

# **READINESS ASSESSMENT**

AROOSTOOK COUNTY HEALTH IMPROVEMENT PARTNERSHIP

JANUARY 2024

## READINESS ASSESSMENT for the

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JANUARY 2024

**Grantee Organization** 

The Aroostook County Agency on Aging

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## **EXECUTIVE SUMMARY**

The Aroostook County Health Improvement Partnership is a demonstration project supported by Maine's Rural Community Health Improvement Partnership (R-CHIP), a DHHS-funded initiative that aims to improve health outcomes and reduce health disparities in rural communities across the state. The initiative focuses on addressing the unique health-related social needs of Maine's rural communities, which often face significant challenges related to access to care, transportation, and economic resources.

In 2021, with support from the Maine Health Access Foundation, the Maine Rural Health Action Network commissioned <u>a</u> report on how a series of demonstration projects in several rural areas of Maine could begin to define and implement transformative approaches to whole-person care that could subsequently be adapted across the state. Maine DHHS made the recommendations of the report a reality by funding several projects intended to demonstrate and document how to transform systems of care in ways that are sensitive to local contexts and needs.

In April of 2023, the Aroostook Agency on Aging was selected as the convener of one such partnership in northern Maine, joining the Somerset Kennebec Counties Community Partnership (SKCCP) and the DownEast Housing Collaborative in a one-year planning grant process.

The ACHIP initiative brings together more than 20 partners, as shown below in Figure 1. Together, we hold a common vision: that Aroostook County residents will thrive because they have access to integrated, person-centered services and support. We'll achieve this by centering equity, innovation, collaboration, and responsiveness in our shared mission of transforming systems of care to meet the needs of The County's people.

### **ACHIP PARTNERS**













































Figure 1: ACHIP Partner Organizations

As a key milestone in its year-long planning process, ACHIP was required to conduct and submit a Readiness Assessment to its funders at the midpoint of the project. A Readiness Assessment is a measure of how prepared an organization is to create significant change – how willing and able is the organization to implement and sustain a program of transformative practices, services, and strategies (<u>Capacity Building Center for States, 2018</u>)? At this moment, when we begin to shift our focus from foundational partnership development activities to "solutionary" work aimed at tackling specific health-related social needs, it is essential to assess the current standing of the partnership, including any gaps that need to be addressed in the second half of the planning year to ensure effective future implementation of these programs.

Our Readiness Assessment identifies four priority populations as the focus for future work: individuals with annual household incomes of less than \$40K; older adults (age 65+); individuals experiencing behavioral health concerns; and single parents and grandparent guardians. Extensive demographic and lived experience research enabled us to validate the challenges faced by these groups, members of which often experience persistent economic distress and social vulnerability, and to hear their voices regarding the lives that they lead here in Aroostook County.

A key finding of our work is the complex and intersectional nature of people's lives, with the challenges of socioeconomic status, behavioral health, aging, and caregiving compounding one another. Each of the priority populations on which our research focused experienced health-related social needs slightly differently, with some populations being more likely to encounter certain barriers than others. For example, our research showed:



People with incomes below \$40K were 1.5 times as likely as the general population in Aroostook County to suffer from chronic pain.



Older adults in Aroostook County were twice as likely as the general population to no longer drive or own a vehicle.



People with behavioral health issues experienced food insecurity, defined in this situation as "cutting the size of or skipping meals due to financial concerns," at a rate that was 2.5 times higher than the general population.



Single parents were two times more likely to experience mental health or substance use disorders than the general population.

Analysis of the lived experience data led to the identification of five key themes affecting the well-being of Aroostook County residents:



FINANCIAL BARRIERS



ACCESS TO HEALTH CARE



BELONGING AND SUPPORT



**TRANSPORTATION** 



HOUSING

These themes are explored in detail, using the words of research participants to amplify the lived experience of our priority populations across each domain.

An analysis of the group's strengths and growth areas follows and identifies the gaps that need to be addressed in clarity, commitment, and capacity to successfully achieve the partnership's goals. Specifically, the partnership must address clarity around roles and responsibilities, governance and decision-making, and project goals and determine how to increase partner capacity for participation.

Finally, the report outlines a series of recommendations and next steps – including tasks in partner development, identification and investigation of determinants, implementation planning, sustainability planning, and community awareness – that will provide a framework for our collaborative work in the second half of the grant year.

#### ACHIP'S APPROACH TO ASSESSING READINESS

To achieve a comprehensive view of ACHIP's readiness status, we undertook efforts to assess the community needs, as well as partner motivation and capacity, as a means of understanding areas that require further development prior to an implementation phase.

#### UNDERSTANDING COMMUNITY NEEDS: THE CHALLENGES TO ADDRESS

To appropriately understand community needs, it was important to hear from individuals with direct experience of unmet social needs that impact health access and equity, as well as of the services providing social and health care. Without this grounding, it would be difficult to develop solutions that are truly responsive to the challenges experienced by people in their everyday lives.

ACHIP employed several strategies to ensure an accurate and comprehensive understanding of the needs of County residents. As outlined below, both primary and secondary data were used to develop the needs assessment.

#### **Methodologies for Collecting Primary Data**

- Quantitative surveys to gather demographic data
- One-on-one interviews with key informants in each of ACHIP's identified priority populations

#### **Methodologies for Collecting Secondary Data**

- Local: Service area hospital/provider Community Health Needs Assessments
- County-wide: Aroostook County Community Health Needs Assessment; District 8 Local Public Health Systems Assessment; ALICE (United Way) data; Aroostook Agency on Aging Area Plan; ACAP Community Needs Assessment
- County and state level: U.S. Census Bureau; Behavioral Risk Factors Surveillance Survey (BRFSS); Maine Integrated Youth Health Survey (MIYHS); Disability Rights Maine Health Access Equity report; Maine Center for Disease Control

#### **PRIMARY DATA METHODOLOGIES**

The partnership conducted extensive demographic and lived experience research, led within the project by a Lived Experience subcommittee, and administered externally by Ethos Marketing and Pan-Atlantic Research. This research focused on four priority populations: people with household incomes of less than \$40,000; older adults; individuals with behavioral health concerns; and single parents and guardians. A total of 800 quantitative surveys were conducted by telephone with a random sample of Aroostook County residents; sixty individuals who identified as belonging to one or more priority populations were subsequently invited to participate in a 30-minute qualitative interview to develop a deeper understanding of their situations.

#### Demographic (Quantitative) Research

In consultation with Ethos Marketing and Pan-Atlantic Research staff members, the Lived Experience Subcommittee identified key areas for exploration and developed a 45-question instrument that was used to conduct telephone surveys with a randomly sampled subset of Aroostook County residents (see Appendix A). Of these calls, approximately 60% were to cell phones and 40% to landlines.

Calls, which lasted approximately ten minutes, were made in the evenings from August 27<sup>th</sup> to October 10<sup>th</sup>, 2023, and explored the following issues:

- Basic demographics
- Access to transportation
- Employment and caregiving
- Access to technology
- Health profile
- Access to health care
- Ability to meet basic needs
- Social connectivity and support

Responses were solicited from 800 County residents, 74% of whom identified as being a member of one or more priority populations.

#### One-on-One Interviews (Qualitative Research)

As with the quantitative research project described above, the Lived Experience Subcommittee identified key issues for exploration and developed a 10-question moderator's guide (see Appendix B) in consultation with Ethos Marketing and Pan-Atlantic Research.

The purpose of this research was to gain deeper insight into population characteristics and barriers to health-related social needs of our four priority cohorts, as well as to begin understanding "what help looks like" for these groups. The moderator's guide provided a framework for facilitating a 30-minute-long conversation about an individual's personal experiences with the key issues confronting them as a member of one or more priority populations, including sources of help and support; barriers to accessing care and services; the impact of community perceptions and identity; experiences accessing health care; impactful programs and attributes thereof; and needs of the community in the current moment.

Potential participants in these interviews were identified through the quantitative surveying process: individuals who identified as belonging to one or more priority populations were asked if they would like to participate in a longer phone interview about their experiences within the next few days. Participation in these interviews was incentivized with a \$100 gift card.

Qualitative interviews were conducted between September 11<sup>th</sup> and October 13<sup>th</sup>, 2023. The goal was to speak with 15 members of each priority population, for a total of 60 interviews. Unfortunately, the number of respondents who identified as single parents was significantly smaller than the other priority populations, so the total number of interviews per population was as follows:

PEOPLE WITH HOUSEHOLD INCOME LESS THAN \$40K	18
OLDER ADULTS (AGE 65+)	19
PEOPLE EXPERIENCING BEHAVIORAL HEALTH CONCERNS	16
SINGLE PARENTS/ GRANDPARENT GUARDIANS	7

(Note that the numbers above reflect only the primary cohort membership; many respondents have intersectional identities – e.g., single parents with mental health issues or older adults with below-median income.)

Findings from this research have been incorporated into this report as a means of documenting the barriers to and enablers of the resources and services needed for good physical and mental health.

#### SECONDARY DATA METHODOLOGIES

To supplement the primary research described above, the ACHIP project team conducted a literature review of other needs assessments relevant to The County. This provided a means of summarizing and synthesizing other inputs that inform an understanding of community and resident needs, including county-level and provider-specific Community Health Needs Assessments (CHNAs) and similar strategic planning documents; the <a href="2023 Disability Rights Maine report">2023 Disability Rights Maine report</a> on health access equity; and the recently-released <a href="Local Public Health Systems Assessment">Local Public Health Systems Assessment</a> for Aroostook County.

In addition, the Readiness Assessment leverages published data sets, including U.S. Census Data, the <u>CDC/ATSDR Social Vulnerability Index</u>, the <u>United Way ALICE</u> (Asset-Limited, Income-Constrained, Employed) data, the <u>Behavioral Risk Factor Surveillance System</u> (BRFSS), and more.

#### UNDERSTANDING PARTNER MOTIVATION & CAPACITY: THE ASSETS WE SHARE

ACHIP is fortunate to bring together more than twenty organizations across public health, health care, and social services, each of which contributes critical assets – knowledge, creativity and innovation, and resources – to the collaborative. One key asset that is essential to measure as part of this process is motivation, which includes "belief in the need for and value of change; a shared commitment to change; compatibility and manageability of selected interventions, prioritization, and visibility of outcomes" (Capacity Building for States, 2018).

In addition, the Readiness Assessment provides an evaluation of foundational capacity – that is, the culture, structure, and resources necessary to effectively advance the partnership's goals. Capacity Building for States (2018) suggests several attributes of foundational capacity, including:

- The ability to acquire and allocate resources, including time, money, effort, and technology
- Strong relationships that bring all of the right people, skills, and knowledge to the table
- Leadership that is effective and supportive at both the partnership and member organization levels
- Structures that enable effective communication and teamwork

(As ACHIP identifies priority interventions in the second half of the planning phase, we will also assess innovation-specific capacity – the abilities necessary to effectively implement a specific program, practice, or policy. These assessments will help to drive project selection and preparation leading to the implementation phase, beginning in mid-2024.)

In its assessment of partner motivation and foundational capacity, this document relies on the November 2023 assessment conducted by personnel from the University of Southern Maine's Maine Rural Health Research Center, who were contracted by MCD as independent evaluators (Appendix C). The data gathered through this process helped to better understand partner perceptions of ACHIP readiness and identified strengths and areas for improvement as we continue the planning process. Foundational capacity is measured against three domains of readiness identified by the MIT D-Lab P·ACT framework (2020): clarity, convergence, and confidence.



# AROOSTOOK COUNTY: THE ECONOMIC, CULTURAL & SOCIAL LANDSCAPE

Aroostook County, the northernmost county in Maine and the largest east of the Mississippi River, comprises more than 6500 square miles, many of which border the Canadian provinces of Quebec to the northwest and New Brunswick to the north and east. Although its land area is bigger than that of Connecticut and Rhode Island combined, its 67,000 residents represent just two percent of the population of those two states. The County is sparsely populated, with 80.3% of its residents living in low population density areas and most communities clustered within 10 miles of the northern and eastern border with Canada. Fort Kent in the St. John Valley, Caribou, and Presque Isle in the central part of the county, and Houlton in southern Aroostook act as regional service centers. The County's southernmost town, Weston, is a journey of more than three hours – along 130 miles of non-highway roads – from the northern border with New Brunswick in Fort Kent.

Nearly 90% of Aroostook County's area consists of heavily wooded land, which has traditionally supported paper and lumber industries. In addition, the County is primarily agricultural, with its potato and broccoli crops contributing significantly to the state's agricultural economy. Aroostook County is also a popular destination for recreational pursuits, including hunting, skiing, snowmobiling, and canoeing, activities that boost the local economy.

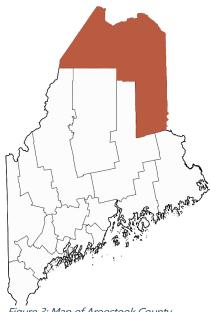


Figure 3: Map of Aroostook County



Figure 4: Logging in The Valley

The northern third of Aroostook County, the St. John Valley, is known for its strong Acadian culture, which dates to the arrival of French settlers in Maine in 1604. Many residents are bilingual, speaking both French and English – in Madawaska, for instance, 83% of residents are fluent in French (Aroostook Rural Communities Opioid Response Program, 2020). Many residents earn their livings in the forestry industry – known locally as "the woods." Fort Kent is the largest community in The Valley, with a 2021 population of 4100 (U.S. Census Bureau, 2022b), and offers the University of Maine at Fort Kent, Northern Maine Medical Center, and a large outdoor heritage center for year-round activities.

Central Aroostook, anchored by the cities of Presque Isle, with a population of 8859 (<u>U.S. Census Bureau</u>, 2022d), and Caribou, with a 2021 population of 7454 (<u>U.S. Census Bureau</u>, 2022a), is heavily involved in the agricultural industry, with farming contributing 1650 jobs and more than \$223M in annual revenues to the economy (<u>Aroostook Rural Communities Opioid Response Program</u>, 2020). Presque Isle is home to the University of Maine at Presque Isle, Northern Maine Community College, a large business district, Northern Light A.R. Gould Hospital, and the only passenger airport in the County. Caribou boasts a new state-of-the-art community school, the city-operated Cary Medical Center, and a sizeable business district. Together, Presque Isle and Caribou comprise more than a guarter of the County's population.



Figure 5: Potato fields near Presque Isle



Figure 6: Aerial view of downtown Houlton

Southern Aroostook is home to the third-largest community in the County – Houlton, with a 2021 population of 6072 (<u>U.S. Census Bureau</u>, 2022c). The northern terminus of the I-95 corridor ends at the Canadian border in Houlton, effectively making the town the primary access point to the rest of the County. Given its proximity to a major border crossing, the area's economy benefits from its New Brunswick neighbors coming to town to purchase less expensive fuel, groceries, and other essentials. In addition to large truck stops servicing commercial cross-border transportation, the region is home to Houlton Regional Hospital, the Aroostook County Jail, and production facilities for several national and international corporations.

Aroostook County sits on the original homelands of two Indigenous Peoples: the Houlton Band of Maliseet Indians, whose community is centered around Meduxnekeag River near Houlton, and the Aroostook Band of Micmacs, 70% of whose members live within 20 miles of Presque Isle (<u>Aroostook Rural Communities Opioid Response Program, 2020</u>). Both tribes maintain their own health centers, prevention services, housing units, and other programs for their members.

From 1953 until 1994, the County's economy was positively affected by both direct and indirect military spending related to Loring Air Force Base in Limestone, a "mega base" with the second largest capacity of all Strategic Air Command bases. The base's closure in 1994, with the concomitant loss of more than 1300 civilian jobs, reduced the regional population by 15 percent (U.S. Department of Defense, Office of Local Defense Community Cooperation, 2017). Additionally, base-affiliated community members actively participated in many service and social activities throughout the County, including Red Cross assistance and volunteerism in many community programs. A 2005 report on the base closure noted that the sense of community pride, both locally and regionally, had not recovered in the ten years

#### **AROOSTOOK COUNTY POPULATION, 1971-2021**

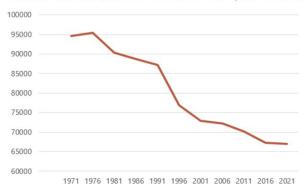


Figure 7: 50 years of population decline

since base operations ceased (Center for Workforce Research and Information, 2005).

Significant outmigration preceded the base's closure, however, as studies show that the decline of agricultural and forest industries, coupled with mechanization and consolidation, caused a large labor surplus that began in the 1960s (Center for Workforce Research and Information, 2005). At this time, workers began leaving the area to seek employment opportunities and higher wages elsewhere in Maine and New England. Between 1972 and 2022, the population of Aroostook County decreased by 29.8%; in comparison, the population of Maine grew by 33.1% in the same period (USAFacts, 2024). Further, the past fifty years have seen significant changes in the age distribution of The County's population, with a decline of more than 40% of

#### **CHANGE IN AGE DISTRIBUTION, 1971-2021**

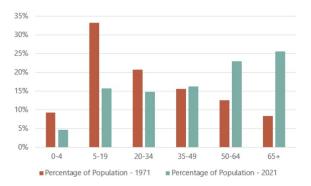


Figure 8: Changes in age distribution

younger residents (those under the age of 35) and a 200% increase in the population of people aged 65 and older (<u>USAFacts, 2024</u>). The simultaneous aging and outmigration of the population have left the County with significant challenges in maintaining a robust workforce, particularly in the health care professions – there are fewer working-age individuals to support an increasing need for services.

Aroostook County's political climate has recently trended in a more socially conservative direction. After voting for the Democratic presidential candidates in the six elections from 1992 through 2020, the Republican candidate won the County with margins of nearly 20 points in 2016 and 2020 (Wikipedia, 2023). The populace historically voted against efforts to legalize same-sex marriage, again by wide margins – 73% in 2009 and 67% in 2012 (Wikipedia, 2023).

Aroostook County residents are known for their strong work ethic, "Yankee ingenuity," and a strong sense of independence and personal responsibility. Kathryn Olmstead, a journalist and educator who has made Aroostook County her home for nearly 50 years, describes her sense of the County as being one of "genuineness, authenticity, lack of pretense. Of pride in a history of hard work and agriculture....[of] being who you are. You don't have to worry about making an impression here – you have to survive. You learn to be resilient" (Kevin, 2022).



# IDENTIFYING & UNDERSTANDING PRIORITY POPULATIONS: BY THE NUMBERS

#### RATIONALE FOR SELECTION OF PRIORITY POPULATIONS

As noted previously, ACHIP began its work with the intention to evaluate the needs of four priority populations:

- People with household income less than \$40K
- Older adults (aged 65+)
- People experiencing behavioral health concerns
- Single parents/guardians and grandparents raising grandchildren

The partnership members reviewed this initial recommendation and, based on their professional knowledge and experience, agreed that understanding the health-related social needs of these cohorts *in Aroostook County* provided the most appropriate starting point for our Lived Experience research.

#### PEOPLE WITH INCOME LESS THAN \$40K

In 2021, more than a quarter of Aroostook County residents lived at or below 150% of the Federal Poverty Level (National Institute on Minority Health and Health Disparities, 2024). Recent data from the United for ALICE initiative amplifies this statistic, indicating that 46% of Aroostook County households are asset-limited, income-constrained, and employed – that is, unable to afford basic expenses on their incomes (United For Alice, 2023). Of these, 16% meet Federal Poverty Level guidelines, a rate that climbs significantly higher for individuals under the age of 25 or age 65 or older (United For Alice, 2023).





<u>United for ALICE, Maine County Reports, 2023</u>

Figure 9: Key socioeconomic data for Aroostook County

We included populations with lower socioeconomic status, which we defined as a household income less than \$40,000 per year, because we anticipated – and through our research, proved – a significant overlap with the three other priority populations. These intersections are explored in more detail later in this report.

#### **OLDER ADULTS**

In 2021, individuals aged 65 and older comprised 24.1% of Aroostook County's population, an increase of 4.6 percentage points over 2016 (<u>U.S. Census Bureau, 2021a</u>). That number only promises to grow as Maine's population continues to age – in 2021, an additional 16,000 county residents (23.6% of the population) were between the ages of 50 and 64 (<u>U.S. Census Bureau, 2021a</u>).

Older adult health represents a unique area of public health, as health conditions common in older age – arthritis, cognitive decline, and chronic disease – exacerbate disparities in access to support and resources that are endemic in rural areas like Aroostook County.

"Community members facing systemic disadvantages can find navigating daily living as an older adult especially challenging. Older adults often live on limited incomes on must rely on the support of others. Barriers and challenges include access to transportation, food insecurity, specialty care, and loneliness."

(Maine CDC, 2022)

#### PEOPLE EXPERIENCING BEHAVIORAL HEALTH CONCERNS

Mental health, along with substance and alcohol use, were identified as top concerns for Aroostook County residents in the 2019 and 2022 Maine Shared Community Health Needs Assessments. This is not surprising, given that nearly a quarter of the County's adult population reported lifetime experience of depression (Maine CDC, 2022); more than 15% of middle and high school students have contemplated suicide; and the number of fatal and non-fatal overdoses, drugrelated arrests, and cases of Hepatitis C are rapidly escalating (Aroostook Rural Communities Opioid Response Program, 2020).

Further, research indicates that rural geographic locations – like Aroostook County – have fewer behavioral health care providers and, therefore, less access to treatment; in addition, rural providers often have less specialized training than their urban counterparts (Morales, Barksdale, & Beckel-Mitchener, 2020). For instance, Aroostook County has just one psychiatrist serving the entire county.

#### SINGLE PARENTS & GRANDPARENT GUARDIANS

In Aroostook County, nearly 30% of households with children under the age of 18 are headed by a single parent (<u>U.S. Census Bureau</u>, 2020). Compared to their peers growing up in two-parent households, children in single-parent families are more likely to experience poor outcomes (<u>The Annie E. Casey Foundation</u>, 2023). Mounting evidence indicates that "underlying factors — such as strong and stable relationships, parental mental health, socioeconomic status and access to resources" — have a greater impact on a child's success than does family structure alone. Again, this reinforces the dynamics of intersectionality across our priority populations (<u>The Annie E. Casey Foundation</u>, 2023).

Aroostook County is also an outlier in terms of the number of grandparents who are raising their grandchildren. More than 8% of children under the age of 18 live with a grandparent householder, a third more of whom have primary responsibility for their grandchildren than elsewhere in the state (U.S. Census Bureau, 2021b).

Our desire is to better understand and support the needs of these parents and guardians to improve intergenerational outcomes. Remediation is necessary to address Adverse Childhood Experiences and the Social Determinants of Health that lead to repeating – or worsening – challenges across successive generations.

# A CLOSER LOOK AT PRIORITY POPULATIONS & ARCHETYPES

#### LOWER-INCOME HOUSEHOLDS IN AROOSTOOK COUNTY

Like many of the counties in the four northeastern border states (Maine, New York, New Hampshire, and Vermont), Aroostook County has been identified as a "distressed" county, with "high rates of poverty, unemployment, and outmigration [and] severe and persistent economic distress and underdevelopment" (Ahrens et al., 2022).

Recent data from the United for ALICE initiative underscores this situation, indicating that 46% of Aroostook County households are asset-limited, income-constrained, and employed – that is, unable to afford basic expenses on their incomes (<u>United For Alice, 2023</u>). The percentage of people living below the ALICE threshold climbs significantly higher for individuals under the age of 25 (64%) and aged 65 or older (56%) (<u>United For Alice, 2023</u>).

In 2021,16% of County residents met Federal Poverty Level guidelines: \$12,880 for a single adult and \$26,500 for a four-person household (<u>United For Alice, 2023</u>; <u>U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2023</u>). U.S. Census data illustrates the significant disparities that exist between demographic groups, with the following data points as examples:

- Individuals with disabilities have a poverty rate that is 1.9 times that of their peers without disabilities (20.1% to 11.6%) (2021c).
- 35.3% of The County's Indigenous (American Indian and Alaska Native) population meets FPL guidelines, more than twice that of the overall population (2021d).
- 17.7% of Aroostook County's children under the age of 18 live below the FPL (2021d).
- Women are disproportionately represented at all levels of poverty, with nearly 1.5 times the likelihood of being in poverty at 50%, 100%, and 125% of the FPL (2021c).
- Households headed by a single female parent are nearly five times as likely to meet FPL guidelines as households with married parents (25.3% compared to 6.2%) (2021c).

In 2021, SNAP benefits were provided to 5562, or 19.2% of, Aroostook County households, of which 70% had at least one member who was employed (<u>U.S. Census Bureau, 2021e</u>). The median household income of SNAP recipients in 2022 was \$19,254, significantly below the qualification levels for the program (<u>U.S. Census Bureau, 2021e</u>).

Although the number of uninsured Aroostook County residents has dropped by almost 35% since the implementation of the Affordable Care Act (U.S. Census Bureau, 2022j), the unwinding of MaineCare's continuous enrollment program is likely to lead to more people with lower socioeconomic status being uninsured. The Kaiser Family Foundation projects disenrollments to be 18%, which would leave 3326 Aroostook County residents without coverage (Burns, Williams, Corallo, & Rudowitz, 2023).

# AROOSTOOK STATISTICS Socioeconomic Status

Individuals with disabilities have a poverty rate that is

1.9x

that of their peers without disabilities.

35.3%

of the Indigenous residents of Aroostook County meet FPL guidelines, more than twice that of the overall population.

Female-headed single-parent households are nearly

**5**x

as likely as married-parent households to live at or below the Federal Poverty Level.



I understand the pain now. I knew it was difficult from my experience as a visiting nurse. I would see my patients and they would tell me stuff. It's like, you can't get any help and it's hard, and it's bad enough that we have to muster up the courage to ask for help. And then they tell usthat we can't get it....I just think that they should make it easier for people to get help. You got to jump through hoops. You got to follow their stupid rules.

-Lisa J.



#### LISA'S BACKGROUND

Lisa J. is a 61-year-old disabled woman with an Associate's degree in nursing who spent twenty years working as a visiting nurse in The County. She experienced a disabling work-related back injury in 2018, and she had a fall last January in which she fractured her hip, resulting in multiple hospitalizations over a six-month period. She has now returned to her home, where she lives alone...16 miles from the nearest service center. She reports that, due to her injuries, she drives much less frequently – and not at all during the winter.

At \$20,150 annually, Lisa's limited income is insufficient to meet her basic needs for survival - the United Way's recently-released ALICE data for Aroostook County suggests that single women like Lisa would need \$23,772 in yearly income to make ends meet (<u>United For Alice, 2023</u>). As a result, Lisa goes without and cuts down on essentials, carefully managing electricity usage, closing off the second level of her home so that she doesn't need to heat it in the winter, and often skimping on nutritious meals. Last winter, she needed to replace her furnace but was not able to get financial assistance through the Central Heating Improvement Program as quickly as was necessary. Lisa reflects: "My father said, 'If you wait, your pipes are going to bust, and it's going to cost you more money. Who's going to pay for that?" Fortunately, with help from her father and sister, Lisa pulled together enough money to pay for the new furnace.

Lisa cites challenges with her instrumental activities of daily living – things like housekeeping, home maintenance, and running errands. She commented "When you're in pain or you can't put weight on your leg, it's kind of hard to get active."

Although Lisa is close to her father and sister, neither lives locally, and she has few nearby social supports. Living in a remote community without easy access to transportation makes it very difficult for Lisa to have meaningful social interactions regularly.

### IN LISA'S WORDS



It's hard. Especially in the winter, especially when I can't drive [because of pain in my right leg]. So if you don't have a friend or a relative that's going to help you, you're pretty much screwed...there's a lot of people I know that don't have anybody they can ask [for help].

I fall right in the donut hole, as they say, where I get more than enough so I can't get any help, but I don't get enough to get help, so I'm stuck there and it's hard to ask for help because it's almost like everybody knows that you got help.



#### OLDER ADULTS IN AROOSTOOK COUNTY

Aroostook County is one of six Maine counties for which the population of residents aged 65+ exceeds 25% – one of the oldest areas in the nation's oldest state (U.S. Census Bureau, 2022e). Older Aroostook Countians are about half as likely to have completed a college degree as their peers statewide (U.S. Census Bureau, 2021f), while they are three times more likely to speak a language other than English at home, owing to the large Franco-American population in the northernmost parts of the county (U.S. Census Bureau, 2021f). In Aroostook County, the percentage of working adults aged 65+ is 36% lower than the numbers for the state as a whole (U.S. Census Bureau, 2021f).

The older adult population of Aroostook County has a rate of disability that is 25% higher than the statewide rate, with significant differences in cognitive and self-care disabilities – 21.2% and 44.1% higher, respectively (<u>U.S. Census Bureau</u>, 2021f). The prevalence of Alzheimer's disease among Aroostook County residents is 10.7% (<u>Dhana et al.</u>, 2023), the highest of any county in Maine; it is the fifth leading cause of death for County residents (<u>Maine CDC</u>, 2022).

Socioeconomic data from the United Way's ALICE initiative shows that 56% of Aroostook County's population aged 65+ lack the financial resources necessary to afford basic expenses (United For Alice, 2023). These challenges are exacerbated for the 48.5% of Aroostook County's older adults who live alone (U.S. Census Bureau, 2022q). The Elder Index (2023), a measure of the income that older adults need to meet their basic needs and age in place with dignity, calculates that the income needed by a single adult aged 65+ in Aroostook County with a "good" health status ranges between \$22,608 and \$29,652 annually, depending on housing status (i.e., rent or own with or without a mortgage); for individuals in poorer health, the Elder Index calculates a range from \$25,440 to \$32,484 (The Elder Index, 2023). In comparison, the median income for an older adult living alone in Aroostook County is just \$19,180 for women and \$22,458 for men, leaving significant financial gaps that many struggle to address (U.S. Census Bureau, 2022j).

Of older adults living alone in The County, 45% live outside of the "service hub" communities; 26% live in communities with fewer than a thousand residents (<u>U.S. Census Bureau</u>, 2022g). These dynamics, coupled with the fact that older adults are less likely to drive, often make it more difficult to establish and maintain social connections – as well as access to key services, like medical facilities, grocery stores, community centers, libraries, and more. Although virtual interactions have become more commonplace, particularly during the COVID-19 pandemic, 34% of older adults in The County do not have Internet or computer access in their homes (<u>U.S. Census Bureau</u>, 2021g).

Finally, older adults in Aroostook County frequently experience challenges in meeting their home maintenance and modification needs. Nearly 75% of the homes owned by older adults were built before 1980 – qualifying them as "aging housing stock" (<u>U.S. Census Bureau, 2022i</u>). A lack of affordable housing leads many older adults to remain in homes of poor quality, ill-suited to safely aging in place (<u>Maine State Housing Authority, 2023</u>).

# AROOSTOOK STATISTICS Older Adults



48.5%

of older adults live alone.

# INCOME TO ADDRESS BASIC NEEDS VS. MEDIAN INCOME

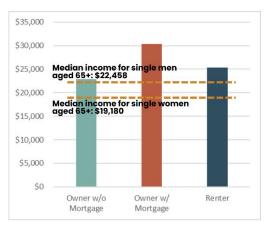
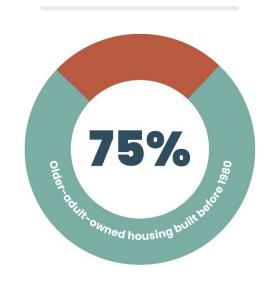


Figure 9: Income by living situation and gender



66

Sometimes I just give up. Like for instance, I know that I need to lose weight and it seems I don't get that much support from my husband. He walks the dog every day, but he walks where it's rugged. It's too hard for me to walk. Of course I've waited too long now, and it's painful for me to walk, so today I finally went to the town hall and asked her a key to go to the Senior Center to walk there. I found it to be lonely in there. It's quiet, there's no noise, full of flies.

-Debra A.



#### **DEBRA'S BACKGROUND**

Debra A. is a 72-year-old retired home health aide who lives with her husband and dog in southern Aroostook County. The couple relocated to The County from another New England state four years ago, and they are working to renovate an older home that they purchased. This project is progressing more slowly than expected, however, as the cost of building materials has increased significantly in that time.

Debra reports having several chronic health conditions, including chronic pain, obesity, COPD, and atrial fibrillation. A recent diagnosis of type 2 diabetes weighs heavily on her, as she has concerns about how to eat appropriately for her condition. Debra feels that her husband isn't supportive of her new dietary needs, and she worries about the cost of food, especially if she needs to make different meals for herself. She also asked to see a dietitian for nutritional counseling but feels that she needs more support than her insurance plan will cover. She also notes that she needs to see a physical therapist for an injury to her arm, although the distance to the office – 15+ miles – is prohibitive for her.

Equally far away is the nearest grocery store, making regular access to healthy food even more difficult. Debra carefully plans her trips into town, especially since she doesn't like to drive after dark. In addition, if she forgets something at the store, she needs to rely on the local superette in between trips – and pays a premium for her purchases there. While a neighbor who works in town has offered to do some shopping for Debra, she won't take any money to pay for the purchases. This makes Debra feel uncomfortable, as she wants to be independent.

Debra is motivated to make changes to improve her health, including losing weight and exercising, but encounters barriers that frustrate her. It is difficult to exercise outdoors, and the limited indoor facilities available are quiet and lonely. Debra admits that she doesn't know where "community things" are and that perhaps other options exist.

## IN DEBRA'S WORDS



Church is helpful. I enjoy going there and it does give me hope, but like I said, when God doesn't seem to be answering me, I tend to give up.

I'm not too fond of my primary care doctor, and it's my understanding that I'm losing her soon....I got to see the doctor more often [where I used to live]. They kept a better eye on my heart condition and stuff. The doctor here says, 'You don't mind seeing me once a year, do you?' And I say it's OK, but I really don't feel comfortable about that. I really think I should be checked more often.



#### PEOPLE WITH BEHAVIORAL HEALTH CONCERNS IN AROOSTOOK COUNTY

Behavioral health issues have risen to the top of the list of community

wellness priorities in Aroostook County, with the entire county designated as a Mental Health Professional Shortage Area (MHPSA). The most recent estimates from SAMHSA (n.d.), covering three years from 2016-2018, indicate that 18.1% of Aroostook County residents received mental health services in the previous year, with 19% of the population reporting any past-year mental illness. Given The County's status as an MHPSA, relatively high levels of uninsured individuals (8.4%), and the stigma associated with behavioral health challenges, it is likely that significantly more people experience concerns and are unable to or elect not to seek treatment.

Maine's age-adjusted depression rate ranks 45th out of 50 states, with 25.3% indicating that they experience "depression generally" (World Population Review, 2024). According to SAMHSA (n.d.), nearly 7.5% of Aroostook County residents experienced major depression and 4% seriously considered suicide. Suicide rates in The County jumped 36% between the five-year periods ending in 2011 and 2019 (Maine CDC, 2022). Events like these led Aroostook County emergency rooms to address 193 behavior-health-related visits per 10,000 population, a rate 6.3% higher than the overall state average 2019 (Maine CDC, 2022).

Particularly sobering are the data captured in the Maine Integrated Youth Health Survey (MIYHS). In 2019, the most recent year for which Aroostook County data are available 21.2% of middle schoolers and 29.9% of high school students felt so sad or hopeless almost every day for a period of two weeks or more that it interfered with their usual activities (Maine Department of Health and Human Services, 2019). In addition, 18.3% of middle school students and 15.6% of high schoolers reported having seriously considered attempting suicide in the past year (Maine Department of Health and Human Services, 2019).

Aroostook County has also seen significant changes concerning substance use in the past five years. Between 2020 and 2022, the rate of suspected and confirmed drug overdose fatalities increased by 135%, with the total number of overdoses growing by 21.3% in the same period (Sorg, Soucier, & Wang, 2023). Aroostook County's EMS crews responded to 490 calls for non-fatal overdoses in 2022, along with an additional 47 incidents that resulted in overdose fatalities (Sorg, Soucier, & Wang, 2023).

In addition, law enforcement agencies throughout Aroostook County are seeing rapidly rising numbers of service calls related to mental health and substance use (Brewer, 2023): Fort Fairfield reported more than a 50% increase in calls in 2022, much of which was linked to incidents involving mental health or substance use issues, while Presque Isle has received 20% more mental health-related calls in the past year. Also in 2022, the Maine Department of Corrections found that 61% of its incarcerated population had an SUD diagnosis (Maine Department of Corrections, 2022).

Again, substance use data for school-age children, collected through MIYHS, paints a concerning picture. Among high school students, nearly 40% indicated that they'd had five or more alcoholic drinks in a row in the past 30 days; 18.3% reported using marijuana in the same timeframe; and 2.9% shared that they'd used prescription medication (such as OxyContin, Percocet, Vicodin, codeine, Adderall, Ritalin, or Xanax) without a prescription (Maine Department of Health and Human Services, 2019).

# AROOSTOOK STATISTICS Behavioral Health

high school students in
Aroostook County say that they
have felt so sad or hopeless for at
least 14 consecutive days in the
past year that it kept them

from their usual activities.



Behavioral health-related emergency department visits are

6.3%

higher in Aroostook County than the statewide average.

The County saw a

135%

increase in the rate of suspected and confirmed drug overdose fatalities between 2020 and 2022.



When I was working and I had insurance, I went and saw a doctor and they said I have some psychosis. They gave me medication and this and that, and it didn't do a f-ing thing for me to be honest, so I just stopped doing that. I quit my job after I got divorced and everything, and I just went stress free. I don't know how to really say it besides, I live off grid. I got no worries.

-Cole M.



#### **COLE'S BACKGROUND**

Cole M. is a 43-year-old divorced man who lives off-grid, 40 miles from the nearest service center. Cole makes ends meet by doing odd jobs, including woodworking, mowing lawns, and shoveling snow. Given that he doesn't have any payments or bills related to his home, he isn't always looking for a paycheck to meet his basic needs.

A history of depression and anxiety in public settings keeps Cole close to home, where he "minds his own business" and pursues hobbies like playing the guitar and singing. Talking things out is an important approach for Cole when considering his challenges, although he finds it difficult to find people that he trusts and laments that technology has changed the way that people interact in ways that aren't positive.

Cole describes a lack of motivation, which he attributes to his mental health and his marital status. Prior to his divorce, he says, he had more reason to get out and about, given his family responsibilities.

Although Cole isn't concerned about what people think of him, he is sensitive to how people's perceptions and biases make finding community difficult for folks like him. He is aware of the stigma associated with being of lower socioeconomic status and how that impacts people's willingness to take advantage of community programs and supports. Cole notes that well-off individuals tend to judge others: "They just sit back and are like, 'Look at this f---er, they're poor, white trash, live in a trailer."

Cole does not have a primary care provider and does not currently seek care for his physical or behavioral health issues. Although his lack of insurance explains part of this, he has struggled to get to appointments and, as a result, no longer sees a point in making them in the first place. He also feels that his providers don't really understand his experience and can't relate well to his needs.

## IN COLE'S WORDS



Our lives shape us and make us who we are in different ways, everybody's different. I'm glad I am who I am, even with all the difficulties, because it's helped me in the long run, it has. It's a long, tough road to build character, but once you get it there, you can't lose it.

Away from here, people aren't worried about other people's business like they are here. It's not in a good way either, usually. A lot of people in different towns look down upon people from around this area.



#### SINGLE PARENTS & GRANDPARENT GUARDIANS IN AROOSTOOK COUNTY

In Aroostook County, 29.8% of households with children under the age of 18 are headed by single parents, with children living with their mothers in 7 of 10 of these homes (U.S. Census Bureau, 2020).

Socioeconomically, The County's single parents face significant challenges: they are 3 times more likely than households headed by married parents to live below the Federal Poverty Level (i.e., an income-to-poverty level ratio of 1 or less) and 5.6 times more likely to live at or below the FPL than at 200% or more (U.S. Census Bureau, 2022h).

Single mothers in Aroostook County are 4.5 times more likely to reside in rental housing than their married counterparts; for single fathers, the likelihood is 3.4 times greater (<u>U.S. Census Bureau, 2021b</u>). This is noteworthy, as research indicates that geography and tenure (specifically, renting) combine to create a disproportionately higher share of housing cost burden among rural renters (<u>Skobba, 2021</u>).

Childcare also presents challenges for single parents in Aroostook County, which has the highest childcare gap in Maine – 2561 children need care, and there is a gap of 565 spaces per a January 2023 report (Bipartisan Policy Center, 2023). This disparity has been exacerbated by the loss of 106 slots following the closure of one of The County's largest facilities in August of 2023 (Lizotte, 2023). With a market rate of nearly \$600 per month for a preschooler's childcare, costs and availability can be barriers to single parents' ability to find employment.

Aroostook County is also an outlier in terms of the number of grandparents who are raising their grandchildren. More than 8% of children under the age of 18 live with a grandparent householder, and Aroostook grandparents have custodial responsibility for their grandchildren at a rate that is 2.1 times the statewide rate (U.S. Census Bureau, 2021b). Of these grandparents, 53% are aged 60 or older; 20% live at or below the Federal Poverty Level; and 49% have had such responsibility for five or more years (U.S. Census, 2021b). Grandparent guardianship has increased in recent years, corresponding to an increase in substance use disorder, mental/physical illness, and parental incarceration. Research from Canada indicates that custodial grandparents often lack access to the community resources necessary to meet their emotional, respite, and financial needs (Martin et al., 2020).

# AROOSTOOK STATISTICS Single Parents & Grandparent Guardians



For every 100 children that require professional childcare



there are only 78 available openings.

Aroostook grandparents have custodial responsibility for their grandchildren at a rate that is

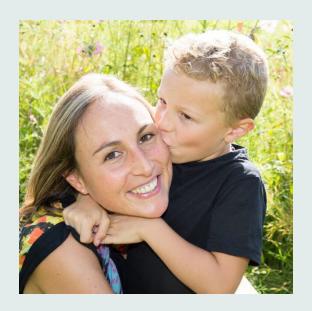
2.1X

the statewide rate.



A stable home is most important to me. We live in housing and they can be really particular about things. Like if I'm fifteen dollars short on my rent, they will send me an eviction notice. They can be really particular about certain things. They need to understand that we're human beings. You can't throw me out over fifteen dollars.

-ANNABELLE P.



#### **ANNABELLE'S BACKGROUND**

Annabelle P. is a 34-year-old single mother of three – a 16-year-old daughter, a 13-year-old son, and a 7-year-old son – who lives in one of central Aroostook's service centers. She's enrolled part-time in an undergraduate degree program at the local university and, until recently, had been employed in a manufacturing plant in town. She left that job to waitress, as the hours were a better fit with her schedule, but the restaurant at which she worked closed, leaving her unemployed.

Annabelle left the father of her sons shortly after her second son was born seven years ago, and for five years, she had to parent "100% alone." She notes the struggles associated with being a single parent, describing the mental and physical exhaustion she experiences by the end of each day. The time and energy spent working and being both mom and dad to her kids takes its toll, although things are better now that her kids are in school full-time and she is less reliant on paid childcare. "It was skin of my teeth getting my youngest daycare around here," she says.

Annabelle relies on informal support from family and friends, as she often finds it difficult to access the benefits she needs. Between long waits for service, lots of bureaucracy, and the limited availability of funds, she typically avoids seeking formal assistance. Annabelle has a criminal record, which has also proven to be a barrier to her family's well-being. She explains that many of the people she knows are in even tougher situations – "there are no means to be successful because the help isn't there" – but also emphasizes the resourcefulness that she and her friends possess as an important strength.

Annabelle and her family rely on the services of a local behavioral health provider. Annabelle receives counseling services related to a lifetime history of abuse, while one of her sons receives case management services. She's grateful for the care and concern she experiences with this provider, as she knows that their resources are often limited. "They make it work," she says.

# IN ANNABELLE'S WORDS



A lot of times I do not bother with [seeking benefits], because I feel sometimes the phone wait times are so long... like for Health and Human Services, you can wait for two hours and then get hung up on or not even get to talk to someone. Sometimes there are so many hoops you have to jump through...

I have seen a lot of desperation for things like daycare. A close friend of mine is trying to find daycare for her younger children so that she can go back to work. She is also a single mom. It's a struggle.



# IDENTIFYING & UNDERSTANDING COMMUNITY NEEDS: LIVED EXPERIENCE RESEARCH

#### DATA STRATEGY & METHODOLOGY

To identify and understand community needs, the partnership conducted extensive demographic and lived experience research, led within the project by a Lived Experience subcommittee and administered externally by Ethos Marketing and Pan-Atlantic Research. This research focused on four priority populations: people with household incomes of less than \$40,000; older adults; individuals with behavioral health concerns; and single parents and guardians. A total of 800 quantitative surveys were conducted by telephone with a random sample of Aroostook County residents; 60 individuals who identified as belonging to one or more priority populations were then invited to participate in a 30-minute qualitative interview to develop a deeper understanding of their situation.

Central to the Readiness Assessment was the analysis of these data in Dedoose, a Web-based mixed-methods research application that allows for in-depth coding and analysis of the qualitative interview transcripts. A strength of this application is its ability to link interviews with the participants previously completed quantitative survey data, defined as descriptive data within Dedoose. This allowed the project team to discover hidden patterns, as well as the ability to navigate narrative content and compare it using quantitative measures more easily.

Considering the large amount of qualitative data, the project team invested a significant amount of time and effort to develop the qualitative coding structure, which helped to ensure that the correct information was investigated and reported as it relates to the unique challenges faced by the priority populations. The coding approach utilized within Dedoose consisted of descriptive coding and simultaneous coding. In vivo coding, sometimes referred to as "verbatim coding" or "inductive coding," was also used throughout the initial analysis and exploration (Saldaña, 2021). These codes were subsequently aggregated into larger topic areas. Descriptive coding, often called "topic coding" or "topic tagging," is an approach to coding that facilitates the categorization of sections of data into broad topic areas (Saldaña, 2021). This style of coding suited the goals of this research and allowed for the investigation of major themes, processes, and interrelationships of unmet health-related social needs within and between populations.

Given the semi-structured nature of the qualitative interviews, descriptive coding allowed the participants' responses to be broadly categorized. While the participants loosely followed the structure of the interview questions, there was a great deal of variability in how they responded – e.g., how long a participant discussed each topic and whether they stayed on topic between questions. Many individuals, even when prompted about other topics, simply elaborated further on the primary issue they were experiencing. Thus, comments originally made under one question could be coded with comments made under a different question if they had similar topics.

In our analysis, we employed simultaneous coding – often called "co-occurrence coding" or "multiple coding" – to allow the same excerpt to have two or more codes assigned to it (Saldaña, 2021). Initial probes into the data illustrated the intersectionality between the core topics of interest (e.g. transportation and income, or sources of help and behavioral health). Thus, while some excerpts have been coded with one code, many have been assigned multiple codes, allowing us to better explore when and why problems co-occurred. This revealed otherwise unknown interactions that increased the ability to drill down into the lived experience of the interview participants.

Finally, an inductive approach helped to expose the variability in responses and account for the many directions in which the conversations went. While the topics were somewhat structured, emergent themes and experiences were iteratively incorporated into the coding structure during the coding process and post-hoc structuring. What resulted was a set of codes that neatly sorted the transcripts into major categories and subcategories related to their challenges, support systems, perceptions of Aroostook County, and emotions related to respondents' lives.

The verbatim quotes included in this report provide evidence to allow the reader to interpret the meaning and feelings behind the participant's words and provide greater insight into how the results are explained and conceptualized within the report. They also help to illustrate complex relationships between the self, society, and the context, thus allowing for the exploration of these interconnected issues and experiences.

#### SUMMARY FINDINGS BY PRIORITY POPULATIONS

One of the aspects regarding Lived Experience reinforced by our research is that respondents' lives are complex and intersectional, with the challenges of socioeconomic status, behavioral health, aging, and caregiving compounding one another. In many instances, it was difficult to tease apart issues – we often asked, "Is this an issue of access to health care or transportation?" and the answer was, equally often, "Yes." Yet each of the priority populations on which our research focused experienced health-related social needs slightly differently, with some populations being more likely to encounter certain barriers than others. To provide a more comprehensive picture of the priority populations, key statistics and themes identified in our research for each are summarized below.

### PEOPLE WITH LOWER SOCIOECONOMIC STATUS (INCOME < \$40K)

#### **KEY STATISTICS**

- More likely to face challenges accessing or affording daycare (36% vs. 22%, among those with children who could require daycare)
- More likely to suffer from chronic pain (17% vs. 12%), diabetes (10% vs. 8%), and chronic lower respiratory disease (6% vs. 5%)
- More likely to say that their last dentist visit was more than one year ago (53% vs. 46%)
- More likely to have worried in the last year about whether their household's food would run out before they got money to buy more (15% vs. 9%)
- More likely to have experienced at least one of the listed housing challenges (31% vs. 22%)

 Experience great difficulty accessing basic needs, like food, housing, and heating; often stuck in unhealthy situations

**KEY THEMES** 

- Frequently mention challenges affording healthrelated expenses, such as travel, medications, and copays; often forgo care due to finances
- Experience severe psychological distress regarding their economic instability, lack of flexibility, and concerns about their future
- Individuals exhibit varying personal perspectives regarding their lifestyle changes due to low income
- People below median income come from highly varied demographics, resulting in high overlap with the other target populations

## **OLDER ADULTS (AGED 65+)**

#### **KEY STATISTICS**

# Less likely than the overall population to own a car (62% vs. 76%) or be able to drive (71% vs. 85%)

- More likely to have difficulty accessing alternative transportation (35% vs. 26%)
- Less likely to have access to both high-speed internet (59% vs. 73%) and reliable cell phone service (67% vs. 80%)
- More likely to suffer from a chronic physical health issue (47% vs. 40%)

#### **KEY THEMES**

- Limited mobility, transportation, and income contribute to isolation
- Managing psychological distress from the loss of personal connections, changes in society, and community
- Limited health care access due to limited income and transportation, and lack of social supports
- Experience issues with getting consistent care and building strong relationships with providers

- Older adults were more likely to suffer from chronic pain (16% vs. 12%), heart disease (12% vs. 9%), and diabetes (10% vs. 8%)
- Struggle to manage chronic conditions and changes in capabilities and activity levels

### PEOPLE WITH BEHAVIORAL HEALTH CONCERNS

#### **KEY STATISTICS**

#### **KEY THEMES**

- Less likely to feel that their job matches their skills and qualifications (54% vs. 69% among employed respondents)
- More likely to have been unable to get needed medical care within the past year (23% vs.14%)
- More likely to have cut the size of meals or skipped meals due to financial concerns (18% vs. 8%)
- Less likely to say that they would be very or somewhat comfortable using benefits that applied to them (45% vs. 51%)

- Often report difficulty maintaining personal relationships with family members, friends, and the community
- Feel judged by their community due to their behavioral health challenges
- People experience diverse emotions concerning their role in supporting family members with behavioral health challenges
- Substance abuse is highly prevalent in the community and contributes to social conflict

## SINGLE PARENTS AND GRANDPARENT GUARDIANS

#### **KEY STATISTICS**

#### **KEY THEMES**

- More likely to be able to drive (96% vs. 85%), to be employed (93% vs. 55%), to have access to highspeed internet access (81% vs. 73%), and to have access to reliable cell service (93% vs. 80%)
- More likely to face challenges accessing or affording daycare (32% vs. 22%, among those with children who could require daycare)
- Less likely to suffer from chronic physical issues (22% vs. 40%), but more likely to suffer from mental health or substance use issues (31% vs. 18%)
- More likely to indicate that they have visited the ER, an Urgent Care Clinic, or a Walk-in Clinic for urgent medical care (74% vs. 63%)

- Issues in finding and paying for childcare were prevalent
- Struggle to manage work with the needs of their children, including recreational activities
- Age of children is a major factor contributing to challenges; parents with older children report fewer challenges
- Single parents often rely on their peers for support going through similar challenges to cope

#### BASIC DEMOGRAPHIC DETAILS OF RESEARCH PARTICIPANTS

Overall, the basic demographic data collected during the research process aligns with population-level data for Aroostook County available through the U.S. Census.

#### PRIORITY POPULATION COMPOSITION

The figure to the right shows the sample size of both the quantitative survey (n=800), and the interview group selected from that sample (n=60). Only individuals who identified as belonging to one or more priority populations were selected for the indepth interviews, thus resulting in higher proportions of the priority population members in the qualitative sample compared to the survey. Further, the percentages do not add up to 100% as individuals could be part of multiple priority populations, allowing an examination of how people experience intersecting challenges.

Many of the survey questions were phrased to gather information at the household level, such as car ownership or the presence of behavioral health or substance abuse issues. Thus, within the qualitative interviews, many respondents reported how someone living with them experiences an issue.

#### Target populations

<u>Group</u>	<u>Quantitative</u> n=800	As %	Qualitative n=60	As %
Older adults	363	45%	33	55%
Median income	328	41%	35	58%
Mental health	142	18%	26	43%
Single Parent	54	7%	9	15%

Figure 10: Priority population proportions for the quantitative and qualitative samples

#### **AGE**

The distribution of age groups in the data shows a small percentage (6%) for people between the ages of 18-34, and the largest group of participants aged 65-74.

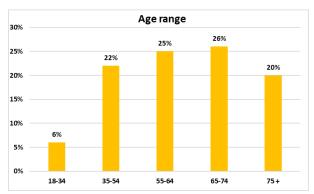


Figure 11: Q42 respondents' age ranges

#### LIVING SITUATION

Living situation, while useful for comparing some groups and relationships, was not a central theme identified within the survey data and served primarily as demographic information. It did, however, come up many times in the qualitative data – for example, when older adults described the impact of living alone or with family. Thus, living situations are relevant to health-related social needs such as housing, access to transportation, or informal support systems.

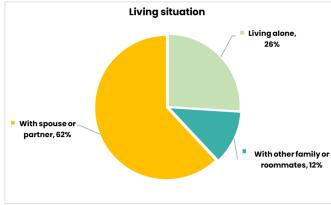


Figure 12: Q44 respondents' living situations

#### **EDUCATION**

Educational demographics within the sample were notably different compared to the U.S. Census data. First, the proportion of individuals with post-graduate degrees was roughly double that of data provided by the 2022 U.S. Census (U.S. Census Bureau, 2022f). Second, data regarding the number of residents with vocational, technical, or Associate's degrees were higher than expected, although this is to be expected, as the census data only includes Associate-level degrees. Data about educational attainment was collected for demographic purposes and did not have an impact on the focus of the lived experience research, although numerous participants in the qualitative interviews made reference to the impact of education on income, access to resources, and ability to manage their health.

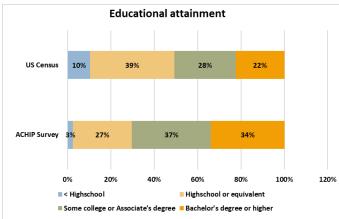


Figure 13: Q42 of the ACHIP Quantitative Survey compared to 2022 US Census data. (U.S. Census Bureau, 2022f)

#### LANGUAGE

Within the survey, only 3% (n= 26) reported that their preferred language was French, compared to 97% English. This proportion of French speakers is significantly lower than what was anticipated, as the U.S. Census Bureau's American Community Survey for 2022 shows that roughly 12% of Aroostook County residents aged 18 years or older speak an Indo-European language (U.S. Census Bureau, 2022f), with the majority speaking French. Participation bias, otherwise known as non-response bias, provides a possible explanation for these results, as Frenchspeaking individuals may have chosen not to respond due to a language barrier. The limited number of responses indicating that French was the individual's preferred first language makes it difficult to draw conclusions about the relationship of language to other factors such as age, income, health profile, and the other determinants of health on which this report focuses.

#### **EMPLOYMENT**

In the quantitative data, 55% of the sample was employed - 30% of respondents held full-time jobs, 17% worked part-time, and 8% reported being self-employed or freelance.

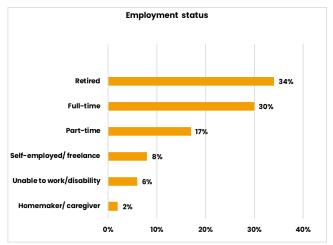


Figure 14: Q8 respondents' employment status

In the interviews, employment was mentioned by many individuals, covering a range of employment settings: paper mills; Job Corps; local health care providers; area educational institutions; agriculture; trucking; logging; retail; and others. In addition, several respondents commented on how they undertake odd jobs and other activities (such as scrapping) to provide themselves with primary or supplemental income.

- 60% of those who were employed (n=442) said that their number of working hours aligns with their preferences
- 69% of those who were employed (n=442) said that their job fully utilizes their skills and qualifications, compared to 54% of people with behavioral health challenges
- 11% of those who were employed are involved in the agricultural sector

#### KEY THEME: FINANCIAL BARRIERS

Of the 800 participants who answered the survey question about income, 47% earned less than \$40K a year. Socioeconomic status and the financial barriers associated with those living below the median income for Aroostook County set the stage for an exploration of the experience of high-need populations in our region, as income and resources play critical roles in other themes.

#### ON THE VERGE OF CRISIS

In our interviews, people with annual household incomes of less than \$40K often indicated the daily struggles of living paycheck to paycheck and counting every dollar spent. While many respondents manage to live with lower income levels, that ability is dependent on a variety of

factors, including social support, health status, home and car ownership, and other costs of living specific to their situation, In Aroostook County, people with lower incomes mentioned having to keep a close eye on how they spend their money, with many reporting the inability to deal with relatively common expenses. Several participants remarked on how they wouldn't know what they would do if their vehicle broke down or if inflation continues to increase the cost of goods and services. This shared feeling is exemplified by Lina M., who said, "I don't have a lot of money saved, and so I guess that part is a little bit scary." Others noted major expenses related to essential needs – for example, a new roof or vehicle – but being unable to

The financial issues have to deal with your psychological issues, because you're worried about, 'Do I have enough money to pay the bills? Am I going to be able to keep vehicle insurance?

Am I going to be able to pay the vehicle loan? Am I going to have enough food for me?'

-Simon L.

afford them or even begin saving up for them. Others cited the increased prices in recent years and the lack of proportionate

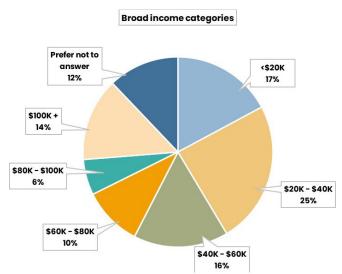


Figure 15: Q45 broad income categories

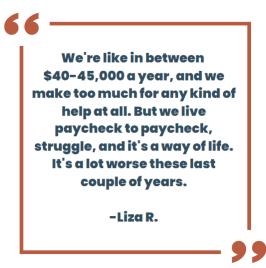


income increases as a major challenge, forcing them to cut back on non-essentials. The costs of food and home heating were major concerns for many, especially considering recent levels of inflation. Karla F. noted, "We keep the heat just comfortable enough," reflecting the need to modify one's life and environment to control costs, even if it creates other challenges. Clara L., who uses SNAP benefits, shared, "With the rising cost of food, [SNAP] doesn't even go half as far as it used to." Many participants facing economic challenges reported that the

stress of living with an income insufficient to meet basic needs and the corresponding lack of security they experience as a result seriously affected their psychological well-being, as Simon L. noted above. Some have learned to live this way and expressed that it has become a way of life: "If I can't get it, I learned to live with it" (Kevin J.).

#### FALLING THROUGH THE CRACKS

Despite the prevalence of financial strain among our respondents, it was clear that people who need help – and even meet the eligibility requirements for assistance – often don't end up getting it. Among respondents, feelings of being overlooked or ignored were common, with many people reporting that, given the nature of their challenges, they do not receive the level of support that they should from community programs, medical providers, or society.



The experience of slipping between the cracks concerning benefits was not limited to those at the lowest levels of income. In Aroostook County, many working people are asset-limited and income-constrained, with earnings that are insufficient to meet their everyday needs. This highlights the spectrum of economic hardship. Respondents frequently cited challenges with making too much money, which pushed them just above the benefit eligibility level and created a barrier to much-needed assistance. Many, like Wilson L., have grown discouraged and no longer seek support: "I make too much money...so I don't bother." Further, programs were perceived to have arbitrary, black-and-white income cut-offs, which led to confusion and frustration and contributed to "people falling between the cracks" or into a "donut hole." Liza R. shared that "the working people get overlooked...they consider our income too much money." The interviews, which highlighted how many get stuck in a spot at which their incomes are simultaneously too much and not enough,

suggest that employment status alone is not a perfect determinant of need. Recognizing the complexity of financial barriers and addressing gaps in the economic safety net can prevent people from falling between the cracks.

#### INCOME IMPACTS MOBILITY

Income affects an individual's economic, social, and geographical mobility, as differences in resources play a key role in where someone lives, what they do, and what their future holds. With a person-centered lens on health improvement, it's important to consider how inequality of opportunity affects physical and mental well-being and overall quality of life. Rural residents, like those in Aroostook County, face challenges in the intersections between physical and social mobility given the limited availability of employment and educational opportunities, services, and infrastructure networks. Mobility and accessibility are strongly linked with rural well-being and social sustainability. Socioeconomic mobility is particularly challenging for those in low-quality jobs, with limited opportunities to leave low-paid or temporary work.

I guess we're living the golden years, but yet we cannot afford to travel and do the things we want to do because everything is getting more and more expensive and we really don't have the means.

-Sara J.

As an example of the intersection between mobility and income, consider the situation faced by the many older adults who seek to maintain their connection to their communities as they age. Often, this means continuing to live in their own homes, but financial barriers can prevent people from maintaining their independence. Nancy L. described how the costs associated with living independently, particularly on a retirement income, become burdensome: "I've got to pay the taxes, the insurance, water, sewer and everything else. I find that very hard." This, combined with the age-related housing issues that are discussed in later sections of this review, shows that mobility, stability, and health status hinge on financial resources.

#### KEY THEME: ACCESS TO HEALTH CARE

Economic, social, and cultural barriers impede access to health care for many individuals, especially in rural areas – and this was a clear message in the Lived Experience research that ACHIP conducted. Some of the most essential data collected for this study involved issues of access, specifically relating to what services are available in The County, what services aren't, and what barriers exist to their access. Emergent themes in this domain, including interactions with health care providers, internal and external challenges in receiving care, and systemic issues in health care within the County, are discussed in this section and provide a closer look at how priority populations experience access to medical and behavioral health care.

The responsiveness and performance of health care professionals was viewed as a complex interaction between systemic issues and the personal attributes of providers and, as a result, individual experiences and attitudes about care received varied significantly.

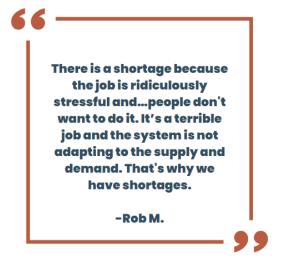
REASONS FOR NOT RECEIVING HEALTH CARE	%
Difficulty getting appointment	43%
Transportation issues	35%
Work and caregiving obligations	5%
No PCP	3%
Financial reasons	2%
Other reasons	13%

Figure 16: Q28 respondents' reasons for not receiving needed health care

#### SYSTEMIC ISSUES

With 14% of survey respondents—109 individuals in total – indicating that they have been unable to get necessary medical care in the past year, it is clear that there are systemic issues that complicate access. The figure above highlights the reasons that individuals reported for being unable to get the care that they needed in their survey responses.

Drilling into the data, we learned that, for 82% of respondents, their last visit to their primary care provider (PCP) was within the last six months, a number that was comparable for people with and without insurance. Only 5% of the overall sample reported that it had been more than a year since their last visit, although this percentage increased to 11% for single parents and 9% for individuals with behavioral health concerns. Nearly 50% more people with behavioral health needs reported challenges in accessing care compared to their peers without such issues.



As in many other rural communities, lack of access to health care is frequently the result of challenges in provider recruitment and retention. Participants in our research linked these issues to medical professionals' aversion to The County. Respondents speculated that the physical environment and geographic isolation of Aroostook County were major reasons for these workforce challenges – as Charlie M. commented, "People don't come to Aroostook County usually because they want to be here." High provider turnover created the impression that doctors were simply here to pay off their debt, and after doing so, they "run back downstate or to another state" (Jake N.). In addition, Rob M., a participant who also works as a physician, provided insight into workforce issues, describing how staffing shortages lead to stress and burnout and create a vicious cycle of turnover.

From a systems-level view, many participants recognized the constraints placed on health care providers and the difficulties of providing care. For example, strict scheduling requirements were viewed as a systemic issue within the health care system, one which contributes to the lack of connection and trust in patient-provider relationships. Respondents believed that their providers would ideally like to spend more time and be more thorough in their interactions, but "their schedules are just so crazy" (Hannah L.). Research participants also shared a perception that doctors do not work for the patients but are instead subject to workplace productivity expectations and insurance company guidelines. Other parties put limits on the time a provider can spend with the patient and the services and procedures that can be offered.

Not only are there challenges in the primary care workforce, but a lack of medical and behavioral health specialists in the area created difficulties for respondents, who often traveled outside of The County to receive treatment and other medical services. Interview data

The care they give you is not necessarily based on what you need. They have to spend time dealing with insurance companies that are...going to deny services they recommend and their hands are tied.

Not a lot they can do.

-Julia R.

supports the need to travel to Bangor, Portland, and Boston regularly. Eddie N. shared, "I have traveled as far as Bangor for some surgery on my leg. I have blood clots in my leg, and I've also got as far as Mass General in Boston." Those with complex health conditions were especially affected, as multiple ongoing health issues require different specialists and interventions. Participants specifically mentioned the lack of psychiatrists, cardiologists, dermatologists, and nephrologists in The County.

#### CONTINUITY OF CARE

Frequent provider turnover arose as one of the most central themes within the qualitative data. As noted above, the constant churn in staffing, specifically for primary care providers, is a widely recognized challenge that frustrates

Even though basic medical services were delivered pretty similarly, each one had their own preferences for what medications they liked, what kinds of things they focused on, and it made it very, very difficult. The continuity of care was very, very hard.

-Susan R.

Aroostook County residents. Turnover creates a situation in which patients constantly need to re-explain their lives, issues, and histories to different people, which is both exhausting and discouraging. Jennifer R. summed up this experience, saying, "It feels like you are telling the doctor what they should be telling you." Similarly, Nancy L. remarked, "We're always stuck with a new doctor." Several participants felt that new providers would just skim through their medical histories and assume that they fully understood the individual's situation. As a result, many respondents reported problems with lack of continuity of care and loss of connection with their provider, making interactions – from refilling medications to addressing complex medical diagnoses – and efforts to get answers particularly difficult. Differences in doctors' techniques and approaches to medication management and treatment processes led to frequent changes in treatment plans and eroded confidence in their providers and the state of respondents' health.

Participants commonly questioned the level of effort put forth by providers in addressing their medical concerns – from a lack of documentation and follow-up to a reluctance to do additional testing – and believed that there was a lack of initiative in investigating health problems. Melissa J. highlighted the concern that "you don't have anybody that's putting the whole picture together," especially with the reliance on urgent care facilities or emergency departments for basic care.

Issues related to barriers in routine medical access and continuity of care may be implicated in visits to urgent care and walk-in clinics and emergency departments. In the past year, 38% of respondents reported receiving care in a clinic or emergency room once or twice; an additional 24% sought care in these facilities three or more times. Of the priority populations, individuals earning less than \$40K were most likely to have sought care five or more times in an emergent setting; single parents were most likely to have received emergent care three or more times. These data support the experiences of individuals within the priority populations who were unable to receive routine care, often due to work requirements, transportation challenges, insufficient income, or lack of insurance.

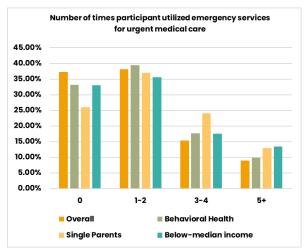


Figure 17: Respondents' use of emergency and urgent care facilities

#### <u>UNDERSTANDING</u>

66

I'm privileged in the sense that where I come from and like my family has a medical background. My father was a surgeon, my mother was a nurse, and I'm a social worker for elderly people. So I have a higher medical IQ than some.

-Rachel F.

In discussing their experiences of health care, participants in the interviews frequently expressed that they felt unheard by their providers. There was a prevailing perception that physicians in Aroostook County "think they know it all" and don't allow patients to provide input and feedback on their treatment. Lina M. summarized this experience: "They don't give you any credit for knowing anything...you're the one that's got the disease, you've had it for X amount of time, but they act like they're the only ones that know anything." Participants with education or work experience within the health care and social services sectors, who were well-represented within the sample, felt that physicians often disregarded their knowledge, even as their abilities and insight into navigating health care services were viewed as major sources of strength for these individuals and their families.

Participants also reported a lack of flexibility and understanding from their providers across a range of issues. Some expressed a lack of empathy and support while making complex health decisions, while others noted a lack of cultural competence – that is, the ability to provide care to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs (Betancourt et al. 2002). Individuals who had specific beliefs about medications, surgeries, and the use of alternative treatments felt that physicians failed to respect and address their views in treatment plans. Given the limited availability of providers in The County, people found it difficult to transition to a provider whose philosophy aligned more fully with their needs.

One thing that would stop me
[from getting care] would be
finding professionals who
understood my faith base that
would offer the kind of helpat least for mental help- that
would line up with my beliefs.

-Caroline R.

Along these lines, respondents commented on their sense that health care providers are quick to group people together and follow a rote process that doesn't take individual patient differences into account. Neither interactions nor interventions seemed personalized, leading participants to indicate that providers were not agile or proactive in prevention. Specifically, younger respondents like Andy R. felt that providers are so used to treating older people that they get "caught in a routine...and treating younger



people becomes more difficult because they're caught in a cookie-cutter mold of elder care" or that PCPs "are too cautious, too 'wait and see', for the level of pain I deal with every day" (Pete R.). Conversely older adults often felt that their health care concerns were dismissed or that their issues were written off as an expected consequence of aging. Receiving age-appropriate care was a concern for both ends of the spectrum which seems to erode patient-provider trust.

When health care professionals failed to meet an individual where they are, in whatever measure, respondents reported compromised relationships, dissatisfaction with care, and the potential for inefficient identification and treatment of health issues.

#### BEHAVIORAL HEALTH

Behavioral health challenges were pervasive throughout all populations in the sample, with 18% of households reporting that at least one person in the home has struggled with mental health or substance use concerns. This number jumps to 31% for single-parent respondents. Rob M. captured the challenges of living with a behavioral health condition: "The long-term effects that mental health issues have on people, they are difficult to overcome....They impact relationships. They make it hard to take care of other aspects of your health."

As with primary care providers and medical specialists, participants described challenges with long wait times for

The hardest part is getting someone to be a mental health advisor...I haven't had one for, I'd say, close to three years now because they don't have any available.

-Hank M.

service. Once connected with a provider, however, respondents expressed a high level of satisfaction with

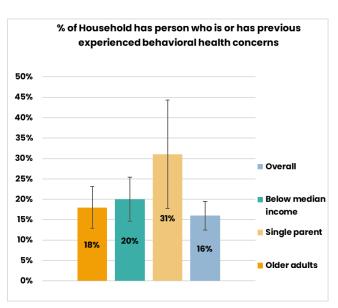


Figure 18: Q22 intersections of behavioral health and priority population membership

the quality of behavioral health practitioners in The County and frequently mentioned how these individuals offered a major source of stability and support during challenging times. Nevertheless, participants often noted it was difficult to find someone trained to address their specific needs – a situation exacerbated by the shortage of mental health professionals in the region.

In the context of behavioral health, telehealth, and online counseling were seen as a way of addressing the limited number of providers and getting access to care. Kylie M. noted, "I actually have a list of therapists but they're all Zoom because there's nobody in town, actually where I live." Even so, many people preferred – if not required – in-person counseling to feel a sense of connection with the provider. Hank M. reflected this sentiment, noting that when services were available, they were provided via telehealth – "I don't want telehealth, I want one-on-one." Further, individuals felt a greater sense of personal connection when a provider was based in The County.

Others in the interviews reflected on past experiences and provided insight into how they've dealt with their own personal challenges or helped others with theirs. A strong sense of peer support exists, as evidenced by Annabelle P.'s comment: "I stick close to my friends and try to be a support for them as well...that helps me in a lot of my challenges because I have friends that are going through very similar challenges." The value of peer support translates into professional relationships, as well, as Simon L. commented, "The counselor I had had addiction issues and mental issues of his own before he got into doing this. So he could associate to me and talk to me...he was actually from the trenches and understood."

#### KEY THEME: BELONGING & SUPPORT

Throughout the qualitative research process, respondents referenced the importance of belonging and inclusion and the challenges they've experienced with social connectedness and isolation in The County. Social supports – family, friends, and community – are critical to well-being, yet only 58% of survey participants strongly agreed that they have people that they can turn to in tough times. This section focuses on how people's origins, identities, and group memberships relate to belonging, social support, and health outcomes.

#### BEING FROM THE COUNTY

Those who specifically mentioned that they were originally from The County had varied experiences and perceptions regarding the social environment. Many reported

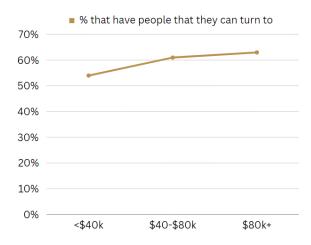
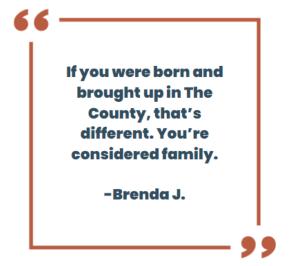


Figure 19: Correlation of income and informal supports

that Aroostook County is an amazing place to live and that their family roots here provide them with a great sense of community, something further reflected in their comments about having robust social networks on which to rely. Caroline R. shared, "It's easy to live here because I understand the people and where they're coming from. So I think having been born here is a plus in that way because I understand." At the same time, several respondents commented on the lack of privacy, perceptions of being judged, and the tendency for people in Aroostook County to be wary of "outsiders." Christine M. commented, "I guess it depends on your name up here, what your bloodline is. And I mean there's only so many families around here and it is all on who you're related to really."



Individuals from Aroostook County shared a variety of thoughts about their rural identity. There was a perception that living here is "just different" than elsewhere – and "in a good way. People care about one another" (Lina M.). Annabelle P. saw an inherent strength in being from The County, commenting, "We are resourceful...I think we are a little bit of a stronger breed from **Aroostook County.**" Several respondents highlighted the strong Franco-American culture in the St. John Valley. Andy R. shared that he's a "Frenchman through and through. I was raised here and intend on dying here, and that is the uniqueness of our little French culture." Even though many of the people interviewed lived in underserved communities with limited resources, there was a strong sentiment among individuals who have lived here throughout their lives that they wouldn't want to live anywhere else. At the same time, Sara J. described how being from a small rural town can be limiting in terms of knowledge, growth, and opportunity, saying, "I've had times when I've struggled within myself because I've wanted more than what we have for a life."

#### BEING "FROM AWAY"

Being from "from away" – that is, not originally from Aroostook County – was a clear theme related to belonging, one that presented several unique challenges described by participants. For many in the interviews, the close-knit community that people from Aroostook County cherished often felt like a barrier to social acceptance and, ultimately, getting the knowledge and resources needed to thrive here. Liza R. commented on her "outsider" status, remarking, "I've been in Maine since 1986, but I'll always be from away. The fact that I married in Maine helps." The research interviews provide insight into this population and the challenges of adapting to the social, physical, and economic environment in The County.

Being "from away" contributed to feelings of isolation for many who were putting down new roots in the area. While some respondents had family members in the area, others had none at all, which made it even more difficult to prepare for, adapt to, and enjoy their new communities. Debra A., an older woman with significant health concerns who moved to The County four years ago, shared, "All the people I know are from church. I don't [know] why I moved out here...I feel like I moved out to Timbuktu and it's been a disadvantage on my part. I can't get my husband to go back to the city."

The experiences of people who have relocated to the area were often dependent on their backgrounds, as many of those from rural communities in other states expressed that their familiarity with rural, agricultural cultures allows them to find acceptance more easily and integrate more effectively into life in The County. Several respondents

If you don't speak French or if you're not connected with, like, the ten families that have been here since the 1800s, I think sometimes you get put on the back burner.

-Maria L.

99

commented on their experiences before moving to The County as a major source of strength and experience for them; as an example, Clara L. said that living elsewhere gave her a sense of "how things work in the real world."

#### CONNECTION WITH AND SUPPORT FROM FAMILY AND FRIENDS

Respondents made frequent reference to the importance of informal support from local friends and family, who were perceived as being both reliable and flexible in helping to meet their needs. Many individuals rely on friends and family to live independently, even with some of the challenges described in this report. It was not uncommon for research participants to share that they rely on informal support to perform daily tasks around the house, help with grocery shopping, and provide transportation when needed. Wilma R. commented that her kids help out a lot, having "taken up the housecleaning and stuff like that." Lewis L. remarked, "I don't know of a thing right now that I don't get from my family."

In addition, respondents often relied on their friends and family for advice and decision-making support. Citing the education, knowledge, and experience of family members, Lina M. said, "[My family members are] very, very intelligent, and if I have any issues I just talk to them." This was particularly true when it came to health care, where informal supports were identified as being essential to increasing communication with providers and helping individuals make informed decisions regarding their care.

I don't get hardly any help. I got a few friends, but they're older, just like me, all older, and they can't do stuff. -Kevin J.

Research participants who did not have strong social networks had varied experiences: some reported that they were doing just fine independently, while others indicated that they had experienced many challenges without support. Lisa J. summed this up: "If you don't have a friend or a relative that's going to help you, you're pretty much screwed." This was particularly true for older adults, interviews with whom revealed that aging leaves many without their original support networks. Sara J. described this situation as feeling like "the glue and the families are no longer there." Jennifer R. currently has strong family support, but said, "I probably would not know where to go if my children were not able to help me, but I would just move forward day by day."

#### FAITH-BASED SUPPORT

Data from 2020 indicates that 51.4% of Aroostook County residents affiliate with a religious community (<u>Association of Religion Data Archives, 2020</u>), so it's unsurprising that many respondents cited their faith as a primary source of support. These mentions occurred in two different contexts.

The first focused on the benefits of being part of a close-knit and like-minded community that is associated by faith. Lina M. noted that she talks to "church people...I have a very strong network," while Rachel F., who has struggled with behavioral health issues, found support among people at her church: "I'm a Christian and I go to a specific church, and that church is very supportive and loving of like everybody and kind of encourages people that have struggled with things like mental health and addiction to feel welcome there." A few participants also reported that they've turned to their faith communities for counseling and, occasionally, economic support.

I went to the church thinking that they might be able to help me out a little bit. I think they have. I think they might have made my whole world different by just seeing somebody every week, even if it's just on a Sunday, that cares about you or at least talks to you.

-Hank M.

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The other centered on how personal perspectives related to religious beliefs gave people hope. Jessica M. indicated that she "pray[s] a lot about the situation to get wisdom from God to know what to do. He has been super helpful." Debra A. found hope in attending church but shared that "when God doesn't seem to be answering me, I tend to give up."

#### **IDENTITY AND PRIDE**

Aroostook County people are well-known for prizing self-sufficiency and independence – self-reliance is a key aspect of the identity of this population. Unsurprisingly, then, several participants in the qualitative research process indicated that they have little awareness of or interest in interacting with community resources and benefit programs. Mike L.'s response was indicative of this mindset: "I've never needed anything. I've always taken care of myself. I've never really thought in those terms, asking for any help about anything. I've never done that."

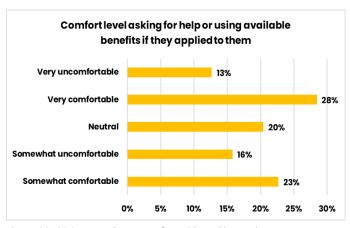


Figure 20: Q36 respondents' comfort with seeking assistance

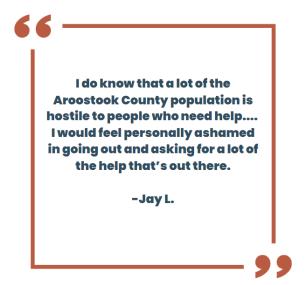
I pride myself on being independent, and I would really have to be in dire need before I would put myself into a situation where I'd have to ask for help.

-Lewis L.

Similarly, Brett L. explained, "I'm a loner, and I try to do everything myself one way or the other. Might not be the right way, but I don't like to bother people." Utilization of assistance programs was not even something that crossed many people's minds, as they were not raised in an environment in which help-seeking was encouraged: "Well, we were brought up that you take care of yourself, don't complain too much, and just keep working at it" (Bob R.). Pride was deeply ingrained into individuals' self-concepts, and it was these internalized values of independence and self-reliance, rather than external barriers to seeking help, that often determined if and how people leveraged available supports in their communities. In short, people frequently eschewed getting help because they had grown to associate receiving assistance with shame.

A common refrain among respondents was that their problems didn't rise to the level of needing help, although it is difficult to determine from their responses whether this attitude was driven by pride or a perception that they manage well enough on their own. Josh L.'s words spoke to this: "We didn't have much, but we had everything we needed." There was also a sense among many participants that others needed help more than they did.

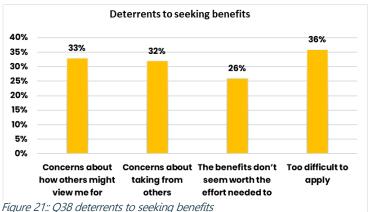
#### <u>ANXIETY AND JUDGMENT</u>



In small rural communities in which "everyone knows everyone," there is an understandable concern about one's privacy and, by extension, judgment of personal choices. Our research identified these factors as barriers to seeking assistance, exemplified by the words of Lisa J.: "It's hard to ask for help because it's almost like everybody knows that you got help. Nobody wants anybody to know that they had to get help." The value that Aroostook County residents place on personal self-sufficiency affects not only whether they interact with services, but also how they view others that do. Bob R. described some of his reluctance to seek help, explaining, "I think if I were to ask for help from some people, they would look at me and compare me to [older] neighbors who are clearly dealing with more issues than I am." Similarly, Cole M. highlighted the common perception that some people exploit assistance, while others go without due to shame: "Some people take advantage of stuff when they don't really need it, and the ones who do need it are too

embarrassed to actually go and participate and feel good about doing it. Then the people that are well off and don't need to...well,, they just sit back like, 'Look at this f\*\*\*er, they're poor, white trash, live in a trailer." This judgmental attitude is perceived not only concerning receipt of assistance, but also other life challenges such as mental health issues, substance use disorder, and criminal histories. Christine M. noted, "Most of my friends are just as broke as me, if not worse, and mentally probably a little disturbed, as well....People like me are typically looked down on, so I try not to do that."

Concerns about exposing details of one's private life in the course of seeking services created another barrier to accessing help. For example, the limited number of behavioral health providers in small communities leads to unavoidable dual relationships. Becky Y. shared, "I know the therapist personally and I know they have confidentiality, but there's still hesitancy, I guess, to go and talk to somebody that I grew **up with as a therapist."** This is true not only in health care but across other assistance programs like SNAP and LIHEAP.



#### OTHER IDENTITY DYNAMICS

Although there were smaller numbers of respondents in the interviews who cited other specific aspects of their identity as factors in their sense of belonging, it is important to highlight the experiences of Indigenous people, people living with disabilities, and members of the LGBTQ+ community.

As mentioned previously, there are two Indigenous tribes that call Aroostook their home: the Houlton Band of Maliseets and the Aroostook Band of Micmacs. While only two individuals in the interviews identified as AIAN (American Indian and Alaska Native), both had positive comments about how their racial identities contribute to belonging and a sense of support. Anna R., a single mother who is an Inupiag Eskimo Alaskan Native, reported finding community with the Micmacs: "The Micmacs are here in my area. It has been a plus for me and my kids. There is a whole other Micmac tribe that I can reach out to." The sense of connection with and reliance on tribal systems – e.g., health and housing services – was apparent in the words of Wilson R., who shared, "I'm here from the last Ice Age, so I would say nothing makes [my experience] worse. I can turn to the tribe sometimes for housing and occasional assistance."

Living with a disability is a major source of disconnection. Brett L. remarked on how differently he is treated when in public: "Since I've been in a wheelchair, I've noticed you get overlooked. It's like you don't matter or they think if you're in a wheelchair or disabled that way, you're probably minimally disabled...but the thing is, they don't really want to look at you." Families of individuals with disabilities also experienced feelings of social isolation, as this dependent relationship limits the caregiver's connections. Megan L., who is a caregiver for her adult son, explained, "Because of his behavior, because when I take him out and the fact that he only wants to be at home...I can't go anywhere because he acts bad and wants to go home if I take him out."

Although there was only one person who identified as LGBTQIA+, their experience is not unlike that of others. Ruby L., feels as though their identity "gets in the way of everything because I feel very unwelcomed in The County."

This research reveals the many ways in which people identify with their communities and how it affects their sense of belonging and well-being. Even in the presence of health or financial challenges, there are opportunities to find a sense of community, which often centers around shared challenges. In recent years, social isolation and loneliness have gained attention for their adverse health impacts, both physically and psychologically. Identity, group membership, and societal perceptions appeared in this research as key factors that impact how a person "fits in" and how well they connect to their communities and their resources.

#### KEY THEME: TRANSPORTATION

As in other rural regions with large geographies and low population densities, transportation is a significant concern in Aroostook County. The sheer size of The County and the distribution of people between its regions makes it difficult for many within our priority populations to reach essential services, which in turn creates a serious threat to healthy living. Specifically, our research indicates that the availability of reliable transportation greatly impacts health care access, social connections, employment, and recreational activities. Indeed, transportation is so critical to well-being that Mary L. commented, "I have seen people that went downhill and died because they were denied a driver's license."



#### DISTANCE TO SERVICES

Distance is at the core of transportation issues in Aroostook County, with many respondents reporting that long distances create conditions that are isolating, discouraging, and dangerous. Among respondents to the quantitative survey, 24% lived twenty or more miles from the nearest hospital, and 40% lived further than five miles from the nearest grocery store. Given these geographies, transportation creates everyday barriers for many residents, especially for those whose driving habits have changed as they've grown older – only 62% of the older adults surveyed own a car, and 71% drive (compared to 97% of the respondents under the age of 65). These challenges are only heightened in the winter when road conditions are often dangerous. Nancy L.

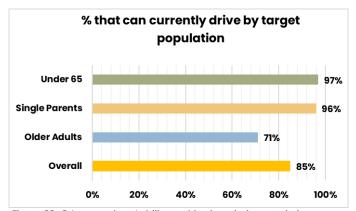


Figure 22: Q4 respondents' ability to drive by priority population

shared, "I don't go anywhere at all in the winter. I don't drive in the winter." Many individuals planned extensively for travel to doctor's appointments, shopping, church, and social visits with friends and family. As Debra

A. commented, "When I go grocery shopping, it's 16 miles one way to the store...I try to get there soon enough that it's not dark when it's time to go home." Similarly, given transportation constraints, Kevin J. shared, "When I go to the grocery store, I end up buying for the whole month." This was a common behavior among respondents, who also noted that their fallback was going to a local convenience store for necessities, a practice that was not only more expensive but also less likely to result in healthy eating choices.

Services tend to be concentrated in the four largest communities – Fort Kent, Caribou, Presque Isle, and Houlton, which act as regional service hubs in northern, central, and southern Aroostook, respectively. For people living outside of these areas, significant travel is often required for the most basic of needs. Pete R. reflected, "Help is a long distance from where we live," while Eddie N. noted, "Any time you need medical attention, well, you have to travel somewhere...and I can see in the future perhaps having trouble getting transportation because I live twelve miles outside of Caribou."

#### ACCESSING CARE

Unreliable access to transportation is a major contributing factor to missed health care appointments and the failure of patients to follow up with their providers. Of the respondents indicating that they had been unable to get needed health care, 35% said that it was because of transportation issues. For those who live alone and lack support networks, this issue is even more concerning. Cole M., who lives off-grid some forty miles from a health care facility, has essentially given up: "I can't know for sure that I'm even going to be able to get to that appointment, so what's the point of making it?" Bob R., who experiences behavioral health concerns, doesn't like to drive at night: "With the days as short as they are, the thought of driving an hour or two after work to see someone is kind of scary...so I probably am not seeking out the help I should get." Transportation issues may also be implicated in emergency room visits, as individuals defer care until the point of emergency. Finally, specialty providers tend to be located in The County's service hubs, if not further afield, creating even more challenges for people who need a higher level of care than provided by their PCPs. Susan R. suggested, "It's very difficult to find specialty services without having to travel long distances, and I think maybe a better sharing of specialty providers throughout The County would be helpful."

#### MAINTENANCE AND USE OF VEHICLE

Keeping a vehicle functioning was a major issue for respondents, particularly for those with income below \$40K annually. These individuals frequently mentioned the cost of gas and maintenance for their vehicle, as well as unanticipated repairs and seasonal maintenance costs – all of which led Mary L. to say that she can "barely afford running a car."

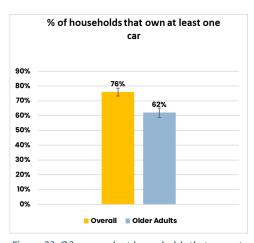


Figure 23: Q3 respondent households that own at least one vehicle

#### ACCESS TO ALTERNATIVE TRANSPORTATION

Access to alternative transportation was a challenge across all priority populations, although 35% of older adults and 31% of individuals with lower socioeconomic status reported that alternative options were somewhat or very difficult, compared to 26% of the overall sample. When seeking other options for personal transportation, people indicated that they most frequently rely on individual support systems, private taxi services, or public transportation. It was generally perceived that public transportation is extremely limited within The County, with limited schedules outside of the service centers. Respondents were frustrated with the lack of reliable local taxi service, even in larger towns, and relying on friends and family members could be inconsistent due to their other obligations.

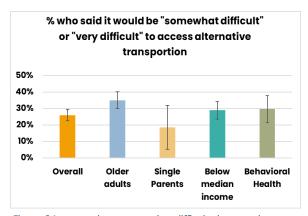


Figure 24: respondents expressing difficulty in accessing alternative transportation by priority population

Public transportation
would be great.
I can never get a ride
anywhere ever.
-Christine M.

#### LIMITED COMMUNITY ENGAGEMENT & ACCESS TO RECREATION

A lack of transportation options frequently restricted access to activities and social engagement for people living in smaller towns or outside of more populated areas. A large proportion of older adults, single parents, and individuals with lower levels of income experienced this in their daily lives, with Hanna J., a single parent, saying, "There's only one of me and we don't live in town. So if [my son] wants to do something after school, he's either going to walk himself or I'm going to leave work."

#### KEY THEME: HOUSING

With a stock of aged properties and little investment in multi-family residential units, housing is becoming an increasingly challenging issue for many, with significant health and economic impacts. In addition to the availability of housing, participants in the research process cited a need for major home repairs and modifications and challenges in meeting utility needs (including keeping homes safely heated during colder months). Participants who had incomes of less than \$40K annually or had behavioral health issues were the most likely priority populations to experience challenges in housing.

HOUSING CHALLENGES	%
Need for major home repairs or modifications	13%
Utility disconnections	5%
Difficulty staying warm in colder months	4%
Concerns about eviction	2%
Being unsheltered	<1%
None of the above	78%

Figure 25: Q33 respondents' challenges with housing issues

#### AVAILABILITY OF HOUSING

The lack of affordable quality housing leads to long waitlists – Annabelle P. emphasized this, saying "To get into any kind of affordable housing is like a three year wait." These waits can be even longer for individuals with specific housing requirements such as older adults who need a first-floor or accessible apartment, single parents who need space for families, or individuals who need to live near their support networks or places of employment.

#### **HOMELESSNESS**

Several individuals remarked on the prevalence of homelessness in The County, although the quantitative data shows that less than 1% of respondents had been unsheltered in the past year. This should not be construed as a lack of need; rather, due to the telephone-based survey methods, unsheltered individuals were likely excluded from the sample. Those who spoke about this issue cited high rents as a cause, with little understanding from landlords about the human struggles of the priority populations. Significant stigma surrounds people who are unsheltered, with Harold J. describing homelessness as "their own doings."

#### AVAILABILITY OF SUPPORTIVE SERVICES

An emergent barrier to healthy living within the research was the exigent need for supportive services to help people stay in their homes. While the quantitative survey did not explore the need for in-home supports such as housekeeping, basic maintenance, or other home-based services, these issues became evident through the interview process. Disability and loss of function put many individuals in difficult situations in which they want to maintain independence within their home, often with their partners, but struggle with the level of effort needed to maintain the household. Veronica L. said, "I love my home, but it is tough to keep the house cleaned and organized," while 86-year-old Mandy J. described doing housework with "one hand on the vacuum, the other on a cane" and having to let many of her chores go. She would fare better if she could get "somebody for at least two hours a week, that is to do the floors and clean the bathroom," but finding local resources to support these needs was challenging, as agencies often do not have the staffing to meet needs throughout Aroostook County. Mandy J. remarked, "I'm on a list, but otherwise than that, there's a lot of people ahead of me."

Older adults mentioned the option of facility-based assisted living as an alternative to staying in their homes, but the costs, availability of beds, and living conditions were seen as barriers to choosing this type of housing, which Veronica L. described as "cubby holes." Individuals without family support who faced challenges with some of the instrumental activities of daily life often found themselves giving up their independence to get assistance with their needs. Increasing the availability of and eligibility parameters for personal support services could help older adults remain in a place where they are comfortable and happy.

#### NEED FOR HOME MAINTENANCE

Quantitative research found that 13% of respondents needed major repairs or modifications to their homes, with this rate jumping to 18% among respondents with incomes of less than \$40K and individuals with behavioral health challenges. The types of repairs include leaking roofs, missing/broken plumbing, issues with heating systems, and health-related home modifications. Participants expressed frustration with the availability of skilled tradespeople; even when respondents were proactive and had funds for these needs, it was nearly impossible to find anyone willing to do the jobs. Individuals with strong support systems were often able to rely on younger family members to perform these kinds of repairs; those without informal support often gave up and lived with the restrictions imposed by their living environment.

[My partner] needed some kind of things to hold onto in the shower, safety bars...I had a devil of a time trying to find somebody to come and put them in for me, and it's those kinds of little things, small handyman type of work.

In addition, financial assistance with needed repairs was difficult to obtain, as some respondents reported being on lengthy waitlists for

economic support – lists that spanned multiple years. Lisa J. described her experience when she needed a new furnace: "I had to wait in line for help to get a new furnace. So my father said, 'If you wait, your pipes are going to bust and it's going to cost you more money, and who's going to pay for that?" Lisa J.'s circumstance exemplifies the reality that many face – assistance programs are often under-resourced and can't meet emergent needs, leading to a cascading effect in which a chain of events "snowballs" and becomes increasingly difficult to mitigate.

## RECOMMENDATIONS AND NEXT STEPS

#### PARTNER DEVELOPMENT

- Leverage the findings from the external evaluation to strengthen project cohesion and commitment among partners; increase the sense of ownership and accountability among partners
- 2 Reinforce partner relationships through collaborative action on prioritized issues
- 3 Recruit any additional partners necessary to achieve specific intervention-level goals

#### IDENTIFICATION AND INVESTIGATION OF AREAS OF FOCUS

- Use the findings of the Lived Experience research to prioritize areas of focus among the many determinants of health that affect the people of Aroostook County
- Identify underlying issues/root causes of disparities for each of the prioritized determinants of health
- Investigate best practices and evidence-based solutions to identify opportunities specific to the prioritized determinants of health

#### IMPI FMFNTATION PI ANNING

- Align partner interests and capacity with solutions that have the greatest impact on residents' ability to thrive, connecting goals and outcomes to specific priority populations or subpopulations
- 8 Integrate Community Voice into the implementation planning process
- 9 Determine data-sharing needs and policies to support implementation and evaluation
- 10 Create intervention-specific implementation workplans, including process for evaluation and continuous improvement
- Evaluate potential operational changes within individual partner organizations needed to support overall ACHIP initiatives

#### SUSTAINABILITY PLANNING

- 12 Create a plan for backbone sustainability
- Develop a plan for securing implementation funding

#### COMMUNITY AWARENESS

Promote work of partnership beyond participating organizations, including the development of an external communication plan

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