currently exist, accurate and available information about the existence or lack of transportation services would assist older people and caregivers in planning daily activities or finding alternate modes of transportation when necessary.

**Housing and Home Repair**

The need for affordable housing and assistance with home repairs and routine home maintenance was a consistent recurring theme in all study components. While nearly all statewide survey respondents (93%) indicated that their home met their current needs, a significant number of respondents (over 200) provided comments related to housing in an open-ended question asking about what would make aging in their homes and communities better. Many noted the need for affordable housing options, and many others noted the need for home repair and maintenance. Others noted that home modifications were needed in order to create a safer environment. These modifications included adding outside ramps, removing stairs, adding chair lifts, and relocating bedrooms, bathrooms, and laundry rooms to the first floor. Themes of affordability—for housing, utilities, heat, home repairs, maintenance, and property taxes were repeatedly mentioned.

These concerns were echoed at the focus groups and all of the listening sessions. Many attendees were frustrated by the unavailability of middle income housing options or of local contractors to perform affordable, high-quality home repair. Participants at these sessions also stressed the need for having a trusted and vetted source of information about providers of home repair and home maintenance services. This was of particular note for older adults who identified as LGBT, who expressed feelings of vulnerability and safety consideration because of the potential for discrimination based on gender identity or sexual orientation. Others expressed concern that they or other older people in their community were unable to afford the cost of repairs and were living in substandard conditions. Many older people living alone do not have the ability nor the resources to accomplish routine home maintenance, such as snow shoveling, yard care, or trash removal. Listening session attendees and tribal key informants expressed particular concern that the inability to perform needed home repairs posed safety risks for older people and may contribute to increased fall risks or hazards from faulty equipment (e.g., furnace).

**Food and Nutrition**

As with transportation-related statewide survey responses, there are challenges around obtaining adequate food and nutrition for between five and eight percent of the statewide survey respondents age 55 and older. Most of these older Mainers identified difficulties in preparing their own meals. Based on other survey data, it is likely this five to eight percent have multiple needs and thereby encounter considerable difficulty aging comfortably at home. These findings are consistent with information gathered at the listening session. While most attendees had enough to eat themselves, in every session commenters noted food insecurity in people they knew and wished for more accessible, affordable options for fresh, homemade food.

There is an interwoven, somewhat complex, relationship between food security, nutrition, transportation, and caregiver workforce. Many older people who cannot drive due to cognitive, mobility, physical health, or financial constraints are dependent on slim transportation and caregiving resources in many areas of the state. This heightens the burden on family caregivers who, according to the stated need for respite care and the high levels of emotional strain, are reaching
burn-out. As basic necessities, food and good nutrition are other “gateway” needs, the absence of which can cause rapid decline in physical and cognitive health.

The safety net for food security - congregate meal sites, food pantries, and commodity distribution - are inaccessible without reliable transportation options. Listening session attendees made multiple requests for food pantry deliveries. Most older Mainers who have difficulty leaving the house (and some who do not) rely on Meals on Wheels, though several requested improved quality, more fresh produce options, and assurances that meals met all their dietary needs.

The focus group discussion on food highlighted the need for culturally sensitive meal site options. This is likely a reflection of the trust and safety issues that many sub-populations of older Mainers experience. They want to be able to convene and socialize over meals in a safe and inclusive environment.

**Need for Information / Outreach and Navigation**

The need for greater access to information about available services and options was a theme across all study components. Over one-quarter (26%) of the statewide survey respondents reported that finding information about available services and programs for older adults and caregivers was either very or somewhat difficult. Among statewide respondents who said they had not received all of the help they needed, forty percent said they did not know whom to ask for help. Among respondents to the on-line caregiver survey, caregivers who said they were not getting the help they needed, twenty-six percent said they did not know whom to ask or where to get the information.

Participants in listening sessions and focus groups added that information is increasingly available only online and that older adults do not always have access or the ability to use a computer or the internet. This is consistent with findings of the statewide survey, which show differences in how people reported accessing information across different age groupings. Participants also recognized that people have a tendency to wait until there is a crisis or urgent need before seeking information, increasing the need for easily accessible, timely and accurate information.

Looking across data sources in this study, there is no “one size fits all” approach to providing outreach and information. Participants at listening sessions and focus groups expressed the need to get information from a trusted or reliable source. In some cases, trust meant being able to have someone who understood a particular culture or language. For others, it meant a place that was free from discrimination or bias. Participants generally expressed that if there was perceived risk involved, older adults will not reach out for help. Participants across listening sessions and focus groups also spoke about the need to do targeted or proactive outreach to underserved populations and those who are most vulnerable (for example, adults with disabilities and individuals with Alzheimer’s disease or dementia).

An issue related to obtaining information that came up across the different ways across surveys, listening sessions, and focus groups was the need for advocacy and assistance in navigating the service system. Listening session attendees described a need for a contact person in their regions, communities, or towns whom they could call with questions about available services and who could connect them directly to a service provider or agency. Some attendees said it was not enough to provide contact information for an agency, a “warm handoff” is needed to help ensure they get connected to the right people. Listening session attendees described needing a navigator system that
participants described the importance of having an advocate, a role often filled by family members. Several participants emphasized that older adults who live alone or are homebound, individuals with Alzheimer’s disease or dementia, and those living with mental illness or trauma are at particular risk for being unable to get the help they need or encounter barriers that require additional advocacy on their behalf.

**Respite Services and Caregiver Workforce**

Across study components respite services was identified as a top need for individuals who are caregiving, particularly in rural areas where the caregiving workforce is especially limited, as noted by many listening session attendees. Thirty-seven percent of caregiver survey respondents indicated that respite services would be helpful and this was the top need identified in that survey. In the listening sessions, many participants mentioned respite or adult day services as essential to being able to engage in daily activities outside the home. Focus group participants noted the need for respite services as a means to reduce social isolation and loneliness and to help relieve caregiver burden.

Respite services, as with transportation, were seen as essential for tending to one’s daily affairs including shopping, medical care, socialization, and caregiver support services. Given that nearly all (88%) caregiver survey respondents reported feeling somewhat or very much emotionally stressed, with forty percent living in the same home as the care recipient, the expressed need for respite services is not surprising.

The availability of respite services is closely linked to issues of affordability and caregiver workforce supply. Those who need the services either cannot find caregiving staff or the cost of hiring paid caregivers is prohibitively expensive. Thirty-two percent of the caregiver survey respondents said they needed help finding other paid or unpaid caregivers.

The caregiver survey open-ended responses and comments made at each of the listening sessions reveal concern - bordering on alarm - about the lack of available paid caregivers around the state. In some listening sessions that spanned both rural and urban areas, family members and health care providers expressed frustration at the lack of available direct care workers. Several survey respondents and listening session attendees linked the lack of paid caregivers to the low reimbursement amounts, yet individuals who pay out of pocket for caregiving staff mentioned their inability to afford paid caregivers. Both MaineCare recipients and those who have the resources to pay privately expressed distress over the “critical shortage” of caregiving staff.

Several listening session attendees associated the lack of paid caregivers with ageism and societal views that the care of older people is not desirous work. This contrasts with tribal key informant comments that tribal elders are accorded much respect, although they also noted a need for additional caregiving services and find it equally challenging to meet these needs.
Education and Training Needs

Viewed across study components, the desire for training and the wide range of topics around which older people and caregivers want education or training is noteworthy. Almost half of respondents (48%) to the statewide survey expressed interest in free or low-cost workshops about their health; over twenty percent of respondents to the caregiver survey identified caregiving classes as a need.

Across listening sessions, participants expressed genuine interest in improving their knowledge and skills in several areas. Survey respondents, listening session attendees, and focus group participants all mentioned the need for more education on several topics, including caregiver support, dementia care, financial literacy, advance care planning, palliative and hospice care, avoiding scams, powers of attorney, MaineCare eligibility and navigation, computer and internet use, chronic pain, and food and nutrition.

While the variety of topics suggests the importance of knowledge acquisition to older Mainers, the number of topics implies that older people either lack access to basic information or they have basic information but still have questions and concerns or need further detail - or both. The volume of listening session and focus group comments about training needs coupled with listening session mentions about the lack of availability of computers or lack of broadband access, suggests that older Mainers may need access to in-person training opportunities or written material, depending on the topic. That said, the lack of transportation, lack of respite care, and lack of access to event information pose potential barriers to attendance even at local training opportunities.

Of note, participants in listening sessions, focus groups, and tribal key informants noted the importance of offering on-going cultural competency training to ensure the delivery of appropriate and quality care to underserved populations. These groups emphasized the need for providers to be trained in delivering trauma informed services and supports to better meet families’ needs. Older adults who identified as LGBT noted that such training should not be limited to services providers but expanded more widely to address discrimination and bias.

Social Engagement

The social needs of older Mainers, as described by participants across study platforms, highlight some of the key differences between social isolation and loneliness. The listening session attendees, tribal key informants, and caregiver survey respondents identified barriers to socialization primarily arising from structural barriers such as lack of transportation, geographic distance from social events, or friends and family, or physical impairments. But for these impediments, these individuals would socialize with others and participate in community life. If these older people had accessible, affordable, and appropriate transportation to the places and events they wished to attend, they would be more socially engaged.

In contrast, many of the focus group participants in all three sessions - and a few listening session attendees who spoke on behalf of some family members, friends, or neighbors unable to attend - identified barriers to social engagement related to a lack of belonging that likely cause them to feel lonely, such as stigma, concerns about discrimination, estrangement from family, inability to connect or fit in with others in similar circles. Even with available transportation to attend events, these individuals are unlikely to feel less lonely and disconnected. Loneliness is a subjective feeling that
one’s social and emotional relationships are inadequate and societal or community-level solutions may be more challenging to identify.

Over half (55%) of the caregiver survey reported feeling sometimes or often lonely or disconnected from people because of their caregiving duties. Given that many caregivers are employed and provide transportation services for the individuals they care for, it is less likely they are feeling socially disconnected due to structural barriers like transportation or geographic distance. It is more likely their loneliness and social disconnection is due to the emotional stress that most of them (88%) experience.

Interestingly, almost one-third (30%) of the statewide survey respondents reported feeling somewhat or often lonely and the open-ended responses indicate a desire for more social activities for older people. In light of the relatively young ages of the statewide survey participants and the diverse reasons that other study component participants provided for feeling lonely or disconnected, it may be useful to focus on this issue in greater detail in future outreach to older Mainers.

**Trust**

Somewhat surprisingly, the issue of trust was raised, albeit in different contexts, in every study component with qualitative data collection (i.e., listening sessions, focus groups, key informant interviews, open-ended responses in statewide survey). In all but the open-ended responses, the topic was mentioned repeatedly.

Older Mainers acknowledge the value of being a “hand-shake state”, full of communities where most people know everyone. Naturally, they gravitate to trusted people and institutions when they need information, assistance, or services. They reach out to physicians, town officials, librarians, or trusted family members, friends, or neighbors. Listening session participants specifically mentioned that while many older people are, by virtue of their independent spirit, often reluctant to reach out to others when they need something, trust in those “others” is essential; in the absence of trust, many older people would rather do without. Focus group participants, tribal key informants, and several people at the listening sessions noted that a lack of trust in others (e.g., prospective service providers) is a significant barrier to getting help they need, including necessary - or critical - services such as food delivery or transportation services, or engaging paid caregivers or a home repair person. For older individuals who have faced past discrimination and trauma, trust is likely to take on greater importance; a lack of trust can lead to withdrawal and social disconnection.

Listening session attendees confirmed that if service providers were recommended by trusted people or institutions, older people would be more likely to use those services. Older people need ready access to trusted individuals for care and service needs, or information about where to find them. Use of local level institutions, trusted public officials or trusted private agencies may be an effective way to leverage existing community social capital to achieve improved quality of life and wellbeing for many older Mainers. A better understanding of the nature of trust, how older people experience trust or breaches of trust, how to establish or expand it, where community level trust lies and how robust and widespread - or limited - it is, can be used as an effective strategy in disseminating information to older people about a wide range of area services. This may be particularly true for older people who are already isolated or lonely, or experience high levels of mistrust.
Safety

Viewed across the study components, older Mainers expressed concerns about safety in the context of physical safety, psychological safety, and feelings of security. Listening session participants spoke about physical safety hazards in the home (e.g., home repairs and upgrades) and also the psychic burdens of worrying about financial scamming, abuse and exploitation, and fear of overt criminal activity (e.g., theft of medications). Eighty-three percent of older Mainers responding to the statewide survey report they do not have concerns for their personal safety (from the concerns listed), leaving nearly one-fifth (17%) who do have one or more of the listed safety and security concerns.

The focus groups participants, particularly the LGBT group, and the tribal key informants spoke often about discrimination and the fear of poor treatment by community members. In this context, feeling psychologically unsafe - as with a lack of trust - can be isolating and pose an impediment to accessing services that could substantially improve health or wellbeing. Populations that have historically been marginalized and discriminated against worry that this behavior will be perpetuated by the larger community; they may not feel safe accessing community benefits and services unless those services are delivered by trusted others. Leveraging what has been learned to address psychological safety and security concerns of sub-populations of older adults may be an effective short term strategy for improving quality of life.

Ageism

Ageism and ageist behavior was mentioned at most listening sessions and at some of the focus groups. It was noted primarily as a systemic cause of adverse societal and community conditions that contribute to decreased quality of life and wellbeing for older people, such as a lack of adequate caregiving workforce. There were several comments such as “[s]ociety needs to put importance on the elderly.” Older Mainers are starting to recognize many people hold ageist attitudes which act as barriers to improved policies, programs, and idea generation to improve their lives.

While there were not widespread direct references to ageism, the worry and frustration that many older people freely expressed about less-than-ideal circumstances in the categories of needs mentioned repeatedly, demonstrates that older people need and want greater visibility, voice, and influence. A few listening session attendees were familiar with and spoke about recent national and state efforts to reframe aging and urged Maine policymakers and aging service organizations to adopt reframing principles such as “using more inclusive language”.

A focus on societal ageism - and effective ways to address it - is an emerging area in the social and communication sciences. Researchers such as The FrameWorks Institute identify ageism as a root cause of the general lack of attention to age-friendly policies, and they offer a range of suggestions and educational options for aging services stakeholders. State agencies and many aging services stakeholders in Maine have already begun to learn about and adopt reframing aging approaches. Continued broad, visible efforts in this area could reassure older people of their worth in the eyes of the agencies and individuals who serve them.
APPENDIX

A. Statewide Survey Instrument
B. Statewide Survey Results
C. Statewide Survey Agency Results
   • Aroostook Agency on Aging
   • Eastern Area Agency on Aging
   • SeniorsPlus
   • Southern Maine Agency on Aging
   • Spectrum Generations
D. Listening Session Flyer
E. Listening Session Protocol
F. Listening Session Presentation
G. Caregiver Survey Instrument
H. Caregiver Survey Report
I. Tribal Interview Protocol
J. Focus Group Questions
K. Maine Council On Aging: Wisdom Summit Session
Maine Aging Study

Thank you for helping with this important survey of people in Maine who are 55 years old or older. The answers we get from you and hundreds of people like you all over the state of Maine will help us learn more about the needs and concerns of Mainers as they age. It has questions about food and nutrition, transportation, housing, and other important issues. This survey will provide the State of Maine with important information as it develops priorities for community programs and services.

The survey is voluntary. Your individual responses are confidential. Responses will only be reported after they are combined with the responses from everyone else who took the survey. There are no right or wrong answers. If you come to a question you don't want to answer, just check "Prefer not to answer" and go on to the next one. If you have any questions about the survey, please contact James Moorhead, Aging Services Manager, Office of Aging and Disability Services at 207-287-9200 or James.Moorhead@maine.gov.

TRANSPORTATION

Q1 How do you usually get around to the places you need to go? (Check all that apply)
- Drive myself
- Have a family member or friend drive me
- Take public or regional transportation
- Use volunteer driver service
- Take a taxi, Uber, Lyft
- Walk or bike
- I rarely leave the house
- Prefer not to answer

Q2 Do you need help finding or arranging transportation?
- Yes
- No
- Prefer not to answer
Q3 In the last 90 days, were you unable to do any of the following because you did not have transportation? (Check all that apply)
- Get to a health care appointment
- Grocery shop or go to a pharmacy
- Go to a social activity that was important to you
- I was able to do all of the above
- Prefer not to answer

Q4 If you needed help with transportation and could not get it, what would you say are the main reasons? (Check all that apply)
- There are no transportation services in my area
- I don't have family or friends who can drive me
- I don't know where to get information about transportation services in my area
- Financial reasons
- Language barrier
- Health related reasons
- Other reason
- Prefer not to answer
If other, please specify:

HOUSING

Q5 How would you describe your current living situation?
- Own my home
- Rent
- Live with family or friends
- Homeless, looking for housing
- Nursing Home or Assisted Living/Residential Care Facility
- Other
- Prefer not to answer

Q6 Does your home meet your current needs?
- Yes
- No
- Prefer not to answer
Q7 Why not? (check all that apply)
- Home needs repairs that I cannot afford (roof, flooring, stairs, etc.)
- Home needs changes to meet physical needs (ramp, bathroom changes, doors widened, etc.)
- Home requires too much upkeep, maintenance
- I cannot afford taxes, rent, mortgage or utilities
- Other
- Prefer not to answer

If other, please specify:

Q8 Are you able to heat your home to a comfortable temperature in the winter?
- Yes
- No
- Prefer not to answer

FOOD AND NUTRITION

Q9 Do you usually have enough money to buy the food you need?
- Yes
- No
- Prefer not to answer

Q10 Do you use food pantries or participate in a food assistance program (such as SNAP)?
- Yes
- No
- Prefer not to answer

Q11 How often do you eat at a community meal site for your main meals?
- Rarely/Never
- Sometimes
- Frequently/Always
- Prefer not to answer

Q12 If only rarely or sometimes, what is the reason?
- I don’t need it
- I don’t like eating in a community group setting
- I don’t like where the meal site is located
- I don’t know how to find out about this in my community
- I don’t have transportation
- Other
- Prefer not to answer

If other, please specify:
Q13  Do you have difficulty preparing or cooking your main meals?
- Yes
- No
- Prefer not to answer

Q14  Are you able to leave your home without assistance or considerable effort?
- Yes
- No
- Prefer not to answer

Q15  Do you participate in a home delivered meal program (Meals on Wheels)?
- Yes
- No
- Prefer not to answer

Q16  Why not?
- My family or friends help me with meals.
- A paid home care provider prepares my main meals
- I do not know how or where to go for assistance
- I don't like asking for help
- I am on a waitlist for services
- I don't like the food that is available
- I don't need help with meals
- Other
- Prefer not to answer
If other, please specify:

____________________________

HEALTH STATUS

Q17  In general, would you say your physical health is:
- Excellent
- Very good
- Good
- Fair
- Poor
- Prefer not to answer

Q18  Do you have concerns about your own memory?
- Yes
- No
- Prefer not to answer
Q19  Do you have concerns about the memory of someone you care for?
    □ Yes
    □ No
    □ Prefer not to answer

Q20  In the last 6 months, how often have you felt lonely and disconnected from other people?
    □ Never
    □ Hardly ever
    □ Sometimes
    □ Often/always
    □ Prefer not to answer

Q21  Please check the statements below that reflect the concerns you have for your personal safety. (Check all that apply).
    □ I worry about the safety of my neighborhood
    □ I fear some members of my family or other people I know
    □ I fear that someone will take advantage of me (i.e. phone scam, take my money or possessions)
    □ I fear that people may steal my medications
    □ I fear that someone might steal my money or valuables
    □ None of the above concern me
    □ Prefer not to answer

Q22  Have you fallen in the last 6 months?
    □ Yes
    □ No
    □ Prefer not to answer

Q23  When you fell in the last 6 months, did you have to: (check all that apply)
    □ Go to the emergency room (ER) or hospital because of the fall
    □ Go to your doctor or medical provider because of the fall
    □ Need someone to help you get up
    □ None of the above
    □ Prefer not to answer

Q24  Do you have tooth or mouth problems that make it hard for you to eat?
    □ Yes
    □ No
    □ Prefer not to answer
Q25 If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending?
- Very
- Somewhat
- A little
- Not very
- Prefer not to answer

Q26 If a little or not very, why not? (Check all that apply)
- Information is not helpful to me/I don’t need it
- Transportation issues
- It depends how far away it is
- I don’t like group activities
- Other
- Prefer not to answer

Q27 In the last 6 months, have you ever gone without your medications because you cannot afford them?
- Yes
- No
- In the last 6 months, I haven’t needed to take any medications
- Prefer not to answer

Q28 Do you have difficulty doing any of the following on your own? (Check all that apply)
- Daily household tasks, such as laundry and vacuuming
- Personal care activities, such as bathing or dressing
- Organizing or managing your medications
- No, I do not have difficulty with any of these tasks
- Prefer not to answer

Q29 Are you currently receiving in-home help with any of those tasks from another person or outside organization?
- Yes
- No
- Prefer not to answer
Q30 If you are not receiving all the help you need with those tasks, is it because

- You do not want it
- You cannot afford it
- You do not know how to get help
- There is no help available
- You are receiving all of the help you need
- Other
- Prefer not to answer

If other, please specify:

___________________________________________________________________________

CAREGIVING

Q31 Do you provide help regularly for any of the following individuals? (Check all that apply)

- Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18
- Yes, I care for an adult age 60 or older (include spouse or parent)
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person)
- No, I do not provide any caregiving supports to others
- Prefer not to answer

Q32 What type of support do you provide to this person/people? (Check all that apply)

- Daily household tasks
- Medical care
- Transportation
- Food or meal preparation
- Help with medications
- Financial management
- Help with personal care such as bathing and dressing
- Financial support
- Other
- Prefer not to answer

What other type(s) of support do you provide?

___________________________________________________________________________
Q33  What are your top needs as a caregiver for this person/people? (Check all that apply)

- Respite (rest, reprieve or break)
- Support Groups
- Information and Referral
- Caregiver Training /Education
- Transportation assistance
- Additional in-home support, help providing care
- Other
- Prefer not to answer

If other, please specify:

___________________________________________________________________________

INFORMATION & SERVICES

Q34  How difficult is it to find information you need about available services and programs for older adults and their caregivers?

- Very difficult
- Somewhat difficult
- Not difficult at all
- Haven’t tried
- Prefer not to answer

Q35  What are the best ways for you to get information about available services for older adults or caregivers? (Check all that apply)

- Internet
- TV
- Radio
- Newspaper
- Newsletters or flyers in mail
- Doctor/health care provider
- Word of mouth
- Senior or Community Center
- Communication with a state or local agency
- Other
- Prefer not to answer

If other, please specify:

___________________________________________________________________________

Appendix A
Q36 How do you primarily access the Internet?
- From my personal home computer, laptop, tablet, etc.
- From my cell phone
- From a public library or other community space
- At a friend’s or family’s home
- I don’t access the Internet
- Prefer not to answer

Q37 Have you called any of these organizations or looked them up online? (Check all that apply)
- Southern Maine Agency on Aging
- Spectrum Generations
- SeniorsPlus
- Eastern Area Agency on Aging
- Aroostook Area Agency on Aging
- Legal Services for the Elderly
- The Long-Term Care Ombudsman Program
- Maine 211
- I haven't called or looked up any of these organizations
- Prefer not to answer

Q38 In the last 6 months, have you needed help with any of the following? (Check all that apply)
- I have not needed help with any of the following items
- General information about community resources
- Food or meals
- Medicare or other health insurance questions
- Transportation
- Adult day services
- Respite or caregiver support
- Managing finances
- Legal services
- Finding volunteer opportunities
- On-going help getting connected to services and benefits
- Help in resolving problems with home care services
- Other
- Prefer not to answer

If other, please specify the other help you have needed:
_________________________________________________________

Q39 Did you get all of the help you needed?
- Yes
- No
- Prefer not to answer
Q40 Why not? (Check all that apply)
- I don't know who to ask
- Culture or language difficulties
- Services are not available
- I prefer not to ask for help
- I don't qualify for help
- There are waitlists for services
- I can't afford the help I need
- Fear of discrimination
- Other
- Prefer not to answer
If other, please specify:

COMMUNITY

Q41 How would you rate your community as a place to live for people as they age?
- Excellent
- Very Good
- Good
- Fair
- Poor
- Not sure
- Prefer not to answer

Q42 What would make aging in your home or community better or easier for you?

DEMOGRAPHICS
We want to make sure we have reached people from many different groups. Please answer the following questions to tell us a little bit more about you. Other than Q43 and Q44, if there are questions in this section that you prefer not to answer, please skip those and go to the next ones.
Q43  What county do you live in? (required)
- Androscoggin
- Aroostook
- Cumberland
- Franklin
- Hancock
- Kennebec
- Knox
- Lincoln
- Oxford
- Penobscot
- Piscataquis
- Sagadahoc
- Somerset
- Waldo
- Washington
- York

Q44  What is your age? (required)
- 55 to 64
- 65 - 74
- 75 - 84
- 85 - 94
- 95 or older

Q45  How many people live in your household?
___________________________________________________________________________

Q46  Which of the following statements best describes who lives with you? (Check all that apply)
- I live alone
- I live with spouse
- I live with other family members (adult children, other relatives)
- I live with friends, roommates
- Other
- Prefer not to answer
If other, please specify:
___________________________________________________________________________
Q47  Please specify your race/ethnicity.
    □  White
    □  Black or African American
    □  Native American or Alaskan Native
    □  Asian / Pacific Islander
    □  Multiracial
    □  Other
    □  Prefer not to answer
If other, please specify:

Q48  Do you consider yourself Hispanic or Latino?
    □  Yes
    □  No
    □  Prefer not to answer

Q49  Is English your primary or preferred language?
    □  Yes
    □  No
    □  Prefer not to answer

Q50  What is your primary language?

Q51  What was your sex at birth (meaning, on your original birth certificate)?
    □  Male
    □  Female
    □  Not listed above
    □  Prefer not to answer
If not listed above, please specify:

Q52  What is your current gender identity?
    □  Male
    □  Female
    □  Transgender
    □  Not listed above
    □  Prefer not to answer
If not listed above, please specify:
Q53 Do you think of yourself as:
   □ Female-to-Male (FTM)/Transgender Male/Trans Man
   □ Male-to-Female (MTF)/Transgender Female/Trans Woman
   □ Not listed above
   □ Prefer not to answer
If not listed above, please specify:

___________________________________________________________________________

Q54 Do you think of yourself as:
   □ Straight, that is, not gay or lesbian
   □ Lesbian or Gay
   □ Bisexual
   □ Not listed above
   □ Not sure
   □ Prefer not to answer
If not listed above, please specify:

___________________________________________________________________________

Q55 What is the highest level of formal education you have completed so far?
   □ Grammar school (Up to 8th grade)
   □ Some high school
   □ High school graduate
   □ Some college or technical training
   □ College degree
   □ Graduate school
   □ Prefer not to answer

Q56 What is your current employment status?
   □ Fully retired
   □ Working part time
   □ Working full time
   □ Seasonal
   □ Prefer not to answer

Q57 Which of the following categories represents your annual household income?
   □ Less than $20,000
   □ $20,000 to under $40,000
   □ $40,000 to under $60,000
   □ $60,000 to under $75,000
   □ $75,000 or more
   □ Don't know
   □ Prefer not to answer

Those are all the questions. When you are done, please hit "submit". Thank you for your help!
2019 Maine Aging Study: Statewide Report

Muskie School of Public Service
Cutler Institute for Health and Social Policy

March 6, 2020
### Demographics

**Statewide Results**

**What county do you live in? (n=2,254)**

<table>
<thead>
<tr>
<th>County</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cumberland</td>
<td>22%</td>
</tr>
<tr>
<td>York</td>
<td>13%</td>
</tr>
<tr>
<td>Penobscot</td>
<td>12%</td>
</tr>
<tr>
<td>Kennebec</td>
<td>10%</td>
</tr>
<tr>
<td>Androscoggin</td>
<td>7%</td>
</tr>
<tr>
<td>Aroostook</td>
<td>6%</td>
</tr>
<tr>
<td>Oxford</td>
<td>5%</td>
</tr>
<tr>
<td>Hancock</td>
<td>5%</td>
</tr>
<tr>
<td>Somerset</td>
<td>3%</td>
</tr>
<tr>
<td>Sagadahoc</td>
<td>3%</td>
</tr>
<tr>
<td>Knox</td>
<td>3%</td>
</tr>
<tr>
<td>Lincoln</td>
<td>3%</td>
</tr>
<tr>
<td>Waldo</td>
<td>3%</td>
</tr>
<tr>
<td>Franklin</td>
<td>2%</td>
</tr>
<tr>
<td>Washington</td>
<td>2%</td>
</tr>
<tr>
<td>Piscataquis</td>
<td>1%</td>
</tr>
</tbody>
</table>

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**Survey Research Center**

3/5/2020
Demographics Statewide Results

What is your age? (n=2,254)

- 55 to 64: 45%
- 65 to 74: 32%
- 75 to 84: 18%
- 85 to 94: 4%
- 95 or older: <1%

How many people live in your household? (n=2,166)

- 1: 31%
- 2: 56%
- 3: 8%
- 4: 3%
- ≥5: 2%

Which of the following statements best describes who lives with you?* (n=2,221)

- I live with a spouse: 58%
- I live alone: 31%
- I live with other family members (adult children, other relatives): 16%
- I live with friends, roommates: 2%
- Other: 2%
- Recoded other: I live with pet(s): 1%

*Multiple responses allowed

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
### Demographics

#### Statewide Results

**Please specify your race and ethnicity (n=2,178)**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>99%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Native American or Alaskan Native</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Other</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

**Do you consider yourself Hispanic or Latino? (n=2,168)**

Approximately 100% of respondents said "no."

**Is English your primary or preferred language? (n=2,241)**

Approximately 99% of respondents said "yes."
Demographics

What was your sex at birth (meaning, on your original birth certificate)? (n=2,216)

- Male: 44%
- Female: 56%
- Intersex: 0%

What is your current gender identity? (n=2,182)

- Male: 44%
- Female: 56%
- Transgender: <1%
- Other: 0%

Do you think of yourself as: (n=2,139)

- Straight, that is, not gay or lesbian: 96%
- Lesbian or gay: 3%
- Bisexual: 1%
- Not sure: 1%
- Not listed above: <1%
### Demographics

**Statewide Results**

#### What is the highest level of formal education you have completed so far? (n=2,214)

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Graduate school</td>
<td>24%</td>
</tr>
<tr>
<td>College degree</td>
<td>30%</td>
</tr>
<tr>
<td>Some college or technical training</td>
<td>28%</td>
</tr>
<tr>
<td>High school graduate</td>
<td>15%</td>
</tr>
<tr>
<td>Some high school</td>
<td>2%</td>
</tr>
<tr>
<td>Grammar school (up to 8th grade)</td>
<td>1%</td>
</tr>
</tbody>
</table>

#### What is your current employment status? (n=2,130)

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully retired</td>
<td>53%</td>
</tr>
<tr>
<td>Working part time</td>
<td>17%</td>
</tr>
<tr>
<td>Working full time</td>
<td>29%</td>
</tr>
<tr>
<td>Seasonal</td>
<td>1%</td>
</tr>
</tbody>
</table>

#### Which of the following categories represents your annual household income? (n=2,254)

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$20K</td>
<td>19%</td>
</tr>
<tr>
<td>$20K to &lt;$40K</td>
<td>21%</td>
</tr>
<tr>
<td>$40K to &lt;$60K</td>
<td>17%</td>
</tr>
<tr>
<td>$60K to &lt;$75K</td>
<td>10%</td>
</tr>
<tr>
<td>≥$75K</td>
<td>33%</td>
</tr>
</tbody>
</table>
How do you usually get around to the places you need to go?* (n=2,242)

- Drive myself: 92%
- Friends/family: 18%
- Walk/bike: 13%
- Public transportation: 4%
- Taxi, Uber, Lyft: 4%
- Rarely leave house: 2%
- Volunteer service: 2%

Do you need help finding or arranging transportation? (n=2,225)

- No: 95%
- Yes: 5%

*Multiple responses allowed
In the last 90 days, were you unable to do any of the following because you did not have transportation?* (n=2,125)

- Grocery shop or go to pharmacy: 5%
- Get to health care appointment: 4%
- Go to social activity important to you: 4%
- I was able to do all these things: 92%

If you needed transportation and could not get it, what would you say are the main reasons?* (n=157)

- No transportation services in my area: 45%
- Financial reasons: 41%
- Don’t have family or friends who can drive me: 34%
- Other reason: 29%
- Health-related reasons: 29%
- Don’t know where to get information about services in my area: 26%
- Language barrier: 1%

*Multiple responses allowed
How would you describe your current living situation? (n=2,229)

- Own my home: 77%
- Rent: 19%
- Live with family or friends: 2%
- Other: 1%
- Homeless, looking for housing: <1%

Does your home meet your current needs? (n=2,193)

- Yes: 93%
- No: 7%
[If your home does not meet your current needs,] why not?* (n=161)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home needs repairs that I cannot afford (roof, flooring, stairs, etc.)</td>
<td>53%</td>
</tr>
<tr>
<td>Home needs changes to meet physical needs (ramp, bathroom changes, doors...)</td>
<td>34%</td>
</tr>
<tr>
<td>Home requires too much upkeep, maintenance</td>
<td>29%</td>
</tr>
<tr>
<td>I cannot afford taxes, rent, mortgage or utilities</td>
<td>24%</td>
</tr>
<tr>
<td>Other</td>
<td>14%</td>
</tr>
<tr>
<td>Recoded other: I need a first-floor home because stairs are a challenge†</td>
<td>14%</td>
</tr>
<tr>
<td>Recoded other: home is difficult to heat/I can’t regulate the heat†</td>
<td>7%</td>
</tr>
<tr>
<td>Recoded other: home is too small and/or lacks adequate storage†</td>
<td>3%</td>
</tr>
</tbody>
</table>

Recoded other: home is too small and/or lacks adequate storage†: Items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed

Are you able to heat your home to a comfortable temperature in the winter? (n=178)

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>56%</td>
</tr>
<tr>
<td>No</td>
<td>44%</td>
</tr>
</tbody>
</table>
Do you usually have enough money to buy the food you need?  (n=2,225)

- Yes: 92%
- No: 8%

Do you use food pantries or participate in a food assistance program (such as SNAP)?  (n=2,231)

- Yes: 12%
- No: 88%
How often do you eat at a community meal site for your main meals? (n=2,220)

- Rarely/Never: 95%
- Sometimes: 4%
- Frequently/Always: 1%

If [you] only rarely or sometimes [eat at a community meal site for your main meals], what is the reason?* (n=2,005)

- I don’t need it: 84%
- I don’t like eating in a community group setting: 8%
- I don’t know how to find out about this in my community: 5%
- I don’t have transportation: 4%
- I don’t like where the meal site is located: 1%
- Other: 5%
- Recoded other: none available/too infrequent/too far away†: 1%
- Recoded other: food is not good/I require special diet†: 1%
- Recoded other: I prefer to stay home†: <1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Do you have difficulty preparing or cooking your main meals? (n=2,225)

- Yes: 5%
- No: 95%

Are you able to leave home without assistance or considerable effort? (n=111)

- Yes: 57%
- No: 43%
Do you participate in a home delivered meal program (Meals on Wheels)? (n=48)

- Yes: 93%
- No: 7%

[If you do not participate in a home delivered meal program], why not?* (n=39)

- My family or friends help me with meals: 35%
- I do not know how or where to go for assistance: 27%
- I don’t like asking for help: 24%
- I don’t need help with meals: 12%
- I don’t like the food that is available: 10%
- A paid home care provider prepares my main meals: 3%
- I am on a waitlist for services: 0%
- Other: 3%
- Recoded other: others need it more†: 9%
- Recoded other: I live too far away from that service†: 3%

*Multiple responses allowed

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
In general, would you say your physical health is:  \( (n=2,239) \)

<table>
<thead>
<tr>
<th>Health Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>16%</td>
</tr>
<tr>
<td>Very good</td>
<td>35%</td>
</tr>
<tr>
<td>Good</td>
<td>29%</td>
</tr>
<tr>
<td>Fair</td>
<td>16%</td>
</tr>
<tr>
<td>Poor</td>
<td>4%</td>
</tr>
</tbody>
</table>

Do you have concerns about your own memory?  \( (n=2,217) \)

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>26%</td>
</tr>
<tr>
<td>No</td>
<td>74%</td>
</tr>
</tbody>
</table>

Do you have concerns about the memory of someone you care for?  \( (n=2,202) \)

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20%</td>
</tr>
<tr>
<td>No</td>
<td>80%</td>
</tr>
</tbody>
</table>
In the last 6 months, how often have you felt lonely and disconnected from other people? (n=2,233)

- Never: 44%
- Hardly ever: 27%
- Sometimes: 23%
- Often/always: 7%

Please check the statements below that reflect the concerns you have for your personal safety.* (n=2,197)

- I fear that someone will take advantage of me (i.e., phone scam, take my money or possessions): 10%
- I fear that someone might steal my money or valuables: 7%
- I worry about the safety of my neighborhood: 6%
- I fear some members of my family or other people I know: 2%
- I fear that people may steal my medications: 2%
- None of the above concern me: 83%

*Multiple responses allowed
Have you fallen in the last 6 months? (n=2,230)

- Yes: 22%
- No: 78%

When you fell in the last 6 months, did you have to:*

- Need someone to help you get up: 23%
- Go to your doctor or medical provider because of the fall: 16%
- Go to the emergency room (ER) or hospital because of the fall: 12%
- None of the above: 60%

*Multiple responses allowed
Do you have tooth or mouth problems that make it hard for you to eat? (n=2,240)

- Yes: 16%
- No: 84%
If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending? (n=2,219)

- Very: 9%
- Somewhat: 22%
- A little: 18%
- Not very: 52%

If a little or not very [interested in attending a workshop], why not?* (n=1,452)

- Information is not helpful to me/I don't need it: 62%
- Other: 22%
- I don't like group activities: 14%
- It depends how far away it is: 8%
- Transportation issues: 5%

*Multiple responses allowed
In the last 6 months, have you ever gone without your medications because you cannot afford them? (n=2,236)

- Yes: 5%
- No: 88%
- In the last 6 months, I haven't needed to take any medications: 6%

Do you have difficulty doing any of the following on your own?* (n=2,221)

- Daily household tasks, such as laundry and vacuuming: 12%
- Personal care activities, such as bathing or dressing: 4%
- Organizing or managing your medications: 3%
- No, I do not have difficulty with any of these tasks: 87%

*Multiple responses allowed
Are you currently receiving in-home help with any of those tasks from another person? (n=301)

- Yes: 41%
- No: 59%

If you are not receiving all the help you need with those tasks, is it because* (n=160)

- You cannot afford it: 40%
- You do not know how to get help: 25%
- You do not want it: 20%
- There is no help available: 13%
- Other: 12%
- Recoded other: reluctant to ask†: 12%
- You are receiving all of the help you need: 18%

*Multiple responses allowed

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Do you provide help regularly for any of the following individuals?* (n=2,185)

- Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18: 4%
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person): 16%
- Yes, I care for an adult age 60 or older (include spouse or parent): 78%
- No, I do not provide any caregiving supports to others: 4%

*Multiple responses allowed
What type of support do you provide to this person/people?* (n=401)

- Transportation: 65%
- Food or meal preparation: 58%
- Daily household tasks: 51%
- Financial management: 48%
- Help with medications: 39%
- Medical care: 36%
- Financial support: 33%
- Help with personal care such as bathing and dressing: 25%
- Other: 10%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
What are your top needs as a caregiver for this person/people?* (n=316)

- Respite (rest, reprieve or break): 36%
- Additional in-home support, help providing care: 33%
- Transportation assistance: 23%
- Information and referral: 22%
- Support groups: 9%
- Caregiver training/education: 7%
- Other: 9%
- Recoded other: none*: 10%
- Recoded other: financial*: 5%
- Recoded other: housing*: 2%

*Multiple responses allowed

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
### Information & Services

**Statewide Results**

**How difficult is it to find information you need about available services and programs for older adults and their caregivers? (n=2,209)**

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very difficult</td>
<td>7%</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>19%</td>
</tr>
<tr>
<td>Not difficult at all</td>
<td>26%</td>
</tr>
<tr>
<td>Haven't tried</td>
<td>48%</td>
</tr>
</tbody>
</table>

**What are the best ways for you to get information about available services for older adults or caregivers?* (n=2,184)**

<table>
<thead>
<tr>
<th>Information Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet</td>
<td>70%</td>
</tr>
<tr>
<td>Doctor/health care provider</td>
<td>53%</td>
</tr>
<tr>
<td>Word of mouth</td>
<td>38%</td>
</tr>
<tr>
<td>TV</td>
<td>28%</td>
</tr>
<tr>
<td>Newspaper</td>
<td>28%</td>
</tr>
<tr>
<td>Newsletters or flyers in mail</td>
<td>27%</td>
</tr>
<tr>
<td>Communication with a state or local agency</td>
<td>24%</td>
</tr>
<tr>
<td>Senior or community Center</td>
<td>20%</td>
</tr>
<tr>
<td>Radio</td>
<td>12%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
<tr>
<td>Recoded other: I don't need information†</td>
<td>1%</td>
</tr>
<tr>
<td>Recoded other: community (town office/city hall/library)†</td>
<td>1%</td>
</tr>
<tr>
<td>Recoded other: church†</td>
<td>1%</td>
</tr>
<tr>
<td>Recoded other: family members†</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How do you primarily access the Internet?*  (n=2,239)

- From my personal home computer: 75%
- From my cell phone: 22%
- I don't access the Internet: 7%
- From a public library or other community space: 1%
- At a friend's or family home: 1%

Have you called any of these organizations or looked them up online?*  (n=2,197)

- Southern Maine Agency on Aging: 12%
- Eastern Area Agency on Aging: 8%
- Legal Services for the Elderly: 6%
- Maine 211: 5%
- SeniorsPlus: 5%
- Spectrum Generations: 5%
- Aroostook Area Agency on Aging: 2%
- The Long-Term Care Ombudsman Program: 2%
- I haven't called or looked up any of these organizations: 70%

*Multiple responses allowed
In the last 6 months, have you needed help with any of the following?*  (n=2,137)

- Medicare or other health insurance questions: 17%
- General information about community resources: 8%
- Transportation: 7%
- Legal services: 6%
- Food or meals: 6%
- On-going help getting connected to services and benefits: 5%
- Managing finances: 4%
- Finding volunteer opportunities: 4%
- Other: 3%
- Respite or caregiver support: 3%
- Help in resolving problems with home care services: 2%
- Adult day services: 1%
- I have not needed help with any of the following items: 68%

*Multiple responses allowed
Did you get all the help you needed? (n=714)

- Yes: 56%
- No: 44%

Why [did you not get all the help you needed]?* (n=308)

- I don't know who to ask: 40%
- I can't afford the help I need: 34%
- Services are not available: 34%
- I don't qualify for help: 28%
- There are waitlists for services: 22%
- I prefer not to ask for help: 11%
- Fear of discrimination: 5%
- Culture or language difficulties: 1%
- Other: 10%

Recoded other: difficulty with insurance†: 5%
Recoded other: agency not helpful‡: 4%
Recoded other: too confusing, frustrating, overwhelming, etc.‡: 2%

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed
How would you rate your community as a place to live for people as they age? (n=2,216)

- Excellent: 13%
- Very good: 28%
- Good: 29%
- Fair: 18%
- Poor: 6%
- Not sure: 7%
2019 Maine Aging Study:
Aroostook Agency on Aging

Muskie School of Public Service
Cutler Institute for Health and Social Policy

March 6, 2020
What county do you live in? (n=308)

Aroostook 100%
Demographics

What is your age? (n=308)

- 55 to 64: 43%
- 65 to 74: 32%
- 75 to 84: 18%
- 85 to 94: 7%
- 95 or older: 1%

How many people live in your household? (n=294)

- 1: 35%
- 2: 54%
- 3: 8%
- 4: 1%
- ≥5: 2%

Which of the following statements best describes who lives with you?* (n=301)

- I live with a spouse: 59%
- I live alone: 35%
- I live with other family members (adult children, other relatives): 13%
- Other: 2%
- I live with friends, roommates: 1%
- Recoded other: I live with pet(s)†: <1%

*Multiple responses allowed

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
## Demographics

### Please specify your race and ethnicity (n=300)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>98%</td>
</tr>
<tr>
<td>Native American or Alaskan Native</td>
<td>1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>1%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Other</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>0%</td>
</tr>
</tbody>
</table>

### Do you consider yourself Hispanic or Latino? (n=303)

Approximately 99% of respondents said "no."

### Is English your primary or preferred language? (n=308)

Approximately 94% of respondents said "yes."
What was your sex at birth (meaning, on your original birth certificate)? (n=301)

- Male: 49%
- Female: 51%
- Intersex: 0%

What is your current gender identity? (n=295)

- Male: 46%
- Female: 54%
- Transgender: <1%
- Other: 0%

Do you think of yourself as: (n=296)

- Straight, that is, not gay or lesbian: 98%
- Lesbian or gay: 2%
- Bisexual: <1%
- Not listed above: 0%
- Not sure: 0%
Demographics

What is the highest level of formal education you have completed so far? (n=301)

- Graduate school: 11%
- College degree: 26%
- Some college or technical training: 28%
- High school graduate: 28%
- Some high school: 4%
- Grammar school (up to 8th grade): 2%

What is your current employment status? (n=279)

- Fully retired: 59%
- Working part time: 13%
- Working full time: 26%
- Seasonal: 1%

Which of the following categories represents your annual household income? (n=308)

- <$20K: 27%
- $20K to <$40K: 25%
- $40K to <$60K: 16%
- $60K to <$75K: 10%
- ≥$75K: 22%
Transportation

Aroostook Agency on Aging

Appendix C

How do you usually get around to the places you need to go?* (n=308)

- Drive myself: 89%
- Friends/family: 24%
- Walk/bike: 14%
- Public transportation: 3%
- Rarely leave house: 3%
- Taxi, Uber, Lyft: 2%
- Volunteer service: 1%

Do you need help finding or arranging transportation? (n=306)

- Yes: 4%
- No: 96%

*Multiple responses allowed
In the last 90 days, were you unable to do any of the following because you did not have transportation?* (n=280)

- Grocery shop or go to pharmacy: 8%
- Get to health care appointment: 4%
- Go to social activity important to you: 4%
- I was able to do all these things: 92%

If you needed transportation and could not get it, what would you say are the main reasons?* (n=21)

- No transportation services in my area: 65%
- Financial reasons: 46%
- Don't have family or friends who can drive me: 30%
- Health-related reasons: 27%
- Other reason: 11%
- Don't know where to get information about services in my area: 9%
- Language barrier: 0%

*Multiple responses allowed
How would you describe your current living situation? (n=305)

- Own my home: 74%
- Rent: 25%
- Live with family or friends: 2%
- Other: <1%
- Homeless, looking for housing: 0%

Does your home meet your current needs? (n=299)

- Yes: 92%
- No: 8%
Housing

[If your home does not meet your current needs,] why not?* (n=27)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home needs repairs that I cannot afford (roof, flooring, stairs, etc.)</td>
<td>48%</td>
</tr>
<tr>
<td>Home requires too much upkeep, maintenance</td>
<td>32%</td>
</tr>
<tr>
<td>I cannot afford taxes, rent, mortgage or utilities</td>
<td>26%</td>
</tr>
<tr>
<td>Home needs changes to meet physical needs (ramp, bathroom changes, doors…)</td>
<td>17%</td>
</tr>
<tr>
<td>Other</td>
<td>17%</td>
</tr>
<tr>
<td>Recoded other: I need a first-floor home because stairs are a challenge†</td>
<td>18%</td>
</tr>
<tr>
<td>Recoded other: home is too small and/or lacks adequate storage†</td>
<td>11%</td>
</tr>
<tr>
<td>Recoded other: home is difficult to heat/I can’t regulate the heat†</td>
<td>0%</td>
</tr>
</tbody>
</table>

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.

Are you able to heat your home to a comfortable temperature in the winter? (n=25)

- Yes: 58%
- No: 42%

*Multiple responses allowed
Do you usually have enough money to buy the food you need? (n=302)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>90%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Do you use food pantries or participate in a food assistance program (such as SNAP)? (n=308)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21%</td>
<td>79%</td>
</tr>
</tbody>
</table>
How often do you eat at a community meal site for your main meals? (n=306)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely/Never</td>
<td>90%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>9%</td>
</tr>
<tr>
<td>Frequently/Always</td>
<td>1%</td>
</tr>
</tbody>
</table>

If [you] only rarely or sometimes [eat at a community meal site for your main meals], what is the reason?* (n=264)

- I don’t need it: 73%
- I don’t like eating in a community group setting: 11%
- I don’t know how to find out about this in my community: 7%
- I don’t have transportation: 4%
- I don’t like where the meal site is located: 1%
- Other: 10%
- Recoded other: none available/too infrequent/too far away†: 5%
- Recoded other: food is not good/I require special diet†: 1%
- Recoded other: I prefer to stay home†: <1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Do you have difficulty preparing or cooking your main meals? (n=306)

- Yes: 5%
- No: 95%

Are you able to leave home without assistance or considerable effort? (n=14)

- Yes: 60%
- No: 40%
Do you participate in a home delivered meal program (Meals on Wheels)? (n=6)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

[If you do not participate in a home delivered meal program], why not?* (n=6)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

*Multiple responses allowed
In general, would you say your physical health is:  (n=308)

- Excellent: 9%
- Very good: 31%
- Good: 35%
- Fair: 19%
- Poor: 6%

Do you have concerns about your own memory?  (n=295)

- Yes: 24%
- No: 76%

Do you have concerns about the memory of someone you care for?  (n=300)

- Yes: 21%
- No: 79%
In the last 6 months, how often have you felt lonely and disconnected from other people? (n=306)

- Never: 47%
- Hardly ever: 24%
- Sometimes: 26%
- Often/always: 4%

Please check the statements below that reflect the concerns you have for your personal safety.* (n=302)

- I fear that someone will take advantage of me (i.e., phone scam, take my money or possessions): 14%
- I fear that someone might steal my money or valuables: 10%
- I worry about the safety of my neighborhood: 9%
- I fear some members of my family or other people I know: 5%
- I fear that people may steal my medications: 4%
- None of the above concern me: 77%

*Multiple responses allowed
Have you fallen in the last 6 months? (n=302)

- Yes: 22%
- No: 78%

When you fell in the last 6 months, did you have to:* (n=69)

- Need someone to help you get up: 21%
- Go to the emergency room (ER) or hospital because of the fall: 14%
- Go to your doctor or medical provider because of the fall: 12%
- None of the above: 67%

*Multiple responses allowed
Do you have tooth or mouth problems that make it hard for you to eat? (n=306)

- Yes: 19%
- No: 81%
If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending? (n=305)

- Very: 8%
- Somewhat: 25%
- A little: 19%
- Not very: 48%

If a little or not very [interested in attending a workshop], why not?* (n=175)

- Information is not helpful to me/I don't need it: 57%
- Other: 20%
- I don't like group activities: 18%
- It depends how far away it is: 10%
- Transportation issues: 6%

*Multiple responses allowed
In the last 6 months, have you ever gone without your medications because you cannot afford them? (n=308)

- Yes: 7%
- No: 86%
- In the last 6 months, I haven't needed to take any medications: 7%

Do you have difficulty doing any of the following on your own?* (n=300)

- Daily household tasks, such as laundry and vacuuming: 17%
- Personal care activities, such as bathing or dressing: 5%
- Organizing or managing your medications: 2%
- No, I do not have difficulty with any of these tasks: 83%

*Multiple responses allowed
Are you currently receiving in-home help with any of those tasks from another person? (n=53)

- Yes: 30%
- No: 70%

If you are not receiving all the help you need with those tasks, is it because* (n=31)

- You do not want it: 39%
- You cannot afford it: 33%
- You do not know how to get help: 25%
- There is no help available: 4%
- Other: 8%
- Recoded other: reluctant to ask†: 8%
- You are receiving all of the help you need: 22%

*Multiple responses allowed

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Do you provide help regularly for any of the following individuals?* (n=297)

- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person) - 4%
- Yes, I care for an adult age 60 or older (include spouse or parent) - 5%
- Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18 - 17%
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person) - 76%

*Multiple responses allowed
What type of support do you provide to this person/people?* (n=61)

- Food or meal preparation: 69%
- Transportation: 60%
- Financial management: 55%
- Daily household tasks: 49%
- Help with medications: 40%
- Financial support: 38%
- Medical care: 36%
- Help with personal care such as bathing and dressing: 32%
- Other: 7%
- Recoded other: emotional support†: 7%
- Recoded other: memory support†: 4%
- Recoded other: companionship, visits, check-ins†: 3%
- Recoded other: maintenance and repair†: 1%
- Recoded other: power of attorney†: 0%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
What are your top needs as a caregiver for this person/people?* (n=47)

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional in-home support, help providing care</td>
<td>34%</td>
</tr>
<tr>
<td>Respite (rest, reprieve or break)</td>
<td>26%</td>
</tr>
<tr>
<td>Information and referral</td>
<td>19%</td>
</tr>
<tr>
<td>Support groups</td>
<td>18%</td>
</tr>
<tr>
<td>Transportation assistance</td>
<td>14%</td>
</tr>
<tr>
<td>Caregiver training/education</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
<tr>
<td>Recoded other: none†</td>
<td></td>
</tr>
<tr>
<td>Recoded other: financial†</td>
<td>0%</td>
</tr>
<tr>
<td>Recoded other: housing†</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How difficult is it to find information you need about available services and programs for older adults and their caregivers? (n=293)

- Very difficult: 7%
- Somewhat difficult: 24%
- Not difficult at all: 27%
- Haven't tried: 43%

What are the best ways for you to get information about available services for older adults or caregivers?* (n=292)
*Multiple responses allowed

- Doctor/health care provider: 52%
- Word of mouth: 50%
- Internet: 48%
- TV: 41%
- Newsletters or flyers in mail: 32%
- Newspaper: 28%
- Communication with a state or local agency: 20%
- Radio: 18%
- Senior or community Center: 14%
- Other: 4%

Recoded other: community (town office/city hall/library)† 1%
Recoded other: family members† <1%
Recoded other: church† <1%
Recoded other: I don’t need information† 0%

†“Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed
Information & Services

Aroostook Agency on Aging

Appendix C

How do you primarily access the Internet?* (n=304)

- From my personal home computer: 65%
- I don't access the Internet: 20%
- From my cell phone: 19%
- At a friend’s or family home: 2%
- From a public library or other community space: 1%

Have you called any of these organizations or looked them up online?* (n=298)

- Aroostook Area Agency on Aging: 34%
- Legal Services for the Elderly: 9%
- Maine 211: 2%
- The Long-Term Care Ombudsman Program: 2%
- Spectrum Generations: 1%
- Eastern Area Agency on Aging: 1%
- Southern Maine Agency on Aging: 1%
- SeniorsPlus: <1%
- I haven't called or looked up any of these organizations: 63%

*Multiple responses allowed
In the last 6 months, have you needed help with any of the following?*  (n=284)

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare or other health insurance</td>
<td>21%</td>
</tr>
<tr>
<td>Transportation</td>
<td>10%</td>
</tr>
<tr>
<td>Legal services</td>
<td>6%</td>
</tr>
<tr>
<td>Food or meals</td>
<td>5%</td>
</tr>
<tr>
<td>General information about community</td>
<td>5%</td>
</tr>
<tr>
<td>Managing finances</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
</tr>
<tr>
<td>On-going help getting connected to</td>
<td>4%</td>
</tr>
<tr>
<td>services and benefits</td>
<td></td>
</tr>
<tr>
<td>Finding volunteer opportunities</td>
<td>4%</td>
</tr>
<tr>
<td>Help in resolving problems with home</td>
<td>2%</td>
</tr>
<tr>
<td>care services</td>
<td></td>
</tr>
<tr>
<td>Respite or caregiver support</td>
<td>1%</td>
</tr>
<tr>
<td>Adult day services</td>
<td>1%</td>
</tr>
<tr>
<td>I have not needed help with any of the</td>
<td>59%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*
Information & Services

Did you get all the help you needed? (n=117)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>66%</td>
<td>34%</td>
</tr>
</tbody>
</table>

Why [did you not get all the help you needed]?* (n=42)

- I don't qualify for help: 38%
- I can't afford the help I need: 38%
- I don't know who to ask: 32%
- I prefer not to ask for help: 23%
- Services are not available: 21%
- There are waitlists for services: 12%
- Culture or language difficulties: 0%
- Fear of discrimination: 0%
- Other: 3%
- Recoded other: difficulty with insurance†: 7%
- Recoded other: agency not helpful‡: 3%
- Recoded other: too confusing, frustrating, overwhelming, etc.†: 0%

*Multiple responses allowed

†"Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

‡"Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How would you rate your community as a place to live for people as they age? (n=301)

- Excellent: 15%
- Very good: 29%
- Good: 36%
- Fair: 13%
- Poor: 5%
- Not sure: 2%
2019 Maine Aging Study:
Eastern Area Agency on Aging

Muskie School of Public Service
Cutler Institute for Health and Social Policy

March 6, 2020
What county do you live in? (n=456)

- Penobscot: 60%
- Hancock: 24%
- Washington: 10%
- Piscataquis: 6%
**Demographics**

**What is your age? (n=456)**

- 55 to 64: 45%
- 65 to 74: 32%
- 75 to 84: 18%
- 85 to 94: 4%
- 95 or older: <1%

**How many people live in your household? (n=444)**

- 1: 33%
- 2: 54%
- 3: 9%
- 4: 2%
- ≥5: 3%

**Which of the following statements best describes who lives with you?* (n=448)**

- I live with a spouse: 58%
- I live alone: 32%
- I live with other family members (adult children, other relatives): 15%
- Other: 3%
- I live with friends, roommates: 1%
- Recoded other: I live with pet(s): 1%

*Multiple responses allowed

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Demographics

Please specify your race and ethnicity (n=438)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>99%</td>
</tr>
<tr>
<td>Native American or Alaskan Native</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
</tr>
</tbody>
</table>

Do you consider yourself Hispanic or Latino? (n=435)

Approximately 100% of respondents said "no."

Is English your primary or preferred language? (n=455)

Approximately 99% of respondents said "yes."
### Demographics

#### What was your sex at birth (meaning, on your original birth certificate)? (n=449)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>45%</td>
</tr>
<tr>
<td>Female</td>
<td>55%</td>
</tr>
<tr>
<td>Intersex</td>
<td>0%</td>
</tr>
</tbody>
</table>

#### What is your current gender identity? (n=447)

<table>
<thead>
<tr>
<th>Gender Identity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>46%</td>
</tr>
<tr>
<td>Female</td>
<td>54%</td>
</tr>
<tr>
<td>Transgender</td>
<td>0%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
</tr>
</tbody>
</table>

#### Do you think of yourself as: (n=443)

<table>
<thead>
<tr>
<th>Identity Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Straight, that is, not gay or lesbian</td>
<td>96%</td>
</tr>
<tr>
<td>Lesbian or gay</td>
<td>2%</td>
</tr>
<tr>
<td>Not sure</td>
<td>1%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>1%</td>
</tr>
<tr>
<td>Not listed above</td>
<td>0%</td>
</tr>
</tbody>
</table>
What is the highest level of formal education you have completed so far? (n=451)

- Graduate school: 22%
- College degree: 28%
- Some college or technical training: 18%
- High school graduate: 18%
- Some high school: 2%
- Grammar school (up to 8th grade): 1%

What is your current employment status? (n=436)

- Fully retired: 52%
- Working part time: 13%
- Working full time: 33%
- Seasonal: 1%

Which of the following categories represents your annual household income? (n=456)

- <$20K: 21%
- $20K to <$40K: 23%
- $40K to <$60K: 18%
- $60K to <$75K: 10%
- ≥$75K: 27%
How do you usually get around to the places you need to go?*  (n=453)

- Drive myself: 92%
- Friends/family: 18%
- Walk/bike: 9%
- Public transportation: 4%
- Rarely leave house: 4%
- Taxi, Uber, Lyft: 3%
- Volunteer service: 2%

Do you need help finding or arranging transportation?  (n=454)

- Yes: 5%
- No: 95%

*Multiple responses allowed
In the last 90 days, were you unable to do any of the following because you did not have transportation?* (n=434)

- Grocery shop or go to pharmacy: 6%
- Go to social activity important to you: 4%
- Get to health care appointment: 3%
- I was able to do all these things: 92%

If you needed transportation and could not get it, what would you say are the main reasons?* (n=35)

- Other reason: 38%
- No transportation services in my area: 37%
- Financial reasons: 31%
- Health-related reasons: 28%
- Don't have family or friends who can drive me: 21%
- Don't know where to get information about services in my area: 9%
- Language barrier: 4%

*Multiple responses allowed
How would you describe your current living situation?  (n=455)

- Own my home: 79%
- Rent: 18%
- Live with family or friends: 2%
- Other: 2%
- Homeless, looking for housing: 0%

Does your home meet your current needs?  (n=453)

- Yes: 91%
- No: 9%
Housing

[If your home does not meet your current needs,] why not? (n=38)

- Home needs repairs that I cannot afford (roof, flooring, stairs, etc.) 64%
- I cannot afford taxes, rent, mortgage or utilities 38%
- Home requires too much upkeep, maintenance 37%
- Home needs changes to meet physical needs (ramp, bathroom changes, doors... 31%
- Other 21%
- Recoded other: I need a first-floor home because stairs are a challenge 8%
- Recoded other: home is too small and/or lacks adequate storage 0%
- Recoded other: home is difficult to heat/I can't regulate the heat 0%

Recoded other: home is too small and/or lacks adequate storage†
Recoded other: I need a first-floor home because stairs are a challenge†
Recoded other: home is difficult to heat/I can't regulate the heat†

*Multiple responses allowed

Are you able to heat your home to a comfortable temperature in the winter? (n=38)

- Yes 49%
- No 51%

† “Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Do you usually have enough money to buy the food you need? (n=456)

- Yes: 89%
- No: 11%

Do you use food pantries or participate in a food assistance program (such as SNAP)? (n=456)

- Yes: 14%
- No: 86%
How often do you eat at a community meal site for your main meals? (n=451)

- Rarely/Never: 95%
- Sometimes: 4%
- Frequently/Always: 1%

If you only rarely or sometimes eat at a community meal site for your main meals, what is the reason?* (n=412)

- I don't need it: 81%
- I don't like eating in a community group setting: 10%
- I don't know how to find out about this in my community: 5%
- I don't have transportation: 4%
- I don't like where the meal site is located: 1%
- Other: 5%
- Recoded other: none available/too infrequent/too far away†: 2%
- Recoded other: food is not good/I require special diet†: 1%
- Recoded other: I prefer to stay home†: <1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Do you have difficulty preparing or cooking your main meals? (n=455)

- Yes: 5%
- No: 95%

Are you able to leave home without assistance or considerable effort? (n=24)

- Yes: 64%
- No: 36%
Do you participate in a home delivered meal program (Meals on Wheels)?  (n=8)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

[If you do not participate in a home delivered meal program], why not?*  (n=6)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

*Multiple responses allowed
In general, would you say your physical health is:  (n=454)

- Excellent: 15%
- Very good: 34%
- Good: 28%
- Fair: 19%
- Poor: 5%

Do you have concerns about your own memory?  (n=449)

- Yes: 29%
- No: 71%

Do you have concerns about the memory of someone you care for?  (n=444)

- Yes: 23%
- No: 77%
In the last 6 months, how often have you felt lonely and disconnected from other people? (n=452)

- Never: 41%
- Hardly ever: 28%
- Sometimes: 24%
- Often/always: 8%

Please check the statements below that reflect the concerns you have for your personal safety.* (n=443)

- I fear that someone will take advantage of me (i.e., phone scam, take my money or possessions): 8%
- I worry about the safety of my neighborhood: 6%
- I fear that someone might steal my money or valuables: 4%
- I fear some members of my family or other people I know: 3%
- I fear that people may steal my medications: 1%
- None of the above concern me: 84%

*Multiple responses allowed
Have you fallen in the last 6 months? (n=451)

- Yes: 22%
- No: 78%

When you fell in the last 6 months, did you have to:* (n=99)

- Need someone to help you get up: 29%
- Go to your doctor or medical provider because of the fall: 13%
- Go to the emergency room (ER) or hospital because of the fall: 10%
- None of the above: 57%

*Multiple responses allowed
Do you have tooth or mouth problems that make it hard for you to eat? (n=455)

- Yes: 20%
- No: 80%
If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending? (n=449)

- Very: 8%
- Somewhat: 20%
- A little: 21%
- Not very: 51%

If a little or not very [interested in attending a workshop], why not?* (n=295)

- Information is not helpful to me/I don't need it: 61%
- Other: 21%
- I don't like group activities: 15%
- It depends how far away it is: 13%
- Transportation issues: 6%

*Multiple responses allowed
In the last 6 months, have you ever gone without your medications because you cannot afford them? (n=452)

- Yes: 7%
- No: 84%
- In the last 6 months, I haven't needed to take any medications: 10%

Do you have difficulty doing any of the following on your own?* (n=452)

- Daily household tasks, such as laundry and vacuuming: 13%
- Personal care activities, such as bathing or dressing: 4%
- Organizing or managing your medications: 3%
- No, I do not have difficulty with any of these tasks: 86%

*Multiple responses allowed
Are you currently receiving in-home help with any of those tasks from another person? (n=62)

- Yes: 43%
- No: 57%

If you are not receiving all the help you need with those tasks, is it because* (n=37)

- You cannot afford it: 46%
- There is no help available: 30%
- You do not know how to get help: 22%
- You do not want it: 6%
- Other: 15%
- Recoded other: reluctant to ask†: 15%
- You are receiving all of the help you need: 20%

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed
Do you provide help regularly for any of the following individuals?* (n=443)

- No, I do not provide any caregiving supports to others: 77%
- Yes, I care for an adult age 60 or older (include spouse or parent): 15%
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person): 6%
- Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18: 4%

*Multiple responses allowed
**What type of support do you provide to this person/people?** *(n=91)*

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>71%</td>
</tr>
<tr>
<td>Food or meal preparation</td>
<td>62%</td>
</tr>
<tr>
<td>Financial management</td>
<td>53%</td>
</tr>
<tr>
<td>Daily household tasks</td>
<td>48%</td>
</tr>
<tr>
<td>Help with medications</td>
<td>47%</td>
</tr>
<tr>
<td>Medical care</td>
<td>43%</td>
</tr>
<tr>
<td>Financial support</td>
<td>33%</td>
</tr>
<tr>
<td>Help with personal care such as bathing and dressing</td>
<td>31%</td>
</tr>
<tr>
<td>Other</td>
<td>11%</td>
</tr>
<tr>
<td>Recoded other: companionship, visits, check-ins†</td>
<td>6%</td>
</tr>
<tr>
<td>Recoded other: emotional support†</td>
<td>3%</td>
</tr>
<tr>
<td>Recoded other: maintenance and repair†</td>
<td>0%</td>
</tr>
<tr>
<td>Recoded other: power of attorney†</td>
<td>0%</td>
</tr>
<tr>
<td>Recoded other: memory support†</td>
<td>0%</td>
</tr>
</tbody>
</table>

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed*
What are your top needs as a caregiver for this person/people?* (n=69)

- Respite (rest, reprieve or break) 39%
- Additional in-home support, help providing care 34%
- Transportation assistance 28%
- Information and referral 17%
- Caregiver training/education 8%
- Support groups 3%
- Other 9%
- Recoded other: none† 8%
- Recoded other: financial† 6%
- Recoded other: housing† 3%

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed
How difficult is it to find information you need about available services and programs for older adults and their caregivers? (n=446)

- Very difficult: 9%
- Somewhat difficult: 18%
- Not difficult at all: 25%
- Haven't tried: 48%

What are the best ways for you to get information about available services for older adults or caregivers?* (n=442)

- Internet: 68%
- Doctor/health care provider: 52%
- Word of mouth: 40%
- Communication with a state or local agency: 28%
- Newspaper: 28%
- TV: 28%
- Newsletters or flyers in mail: 26%
- Senior or community Center: 15%
- Radio: 11%
- Other: 5%

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.

*Multiple responses allowed
### How do you primarily access the Internet?* (n=453)

<table>
<thead>
<tr>
<th>Access Method</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>From my personal home computer</td>
<td>74%</td>
</tr>
<tr>
<td>From my cell phone</td>
<td>22%</td>
</tr>
<tr>
<td>I don't access the Internet</td>
<td>7%</td>
</tr>
<tr>
<td>From a public library or other community space</td>
<td>1%</td>
</tr>
<tr>
<td>At a friend’s or family home</td>
<td>1%</td>
</tr>
</tbody>
</table>

### Have you called any of these organizations or looked them up online?* (n=446)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern Area Agency on Aging</td>
<td>32%</td>
</tr>
<tr>
<td>Maine 211</td>
<td>5%</td>
</tr>
<tr>
<td>Southern Maine Agency on Aging</td>
<td>4%</td>
</tr>
<tr>
<td>Legal Services for the Elderly</td>
<td>4%</td>
</tr>
<tr>
<td>SeniorsPlus</td>
<td>2%</td>
</tr>
<tr>
<td>The Long-Term Care Ombudsman Program</td>
<td>2%</td>
</tr>
<tr>
<td>Aroostook Area Agency on Aging</td>
<td>1%</td>
</tr>
<tr>
<td>Spectrum Generations</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>I haven't called or looked up any of these</td>
<td>65%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*
In the last 6 months, have you needed help with any of the following?*  (n=438)

- Medicare or other health insurance questions: 15%
- Transportation: 8%
- General information about community resources: 7%
- Food or meals: 7%
- Legal services: 6%
- On-going help getting connected to services and benefits: 5%
- Managing finances: 4%
- Respite or caregiver support: 3%
- Other: 3%
- Help in resolving problems with home care services: 2%
- Finding volunteer opportunities: 2%
- Adult day services: 1%
- I have not needed help with any of the following items: 67%

*Multiple responses allowed
Did you get all the help you needed? (n=146)

- Yes: 46%
- No: 54%

Why [did you not get all the help you needed]?* (n=74)

- Services are not available: 42%
- I don't qualify for help: 36%
- I don't know who to ask: 34%
- I can't afford the help I need: 33%
- There are waitlists for services: 13%
- Fear of discrimination: 3%
- Culture or language difficulties: 3%
- I prefer not to ask for help: 3%
- Other: 11%

- Recoded other: agency not helpful†: 4%
- Recoded other: too confusing, frustrating, overwhelming, etc.†: 3%
- Recoded other: difficulty with insurance†: 2%

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed
How would you rate your community as a place to live for people as they age? (n=451)

- Excellent: 10%
- Very good: 24%
- Good: 30%
- Fair: 23%
- Poor: 7%
- Not sure: 6%
2019 Maine Aging Study: SeniorsPlus

Muskie School of Public Service
Cutler Institute for Health and Social Policy

March 6, 2020
Demographics

What county do you live in? (n=424)

- Androscoggin: 51%
- Oxford: 34%
- Franklin: 15%

SeniorsPlus: 100%
**Demographics**

**What is your age? (n=424)**

- 55 to 64: 46%
- 65 to 74: 32%
- 75 to 84: 17%
- 85 to 94: 5%
- ≥ 95: <1%

**How many people live in your household? (n=398)**

- 1: 28%
- 2: 59%
- 3: 8%
- 4: 5%
- ≥ 5: <1%

**Which of the following statements best describes who lives with you?* (n=416)**

- I live with a spouse: 64%
- I live alone: 28%
- I live with other family members (adult children, other relatives): 14%
- I live with friends, roommates: 2%
- Other: 1%
- Recoded other: I live with pet(s)†: <1%

*“Recoded other” item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed*
### Demographics

#### Please specify your race and ethnicity (n=409)

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>99%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Other</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>0%</td>
</tr>
<tr>
<td>Native American or Alaskan Native</td>
<td>0%</td>
</tr>
</tbody>
</table>

#### Do you consider yourself Hispanic or Latino? (n=398)

Approximately 100% of respondents said "no."

#### Is English your primary or preferred language? (n=417)

Approximately 100% of respondents said "yes."
### Demographics

**What was your sex at birth (meaning, on your original birth certificate)?** (n=413)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>41%</td>
</tr>
<tr>
<td>Female</td>
<td>59%</td>
</tr>
<tr>
<td>Intersex</td>
<td>0%</td>
</tr>
</tbody>
</table>

**What is your current gender identity?** (n=392)

<table>
<thead>
<tr>
<th>Gender Identity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>43%</td>
</tr>
<tr>
<td>Female</td>
<td>57%</td>
</tr>
<tr>
<td>Transgender</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Do you think of yourself as:** (n=400)

<table>
<thead>
<tr>
<th>Identity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Straight, that is, not gay or lesbian</td>
<td>96%</td>
</tr>
<tr>
<td>Lesbian or gay</td>
<td>3%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>1%</td>
</tr>
<tr>
<td>Not listed above</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Not sure</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>
What is the highest level of formal education you have completed so far? (n=410)

- Graduate school: 18%
- College degree: 32%
- Some college or technical training: 28%
- High school graduate: 17%
- Some high school: 4%
- Grammar school (up to 8th grade): 1%

What is your current employment status? (n=399)

- Fully retired: 56%
- Working part time: 14%
- Working full time: 28%
- Seasonal: 1%

Which of the following categories represents your annual household income? (n=424)

- <$20K: 20%
- $20K to <$40K: 24%
- $40K to <$60K: 18%
- $60K to <$75K: 10%
- ≥$75K: 27%
## How do you usually get around to the places you need to go? (n=415)

<table>
<thead>
<tr>
<th>Method</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drive myself</td>
<td>93%</td>
</tr>
<tr>
<td>Friends/family</td>
<td>15%</td>
</tr>
<tr>
<td>Walk/bike</td>
<td>10%</td>
</tr>
<tr>
<td>Taxi, Uber, Lyft</td>
<td>2%</td>
</tr>
<tr>
<td>Rarely leave house</td>
<td>1%</td>
</tr>
<tr>
<td>Volunteer service</td>
<td>1%</td>
</tr>
<tr>
<td>Public transportation</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

## Do you need help finding or arranging transportation? (n=421)

- Yes: 5%
- No: 95%

*Multiple responses allowed*
In the last 90 days, were you unable to do any of the following because you did not have transportation?*  (n=394)

- Get to health care appointment: 4%
- Grocery shop or go to pharmacy: 2%
- Go to social activity important to you: 2%
- I was able to do all these things: 94%

If you needed transportation and could not get it, what would you say are the main reasons?*  (n=23)

- No transportation services in my area: 65%
- Health-related reasons: 60%
- Don't have family or friends who can drive me: 56%
- Financial reasons: 54%
- Don't know where to get information about services in my area: 19%
- Other reason: 11%
- Language barrier: 0%

*Multiple responses allowed
How would you describe your current living situation? (n=418)

- Own my home: 76%
- Rent: 21%
- Live with family or friends: 2%
- Other: 1%
- Homeless, looking for housing: 0%

Does your home meet your current needs? (n=396)

- Yes: 94%
- No: 6%
[If your home does not meet your current needs,] why not?* (n=32)

- Home needs repairs that I cannot afford (roof, flooring, stairs, etc.) 49%
- Home needs changes to meet physical needs (ramp, bathroom changes, doors...) 23%
- Home requires too much upkeep, maintenance 20%
- I cannot afford taxes, rent, mortgage or utilities 13%
- Other 11%
- Recoded other: home is too small and/or lacks adequate storage† 0%
- Recoded other: I need a first-floor home because stairs are a challenge† 7%
- Recoded other: home is difficult to heat/I can't regulate the heat† ~~~

Are you able to heat your home to a comfortable temperature in the winter? (n=41)

- Yes 59%
- No 41%

*Multiple responses allowed
Do you usually have enough money to buy the food you need? (n=419)

- Yes: 96%
- No: 4%

Do you use food pantries or participate in a food assistance program (such as SNAP)? (n=419)

- Yes: 12%
- No: 88%
How often do you eat at a community meal site for your main meals?  (n=410)

- Rarely/Never: 94%
- Sometimes: 5%
- Frequently/Always: <1%

If [you] only rarely or sometimes [eat at a community meal site for your main meals], what is the reason?*  (n=368)

- I don't need it: 87%
- I don't know how to find out about this in my community: 4%
- I don't like eating in a community group setting: 4%
- I don't have transportation: 2%
- I don't like where the meal site is located: <1%
- Other: 5%
- Recoded other: none available/too infrequent/too far away†: 2%
- Recoded other: I prefer to stay home†: 1%
- Recoded other: food is not good/I require special diet†: <1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Do you have difficulty preparing or cooking your main meals? (n=412)

- Yes: 4%
- No: 96%

Are you able to leave home without assistance or considerable effort? (n=21)

- Yes: 51%
- No: 49%
Do you participate in a home delivered meal program (Meals on Wheels)?  (n=10)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

[If you do not participate in a home delivered meal program], why not?*  (n=5)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

*Multiple responses allowed
In general, would you say your physical health is: (n=422)

- Excellent: 13%
- Very good: 37%
- Good: 31%
- Fair: 14%
- Poor: 5%

Do you have concerns about your own memory? (n=419)
- Yes: 25%
- No: 75%

Do you have concerns about the memory of someone you care for? (n=408)
- Yes: 23%
- No: 77%
In the last 6 months, how often have you felt lonely and disconnected from other people? (n=423)

- Never: 42%
- Hardly ever: 31%
- Sometimes: 21%
- Often/always: 6%

Please check the statements below that reflect the concerns you have for your personal safety.* (n=403)

- I fear that someone will take advantage of me (i.e., phone scam, take my money or possessions): 12%
- I fear that someone might steal my money or valuables: 7%
- I worry about the safety of my neighborhood: 7%
- I fear some members of my family or other people I know: 2%
- I fear that people may steal my medications: 1%
- None of the above concern me: 80%

*Multiple responses allowed
Have you fallen in the last 6 months? (n=420)

- Yes: 24%
- No: 76%

When you fell in the last 6 months, did you have to:* (n=100)

- Need someone to help you get up: 12%
- Go to your doctor or medical provider because of the fall: 8%
- Go to the emergency room (ER) or hospital because of the fall: 7%
- None of the above: 78%

*Multiple responses allowed*
Do you have tooth or mouth problems that make it hard for you to eat? (n=421)

- Yes: 13%
- No: 87%
If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending? (n=409)

- Very: 8%
- Somewhat: 20%
- A little: 18%
- Not very: 54%

If a little or not very [interested in attending a workshop], why not?*  (n=274)

- Information is not helpful to me/I don't need it: 59%
- Other: 22%
- I don't like group activities: 12%
- Transportation issues: 8%
- It depends how far away it is: 7%

*Multiple responses allowed
In the last 6 months, have you ever gone without your medications because you cannot afford them? (n=422)

- Yes: 6%
- No: 84%
- In the last 6 months, I haven't needed to take any medications: 10%

Do you have difficulty doing any of the following on your own?* (n=422)

- Daily household tasks, such as laundry and vacuuming: 13%
- Personal care activities, such as bathing or dressing: 5%
- Organizing or managing your medications: 4%
- No, I do not have difficulty with any of these tasks: 87%

*Multiple responses allowed
### Are you currently receiving in-home help with any of those tasks from another person? (n=56)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>47%</td>
<td>53%</td>
</tr>
</tbody>
</table>

### If you are not receiving all the help you need with those tasks, is it because* (n=25)

- You cannot afford it: 40%
- You do not know how to get help: 31%
- There is no help available: 24%
- You do not want it: 16%
- Other: 8%
- Recoded other: reluctant to ask†: 8%
- You are receiving all of the help you need: 12%

*Multiple responses allowed

† “Recoded other” item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Do you provide help regularly for any of the following individuals?* (n=412)

- No, I do not provide any caregiving supports to others: 75%
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person): 18%
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person): 5%
- Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18: 3%

*Multiple responses allowed
### What type of support do you provide to this person/people?* (n=92)

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily household tasks</td>
<td>62%</td>
</tr>
<tr>
<td>Food or meal preparation</td>
<td>62%</td>
</tr>
<tr>
<td>Transportation</td>
<td>62%</td>
</tr>
<tr>
<td>Medical care</td>
<td>44%</td>
</tr>
<tr>
<td>Help with medications</td>
<td>40%</td>
</tr>
<tr>
<td>Financial management</td>
<td>38%</td>
</tr>
<tr>
<td>Financial support</td>
<td>23%</td>
</tr>
<tr>
<td>Help with personal care such as bathing and dressing</td>
<td>21%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

Recoded other: companionship, visits, check-ins† | 5%          |
Recoded other: power of attorney†              | 1%          |
Recoded other: maintenance and repair†        | 1%          |
Recoded other: emotional support†              | <1%         |
Recoded other: memory support†                 | 0%          |

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
### Caregiving

#### What are your top needs as a caregiver for this person/people?* (n=70)

<table>
<thead>
<tr>
<th>Need</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite (rest, reprieve or break)</td>
<td>47%</td>
</tr>
<tr>
<td>Additional in-home support, help providing care</td>
<td>32%</td>
</tr>
<tr>
<td>Information and referral</td>
<td>18%</td>
</tr>
<tr>
<td>Transportation assistance</td>
<td>14%</td>
</tr>
<tr>
<td>Support groups</td>
<td>11%</td>
</tr>
<tr>
<td>Caregiver training/education</td>
<td>8%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
</tr>
<tr>
<td>Recoded other: none†</td>
<td>8%</td>
</tr>
<tr>
<td>Recoded other: financial†</td>
<td>5%</td>
</tr>
<tr>
<td>Recoded other: housing†</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How difficult is it to find information you need about available services and programs for older adults and their caregivers? (n=412)

- Very difficult: 8%
- Somewhat difficult: 14%
- Not difficult at all: 25%
- Haven’t tried: 53%

What are the best ways for you to get information about available services for older adults or caregivers?* (n=398)

- Internet: 71%
- Doctor/health care provider: 49%
- Word of mouth: 37%
- TV: 30%
- Newspaper: 29%
- Newsletters or flyers in mail: 24%
- Senior or community Center: 22%
- Communication with a state or local agency: 19%
- Radio: 9%
- Other: 2%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
How do you primarily access the Internet?* (n=419)

- From my personal home computer: 74%
- From my cell phone: 20%
- I don't access the Internet: 8%
- From a public library or other community space: 2%
- At a friend’s or family home: 1%

Have you called any of these organizations or looked them up online?* (n=411)

- SeniorsPlus: 22%
- Legal Services for the Elderly: 7%
- Maine 211: 5%
- Southern Maine Agency on Aging: 5%
- The Long-Term Care Ombudsman Program: 3%
- Eastern Area Agency on Aging: 1%
- Spectrum Generations: 1%
- Aroostook Area Agency on Aging: 0%
- I haven't called or looked up any of these organizations: 72%

*Multiple responses allowed
In the last 6 months, have you needed help with any of the following?* (n=390)

- Medicare or other health insurance questions: 14%
- General information about community resources: 10%
- Transportation: 7%
- Legal services: 5%
- Food or meals: 5%
- On-going help getting connected to services and benefits: 4%
- Other: 4%
- Managing finances: 4%
- Finding volunteer opportunities: 3%
- Respite or caregiver support: 2%
- Help in resolving problems with home care services: 1%
- Adult day services: 1%
- I have not needed help with any of the following items: 71%

*Multiple responses allowed
Did you get all the help you needed? (n=129)

- Yes: 62%
- No: 38%

Why [did you not get all the help you needed]?* (n=49)

- Services are not available: 47%
- I don't qualify for help: 34%
- There are waitlists for services: 27%
- I can't afford the help I need: 20%
- I prefer not to ask for help: 13%
- Fear of discrimination: 9%
- Culture or language difficulties: 5%
- I don't know who to ask: 5%
- Other: 0%

*Multiple responses allowed

† Recoded other* items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How would you rate your community as a place to live for people as they age? (n=405)

- Excellent: 8%
- Very good: 28%
- Good: 32%
- Fair: 19%
- Poor: 6%
- Not sure: 8%
2019 Maine Aging Study:
Southern Maine Agency on Aging

Muskie School of Public Service
Cutler Institute for Health and Social Policy

March 6, 2020
What county do you live in? (n=596)

- Cumberland: 63%
- York: 37%

100%
Demographics

Southern Maine Agency on Aging

Survey Research Center

Appendix C

What is your age? (n=596)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>55 to 64</td>
<td>46%</td>
</tr>
<tr>
<td>65 to 74</td>
<td>31%</td>
</tr>
<tr>
<td>75 to 84</td>
<td>19%</td>
</tr>
<tr>
<td>85 to 94</td>
<td>3%</td>
</tr>
<tr>
<td>95 or older</td>
<td>0%</td>
</tr>
</tbody>
</table>

How many people live in your household? (n=567)

<table>
<thead>
<tr>
<th>Number of People</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>29%</td>
</tr>
<tr>
<td>2</td>
<td>57%</td>
</tr>
<tr>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>≥5</td>
<td>2%</td>
</tr>
</tbody>
</table>

Which of the following statements best describes who lives with you?* (n=586)

- I live with a spouse: 57%
- I live alone: 30%
- I live with other family members (adult children, other relatives): 17%
- I live with friends, roommates: 3%
- Other: 1%
- Recoded other: I live with pet(s): 1%

*Multiple responses allowed

† “Recoded other” item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Please specify your race and ethnicity (n=573)

- **White**: 98%
- **Multiracial**: 1%
- **Asian/Pacific Islander**: <1%
- **Other**: <1%
- **Native American or Alaskan Native**: <1%
- **Black or African American**: <1%

**Do you consider yourself Hispanic or Latino? (n=573)**

Approximately 100% of respondents said "no."

**Is English your primary or preferred language? (n=592)**

Approximately 99% of respondents said "yes."
**Demographics**

**What was your sex at birth (meaning, on your original birth certificate)?** (n=589)
- Male: 43%
- Female: 57%
- Intersex: 0%

**What is your current gender identity?** (n=582)
- Male: 42%
- Female: 58%
- Transgender: <1%
- Other: 0%

**Do you think of yourself as:** (n=564)
- Straight, that is, not gay or lesbian: 96%
- Lesbian or gay: 3%
- Bisexual: 1%
- Not sure: <1%
- Not listed above: 0%
What is the highest level of formal education you have completed so far? (n=586)

- Graduate school: 32%
- College degree: 30%
- Some college or technical training: 27%
- High school graduate: 10%
- Some high school: 1%
- Grammar school (up to 8th grade): <1%

What is your current employment status? (n=561)

- Fully retired: 51%
- Working part time: 18%
- Working full time: 29%
- Seasonal: 1%

Which of the following categories represents your annual household income? (n=596)

- <$20K: 15%
- $20K to <$40K: 18%
- $40K to <$60K: 15%
- $60K to <$75K: 10%
- ≥$75K: 42%
### Transportation

**How do you usually get around to the places you need to go?** (n=595)

<table>
<thead>
<tr>
<th>Method</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drive myself</td>
<td>93%</td>
</tr>
<tr>
<td>Friends/family</td>
<td>16%</td>
</tr>
<tr>
<td>Walk/bike</td>
<td>15%</td>
</tr>
<tr>
<td>Taxi, Uber, Lyft</td>
<td>6%</td>
</tr>
<tr>
<td>Public transportation</td>
<td>6%</td>
</tr>
<tr>
<td>Volunteer service</td>
<td>2%</td>
</tr>
<tr>
<td>Rarely leave house</td>
<td>1%</td>
</tr>
</tbody>
</table>

**Do you need help finding or arranging transportation?** (n=585)

- **Yes**: 2%
- **No**: 98%

*Multiple responses allowed*
In the last 90 days, were you unable to do any of the following because you did not have transportation?*  (n=567)

- Go to social activity important to you: 5%
- Get to health care appointment: 4%
- Grocery shop or go to pharmacy: 4%
- I was able to do all these things: 92%

If you needed transportation and could not get it, what would you say are the main reasons?*  (n=40)

- No transportation services in my area: 45%
- Financial reasons: 43%
- Don't have family or friends who can drive me: 42%
- Other reason: 38%
- Health-related reasons: 29%
- Don't know where to get information about services in my area: 25%
- Language barrier: 0%

*Multiple responses allowed
How would you describe your current living situation? (n=587)

- Own my home: 77%
- Rent: 20%
- Live with family or friends: 2%
- Other: 1%
- Homeless, looking for housing: 0%

Does your home meet your current needs? (n=587)

- Yes: 94%
- No: 6%
### Housing

#### Are you able to heat your home to a comfortable temperature in the winter? (n=42)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>63%</td>
<td>37%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*

---

#### [If your home does not meet your current needs,] why not?* (n=36)

- **Home needs repairs that I cannot afford (roof, flooring, stairs, etc.):** 52%
- **Home needs changes to meet physical needs (ramp, bathroom changes, doors...):** 35%
- **Home requires too much upkeep, maintenance:** 35%
- **I cannot afford taxes, rent, mortgage or utilities:** 13%
- **Other:** 14%
- **Recoded other: I need a first-floor home because stairs are a challenge†:** 2%
- **Recoded other: home is too small and/or lacks adequate storage†:** 8%
- **Recoded other: home is difficult to heat/I can't regulate the heat†:** 2%

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Do you usually have enough money to buy the food you need?  (n=592)

- Yes: 93%
- No: 7%

Do you use food pantries or participate in a food assistance program (such as SNAP)?  (n=589)

- Yes: 92%
- No: 8%
How often do you eat at a community meal site for your main meals? (n=590)

- Rarely/Never: 98%
- Sometimes: 1%
- Frequently/Always: 1%

If [you] only rarely or sometimes [eat at a community meal site for your main meals], what is the reason?* (n=539)

- I don't need it: 88%
- I don't like eating in a community group setting: 8%
- I don't know how to find out about this in my community: 3%
- I don't have transportation: 3%
- I don't like where the meal site is located: 1%
- Other: 4%
- Recoded other: food is not good/I require special diet†: 2%
- Recoded other: none available/too infrequent/too far away†: <1%
- Recoded other: I prefer to stay home†: <1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Do you have difficulty preparing or cooking your main meals? (n=591)

- Yes: 3%
- No: 97%

Are you able to leave home without assistance or considerable effort? (n=20)

- Yes: 71%
- No: 29%
Do you participate in a home delivered meal program (Meals on Wheels)?  (n=6)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

[If you do not participate in a home delivered meal program], why not?*  (n=6)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

*Multiple responses allowed
In general, would you say your physical health is: (n=589)

- Excellent: 21%
- Very good: 35%
- Good: 26%
- Fair: 14%
- Poor: 3%

Do you have concerns about your own memory? (n=586)

- Yes: 22%
- No: 78%

Do you have concerns about the memory of someone you care for? (n=589)

- Yes: 18%
- No: 82%
**Health Status**

**In the last 6 months, how often have you felt lonely and disconnected from other people? (n=592)**

- Never: 47%
- Hardly ever: 27%
- Sometimes: 20%
- Often/always: 6%

**Please check the statements below that reflect the concerns you have for your personal safety.* (n=584)**

- I fear that someone will take advantage of me (i.e., phone scam, take my money or possessions): 10%
- I fear that someone might steal my money or valuables: 9%
- I worry about the safety of my neighborhood: 7%
- I fear that people may steal my medications: 2%
- I fear some members of my family or other people I know: 2%
- None of the above concern me: 82%

*Multiple responses allowed*
Have you fallen in the last 6 months? (n=590)

- Yes: 19%
- No: 81%

When you fell in the last 6 months, did you have to:* (n=113)

- Need someone to help you get up: 23%
- Go to your doctor or medical provider because of the fall: 22%
- Go to the emergency room (ER) or hospital because of the fall: 12%
- None of the above: 53%

*Multiple responses allowed*
Do you have tooth or mouth problems that make it hard for you to eat? (n=594)

- Yes: 13%
- No: 87%
If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending? (n=591)

- Very: 9%
- Somewhat: 21%
- A little: 15%
- Not very: 55%

If a little or not very [interested in attending a workshop], why not?* (n=400)

- Information is not helpful to me/I don’t need it: 68%
- Other: 22%
- I don’t like group activities: 11%
- It depends how far away it is: 5%
- Transportation issues: 3%

*Multiple responses allowed
In the last 6 months, have you ever gone without your medications because you cannot afford them? (n=590)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>3%</td>
<td>93%</td>
</tr>
</tbody>
</table>

In the last 6 months, I haven't needed to take any medications

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>3%</td>
<td>97%</td>
</tr>
</tbody>
</table>

Do you have difficulty doing any of the following on your own?* (n=584)

<table>
<thead>
<tr>
<th>Task</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily household tasks, such as laundry and vacuuming</td>
<td>10%</td>
</tr>
<tr>
<td>Personal care activities, such as bathing or dressing</td>
<td>3%</td>
</tr>
<tr>
<td>Organizing or managing your medications</td>
<td>1%</td>
</tr>
<tr>
<td>No, I do not have difficulty with any of these tasks</td>
<td>89%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed
Are you currently receiving in-home help with any of those tasks from another person? (n=69)

- Yes: 48%
- No: 52%

If you are not receiving all the help you need with those tasks, is it because* (n=30)

- You cannot afford it: 34%
- You do not want it: 26%
- You do not know how to get help: 16%
- There is no help available: 4%
- Other: 18%
- Recoded other: reluctant to ask†: 18%
- You are receiving all of the help you need: 16%

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.

*Multiple responses allowed
### Do you provide help regularly for any of the following individuals?* (n=585)

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, I do not provide any caregiving supports to others</td>
<td>81%</td>
</tr>
<tr>
<td>Yes, I care for an adult age 60 or older (include spouse or parent)</td>
<td>13%</td>
</tr>
<tr>
<td>Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18</td>
<td>4%</td>
</tr>
<tr>
<td>Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person)</td>
<td>3%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*
### What type of support do you provide to this person/people?* (n=91)

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>55%</td>
</tr>
<tr>
<td>Financial management</td>
<td>50%</td>
</tr>
<tr>
<td>Food or meal preparation</td>
<td>49%</td>
</tr>
<tr>
<td>Daily household tasks</td>
<td>46%</td>
</tr>
<tr>
<td>Help with medications</td>
<td>36%</td>
</tr>
<tr>
<td>Financial support</td>
<td>31%</td>
</tr>
<tr>
<td>Medical care</td>
<td>26%</td>
</tr>
<tr>
<td>Help with personal care such as bathing and dressing</td>
<td>22%</td>
</tr>
<tr>
<td>Other</td>
<td>13%</td>
</tr>
<tr>
<td>Recoded other: companionship, visits, check-ins†</td>
<td>6%</td>
</tr>
<tr>
<td>Recoded other: emotional support†</td>
<td>5%</td>
</tr>
<tr>
<td>Recoded other: power of attorney†</td>
<td>1%</td>
</tr>
<tr>
<td>Recoded other: maintenance and repair†</td>
<td>1%</td>
</tr>
<tr>
<td>Recoded other: memory support†</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
What are your top needs as a caregiver for this person/people?* (n=75)

<table>
<thead>
<tr>
<th>Need</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite (rest, reprieve or break)</td>
<td>31%</td>
</tr>
<tr>
<td>Additional in-home support, help providing care</td>
<td>28%</td>
</tr>
<tr>
<td>Transportation assistance</td>
<td>25%</td>
</tr>
<tr>
<td>Information and referral</td>
<td>25%</td>
</tr>
<tr>
<td>Support groups</td>
<td>10%</td>
</tr>
<tr>
<td>Caregiver training/education</td>
<td>5%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
</tr>
<tr>
<td>Recoded other: none†</td>
<td>11%</td>
</tr>
<tr>
<td>Recoded other: financial†</td>
<td>5%</td>
</tr>
<tr>
<td>Recoded other: housing†</td>
<td>4%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How difficult is it to find information you need about available services and programs for older adults and their caregivers? (n=588)

- Very difficult: 4%
- Somewhat difficult: 20%
- Not difficult at all: 27%
- Haven't tried: 49%

What are the best ways for you to get information about available services for older adults or caregivers?* (n=584)

- Internet: 75%
- Doctor/health care provider: 52%
- Word of mouth: 35%
- Newspaper: 29%
- Newsletters or flyers in mail: 27%
- TV: 27%
- Communication with a state or local agency: 24%
- Senior or community Center: 22%
- Radio: 11%
- Other: 2%
  - Recoded other: I don't need information: 1%
  - Recoded other: community (town office/city hall/library): 1%
  - Recoded other: church: <1%
  - Recoded other: family members: <1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
### How do you primarily access the Internet?* (n=594)

<table>
<thead>
<tr>
<th>Access Method</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>From my personal home computer</td>
<td>79%</td>
</tr>
<tr>
<td>From my cell phone</td>
<td>23%</td>
</tr>
<tr>
<td>I don't access the Internet</td>
<td>4%</td>
</tr>
<tr>
<td>From a public library or other community space</td>
<td>1%</td>
</tr>
<tr>
<td>At a friend’s or family home</td>
<td>1%</td>
</tr>
</tbody>
</table>

### Have you called any of these organizations or looked them up online?* (n=582)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Southern Maine Agency on Aging</td>
<td>28%</td>
</tr>
<tr>
<td>Legal Services for the Elderly</td>
<td>6%</td>
</tr>
<tr>
<td>Maine 211</td>
<td>5%</td>
</tr>
<tr>
<td>SeniorsPlus</td>
<td>2%</td>
</tr>
<tr>
<td>The Long-Term Care Ombudsman Program</td>
<td>1%</td>
</tr>
<tr>
<td>Spectrum Generations</td>
<td>1%</td>
</tr>
<tr>
<td>Eastern Area Agency on Aging</td>
<td>1%</td>
</tr>
<tr>
<td>Aroostook Area Agency on Aging</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>I haven't called or looked up any of these organizations</td>
<td>69%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*
In the last 6 months, have you needed help with any of the following?*  (n=570)

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare or other health insurance questions</td>
<td>16%</td>
</tr>
<tr>
<td>General information about community resources</td>
<td>7%</td>
</tr>
<tr>
<td>Legal services</td>
<td>6%</td>
</tr>
<tr>
<td>Transportation</td>
<td>6%</td>
</tr>
<tr>
<td>Managing finances</td>
<td>5%</td>
</tr>
<tr>
<td>Food or meals</td>
<td>5%</td>
</tr>
<tr>
<td>On-going help getting connected to services and benefits</td>
<td>4%</td>
</tr>
<tr>
<td>Finding volunteer opportunities</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td>Respite or caregiver support</td>
<td>2%</td>
</tr>
<tr>
<td>Help in resolving problems with home care services</td>
<td>1%</td>
</tr>
<tr>
<td>Adult day services</td>
<td>1%</td>
</tr>
<tr>
<td>I have not needed help with any of the following items</td>
<td>71%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*
Information & Services  
Southern Maine Agency on Aging

**Did you get all the help you needed? (n=172)**

- Yes: 62%
- No: 38%

**Why [did you not get all the help you needed]?* (n=67)**

- I don't know who to ask: 43%
- Services are not available: 30%
- I can't afford the help I need: 30%
- There are waitlists for services: 24%
- I don't qualify for help: 20%
- I prefer not to ask for help: 14%
- Fear of discrimination: 6%
- Culture or language difficulties: 1%
- Other: 14%
- Recoded other: difficulty with insurance†: 5%
- Recoded other: too confusing, frustrating, overwhelming, etc.†: 2%
- Recoded other: agency not helpful†: 1%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How would you rate your community as a place to live for people as they age? (n=587)

- Excellent: 18%
- Very good: 29%
- Good: 27%
- Fair: 15%
- Poor: 4%
- Not sure: 7%
2019 Maine Aging Study:
Spectrum Generations

Muskie School of Public Service
Cutler Institute for Health and Social Policy

March 6, 2020
What county do you live in? (n=470)

- Kennebec: 39%
- Somerset: 14%
- Sagadahoc: 13%
- Knox: 12%
- Lincoln: 12%
- Waldo: 10%
Demographics Spectrum Generations

What is your age? (n=470)

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>55 to 64</td>
<td>45%</td>
</tr>
<tr>
<td>65 to 74</td>
<td>33%</td>
</tr>
<tr>
<td>75 to 84</td>
<td>18%</td>
</tr>
<tr>
<td>85 to 94</td>
<td>5%</td>
</tr>
<tr>
<td>95 or older</td>
<td>0%</td>
</tr>
</tbody>
</table>

How many people live in your household? (n=459)

<table>
<thead>
<tr>
<th>Number Live</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>33%</td>
</tr>
<tr>
<td>2</td>
<td>54%</td>
</tr>
<tr>
<td>3</td>
<td>7%</td>
</tr>
<tr>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>≥5</td>
<td>1%</td>
</tr>
</tbody>
</table>

Which of the following statements best describes who lives with you?* (n=467)

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I live with a spouse</td>
<td>57%</td>
</tr>
<tr>
<td>I live alone</td>
<td>31%</td>
</tr>
<tr>
<td>I live with other family members (adult children, other relatives)</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
<tr>
<td>I live with friends, roommates</td>
<td>2%</td>
</tr>
<tr>
<td>Recoded other: I live with pet(s)†</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

† “Recoded other” item was created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Please specify your race and ethnicity (n=459)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>100%</td>
</tr>
<tr>
<td>Other</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>0%</td>
</tr>
<tr>
<td>Native American or Alaskan Native</td>
<td>0%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>0%</td>
</tr>
</tbody>
</table>

Do you consider yourself Hispanic or Latino? (n=458)

Approximately 100% of respondents said "no."

Is English your primary or preferred language? (n=469)

Approximately 100% of respondents said "yes."
What was your sex at birth (meaning, on your original birth certificate)? (n=461)

- Male: 46%
- Female: 54%
- Intersex: 0%

What is your current gender identity? (n=457)

- Male: 46%
- Female: 54%
- Transgender: 0%
- Other: 0%

Do you think of yourself as: (n=440)

- Straight, that is, not gay or lesbian: 93%
- Lesbian or gay: 3%
- Bisexual: 2%
- Not sure: 1%
- Not listed above: <1%
What is the highest level of formal education you have completed so far? (n=462)

- Graduate school: 22%
- College degree: 31%
- Some college or technical training: 26%
- High school graduate: 17%
- Some high school: 2%
- Grammar school (up to 8th grade): 1%

What is your current employment status? (n=447)

- Fully retired: 53%
- Working part time: 18%
- Working full time: 28%
- Seasonal: 1%

Which of the following categories represents your annual household income? (n=470)

- < $20K: 19%
- $20K to < $40K: 22%
- $40K to < $60K: 17%
- $60K to < $75K: 11%
- $75K+: 31%
How do you usually get around to the places you need to go?*  (n=469)

- Drive myself: 90%
- Friends/family: 20%
- Walk/bike: 14%
- Public transportation: 3%
- Taxi, Uber, Lyft: 3%
- Rarely leave house: 3%
- Volunteer service: 2%

Do you need help finding or arranging transportation?  (n=463)

- Yes: 7%
- No: 93%
In the last 90 days, were you unable to do any of the following because you did not have transportation?*  (n=441)

- Grocery shop or go to pharmacy: 7%
- Get to health care appointment: 5%
- Go to social activity important to you: 4%
- I was able to do all these things: 91%

If you needed transportation and could not get it, what would you say are the main reasons?*  (n=36)

- Don't know where to get information about services in my area: 46%
- No transportation services in my area: 41%
- Financial reasons: 40%
- Don't have family or friends who can drive me: 27%
- Other reason: 24%
- Health-related reasons: 17%
- Language barrier: 0%

*Multiple responses allowed
**How would you describe your current living situation? (n=465)**

- Own my home: 77%
- Rent: 17%
- Live with family or friends: 3%
- Other: 2%
- Homeless, looking for housing: 1%

**Does your home meet your current needs? (n=453)**

- Yes: 93%
- No: 7%
[If your home does not meet your current needs,] why not?* (n=33)

- Home needs repairs that I cannot afford (roof, flooring, stairs, etc.) 47%
- Home needs changes to meet physical needs (ramp, bathroom changes, doors...) 46%
- I cannot afford taxes, rent, mortgage or utilities 31%
- Home requires too much upkeep, maintenance 22%
- Other 10%
- Recoded other: home is difficult to heat/I can't regulate the heat† 7%
- Recoded other: I need a first-floor home because stairs are a challenge† 2%
- Recoded other: home is too small and/or lacks adequate storage† 0%

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.

Are you able to heat your home to a comfortable temperature in the winter? (n=36)

- Yes 50%
- No 50%

*Multiple responses allowed
Do you usually have enough money to buy the food you need? (n=456)

- Yes: 91%
- No: 9%

Do you use food pantries or participate in a food assistance program (such as SNAP)? (n=462)

- Yes: 13%
- No: 87%
How often do you eat at a community meal site for your main meals? (n=462)

- 92% Rarely/Never
- 6% Sometimes
- 2% Frequently/Always

If [you] only rarely or sometimes [eat at a community meal site for your main meals], what is the reason?* (n=413)

- 81% I don’t need it
- 9% I don’t like eating in a community group setting
- 6% I don’t know how to find out about this in my community
- 4% I don’t have transportation
- 2% I don’t like where the meal site is located
- 5% Other

Recoded other: none available/too infrequent/too far away†
Recoded other: I prefer to stay home†
Recoded other: food is not good/I require special diet†

*Multiple responses allowed
† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an “other” reason.
Do you have difficulty preparing or cooking your main meals? (n=460)

- Yes: 7%
- No: 93%

Are you able to leave home without assistance or considerable effort? (n=32)

- Yes: 46%
- No: 54%
Do you participate in a home delivered meal program (Meals on Wheels)? (n=19)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

[If you do not participate in a home delivered meal program], why not?* (n=15)

THERE ARE NOT ENOUGH RESPONSES TO REPORT

*Multiple responses allowed
In general, would you say your physical health is: (n=468)

- Excellent: 14%
- Very good: 34%
- Good: 33%
- Fair: 16%
- Poor: 3%

Do you have concerns about your own memory? (n=464)
- Yes: 31%
- No: 69%

Do you have concerns about the memory of someone you care for? (n=457)
- Yes: 21%
- No: 79%
### In the last 6 months, how often have you felt lonely and disconnected from other people? (n=462)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>41%</td>
</tr>
<tr>
<td>Hardly ever</td>
<td>26%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>25%</td>
</tr>
<tr>
<td>Often/always</td>
<td>7%</td>
</tr>
</tbody>
</table>

### Please check the statements below that reflect the concerns you have for your personal safety.* (n=462)

- I fear that someone will take advantage of me (i.e., phone scam, take my money or possessions): 10%
- I fear that someone might steal my money or valuables: 5%
- I worry about the safety of my neighborhood: 4%
- I fear that people may steal my medications: 4%
- I fear some members of my family or other people I know: 2%
- None of the above concern me: 86%

*Multiple responses allowed*
Have you fallen in the last 6 months? (n=465)

- Yes: 26%
- No: 74%

When you fell in the last 6 months, did you have to:* (n=121)

- Need someone to help you get up: 25%
- Go to your doctor or medical provider because of the fall: 17%
- Go to the emergency room (ER) or hospital because of the fall: 17%
- None of the above: 58%

*Multiple responses allowed
Do you have tooth or mouth problems that make it hard for you to eat? (n=464)

- Yes: 17%
- No: 83%
If free or low-cost workshops or classes were available to you to learn about keeping yourself healthy, how interested would you be in attending? (n=463)

- Very: 10%
- Somewhat: 24%
- A little: 19%
- Not very: 47%

If a little or not very [interested in attending a workshop], why not?* (n=292)

- Information is not helpful to me/I don't need it: 59%
- Other: 21%
- I don't like group activities: 18%
- It depends how far away it is: 10%
- Transportation issues: 6%

*Multiple responses allowed
In the last 6 months, have you ever gone without your medications because you cannot afford them? (n=465)

- Yes: 8%
- No: 88%
- In the last 6 months, I haven't needed to take any medications: 4%

Do you have difficulty doing any of the following on your own?* (n=462)

- Daily household tasks, such as laundry and vacuuming: 13%
- Personal care activities, such as bathing or dressing: 5%
- Organizing or managing your medications: 3%
- No, I do not have difficulty with any of these tasks: 85%

*Multiple responses allowed
Are you currently receiving in-home help with any of those tasks from another person? (n=69)

- Yes: 32%
- No: 68%

If you are not receiving all the help you need with those tasks, is it because* (n=43)

- You cannot afford it: 42%
- You do not know how to get help: 30%
- You do not want it: 21%
- There is no help available: 8%
- Other: 9%
- Recoded other: reluctant to ask†: 9%
- You are receiving all of the help you need: 19%

*Multiple responses allowed

† "Recoded other" item was created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
Do you provide help regularly for any of the following individuals?*  (n=447)

- No, I do not provide any caregiving supports to others  78%
- Yes, I care for an adult age 60 or older (include spouse or parent)  17%
- Yes, I have assumed parental responsibility for a grandchild or other relative under the age of 18  4%
- Yes, I care for a person with a disability age 18-59 (include spouse, adult child, parent, or other person)  4%

*Multiple responses allowed
What type of support do you provide to this person/people?*  (n=79)

- Transportation: 75%
- Food or meal preparation: 59%
- Daily household tasks: 53%
- Financial support: 43%
- Financial management: 43%
- Medical care: 35%
- Help with medications: 35%
- Help with personal care such as bathing and dressing: 23%
- Other: 7%
- Recoded other: companionship, visits, check-ins+: 7%
- Recoded other: emotional support+: 6%
- Recoded other: maintenance and repair+: 5%
- Recoded other: power of attorney+: 1%
- Recoded other: memory support+: 1%

*Multiple responses allowed

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
What are your top needs as a caregiver for this person/people?*  (n=62)

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional in-home support, help providing care</td>
<td>40%</td>
</tr>
<tr>
<td>Respite (rest, reprieve or break)</td>
<td>37%</td>
</tr>
<tr>
<td>Information and referral</td>
<td>26%</td>
</tr>
<tr>
<td>Transportation assistance</td>
<td>25%</td>
</tr>
<tr>
<td>Support groups</td>
<td>11%</td>
</tr>
<tr>
<td>Caregiver training/education</td>
<td>10%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
</tr>
<tr>
<td>Recoded other: none†</td>
<td>8%</td>
</tr>
<tr>
<td>Recoded other: financial†</td>
<td>4%</td>
</tr>
<tr>
<td>Recoded other: housing†</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed

† "Recoded other" items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
### Information & Services Spectrum Generations

#### How difficult is it to find information you need about available services and programs for older adults and their caregivers? (n=462)

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very difficult</td>
<td>9%</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>19%</td>
</tr>
<tr>
<td>Not difficult at all</td>
<td>26%</td>
</tr>
<tr>
<td>Haven't tried</td>
<td>46%</td>
</tr>
</tbody>
</table>

#### What are the best ways for you to get information about available services for older adults or caregivers?* (n=457)

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet</td>
<td>69%</td>
</tr>
<tr>
<td>Doctor/health care provider</td>
<td>56%</td>
</tr>
<tr>
<td>Word of mouth</td>
<td>39%</td>
</tr>
<tr>
<td>TV</td>
<td>28%</td>
</tr>
<tr>
<td>Newsletters or flyers in mail</td>
<td>27%</td>
</tr>
<tr>
<td>Newspaper</td>
<td>25%</td>
</tr>
<tr>
<td>Communication with a state or local agency</td>
<td>24%</td>
</tr>
<tr>
<td>Senior or community Center</td>
<td>20%</td>
</tr>
<tr>
<td>Radio</td>
<td>14%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
</tbody>
</table>

*Recoded other: I don't need information† 1%  
Recoded other: community (town office/city hall/library)† 1%  
Recoded other: family members† 1%  
Recoded other: church† 1%  

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How do you primarily access the Internet?*  (n=466)

- From my personal home computer: 71%
- From my cell phone: 25%
- I don't access the Internet: 7%
- From a public library or other community space: 1%
- At a friend’s or family home: 1%

Have you called any of these organizations or looked them up online?*  (n=459)

- Spectrum Generations: 16%
- Legal Services for the Elderly: 7%
- Maine 211: 5%
- Southern Maine Agency on Aging: 4%
- Eastern Area Agency on Aging: 3%
- SeniorsPlus: 2%
- The Long-Term Care Ombudsman Program: 2%
- Aroostook Area Agency on Aging: <1%
- I haven't called or looked up any of these organizations: 76%

*Multiple responses allowed
**Information & Services**

**Spectrum Generations**

---

**In the last 6 months, have you needed help with any of the following?** *(n=445)*

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare or other health insurance questions</td>
<td>13%</td>
</tr>
<tr>
<td>General information about community resources</td>
<td>9%</td>
</tr>
<tr>
<td>Legal services</td>
<td>7%</td>
</tr>
<tr>
<td>Transportation</td>
<td>7%</td>
</tr>
<tr>
<td>On-going help getting connected to services and benefits</td>
<td>6%</td>
</tr>
<tr>
<td>Food or meals</td>
<td>6%</td>
</tr>
<tr>
<td>Managing finances</td>
<td>5%</td>
</tr>
<tr>
<td>Finding volunteer opportunities</td>
<td>4%</td>
</tr>
<tr>
<td>Respite or caregiver support</td>
<td>4%</td>
</tr>
<tr>
<td>Help in resolving problems with home care services</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td>Adult day services</td>
<td>1%</td>
</tr>
<tr>
<td>I have not needed help with any of the following items</td>
<td>65%</td>
</tr>
</tbody>
</table>

*Multiple responses allowed*
Did you get all the help you needed? (n=161)

- Yes: 53%
- No: 47%

Why [did you not get all the help you needed]?* (n=76)

- I don’t know who to ask: 45%
- I can’t afford the help I need: 38%
- I don’t qualify for help: 31%
- Services are not available: 28%
- There are waitlists for services: 26%
- I prefer not to ask for help: 12%
- Fear of discrimination: 7%
- Culture or language difficulties: 0%
- Other: 8%
- Recoded other: difficulty with insurance†: 7%
- Recoded other: agency not helpful‡: 7%
- Recoded other: too confusing, frustrating, overwhelming, etc.‡: 4%

*Multiple responses allowed

† “Recoded other” items were created by recategorizing similar items from the answers provided by respondents who indicated they had an "other" reason.
How would you rate your community as a place to live for people as they age? (n=467)

- Excellent: 10%
- Very good: 28%
- Good: 29%
- Fair: 20%
- Poor: 7%
- Not sure: 6%
Maine State Plan on Aging
Public Listening Sessions

Are you an older adult, an adult with a physical disability, a caregiver, a pre-retiree, a veteran or a service provider?

The Office of Aging and Disability Services wants to hear your input and learn from your experiences as we design a strategic plan to address our communities’ needs. We are hosting 8 regional sessions around the state to gather your input on the priorities and strategies that are important to you.

### Public Listening Sessions Schedule

<table>
<thead>
<tr>
<th>Area Agency on Aging</th>
<th>Date</th>
<th>Time (pm)</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aroostook Agency on Aging</td>
<td>10/02/19</td>
<td>2:00 - 4:00</td>
<td>Ashland Community Recreation Center Exchange St, Ashland, ME 04732</td>
</tr>
<tr>
<td>Spectrum Generations</td>
<td>10/08/19</td>
<td>2:00 - 4:00</td>
<td>VFW Hall 50 Mill Street, Waldoboro, ME 04572</td>
</tr>
<tr>
<td>Eastern Area Agency on Aging</td>
<td>10/15/19</td>
<td>2:00 - 4:00</td>
<td>Eastern Area Agency on Aging Offices 240 State St, Brewer, ME 04412</td>
</tr>
<tr>
<td>Spectrum Generations</td>
<td>10/16/19</td>
<td>2:00 - 4:00</td>
<td>Spectrum Generations Muskie Center 38 Gold St, Waterville, ME 04901</td>
</tr>
<tr>
<td>Eastern Area Agency on Aging</td>
<td>10/16/19</td>
<td>2:00 - 4:00</td>
<td>Uni. of Machias, Performing Arts Center 116 O'Brien Avenue, Machias, ME 04654</td>
</tr>
<tr>
<td>SeniorsPlus</td>
<td>10/22/19</td>
<td>1:00 - 3:00</td>
<td>SeniorsPlus Offices 10 Falcon Rd, Lewiston, ME 04240</td>
</tr>
<tr>
<td>SeniorsPlus</td>
<td>10/23/19</td>
<td>1:00 - 3:00</td>
<td>Comfort Inn &amp; Suites 1026 US-2, Wilton, ME 04294</td>
</tr>
<tr>
<td>Southern Maine Agency on Aging</td>
<td>10/24/19</td>
<td>2:00 - 4:00</td>
<td>USM, Glickman Library, 7th Floor 314 Forest Ave, Portland, ME 04103</td>
</tr>
</tbody>
</table>

If you need an accommodation, please contact James Moorhead at 207.287.9200 and TTY Users call Maine Relay 711. Requests should be made as soon as possible but at least one week prior to the scheduled meeting.

Maine Department of Health and Human Services, Office of Aging and Disability Services
Contact: James Moorhead | 207.287.9200 | james.moorhead@maine.gov
Arrival time: 1:15 PM
Set up: 1:30 – 1:50 PM
Greet attendees: 1:50 – 2:00 PM
  - Optional name tags – first names only.
  - Provide each attendee with pen and index cards (2)

Note takers: Notetaker #1 and Notetaker #2
Lead Facilitator: Name of Lead Facilitator
Co-facilitator: Name of Co-Lead Facilitator
Supplies: projector, wireless mic, batteries, note cards, pens, name tags, flip chart, paper, hand-held mic, 2 extension cords, signs for exterior doors, PPT loaded on flash drive, laptop and USB cord, snacks, water, WIFI password?

To Do: [Add name of AAA staff to PowerPoint slide 2nd. Have PowerPoint on 1st slide as participants are coming in. Advance to “Welcome and Introductions” slide when “welcome” begins. Facilitators should have laptop facing them so they can see what is on-screen. Lead Facilitator will advance slides throughout. Both will keep track of time].

Welcome, Introductions, Context [10 minutes]
Add name of agency doing welcome: [Welcome and brief remarks] Add name of AAA staff or other person

James (or Karen): Introduce the State plan of Aging and broad overview of the older Americans Act.

Good afternoon and thank you all for coming here today. I am XX from the Office of Aging and Disability Services, the State office that coordinates services for older adults in Maine. We are part of the Department of Health and Human Services. I wanted to give you a little background
on the Older Americans Act, Maine’s State Plan on Aging, and why we are here today asking for your help.

- Maine receives federal funding under the Older Americans Act, much of which is distributed to five organizations across the State to provide community services to older adults. These agencies are known as the Area Agencies on Aging. In this area, that organization is XX.

- For those who may not know, the Area Agencies on Aging are the agencies that administer Meals on Wheels, provide Medicare and other health insurance counseling, and help with caregiver supports. They offer many other services and programs; each one is a little different.

- The Older Americans Act also puts special emphasis on serving individuals in rural areas, those in greatest economic and social need, individuals with Alzheimer’s disease and their caretakers, as well as other older adults who are at risk of institutional (nursing facility) placement.

- Every 4 years, the five Area Agencies on Aging develop area plans saying how they will provide services under the Older Americans Act. The State also develops a statewide plan which must be submitted to the federal government. It tells the federal government how services statewide under the Older Americans Act will be provided over the next four years.

- Maine drafts its State Plan based on information gathered from Maine residents, including all of you! The state will hold 8 listening sessions all around the state over the next 6 weeks. In addition, it is sending out statewide survey, as well as conducting a survey specifically for Maine caregivers. We have asked the Muskie School of Public Service to help us with this project and they will be facilitating today’s session and taking notes.

- Even though we call it the State Plan on Aging – which makes it sound very comprehensive – it is one part of a larger effort to plan for Maine’s older residents. The State Plan focuses on a particular set of community services that support older
Mainers living comfortably in our homes and communities as we age – which really is the theme of these listening sessions.

- Once the plan is developed, it will be open to public comment so you will have another opportunity to weigh in. As part of developing the area and state plans, we are going around the state collecting as much feedback as we can from older adults, caregivers and community representatives.

- Your being here today helps us understand how to prioritize services and use our resources in the most effective ways possible to support older adults to live comfortably in their homes and communities. Thank you for participating!

Facilitator [7 minutes]

Good afternoon and welcome to this community listening session. My name is ______________, and I will be facilitating this afternoon’s session along with my colleague, __________. As XX mentioned, we are both with the Muskie School of Public Service at the University of Southern Maine.

Before we begin, let me tell you about the structure of the listening session:

- We will be asking you a series of open-ended questions about the types of community services and supports that are important to you.
- Please know that there are no right/wrong answers to any of these questions.
- We will start with a few “hand-raising” questions to get a sense of who is here, and then we will move on to a larger discussion questions on specific topics. We will have the questions up on the screen to help guide the conversation.
- Anyone can answer and please only say what you feel comfortable sharing - but know that anything you can contribute is appreciated and important to us.
- If you don’t feel comfortable speaking out loud, please write things down on the notecards and hand them to any one of us.
• Since this is a public setting, nothing you say is confidential, but please be respectful of your friends and neighbors regarding individual stories or information that you learn – you are free to tell people that you came to the session, but we would ask you not to repeat any personal stories you might hear here today
• We are here until 4:00 and we want to hear from as many of you as possible, but we may need to move on from certain topics to cover as much as we can. So we apologize in advance if we have to move the discussion along in the interests of time.
• Importantly, we are here to listen. We are not able to respond to specific concerns or questions that you may have but your questions or concerns will be noted and taken into consideration by the state as it develops the State Plan.

Co-Facilitator:
You might be wondering what will happen with all the information we gather in these listening sessions and from the surveys. You can see that our colleagues, ______ and _____ are here taking notes but we are not recording the conversations or taking down individual names. We will compile all the notes and from all the sessions and then analyze those notes for common themes and urgent issues across the state. We may use quotes from the sessions in our report, but they will not be attributable to a particular person.

• The findings from the surveys and listening sessions will be combined into a report that the Muskie School will draft and submit to Maine’s Office of Aging and Disability Services and that office will draft the State Plan. That Plan will be available for public view and comment and, when finalized, submitted to the federal government.

We have a couple of ground rules to review before we begin:
• Please put your cellphones on silent.
• We ask that you not interrupt each other - since we are taking notes, we need just one person talking at a time.
• We will not be taking a break so please feel free to move around as needed – the bathrooms are…. 
• And we have water and snacks at the ___ table.
As we mentioned, the overall theme for our discussions is **how we can live comfortably in our homes and communities as we age.** While we want to hear from you about anything that would make it easier for you or people you know to remain in their homes and communities, this list of icons on the bottom of the slide [point to slide] represents most of the primary aspects of daily life that - if you have needs in these areas - those needs must be met in order to remain at home: maybe you are a caregiver, or have need of one; and then transportation, health care, housing, food & nutrition, safety, and socializing.

Keep these parts of life in mind as you respond to our discussion questions in a minute.

**Part 1 – Raise hand questions** [5-10 minutes]

We will start by asking a few “background-type” questions -- again, only answer what you feel comfortable answering.

**Age** [facilitator and co-facilitator help count and give numbers to note-takers.]

- How many of you are under the age of 55?
- How many between the ages of 55-64?
- 65-74?
- 75-84?
- 85 and older?

**Caregiver status**

- Other than caring for your own minor children, how many of you are caregivers? And by caregivers, we mean a very broad definition: providing help to another person such as helping with groceries or transportation -- or providing hands-on personal care. It can also mean helping to manage medical appointments or helping to pay bills.
  - For those of you who are caregivers:
    - How many are caring for an older person 60 or older?
    - How many are caring for an adult between the ages of 18 and 59 who has a disability?
    - And are any of you caring for a minor grandchild or other minor relative?

**Public official**

- How many of you are public officials or work for a public institution -- and by that we mean in any capacity and at any level of government – federal, state, or local.
  - [if asked, we do include librarians and other staff of public institutions]
Service Providers in the room

- How many of you work for a service provider organization that is not an Area Agency on Aging?

AAA Help

- These listening sessions are a partnership between the State of Maine and the Area Agencies on Aging, so we are interested to know about Area Agency participation.
  - How many of you have either called their Area Agency on Aging or looked up information on their website, or used AAA services at any time in the past year?
- And are there any AAA staff present?
- What about AAA volunteers?

[target: 2:25 - 2:30]

Part 2 – Discussion Questions [90 minutes -- 13 questions/5-7 minutes each. If needed, have James/Karen or one of the AAA staff bring hand-held microphone to participants].

Facilitator: Now we will get into our discussion questions. We are going to start with “positive” questions -- things that are working well for you at home or in your communities, and then we will move on to areas where you, or people you know, have concerns or experience things that are not working so well.

And then towards the end, we will be asking you for ideas on how to address the concerns that you or others have identified.

**Topic A – Community Assets**

Our first question is a very broad one -- we want to know about things that are working well in your area.

**Question:** What do you love about your community? You can just throw out a 1 or 2-word answer, if you wish - such “walking trails”, “this community center”.

- Prompt: What are the places that are important to you or to people you know?
- Prompt: Who are some of the people who are important to this community – not names, but their roles/positions? Or particular organizations?
**Question**: What are some of the opportunities that older people have to socialize here? Tell us about the places and options for socializing with other people in your community.

[**target: 2:40-2:45**]

---

**Topic B – Needs**

Next we want to ask about living in your home/community as you age and the services you may need.

**Question**: Thinking about your own situation - or a family member or friend who could not be here today – what do you - or a friend or neighbor – need to live comfortably in your home or in your community as you age?

- **Prompt**: Tell us about access to health services
- **Prompt**: Tell us about access to nutritious, affordable food
  - We know that many older people struggle getting enough to eat, tell us about what this community offers, such as food pantries, community meals sites, or other volunteer efforts to get food to people (e.g. gleaning)
- **Prompt**: What about housing? What do you see as the housing needs in the area?
- **Prompt**: What about transportation? What do you see as the transportation needs in the area?

**Question**: Do you, or do your friends and neighbors, feel safe at home or living in this community? This can be any type of safety. For example, do you feel safe in your home? Do you feel safe in your neighborhood? Why or why not?

**Question**: Can you tell us about some things that cause older people to have to move out of their homes?

**Question**: We know that many older people living in rural communities are sometimes isolated or feel lonely. Can you give us some examples of the social needs here or describe the characteristics of people you know - not their names - who you believe are isolated or lonely?

**Question**: And, finally, for those of you who are caregivers, is there anything else you want to tell us about what would be helpful? What kinds of things could make caregiving easier?

- **Prompt**: Things like more respite care, more training, more adult daycare?

[**target: 3:15 - 3:20**]
**Topic C - Barriers**

Next we want to know the reasons people aren’t getting the help they need.

**Question:** Tell us about some of the reasons you think people are not getting what they need.

- Prompt: What are some of the complaints and worries that you hear from friends and neighbors (or what do you complain about)?
- Prompt: In thinking about services, is it that services don’t exist or are hard to get to?
- Prompt: In thinking about people, do you think people are reluctant to ask for help? Do you think that is true? What might be some of the reasons? Is it financial? Is it pride or stigma? Fear that people will lose their independence?
- Prompt: Are there language or cultural barriers?

**Question:** What might make it easier for people to get help when they need it?

**Question:** Now thinking about your future living at home or in this community as you age, what are some of your biggest concerns?

[target: 3:35]

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**Topic D - Information /Navigation**

Next we want to ask you about how you hear about services or events in the area.

**Question:** Thinking about the area where you live - and the issues we’ve just been talking about - how or where do people generally get information? What or who is most helpful in getting information?

- Prompt: For example, if you knew your neighbor needed help getting to the grocery store, or if you were worried about your spouse or your aging parent falling -- where would you go for information?
- Prompt: We hear that lots of people have a hard time figuring out what they need or where to get what they need. Do you think that is true? Does anyone have an example or a story to share? Can you tell us about your – or a friend or neighbor’s - experiences with this in your community.
  - **Probe for 211..........do folks use it? How helpful is it?**
When you do reach out to XXX, we want to know whether you get helpful information. (Prompt: Do you have to call several different people to get an answer?)

Prompt: Who are the people or the agencies that are helping you or your neighbors and friends figure out what you need or how to get help?

[Check-in with co-facilitator]: If we have not heard comments on volunteering, or on safety issues in the community or if there is a topic that hasn’t been well covered, we can ask about it here: “We have not heard much about XX today, can you tell us about XX?”

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**Topic E - “Magic Wand”**

Finally, we want to hear about your wishes and creative ideas about what would help people.

**Question**: If you had a ‘magic wand’, tell us about some things that would make it easier for people in your area to age comfortably at home?

- Prompt: This can be something specific to you or your family and friends, or it can be something broader that would help older Mainers generally.
- Prompt: Or it could be community services or other types of support.
- Prompt: Looking ahead, what are the things you think you will need to stay living in your area?

**Question**: In thinking about everything we have just heard, how do you think that the State can better help your community in supporting older adults now and in the future?

- Prompt: are there any examples of community needs that you think the state could help with?
- Are there things you would like to see the state do to improve the lives of older adults in Maine that we haven’t already touched on?

[target: 4:00]

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**Wrap-Up [2 minutes]**
Facilitator:
We have reached the end of our discussion questions. Thank you for your participation today. Before we end, we want you to write down on one of your note cards anything else you want us to know that we did not have a chance to talk about today. Please hand your cards to one of the staff on your way out.

One final note about the surveys: There will be a caregiver survey that we hope anyone who is providing care—whether for an adult or anyone who has assumed custodial care of a child—will complete. We hope people will get a copy of the link through mailing lists they are currently on but if not, it will be posted on the website for the Office of the Aging and Disability Services.

Post-session 4:00 – 4:15 PM
Compile sign-in sheet and all note cards and label “Place of session”
Gather equipment and supplies
Return room to pre-meeting status

Debrief: Plus/Delta 4:15-4:45 PM
MAINE STATE PLAN ON AGING

Listening Sessions

Date
Location
WELCOME AND INTRODUCTIONS

Area on Aging Representative

State of Maine Office of Aging and Disability Services Representative

Muskie School of Public Service Team, University of Southern Maine
TODAY'S AGENDA

Welcome
Why are we here?
Questions & Discussion
Wrap-up
OUR THEME TODAY

Living comfortably in our homes and communities as we age
RAISE-YOUR-HAND QUESTIONS

Age
Caregiver Status
Public Official
Service Provider
AAA
What do you **love** about your community?
DISCUSSION QUESTIONS

What opportunities are there to socialize?
DISCUSSION QUESTIONS

What do you - or a friend - need to live comfortably in your home or community?
DISCUSSION QUESTIONS

Do you feel safe at home or in your community?
DISCUSSION QUESTIONS

What are some things that cause older people to move out of their homes?
DISCUSSION QUESTIONS

What are some of the **social needs** in your community?
Caregivers: what are some other things that would be helpful to you?
DISCUSSION QUESTIONS

What are some reasons people are **not** getting the help they need?
DISCUSSION QUESTIONS

What would make it easier for people to get help when they need it?
DISCUSSION QUESTIONS

Thinking about your future – aging at home or in your community - what are your biggest concerns?

Caregiving  Transportation  Health Care  Housing  Nutrition  Safety  Socialization
DISCUSSION QUESTIONS

In your area, who or what is most helpful in getting information?
If you had a "magic wand", what would make it easier for people in your area to live comfortably at home?
DISCUSSION QUESTIONS

How can the State of Maine better help your community support older people - now and in the future?
Please write down on a note card anything else you want us to know. Leave cards with any staff member. Thank you for participating!
Thank you for participating!
INTRO

Thank you for helping with this important study of people in Maine who provide help or care to others. The person you help may be a spouse, family member or friend. Being a caregiver can mean helping someone with household chores or personal needs such as bathing and dressing. It might be helping manage someone’s finances, arranging health care services, or visiting regularly to see how someone is doing. You might provide a little help or a lot. Caregivers also include older adults who have assumed primary responsibility for a grandchild or other relative under the age of 18 in the place of a parent. We would like to hear from unpaid caregivers as well as caregivers who are paid to provide help to a relative or friend. The answers we get from you and others like you all over the state of Maine will help us learn more about the needs and concerns of caregivers. This survey will provide the State with important information as they develop priorities for community programs and services.

This statewide survey is being conducted by the Muskie School of Public Service at the University of Southern Maine (USM) on behalf of Maine’s Office of Aging and Disability Services. While we hope you choose to participate, you are not required to complete this survey and you do not need to answer any question you do not want to answer. If you come to a question you do not want to answer, just leave it blank and go on to the next question. Your individual responses are confidential. Responses will only be reported after they are combined with the responses from everyone who took the survey. Your responses will not affect any services or benefits you receive.

If you have any questions about the survey, please contact James Moorhead, Aging Services Manager, Maine’s Office of Aging and Disability Services at 207-287-9200 or James.Moorhead@maine.gov.

1. So that we can be sure that we ask you the right set of questions please choose one of the following:

   □ A. I have provided care in the last six months to an older adult or an adult with a disability.
   □ B. I am an adult age 55 or older who has assumed primary responsibility for a grandchild or other relative under the age of 18 in the place of a parent.
   □ C. Both A. and B. apply to me.
   □ Neither A nor B apply to me. (Survey ends. Thank you for your time.)

Section A - Caregiving of older adults and adults with disabilities

2. How many adults have you provided care to in the last 6 months?
   __________

Now, we would like to get some information about the person you help. If you help more than one adult, please think about the person you help the most.

3. How old is that adult?
   *Your best guess is fine.*
   ___ ___ ___ years old
4. What is their relationship to you?
   - Your spouse or partner
   - Your parent/step-parent/in-law
   - Your adult child/step-child
   - Your grandparent/step-grandparent
   - Other adult relative
   - A friend or neighbor
   - Other________

5. Where does this person live?
   - In the same home as you (skip to Q9)
   - Within twenty minutes of your home
   - Between twenty minutes and an hour from your home
   - One to two hours from your home
   - More than two hours away

6. Does this person live in:
   - Own home or apartment (whether owned or rented)
   - Assisted Living Facility/Residential Care
   - Nursing Home
   - Housing with services
   - Other ______________

7. [IF NOT IN HOUSEHOLD]: On average, how often do you visit this person?
   - More than once a week
   - Once a week
   - Few times a month
   - Once a month
   - Few times a year or less

8. Does this person live alone?
   - Yes
   - No

9. How long have you been providing care to this person? *Your best guess is fine.*
   - Less than 6 months
   - 6 months to about 1 year
   - 1-3 years
   - 4-6 years
   - 7+ years
   - Don't Know/ Not Sure

10. What is the primary condition of the person you care for?
    - Alzheimer’s disease or dementia
    - Traumatic Brain Injury
    - Cancer or lymphoma
    - Intellectual or developmental disability
    - Physical disability
    - Heart or lung disease
Chronic health condition  
- No diagnosis  
- Other: _________________________  
- I prefer not to say

11. What kinds of help do you provide? (check all that apply)  
- Companionship (talking, reading, keeping company) or supervision  
- Daily or frequent check-in by phone or email or electronic contact  
- Transportation (driving to doctor’s appointments, driving for errands)  
- Homemaking (shopping, cleaning, preparing meals)  
- Personal care assistance (feeding, bathing, toileting, dressing, grooming)  
- Medication assistance (preparing, managing, dispensing)  
- Medical nursing tasks (such as catheter changes, suctioning, wound care, tube feeding, injections)  
- Financial management assistance (paying bills, managing budget)  
- Financial support  
- Talking with health care professionals, social services agencies and other service providers about their care needs.  
- Other (please describe): _________________________

12. How much time do you typically spend each week helping this friend or family member?  
- 5 hours per week or less  
- 6 to 20 hours per week  
- 21 to 40 hours per week  
- More than 40 hours per week  
- Not sure

13. What services would be most helpful to you as a caregiver? (check all that apply)  
- A help line (or central place to call to find out what kind of help is available and where to get it)  
- Someone to talk to or counseling services or support group  
- Getting respite services (where someone else helps short term to give you a break from providing care)  
- Free or low cost training classes about caregiving  
- Adult day services  
- Medical alert/emergency response system for falls or other emergencies  
- Help with finding other paid or unpaid caregivers  
- Help with finding services for the person I care for (transportation, fuel assistance, etc)  
- Help with finding a nursing home or assisted living services  
- Help with living wills and advance directives  
- Having non-English language caregiver materials  
- On-line caregiver support resources  
- Other (please specify____________________)

14. Are you currently receiving the help that you need as a caregiver?  
- Yes  
- No  
- Not sure
15. If you are not getting this help, why not? (check all that apply)

☐ I don’t know who to ask or where to get information
☐ There are no services in the area
☐ Services are too expensive
☐ The person I help doesn’t want any services
☐ Available services do not fit language or cultural needs
☐ I am worried about discrimination
☐ Other (please specify) _________________________________

Hospitalization
16. In the last 12 months, how many times was the person you care for hospitalized overnight?

☐ None (skip to Q19)
☐ One time
☐ 2 times
☐ 3 or more times
☐ Not sure

17. When this person was in the hospital, were you included by health care workers, (like nurses, doctors, or social workers) in discussions about their care?

☐ Yes, all the time
☐ Only some of the time
☐ No and I should have been
☐ No, but I did not need to be
☐ Not sure

18. Before this person left the hospital or was discharged, did you receive clear instructions about any medical or care tasks you would need to help with?

☐ Yes
☐ No
☐ Not sure
☐ Not applicable

OTHER CAREGIVER/PROVIDER SUPPORT
19. Has anyone else provided unpaid help to this person during the last 6 months?

☐ Yes
☐ No
☐ Not sure

20. Who provides most of the unpaid care for this person?

☐ You (yourself)
☐ Someone else
☐ We split it evenly

21. Do you get paid for any of the help you provide to this person?

☐ Yes
☐ No
☐ Prefer not to answer
22. During the last 6 months, did this person receive paid help from any aides, housekeepers, or other people who were paid to help him/her?
   □ Yes
   □ No
   □ Not sure

23. Please think about other providers who help this person. How easy or difficult is it for you to coordinate or organize care with those providers?
   □ Very easy
   □ Somewhat easy
   □ Somewhat difficult
   □ Very difficult
   □ I don't help with this.

OLDER RELATIVE CAREGIVER OF A CHILD/CHILDREN: The next set of questions is for older adults who have primary responsibility for the care of a grandchild or other relative under the age of 18. You will only be asked to complete this section if you check "yes" in response to Question 24. If you check "no" you will automatically move to the next section of the survey.

24. Are you age 55 or older and have assumed primary responsibility for a grandchild or other relative under the age of 18?
   □ Yes
   □ No (SKIP TO Q35)

25. How many children are you currently caring for?
   __________

26. How old is each child? Give the number of children you care for within each age range. OR for SNAP purposes: What age ranges cover the child/children you care for? (check all that apply)

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number of children in each age range</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 years old</td>
<td></td>
</tr>
<tr>
<td>4-6 years old</td>
<td></td>
</tr>
<tr>
<td>7-10 years old</td>
<td></td>
</tr>
<tr>
<td>11-14 years old</td>
<td></td>
</tr>
<tr>
<td>15-17 years old</td>
<td></td>
</tr>
<tr>
<td>18 years old or older</td>
<td></td>
</tr>
</tbody>
</table>

27. What is their relationship to you?
   □ Grandchild/Step-grandchild
   □ Niece/Nephew
   □ Other (please specify________________)

28. Do you share care responsibilities with your spouse, partner or another family member?
   □ Yes
   □ No

29. How long have you been providing care to this child/children? Your best guess is fine.
Less than six months  
Six months to less than 1 year  
1-3 years  
4-6 years  
7+ years  
Don’t Know/ Not Sure  

30. Do you need help getting specific services for the child/children you care for?  
☐ Yes  
☐ No (skip to Q**)  

31. What types of services do you need help getting for the child/children that you care for? (check all that apply)  
☐ Educational  
☐ Medical  
☐ Child care  
☐ Counseling  
☐ Transportation  
☐ Other (please specify)  

32. Thinking about your role as a caregiver, what kinds of help or information would be valuable to you? (check all that apply)  
☐ A help line (or central place to call to find out what kind of help is available and where to get it)  
☐ Support group  
☐ Counseling services  
☐ Navigating legal system (custody, guardianship, decision-making authority)  
☐ On-line caregiver support resources  
☐ Caregiver training  
☐ Financial assistance  
☐ Other (please specify: ______________________ )  

33. Are you currently receiving the help that you need to care for this child?  
☐ Yes  
☐ No  

34. If you are not getting the help you need, why not? (check all that apply)  
☐ I don’t know who to ask or where to get information  
☐ There are no services in the area  
☐ Services are too expensive  
☐ Not eligible for services  
☐ I do not have legal authority to apply for services  
☐ Available services do not fit language or cultural needs  
☐ I am worried about discrimination  
☐ Other (please specify) _________________________________  

HEALTH STATUS
35. Now we have some questions about you. In general, would you say your physical health is:
   - Excellent
   - Very good
   - Good
   - Fair
   - Poor

36. How much of a physical strain would you say that caregiving is for you?
   - Not much at all
   - Somewhat
   - Very much
   - Prefer not to answer

37. How emotionally stressful would you say that caregiving is for you?
   - Not much at all
   - Somewhat
   - Very much
   - Prefer not to answer

38. How much of a financial strain would you say that caregiving is for you?
   - Not much at all
   - Somewhat
   - Very much
   - Prefer not to answer

39. In the last 6 months, how often have you felt lonely and/or disconnected from other people due to caregiving?
   - Never
   - Hardly ever
   - Sometimes
   - Often/always

WORKING CAREGIVERS
40. Are you currently employed?
   - Yes
   - No

41. Have you been employed at any time in the last six months while you were also providing care to the person you help?
   - Yes
   - No

42. Did you leave a job as a result of being a caregiver for the person you help?
   - Yes
   - No

43. As a result of caregiving, did you ever experience any of these things at work?
   - Went in late, left early, or took time off during the day to provide care
   - Took a leave of absence
☐ Went from working full-time to part-time, or cut back your hours
☐ Turned down a promotion
☐ Lost any of your job benefits
☐ Experienced negative reactions from co-workers or supervisors
☐ Gave up working entirely
☐ Retired early
☐ Received a warning about your performance or attendance at work
☐ I have not worked while caregiving
☐ I have not experienced any of these things

DEMOGRAPHICS
We want to make sure we have talked with people from many different groups. Please answer the following questions to tell us a little bit more about you. If there are questions that you prefer not to answer, please skip those and go the next ones.

44. What county do you live in?
☐ Androscoggin ☐ Oxford
☐ Aroostook ☐ Penobscot
☐ Cumberland ☐ Piscataquis
☐ Franklin ☐ Sagadahoc
☐ Hancock ☐ Somerset
☐ Kennebec ☐ Waldo
☐ Knox ☐ Washington
☐ Lincoln ☐ York

45. What is your age?
☐ 25 to 54
☐ 55 to 64
☐ 65-74
☐ 75-84
☐ 85-94
☐ 95 or older

46. How many people live in your household? _______

47. Please specify your race/ethnicity.
☐ White
☐ Black or African American
☐ Native American or Alaskan Native
☐ Asian / Pacific Islander
☐ Multiracial
☐ Other (specify) ______
☐ Prefer not to answer

48. Do you consider yourself Hispanic or Latino/a/x?
☐ Yes
49. Is English your primary or preferred language?
   □ Yes
   □ No
   □ Prefer not to answer

50. If English is not your primary language, what is your primary language? ____________

51. What was your sex at birth (meaning, on your original birth certificate)?
   □ Male
   □ Female
   □ Not listed above (specify) ________________
   □ Prefer not to answer

52. What is your current gender identity?
   □ Male
   □ Female
   □ Transgender
   □ Not listed (please specify) ________________
   □ Prefer not to answer

53. Do you think of yourself as:
   □ Straight, that is, not gay or lesbian
   □ Lesbian or Gay
   □ Bisexual
   □ Not listed (please specify) ________________
   □ Not sure
   □ Prefer not to answer

54. What is the highest level of formal education you have completed?
   □ Grammar school (Up to 8th grade)
   □ Some high school
   □ High school graduate
   □ Some college or technical training
   □ College degree
   □ Graduate school
   □ Prefer not to answer

55. What is your current employment status?
   □ Fully retired
   □ Working part time
   □ Working full time
   □ Seasonal
   □ Prefer not to answer

56. Which of the following categories represents your annual household income?
57. Is there anything else you would like to share with us about your caregiving experience?

________________________________
________________________________

Thank you for taking the time to complete this survey!
State Plan on Aging Needs Assessment

Caregiver Survey Results

Muskie School of Public Service
Cutler Institute for Health and Social Policy
STATE PLAN ON AGING NEEDS ASSESSMENT

Caregiver Survey Results

Prepared by:

Nadine Edris

Elizabeth Gattine

Louise Olsen

Kimberly Snow

Funded by:

Maine Department of Health and Human Services
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Background and Purpose

To help inform the development of the State Plan on Aging, OADS partnered with the Muskie School of Public Service to conduct a statewide needs assessment of older adults and caregivers. OADS convened an advisory group of stakeholders to help guide the scope of work. The Advisory Group met three times in July and August of 2019. Members actively engaged in the planning process identifying project objectives, outreach strategies and methods, data collection measures, and a project timeline. This caregiver survey tool was developed to capture information specific to caregiving, particularly since some caregivers would not otherwise be able to participate in listening sessions because of their caregiving responsibilities.

This report summarizes the findings of an online survey for caregivers. The data collected through the use of this online survey complements other information on caregiver needs collected through other methods as part of this project including a separate mixed methods statewide survey; feedback received from caregivers as part of regional community listening sessions; and focus group findings of underserved populations.¹ Those findings have been reported separately.

Methods

This survey was developed and reviewed with input from the State Plan on Aging Advisory Group. The survey was conducted online and available to caregivers interested and willing to complete it. The survey went live on November 18, 2019; it closed December 10, 2019. The survey was promoted through OADS, members of the Advisory Group, and other community partners serving older adults and caregivers. Publication strategies included notification on listservs, websites, Facebook, newsletters, emails and other distribution methods. People were encouraged to share the survey link with anyone who might be interested in completing the survey. The survey incorporated a broad definition of caregiving, and did not exclude those who were paid to provide care to a family member or friend. It did not exclude caregivers based on care setting. The survey was limited to individuals able to complete the survey on-line. Survey results were not weighted.

¹ Three focus groups were funded separately through the Maine Health Access Foundation (MeHAF).
Survey Results
The following charts and tables describe the results of the survey. A total of 444 caregivers completed the survey. Some respondents chose not to answer all of the questions. The number of respondents per question is shown on each figure. The survey included skip patterns affecting the total number of respondents for some questions.

The first survey question ascertained whether the respondent met the survey inclusion criteria of either providing care in the prior six months to an older adult or an adult with a disability, being age 55 or older and having primary responsibility to care for a grandchild or other minor child in place of the parent, or both. Of the 444 respondents who completed the survey, 98% provide care to an older adult or an adult with disabilities.

RESPONDENT DEMOGRAPHICS
Respondents to the survey ranged in age, with the highest percent (37%) between ages 55 and 64 years old. Twenty-seven percent were caregivers under the age of 55; twenty-five percent were between 65 and 74 years old. Twelve percent were 75 years or older. Almost half of respondents (49%) lived in a two-person household. Ninety-five percent identified as white, with ninety-eight percent selecting English as their primary language.²

² Additional demographic information is included in the appendix to this report.
What county do you live in?

The highest percentage of responses were from caregivers in Cumberland County, followed by Penobscot, Kennebec and York counties. These counties include the population centers of the Portland, Bangor and Augusta areas.

<table>
<thead>
<tr>
<th>WHAT COUNTY DO YOU LIVE IN? (N=385)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Androscoggin</td>
<td>9%</td>
</tr>
<tr>
<td>Aroostook</td>
<td>6%</td>
</tr>
<tr>
<td>Cumberland</td>
<td>20%</td>
</tr>
<tr>
<td>Franklin</td>
<td>2%</td>
</tr>
<tr>
<td>Hancock</td>
<td>2%</td>
</tr>
<tr>
<td>Kennebec</td>
<td>11%</td>
</tr>
<tr>
<td>Knox</td>
<td>5%</td>
</tr>
<tr>
<td>Lincoln</td>
<td>4%</td>
</tr>
<tr>
<td>Oxford</td>
<td>3%</td>
</tr>
<tr>
<td>Penobscot</td>
<td>13%</td>
</tr>
<tr>
<td>Piscataquis</td>
<td>0.3%</td>
</tr>
<tr>
<td>Sagadahoc</td>
<td>4%</td>
</tr>
<tr>
<td>Somerset</td>
<td>4%</td>
</tr>
<tr>
<td>Waldo</td>
<td>3%</td>
</tr>
<tr>
<td>Washington</td>
<td>3%</td>
</tr>
<tr>
<td>York</td>
<td>11%</td>
</tr>
</tbody>
</table>
Nature of Caregiving Relationship

Some survey questions differed depending on whether individuals identified as caring for an older adult or an adult with a disability as compared to an older adult caring for a minor grandchild or other family member. This section of the report summarizes the responses received from caregivers of older adults and adults with disabilities. It provides a profile of the caregiving relationship, as well as information on caregiver health status, employment status, and caregiver needs.

How many adults have you provided care to in the last 6 months?

Sixty-five percent (281 respondents) provide care to one adult. Four percent of respondents provide care to more than twelve people. These may be people working or caregiving in supported housing (assisted living, residential care).  

![Bar chart showing number of adults cared for](chart)

How old is the adult you care for?

The average age of cared for adults is 75 years old.

<table>
<thead>
<tr>
<th>HOW OLD IS THE ADULT YOU CARE FOR? (N=437)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 21</td>
<td>1%</td>
</tr>
<tr>
<td>22-64</td>
<td>16%</td>
</tr>
<tr>
<td>65-74</td>
<td>17%</td>
</tr>
</tbody>
</table>

3 The survey did not exclude individuals who were paid caregivers.
Appendix H

**HOW OLD IS THE ADULT YOU CARE FOR?**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>75 and older</td>
<td>66%</td>
</tr>
</tbody>
</table>

**What is their relationship to you?**

Thirty-nine percent of caregivers are caring for their parents, step-parents, or in-laws.

**Relationship to Caregiver (N=432)**

- Your grandparent/step-grandparent: 3%
- Other adult relative: 5%
- Your adult child/step-child: 7%
- A friend or neighbor: 8%
- Other: 17%
- Your spouse or partner: 20%
- Your parent/step-parent/in-law: 39%

**Where does the person you care for live?**

Forty percent of caregivers share the same home as the adults they care for.

**WHERE DOES THIS PERSON LIVE? (N=435)**

<table>
<thead>
<tr>
<th>Location</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the same home as you</td>
<td>40%</td>
</tr>
<tr>
<td>Within twenty minutes of your home</td>
<td>37%</td>
</tr>
<tr>
<td>Between twenty minutes and an hour from your home</td>
<td>16%</td>
</tr>
<tr>
<td>One to two hours from your home</td>
<td>4%</td>
</tr>
<tr>
<td>More than two hours away</td>
<td>3%</td>
</tr>
</tbody>
</table>
If the person does not live with you, where do they live?

Of the adults who do not live with their caregivers, the majority (67%) live in their own homes or apartments.

<table>
<thead>
<tr>
<th>DOES THIS PERSON LIVE IN: (N=257)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own Home or apartment (whether owned or rented)</td>
<td>67%</td>
</tr>
<tr>
<td>Assisted Living Facility/Residential Care</td>
<td>20%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
</tr>
<tr>
<td>Housing with services</td>
<td>4%</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>3%</td>
</tr>
</tbody>
</table>

If you do not live with the person you care for, how often do you visit them?

Among caregivers who do not live with the adults they care for, sixty-six percent visit them more than once a week. Eighty-five percent of caregivers visit at least once a week.

<table>
<thead>
<tr>
<th>[IF NOT IN HOUSEHOLD]: ON AVERAGE, HOW OFTEN DO YOU VISIT THIS PERSON? (N=262)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than once a week</td>
<td>66%</td>
</tr>
<tr>
<td>Once a week</td>
<td>19%</td>
</tr>
<tr>
<td>Few times a month</td>
<td>8%</td>
</tr>
<tr>
<td>Once a month</td>
<td>5%</td>
</tr>
<tr>
<td>Few times a year or less</td>
<td>2%</td>
</tr>
</tbody>
</table>

If the person you care for does not live with you, do they live alone?

Fifty-one percent of those who do not live with their caregiver, live alone.

<table>
<thead>
<tr>
<th>DOES THIS PERSON LIVE ALONE? (N=261)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>49%</td>
</tr>
<tr>
<td>Yes</td>
<td>51%</td>
</tr>
</tbody>
</table>
How long have you been providing care to this person?

Over one-third of caregivers have been providing care for between one and three years. One-quarter have been providing care for seven or more years.

<table>
<thead>
<tr>
<th>HOW LONG HAVE YOU BEEN PROVIDING CARE TO THIS PERSON? (N= 437)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>6%</td>
</tr>
<tr>
<td>6 months to about 1 year</td>
<td>14%</td>
</tr>
<tr>
<td>1-3 years</td>
<td>33%</td>
</tr>
<tr>
<td>4-6 years</td>
<td>21%</td>
</tr>
<tr>
<td>7+ years</td>
<td>25%</td>
</tr>
</tbody>
</table>

What is the primary condition of the person you care for?

Thirty-nine percent of caregivers are providing care for adults with Alzheimer’s disease or other dementia.

Primary Condition (N=433) (check all that apply)

- Alzheimer’s disease or dementia: 39%
- Other: 22%
- Physical disability: 21%
- Chronic health condition: 18%
- Intellectual or developmental disability: 12%
- Heart or lung disease: 10%
- Cancer or lymphoma: 5%
- No diagnosis: 5%
- Traumatic Brain Injury: 3%
- I prefer not to say: 2%
What kinds of help do you provide?

Over 50 percent of respondents identified companionship, transportation, coordination with health care providers, homecare tasks, and financial management as types of care they provided. Some respondents provided additional detail in open-ended responses, including descriptions of the types of homemaker activities provided (e.g., laundry, grocery shopping, meal preparation, and errands) and mentioning coordination with family members as well as with health care providers. Other examples of help respondents described included:

- Doing home maintenance chores (e.g., yardwork, snow removal, heavy chores)
- Arranging and going on social outings and recreational activities
- Accompanying friend or family member on walks and with exercise
- Providing emotional support
- Advocacy for durable medical equipment and other needs
- Providing oversight and supervision
- Helping friend or family member to use a computer

How much time do you typically spend each week helping this friend or family member?

Over forty percent (42%) provide over 20 hours of care per week. Just over a quarter (26%) provide more than 40 hours per week of support.
Caregiver Support and Needs

Has anyone else provided unpaid help to this person during the last 6 months?

Thirty-three percent of respondents reported being the only unpaid caregiver helping their family or friend.
Who provides most of the unpaid care for this person?

Sixty-three percent of respondents identified themselves as the person providing the most unpaid support to the care recipient.

Do you get paid for any of the help you provide to this person?

Just over eighty percent of respondents said that they are not paid for the care they provide.

During the last 6 months, did this person receive paid help from any aides, housekeepers, or other people who were paid to help him/her?
A little over half (53%) of care recipients also received care from paid staff. Forty two percent of care recipients are not receiving paid in-home care.

During last 6 months, did person receive paid help from aides, housekeepers, other paid help? (N=402)

Please think about other providers who help this person. How easy or difficult is it for you to coordinate or organize care with those providers?

Of those respondents who help coordinate in-home services, forty-one percent said it was very or somewhat difficult to organize care with in-home providers; forty-one percent reported coordination as very or somewhat easy.
What services would be most helpful to you as a caregiver?

Thirty-seven percent of respondents identified respite as a service that would be helpful. Thirty-four percent said having a centralized place for information would be helpful and thirty-three percent identified counseling or a support group as a beneficial service.

Thirty-two percent of respondents needed help with finding other paid or unpaid caregivers. Twenty-nine percent of respondents said that assistance with finding services for the care recipient would be helpful.

Respondents provided specific examples in the open-ended section of this question about the types of services they were seeking for the care recipient. These included:

- Homemaker services and other in-home supports (including comments about the need to increase worker reimbursement)
- Reliable transportation services to adult day, medical appointment and shopping
- Housing
- Home modifications (e.g. ramps, lifts)
- Friendly visitors or wellness checks
- Help with MaineCare applications and accessing services through the Veteran’s Administration

Several caregivers added responses about their need for financial assistance to be able to afford to not work/miss work and provide care. Other caregiver needs that were provided as part of the open-ended question included:

- Help finding out what information is available, including LGBT specific resources
- Senior congregate meal program
- Training and education on communication and caregiving
- Improved communication and coordination with health care providers; extended provider hours to help caregivers who work
- Psychiatric beds for people in crisis
- Support for becoming a guardian or conservator

<table>
<thead>
<tr>
<th>SERVICES NEEDED (N=411) (CHECK ALL THAT APPLY)</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting respite services (where someone else helps short term to give you a break from providing care)</td>
<td>37%</td>
</tr>
<tr>
<td>SERVICES NEEDED (N=411) (CHECK ALL THAT APPLY)</td>
<td>PERCENT</td>
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<td>----------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>A help line (or central place to call to find out what kind of help is available and where to get it)</td>
<td>34%</td>
</tr>
<tr>
<td>Someone to talk to or counseling services or support group</td>
<td>33%</td>
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<tr>
<td>Help with finding other paid or unpaid caregivers</td>
<td>32%</td>
</tr>
<tr>
<td>Help with finding services for the person I care for (transportation, fuel assistance, etc)</td>
<td>29%</td>
</tr>
<tr>
<td>Online caregiver support resources</td>
<td>25%</td>
</tr>
<tr>
<td>Adult day services</td>
<td>25%</td>
</tr>
<tr>
<td>Medical alert/emergency response system for falls or other emergencies</td>
<td>22%</td>
</tr>
<tr>
<td>Free or low cost training classes about caregiving</td>
<td>21%</td>
</tr>
<tr>
<td>Help with finding a nursing home or assisted living services</td>
<td>16%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>15%</td>
</tr>
<tr>
<td>Help with living wills and advance directives</td>
<td>14%</td>
</tr>
<tr>
<td>Having non-English language caregiver materials</td>
<td>1%</td>
</tr>
</tbody>
</table>
Are you currently receiving the help that you need as a caregiver?

Over half of caregivers (62%) are either not receiving the help they need or are unsure that they are receiving the help they need as caregivers. Thirty-eight percent said they were receiving the help they need.

If you are not getting this help, why not?

Respondents reported the following barriers to getting the help they need: the high cost of services (35%) and the care recipient not wanting or accepting help (34%).

Respondents provided the following additional reasons in open-ended responses under “Other”:

- In-home staff and nurses are not available (workforce shortages)
- Lack of affordable housing
• Care recipient is on a waitlist for services
• Lack of adult day services
• No support groups in the area
• No respite care available/having to manage paperwork for respite services
• The time commitment needed to find information and navigate services
• Quality concerns with available services

## Hospitalizations

In the last 12 months, how many times was the person you care for hospitalized overnight?

Forty-four percent of respondents said that the person they care for was hospitalized overnight at least once in the last 12 months.

In the last 12 months, how many times was the person you care for hospitalized overnight? (N=426)

- None: 54%
- One time: 23%
- 2 times: 12%
- 3 or more times: 9%
- Not sure: 2%
When this person was in the hospital, were you included by health care workers (like nurses, doctors, or social workers) in discussions about their care?

Nearly one-quarter of caregivers said they were included in care discussions only some of the time. Six percent said they were not included when they should have been.

![Bar chart showing inclusion in care discussions.](chart1)

Before this person left the hospital or was discharged, did you receive clear instructions about any medical or care tasks you would need to help with?

Sixty-two percent of respondents said that they received clear instructions about medical or care tasks they needed to help with.

![Bar chart showing receipt of instructions.](chart2)
Health Status of Caregiver

In general, how would you rate your physical health?

Half of the caregivers (50\%) rated their health as very good or excellent, while fifteen percent rated their health as fair.

How much of a physical strain would you say that caregiving is for you?

Two-thirds (66\%) of caregivers said that caregiving was somewhat or very much a physical strain on them.
How emotionally stressful would you say that caregiving is for you?

Eighty-eight percent of caregivers said that caregiving was somewhat or very emotionally stressful for them.

How much of a financial strain would you say that caregiving is for you?

Forty-three percent said that caregiving was not much of a financial strain. Sixteen percent said caregiving was very much of a financial strain.
How often have you felt lonely and/or disconnected from other people due to caregiving?

Forty-one percent said that in the last six months, they sometimes felt lonely or disconnected from other people due to caregiving. Fourteen percent of caregivers said they often/always felt disconnected from other people due to caregiving.

In the last 6 months, how often have you felt lonely and/or disconnected from other people due to caregiving:
(N=380)

- Never: 27%
- Hardly ever: 18%
- Sometimes: 41%
- Often/always: 14%

**Employment Status**

Are you currently employed?

Sixty-four percent of respondents are currently employed.

Are you currently employed? (N=376)

- Yes: 64%
- No: 36%
What is your current employment status?

Forty-five percent of respondents reported working full time.

![Employment status chart](chart)

Have you been employed at any time in the last six months while you were also providing care to the person you help?

Sixty-six percent of caregivers have been employed while also providing care.

![Employment chart](chart)
Did you leave a job because of being a caregiver for the person you help?

Twenty percent of respondents said that they have left a job because of caregiving responsibilities.

As a result of caregiving, did you ever experience any of these things at work?

Twenty-one percent of respondents went from working full-time to part-time, or cut back on hours.
Other Caregiver Comments

The survey provided an opportunity for caregivers to let us know anything else they wanted to share about their caregiving experience. Approximately 120 respondents wrote in comments or information as part of the last open-ended question. Key themes included:

- Need for better wages and/or financial assistance for caregivers
- Need for affordable respite and adult day services
- Lack of affordable or accessible services for care recipient
- Difficulties with navigating service systems
- Physical, emotional and financial toll of caregiving
- Need for affordable housing
- Need for transportation
- Rewards of being a caregiver

Kinship Care

The survey included questions for older adults who have primary responsibility for the care of a grandchild or other relative under the age of 18. Twenty-two respondents identified as caregivers who have assumed primary responsibility for a grandchild or other relative under the age of 18. Almost all respondents reporting caring for a grandchild/grandchildren. Thirteen of the 22 are caring for one child with the remaining caring for more than one child. The children ranged in age. Seventy-nine percent (79%) report that they share care responsibilities with someone while 21% have sole care responsibility. Almost half (48%) have been providing care for over 7 years.

Respondents identified needing help to get medical services and education services for the child/children they cared for. Other needed services included transportation, childcare and counseling services. In their role as caregiver, respondents said they needed:

- Financial assistance
- Help navigating the legal system
- Counseling services
- A help-line for information
- Support groups
- Caregiver training
- Online caregiver support resources
- Respite care (mentioned several times in the ‘other’ category)
About half of the respondents (51%) felt they were not getting the help they needed. Reasons included that there were no services in the area, ineligibility for services, or services were too expensive. Some respondents said they did not know where to go for information. Other reasons included not having legal authority to apply for services as well as fear of discrimination and services not meeting language or cultural needs.
Appendix

Additional Respondent Demographics

How many people live in your household?
Most respondents live in a household with two people.

![Bar chart showing the number of people living in each household size.]

- 13% live in a household with 1 person
- 49% live in a household with 2 people
- 18% live in a household with 3 people
- 14% live in a household with 4 people
- 6% live in a household with 5 or more people

Please specify your race/ethnicity.
Ninety-five percent (95%) of 382 respondents selected white for race. About 3% preferred not to answer and 2% as African-American, Asian, Native American or multi-racial.

Do you consider yourself Hispanic or Latino/a/x?
Of the 376 respondents for this question, ninety-seven percent responded ‘no’ and the remaining three percent preferred not to answer.

Is English your primary or preferred language?
Ninety-eight percent (98%) said English is their primary language.

If English is not your primary language, what is your primary language?
One person entered French as their primary language.
What was your sex at birth (meaning, on your original birth certificate)?
Of 390 respondents, eighty-six percent said female and thirteen percent said male. Two percent chose not to answer.

What is your current gender identity?
Of 389 respondents, eighty-five percent identified as female with thirteen percent as male. Two percent chose not to answer.

Do you think of yourself as:

![Sexual Orientation Chart](chart1)

What is the highest level of formal education you have completed?

![Education Chart](chart2)
Which of the following categories represents your annual household income?

**Household Income (N=371)**

- Don't know: 7%
- Less than $20,000: 7%
- $20,000 to under $40,000: 25%
- $40,000 to under $60,000: 20%
- $60,000 to under $75,000: 12%
- $75,000 or more: 29%
TRIBAL KEY INFORMANT INTERVIEW

Tribal Elder Information

We would like to get some information about the needs of Tribal Elders living in the community, from your perspective and experience.

QUERY: NEEDS

From your perspective, what is working well right now for Tribal Elders living in cities, towns and communities across Maine [or other people you know in your community]?

What do you think some of the biggest concerns are about aging at home?

What services do you think Tribal Elders need now, or think might need, in order to remain living in their homes as they age?

QUERY: BARRIERS TO SERVICE

In your opinion, are Tribal Elders getting the services that they need to remain in their homes? If not, why not?

Are there services that you feel Tribal Elders are not comfortable seeking out, even if they need them?

For those who may not seek out these services, what are the types of concerns do you feel Tribal Elders have with using these services?

What are the things that would make Tribal Elders more comfortable about using these services?

QUERY: SAFETY

What do you think might be concerns for Tribal Elders re: their safety?

QUERY: SOCIAL ISOLATION and LONELINESS

What would help and encourage Tribal Elders to be more socially engaged?

Are there activities/interventions that are working well now?
**QUERY: CAREGIVING**
Thinking about Tribal Elders who are also caregivers for other elders, or adults with disabilities, or perhaps grandchildren or grandnieces or nephews -- is there anything else you want to tell us about caregiving needs?

What would make the caregiving role easier?

Would having adult day services or respite be helpful? Why or why not?

**QUERY: [TRUSTED] SOURCES OF INFORMATION**

If elders needed help with an “aging issue” - maybe caregiver support services or help with understanding their Medicare benefits, where would they go for information?

What are the ways that outreach by AAAs or other community organizations could be improved to Tribal Elders?

**QUERY: CATCH-ALL**

Is there anything else you want to tell us about Tribal Elders living in the community?

Thank you for your participation today!
FOCUS GROUP QUESTIONS

Is everyone here 55 or older?
55-64?
65-74?
75-84?
85 and older?

How many of you are caregivers/older adult/adult with disability/ grandchild?

**Needs**

What is working well right now in your community supporting you as an older adult [or other people you know in your community]?

What are your biggest concerns about aging at home?

What services do you need now, or think you might need, in order to remain in your home as you age? You can also think about other people you know.

**Safety**

We also know people need to feel safe in their home and communities. This can be safety at home as well as safety in your community. Do you feel safe living in your community? What about your home? Why or why not?

**Barriers to Service**

Are you or people you know getting the services that are needed to remain in your own homes? If not, why not

Are there services that you are not comfortable seeking out, even if you need them?

For those who may not seek out these services, what are the types of concerns you have with using these services?

What are the things that would make you more comfortable about using these services?

**SOCIAL ISOLATION and LONELINESS**

Generally, we know that being socially isolated and lonely impacts quality of life and health.

What would help and encourage older people in your community to be more socially engaged?
CAREGIVING

For those who are caregivers, is there anything else you want to tell us would be helpful? What would make your caregiving role easier?

Would having adult day services be helpful? Why or why not?

Trusted sources of information?

If you needed help with an “aging issue” - maybe caregiver support services or help with understanding your Medicare benefits, where would you go for information?

How many of you have called or otherwise connected in some way with your local Area on Aging?

If yes, for what kinds of help?

What are the ways that outreach by your local Area on Aging or other community organizations could be improved? Suggestions?

Magic Wand

If you had a ‘magic wand’, tell us about some things that would make it easier for you to age comfortably at home?

Thank you for your participation today!
MAINE COUNCIL ON AGING: WISDOM SUMMIT SESSION

OADS convened the first listening session at the MCOA’s Wisdom Summit on September 24, 2019. James Moorhead, Aging Services manager, led a discussion with 19 attendees. Attendees included service providers, community members, municipal and state public officials, and academic professionals. Staff from the Muskie School attended to listen and acted as note-takers.

Information Access

Participants noted a wide variety of sources of information on services and supports for older adults including, health care (physician offices, hospital social work), community organizations (Community Action Program (CAP) agencies, Area Agencies on Aging (AAA) and housing entities), municipal locations (town offices and libraries) and word of mouth.

Attendees reported mixed experience with 211 as an information resource. Several noted the challenge of maintaining current, updated, and accurate information. One also voiced the opinion that informational content was oriented to children and families, not services for older adults.

The ways older Mainers access information was also discussed. While the internet was acknowledged as a common source, participants raised several cautions and concerns, including that broadband access is uneven statewide, leaving many older adults without access. This factor, coupled with difficulty in website navigation and sometimes poor website design, limited the utility of this option. However participants acknowledged that the internet is a critical tool to disseminate information.

Attendees stressed that older adults “want to talk to somebody.” They do not want to leave a message and have someone they do not know return their call. Additionally, some older adults cannot stay on hold for long periods of time due to disability or health conditions. Trusted sources of information was felt to be vital to meeting the service needs of older adults.

Case management

Attendees noted that existing case management services were “silod”, “very limited” and “piecemeal” despite how important the service is to older adults, particularly for those with complex conditions or multiple needs. One participant commented that in Blue Hill, care managers in physician offices help with referrals and follow up (e.g. transportation needs). Another noted that a phone call is not always sufficient and older residents would be better served by having a visit from a case manager or care coordinator. HealthInfoNet was specifically mentioned as a mechanism to coordinate care between various services, although it was noted that all providers did not uniformly use this system.
Elder abuse and exploitation

Several areas were noted as strengths in efforts to prevent or intervene in situations of elder abuse. Attendees mentioned several areas where publicity and getting the word out made a difference (e.g. working with banks to alert them to unusual activity, information about scams being pushed out routinely) and increased prosecution. One participant noted new legislation which increases penalties on certain crimes.

However, several barriers were also noted. In particular, one participant offered that cases that do not rise to level for APS involvement may fall through the cracks. “There is a big hole in the system - see a problem coming but you cannot stop it.” Another noted that adults can still make poor choices and that in some cases older adults may fear government involvement in their business.

Final comment

One attendee noted how interrelated some of these issues are. The example shared involved a person who needed transportation to get to medical appointments but had difficulty getting transportation because of their medical needs.