

**"I DON'T GET THE
CARE I NEED":
EQUITABLE ACCESS TO
HEALTH CARE FOR
MAINERS WITH
DISABILITIES**

2023

DISABILITY
RIGHTS
MAINE 

Acknowledgments

Disability Rights Maine (DRM) and JSI Research & Training Institute (JSI) would like to thank the hundreds of Maine residents with disabilities who participated in this assessment effort. Whether you responded to a survey, attended a focus group, or had a conversation with us—we are grateful that you entrusted us with your stories and experiences. We would also like to thank the Maine Health Access Foundation, whose funding and support made this project possible.

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This report is available in alternate formats 

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About Disability Rights Maine

Disability Rights Maine (DRM) is Maine's designated Protection and Advocacy (P&A) agency, a 501(c)3 organization authorized and mandated to protect and advocate for the rights of Maine people with disabilities. DRM's mission is to advance justice and equality by enforcing rights and expanding opportunities for people with disabilities in Maine.

DRM represents individuals whose rights have been violated or have faced discrimination based on their disability. Additionally, DRM offers training on rights and self-advocacy while actively advocating for reforms in public policies.

DRM believes that people with disabilities must:

- Be treated with respect and be free from abuse;
- Control the decisions that affect their lives;
- Receive the services and supports necessary to live independently;
- Have the opportunity to work and contribute to society;
- Have equal access to the same opportunities afforded all people; and
- Fully participate in all aspects of society, including education, work, and community.

DRM is part of a nationwide network of disability rights organizations established by Congress to protect the rights of all individuals with disabilities.

Language Disclaimer

Language is a powerful tool that shapes meaning and understanding. This report uses person-first and identity-first language interchangeably to reflect the diverse ways the disability community identifies. Person-first language places the person before their disability. Identity-first language embraces disability as a fundamental aspect of one's identity and places identity first. For more information about combating ableism through language, we recommend the following:

- [National Disability Rights Network: Communicating About People with Disabilities](#)
- [National Center on Disability and Journalism: Disability Language Style Guide](#)
- [Autistic Self-Advocacy Network: Identity-First Language](#)

Assessment Purpose

DRM has increasingly recognized the urgent need for advocacy to improve health care access and equity for people with disabilities. DRM has always handled cases that involve issues of health care access and equity, but, in recent years, cases have become more common and troubling. It has become clear to DRM that Mainers with disabilities face stark inequalities as they navigate Maine's health care system. Despite the lack of equity for people with disabilities in attaining the resources they need to achieve health and wellness, these issues are not rights violations that Protection and Advocacy agencies traditionally address. DRM knew they had to take action to shine a light on these dangerous problems.

In 2022, DRM formed a Health Equity Work Group to identify systemic approaches to removing barriers and improving access to health care for people with disabilities across Maine. In doing this, one issue became

The COVID-19 pandemic heightened the focus on inequities as people with disabilities grappled with challenges accessing testing, treatment, and vaccines. In certain instances, health care providers explicitly deprioritized them for life-saving care.

glaringly apparent: there was a lack of data to characterize the issues that Mainers with disabilities face when seeking health care. DRM's Health Equity Work Group sought and received funding from the Maine Health Access Foundation to conduct a project to gather data and produce a report on barriers to health care for people with disabilities in Maine.

While researchers have conducted numerous studies examining barriers and access issues from the provider's perspective, relatively few have focused on the direct experiences of people with disabilities and their encounters when navigating the health care system. DRM contracted with John Snow Inc. (JSI), a public health consulting and research organization, to lead this research project. The following report will hopefully result in meaningful change to improve access, choice, and health care quality for people with disabilities across Maine.

Background

People with disabilities are the largest minority group in the United States, with an estimated one in four adults (approximately 61 million) reporting a disability.¹ Disability crosses all age groups, gender identities, races, ethnicities, and social groups. Anyone, at any time, can join the ranks of disabled people, whether through an accident, illness, or the effects of aging.

Despite the common occurrence of disability, health disparities faced by individuals with disabilities remain highly prevalent and largely unaddressed. Socially disadvantaged populations experience preventable differences in the burden of disease, injury, violence, and opportunities to achieve optimal health, known as health disparities.²

Health disparities for people with disabilities are wide, varied, and impact all aspects of life. It is well-documented that, compared to those without disabilities, people with disabilities are:

- Significantly more likely to have unmet medical, dental, and prescription needs;³
- Three times more likely to have arthritis, diabetes, or a heart attack;⁴
- Five times more likely to report a stroke, chronic obstructive pulmonary disease, or depression;⁴
- Less likely to receive a pap smear or mammogram;⁵ and
- More likely to have a lower life expectancy.⁶

People with disabilities are also more likely to be denied health care than people without disabilities, and face unique barriers and stigma when accessing health care. Women with disabilities are more likely to receive poor maternity care, experience severe pregnancy and birth-related complications, and are eleven times more likely to experience maternal death.^{7,8,9,10} Additionally, people who are Deaf or hard of hearing are three times as likely to report being in fair or poor health compared to those who are not Deaf or hard of hearing.¹¹ Living in a rural area increases the barriers to accessing health care, and for people of color with disabilities, the disparities are even further compounded.^{12,13}

Disabled people also encounter unique systemic and policy-level barriers that impact their health care. The rare inclusion of disability status in demographic data renders it nearly impossible to analyze disparities and outcomes for individuals with disabilities within federal, state, and local data sources. Inaccessible offices and medical equipment hinder the entry of people with disabilities into physical spaces to receive care, and health care providers callously deny procedures to disabled individuals when accessible medical or diagnostic equipment is unavailable. Limited provider training and awareness of disabilities results in a lack of clinical knowledge and comfort in treating such patients.

Stigma and bias also play a role. In a 2021 survey of 714 practicing physicians across the United States, 82% reported that people with significant disabilities have a worse quality of life than people without disabilities, and only 56% strongly agreed that they welcomed patients with disabilities into their practice. Only 41% of these physicians felt confident in their ability to provide the same quality of care to patients with a disability as they could to patients without a disability.¹⁴

Other complex, widespread, and long-standing social inequalities are inextricably linked to the health disparities experienced by disabled people. For example, people with disabilities have fewer years of education,¹⁵ lower rates of employment,¹⁵ higher rates of poverty,¹⁵ more transportation barriers, lower rates of vehicle ownership,¹⁶ and higher rates of housing insecurity.¹⁷

Inequities are compounded when other systems of oppression are layered upon disability. For example, women with disabilities experience more significant income, educational, and employment related disparities. Individuals who identify as both disabled and as part of the LGBTQIA+ community also face additional barriers that exacerbate structural disadvantages.

The onset of the COVID-19 pandemic amplified many of these issues. The exclusion of disability status from federal and state health care data collection efforts resulted in policymakers and researchers being unable to gather precise information about the effects of COVID-19 and the healthcare disparities experienced by individuals with disabilities. People with intellectual or developmental disabilities, often medically fragile or dependent on technology, faced a higher risk of being triaged out of COVID-19 treatment when hospital beds, supplies, and staff were scarce.¹⁸ Crisis Standards of Care often targeted people with specific disabilities to be denied care during COVID-19 surges. People who lived in group homes, nursing homes, psychiatric facilities, and other institutions contracted COVID-19 and died from the virus in higher numbers, yet people with disabilities and chronic health conditions, including those in group homes, were not recognized as priority populations when vaccines were first made available.¹⁹ Even in Maine, people with disabilities were not prioritized in vaccine distribution plans.²⁰ A 2021 report found that intellectual disability was the single strongest predictor for COVID-19 infection and the second strongest predictor for COVID-19 death.²¹

The need to act is clear. These disparities highlight the urgency of improving the health care system for people with disabilities and preventing a future pandemic response that repeats the same failures. Building a system that reduces barriers and disparities is possible. However, to do so, we must focus on achieving health equity.

Health equity is the principle that every person should have a fair and just opportunity to attain good health and well-being, regardless of race, ethnicity, socioeconomic status, disability, education, or geography.²² Achieving health equity requires recognizing that some groups of people, including those with disabilities, face systemic and structural inequalities that result in unequal access to health care and reduced health outcomes. These realities compel us to act to identify and address these disparities through policies and practices. Maximizing individual health enables people with disabilities to lead independent and fulfilling lives.

DRM believes that the information gathered in this report is an essential step in identifying the barriers that disabled Mainers face in accessing health care, and offering solutions to improve access and quality of care.

Approach & Methods

Overall Approach

This assessment utilized a mixed-methods approach that integrated quantitative and qualitative data to understand the leading barriers to care for Mainers with disabilities. The effort focused on compiling information through extensive community engagement activities, as described below.

Collection of Literature and Secondary Data

With the assistance of JSI, DRM collected relevant and timely research to characterize access to care and equity issues for people with disabilities in Maine and throughout the United States. Through this research, it became clear that the problems individuals face in Maine are common. However, our population faces distinct challenges because of the state's rural geography and older population.

The literature cited in this report includes articles in professional journals, reliable print sources (e.g., established newspapers), and statistical data from government websites and reports.

Health Care Access Survey

The Health Care Access Survey was developed jointly between DRM and JSI. It intended to gather information directly from Mainers with disabilities to better understand the barriers they face when seeking access to health care and interacting with providers.

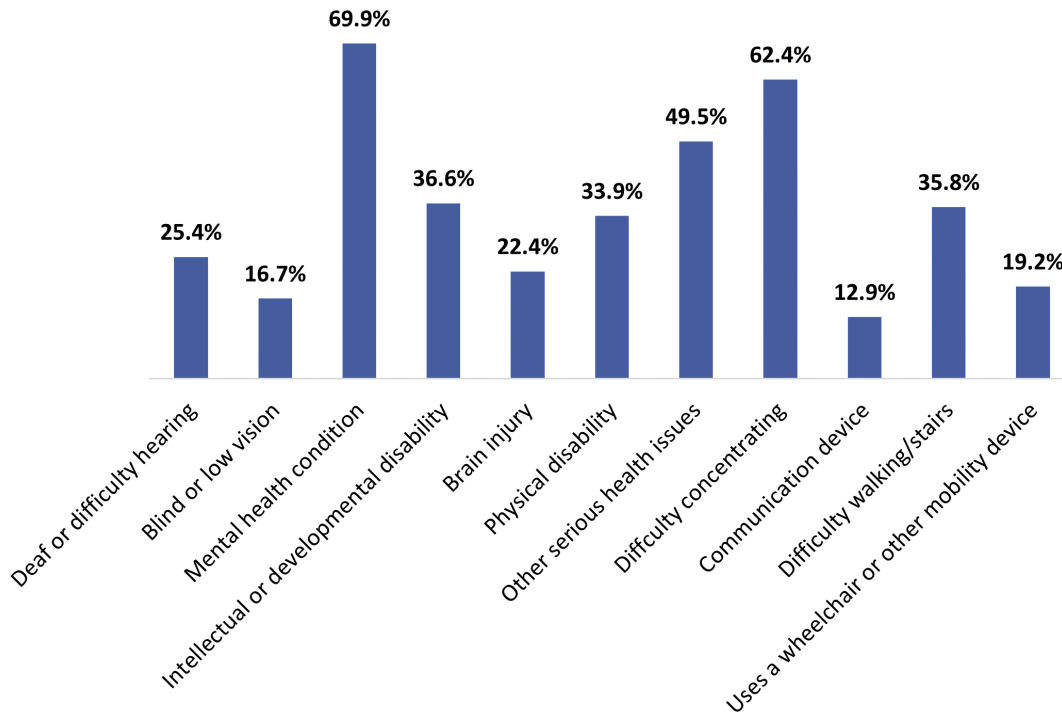
The survey was available in both web-based and paper formats. Two web-based versions were available: one in English and one in American Sign Language (ASL). The ASL version of the survey included accompanying videos for each question, with a Certified Deaf Interpreter signing questions and potential answers. Interpretation in other languages was available upon request. Though there were limited requests for direct assistance, DRM staff were available to assist individuals taking the survey.

The survey was launched in November 2022 and remained open until the new year. During the dissemination phase, DRM made significant efforts to distribute the survey throughout the state to reach a diverse range of respondents, considering factors such as their location, disability type, age, housing status, income, and life experience. Hundreds of organizations helped to distribute the survey to their clients, patients, residents, colleagues, and others. After data cleaning, the final survey count was 598 responses.

Survey results were organized based on various factors, such as the specific types of disability people had, their age, income, living situation, and their health insurance coverage.

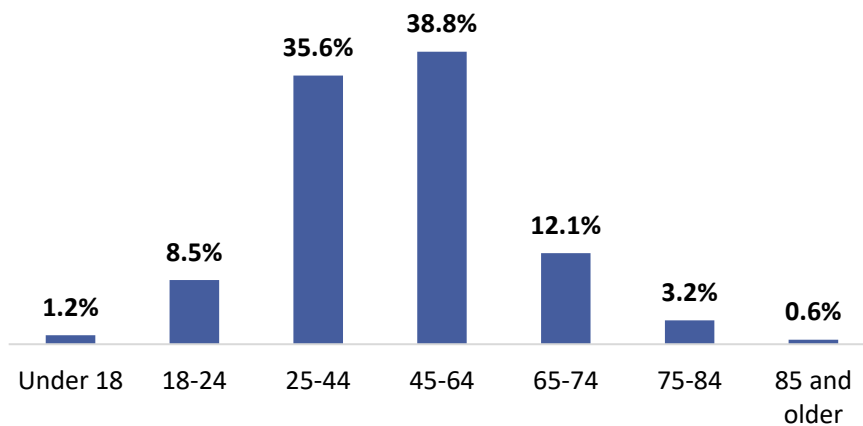
Survey respondents represented a diverse range of disabilities. Respondents could identify across multiple disability categories, in recognition of the multifaceted experiences and intersectionality across disability types.

Figure 1: Percent of Survey Respondents by Disability Type



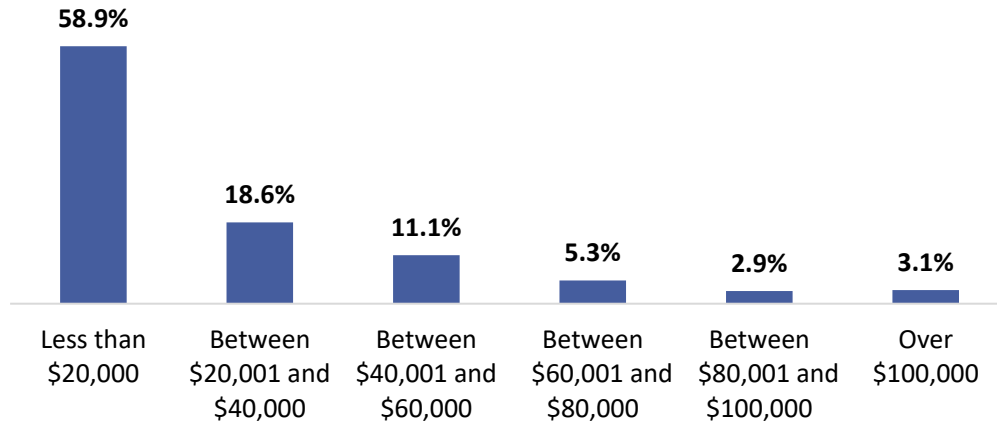
Survey responses were highest among the 45-64 age cohort.

Figure 2: Percent of Survey Respondents by Age



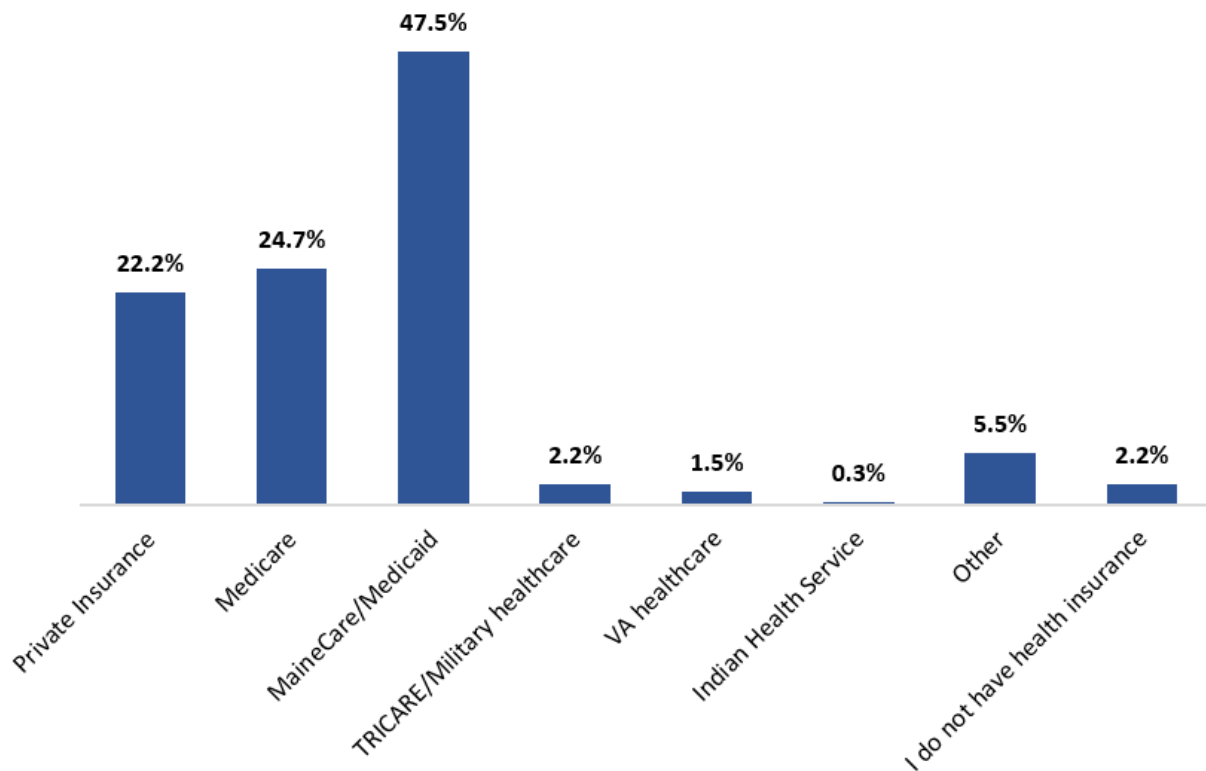
Nearly 60% of survey respondents reported that their annual income was less than \$20,000.

Figure 3: Percent of Survey Respondents by Annual Income



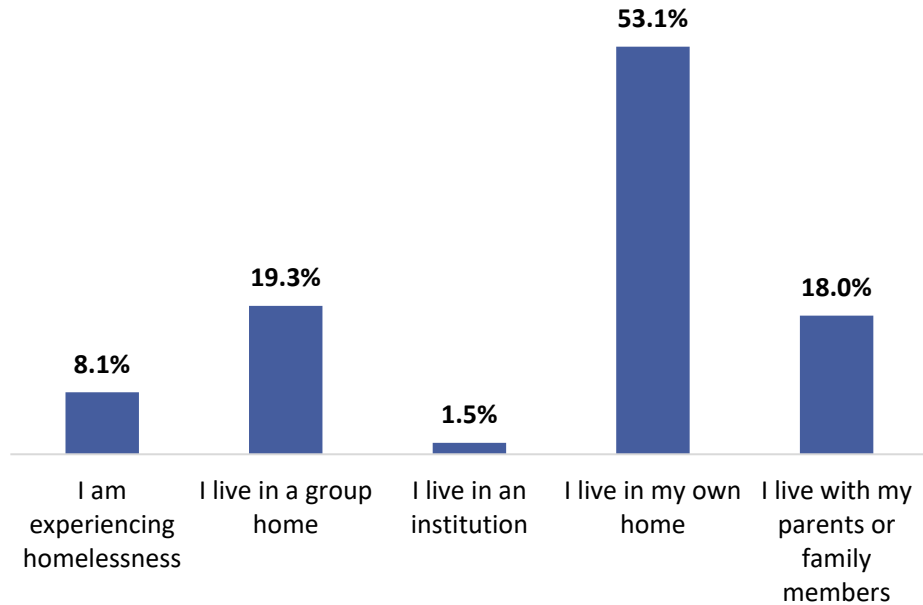
Nearly half of the survey respondents (48%) were insured through Mainecare/Medicaid.

Figure 4: Percent of Survey Respondents by Type(s) of Health Insurance



Most survey respondents (53%) reported living in their own homes.

Figure 5: Percent of Survey Respondents by Living Situation



Appendix A of this report contains the full survey text, a summary of results, and direct quotes from open ended responses.

Focus Groups and Open Forums

In addition to the survey, nine focus groups and two open forums were conducted as part of this assessment. Focus groups allowed for the collection of critical input from small groups based on disability type, with an emphasis on providing a forum for individuals to share their personal experiences. Open forums were marketed broadly and were available for anyone with a disability to attend. DRM organized focus groups in collaboration with community organizations, advocacy groups, and individuals who worked closely with the target cohorts. Focus groups were conducted virtually and in-person, depending on the communication needs of each group. A focus group guide is included in Appendix B. Key themes and quotes from focus groups and open forums are included throughout this report.

Focus group cohorts

- Blind or low-vision
- Deaf or hard of hearing
- Individuals with a mental health diagnosis or label
- Youth
- Physical disabilities
- Brain injuries
- Individuals with a label or diagnosis of an intellectual or developmental disability
- People with dementia
- Family members and caregivers of people with disabilities

Stakeholder Interviews

The approach to conducting stakeholder interviews encompassed a deliberate effort to acknowledge the experience of historically marginalized populations. Acknowledging the substantial time needed to establish trust, DRM embarked on a mission to enhance relationships with immigrant, tribal, and other communities across Maine. This effort focused on engaging the organizations and individuals who work closely with these populations. Through five one-on-one stakeholder interviews, DRM sought to catalogue experiences and gain insights into the challenges encountered when seeking and accessing care. Furthermore, DRM recognizes the importance of addressing the specific barriers and considerations faced by individuals living with HIV/AIDS. By engaging in conversations with experts, DRM obtained contextual information that deepened their understanding of the health care landscape in Maine.

Key Findings and Recommendations

This report has organized findings into five priority areas:

- Data Collection
- Provider Education
- Barriers to Care
- Communication
- Physical Spaces

Within each priority area are three sections. The first section contains background information drawn primarily from the literature. The second section focuses on key findings and highlights information from this assessment's efforts, including secondary data, focus groups, the Health Care Access Survey, and stakeholder interviews. The third section includes a table of recommendations and potential strategies to address issues within these priority areas. Appendix C provides a list of recommendations and strategies organized by the type of entity that would be responsible for implementation (e.g., policymakers, health care organizations, etc.).

Priority Area 1: Data Collection

Background

Unlike race, ethnicity, and age, disability status is not a standard demographic question, which creates a global lack of data on people with disabilities. The inadequate data contributes to an underrepresentation of disabilities in official statistics, causing policymakers to frequently disregard the needs of this population. Moreover, the lack of data poses challenges in identifying these needs, resulting in a scarcity of comprehensive programs and services to address them. This absence of data also makes it difficult to monitor progress or challenges over time. Given the substantial disparities in health care access, quality, and outcomes experienced by individuals with disabilities, it is imperative that data collection efforts capture their unique experiences and characteristics.

In the United States, many federal agencies track disability data, including the Department of Health and Human Services, the Social Security Administration, the Centers for Disease Control and Prevention, the Department of Justice, and the Department of Labor. The US Census Bureau also collects information on people with disabilities through various surveys. Though these efforts are essential, they are limited by gaps in specific tabulations, varying approaches to classifying disability types across agencies, and poor engagement with the population of people with disabilities. It is critical that future data collection efforts, at both the federal and state levels, involve people with disabilities in data collection processes to ensure inclusive samples and address historical disparities.²³

The nature of disability is diverse and complex, and individuals experience disability uniquely. The absence of a standard definition of disability in data collection efforts can cause several problems. It can lead to inconsistent and incompatible data, underreporting of disability, limited understanding of the needs and experiences of people with disabilities, and inadequate policy reform and resource allocation. While it would not be possible to create a universal definition, disability status should be a standard demographic question, and should be asked in a way that makes data more comparable across data sets.

Additionally, many data collection efforts rely on individuals to self-report. Individuals may be reluctant to report their disability or diagnosis for fear of discrimination or disparate treatment.²⁴ A survey of over 3,500 adults in the United States working in "white collar" positions found that 30% have disabilities, but only 3% self-identify to their employer.²⁵ The "visibility" of a disability significantly impacts data collection efforts and an individual's experience in life, health care settings, education, and the workplace. In the same survey, 44% of respondents with a visible disability reported that they had experienced negative bias or discrimination at their companies, compared to 30% of those who defined their disability as invisible.²⁶

When looking at the available data describing people with disabilities living in Maine, US Census Data for 2017-2021 shows that 16% of Maine's civilian non-institutionalized population (211,861 people) had one or more disabilities.²⁷ This proportion was higher than that of the United States, where an estimated

13% of residents had a disability. Piscataquis County, the least populated county in Maine, has the highest percentage of people with disabilities (26%). The following highest counties are Washington County (23%), Aroostook County (22%), and Somerset County (20%).²⁸

The most common types of disabilities in Maine are:

- Ambulatory difficulties (7%);
- Cognitive difficulties (7%);
- Independent living difficulties (6%);
- Deaf or hard of hearing (5%);
- Self-care difficulties (3%);
- Vision difficulties (2%).²⁹

It is important to note that the demographic data presented in this report pulls from the US Census Bureau's American Community Survey. Because of the survey design, estimates of disability characteristics draw from smaller sample sizes, which results in higher margins of error (the degree of uncertainty results may have). Higher margins of error mean that data is less reliable in smaller geographies (e.g., counties), especially when looking at data for subgroups (e.g., race and ethnicity).³⁰

Key Findings

A scoping literature review found that the lack of representation of disabled people in public health data collection leads to a lack of understanding of their health needs and experiences. There are several challenges to collecting accurate and representative data on disability and health, including issues related to survey design, access to health care, and stigma and discrimination. Efforts to improve data collection and analysis on disability and health are necessary to address health disparities among people with disabilities.³¹

During the data collection process conducted as part of this project, it became apparent that there is a lack of data and data repositories available to accurately represent the total population of individuals with disabilities in Maine. For instance, the Maine Immunization Registry does not track disability status, resulting in a local example of data exclusion. This lack of data has made it challenging to monitor equity and access concerns related to the COVID-19 vaccine for people with disabilities, and actual vaccination rates remain unknown.

People with disabilities experience disparities in health behaviors, outcomes, and chronic disease risk factors. Individuals with disabilities were more likely than those without disabilities to have depression, smoke tobacco, have diabetes, and have heart disease.³² Individuals with disabilities have a higher prevalence of chronic and secondary health conditions, higher rates of mental health conditions or labels, lower rates of engagement in preventive care, and experience more frequent barriers when accessing health care services. Additionally, research suggests that individuals with disabilities who belong to marginalized racial or gender groups experience compounded health disparities. Addressing

these disparities is crucial to achieving health equity and improving the overall health outcomes of people with disabilities.^{33,34,35}

Recommendations

Recommendation	Potential Strategies
<p>Make disability status a standard demographic indicator in data collection and surveillance efforts.</p>	<p>Establish rules and guidelines for all state-funded grants and surveillance efforts to include disability as a demographic indicator.</p>
	<p>Require self-reported disability status as part of standard demographic information collected in electronic health records.</p>
	<p>Tie state Medicaid and block grant funding to substantive evidence of health equity for people with disabilities.³⁶</p>
	<p>Improve the quality of disability data through cross-agency collaboration on data collection/sharing to include standardized questions on disability.</p>
<p>Data on individuals with disabilities should be relevant, up-to-date, and accessible.</p>	<p>Establish a data dashboard that holds all state-wide data associated with health equity and disability in one place, similar to the Maine Statewide Epidemiological Outcomes Dashboard.³⁷</p>
	<p>Develop annual reports that compile data from all statewide sources.</p>
	<p>Engage in feedback loops that prioritize community engagement in all steps of data collection, analysis, reporting, and dissemination processes.</p>
<p>Individuals with disabilities must be represented in public health surveillance efforts.</p>	<p>Ensure that individuals with disabilities are represented statewide and on state-level advisory councils to direct statewide guidance related to health care planning, health equity, and assessment processes.</p>
	<p>Advocate for better representation of people with disabilities in national surveillance efforts, such as the Behavioral Risk Factor Surveillance System (BRFSS) and the American Community Survey (ACS).</p>
	<p>Require that surveillance efforts engage individuals with disabilities residing in group homes or other institutional placements.</p>

Priority Area 2: Provider Education

Background

This section will provide background, findings, and recommendations regarding the lack of clinical knowledge and cultural competency among health care providers. This issue significantly and adversely impacts the quality of care that disabled people receive.

Despite calls from the US Surgeon General, the World Health Organization, and the American Association of Medical Colleges for increased training on treating people disabilities, there are no specific requirements for US medical schools to teach about disabilities. Research has found that only half of US medical schools report having any disability awareness program as part of their curriculum.^{38,39} A 2015 study stated that "every major report addressing the poor health of people with disabilities has called for improvements in the training of health care providers about adults with disabilities," highlighting the overwhelming need for provider training that focuses on improving care for people with disabilities.⁴⁰

Through numerous studies, including this one, people with disabilities have reported experiences that illustrate the negative impacts of this lack of education and training. People with disabilities report that providers hold biases and are hyper-focused on their disabilities rather than the health concern they're being seen for. Disabled people also report that they have to educate providers about the basics of their disability.⁴¹

In health care, disability has traditionally been approached from the medical model perspective. This model views disability as a product of biology and a departure from a "normal" structure or functioning. This perspective assumes a need to "fix" or reduce the effects of disability on individual functioning, with a near-exclusive focus on deficits and negative impacts on the lives of people with disabilities. These assumptions lead to biases, stigma, and the belief that the lives of people with disabilities are lower in quality and, therefore, less valuable.⁴² Alternatively, many people with disabilities prefer the social model, which recognizes that the most significant barriers that people with disabilities face are the environments and societies in which people live and interact.⁴³

Without sufficient education and training on disabilities, providers lack both clinical knowledge about disabilities and the wide variety of ways people can experience or have their health impacted by their disability. This can cause immense harm. Misdiagnosis or delayed diagnosis of health issues can

Research has shown that for individuals with disabilities, interacting with health care providers who don't understand their disability can make them feel ignored, isolated, and even afraid to seek the care they need.

cause unnecessary suffering and worsen existing health problems.⁴⁴ Health care providers must take the time to educate themselves about disabilities and work to provide compassionate care to all of their patients. Lagu et al.'s 2022 study described instances where providers denied care or

discharged people with disabilities from their practices. As an example of an instance where providers deferred care for patients with disabilities, one primary care provider who participated said, "We talk to the caregiver or the patient or whatever, and just explain to them that it is very unlikely that they are

"I think the problem is that you cannot refuse them [patients] straight. We have to give [patients] an appointment. You have to come up with a solution that [tells the patient] that this is a small facility, we are not doing justice to you, it is better [that] you would be taken care of in a special facility."

– Lagu et al., 2022

going to develop cervical cancer." Study participants reported that they knew they could not outright deny someone care due to their disability, but would find reasons to justify why they were not the best person or best practice to provide care. Some providers who participated in the study reported telling patients that they needed more care than the practice could offer, or would tell prospective patients with disabilities that they were no longer accepting new patients.

There is also a need for providers to develop greater cultural competency with disability. Culturally competent care involves being able to communicate effectively with people and being able to work with them in a way that is inclusive and respectful.⁴⁵ Though it is often discussed in the context of race, ethnicity, and religion, cultural competency is a crucially important factor in treating people with disabilities, as it is with all population groups that are at risk for stigmatization or face health disparities.⁴⁶ The results of Lagu et al.'s 2022 study supports this need. Physicians who participated in the study described a lack of clinical knowledge and negative attitudes towards people with disabilities, often mentioning they were scared they would hurt themselves or their patients when providing care.⁴⁷ Many of the study participants said that providing accommodations for people with disabilities was burdensome.

To create a health care environment that is culturally competent for people with disabilities, providers must learn how to communicate and interact comfortably with patients. It is also crucial for health care providers to understand and identify common biases and stigmas related to disability that can negatively impact patient care, such as the belief that people with disabilities cannot speak or make decisions for themselves, are asexual, or have a lower quality of life. Further, studies have shown that providers' biases and hesitance to care for people with disabilities perpetuate health care access and outcome disparities.⁴⁸

The COVID-19 pandemic exacerbated existing health disparities experienced by people with disabilities, particularly those from historically marginalized communities. People with disabilities are more likely to have underlying health conditions, which put them at higher risk for severe illness or death from COVID-19. Additionally, many individuals with disabilities face barriers to accessing health care, including testing and vaccinations, due to inaccessible testing sites or lack of accommodations. There were also challenges faced by people with disabilities in accessing information about the pandemic. Many public health messages and resources were not accessible. Video materials were often not captioned, and materials were rarely provided in ASL.

The lack of accessible information meant that people with disabilities may not have been able to fully understand the risks associated with the pandemic or how to protect themselves.^{49,50,51}

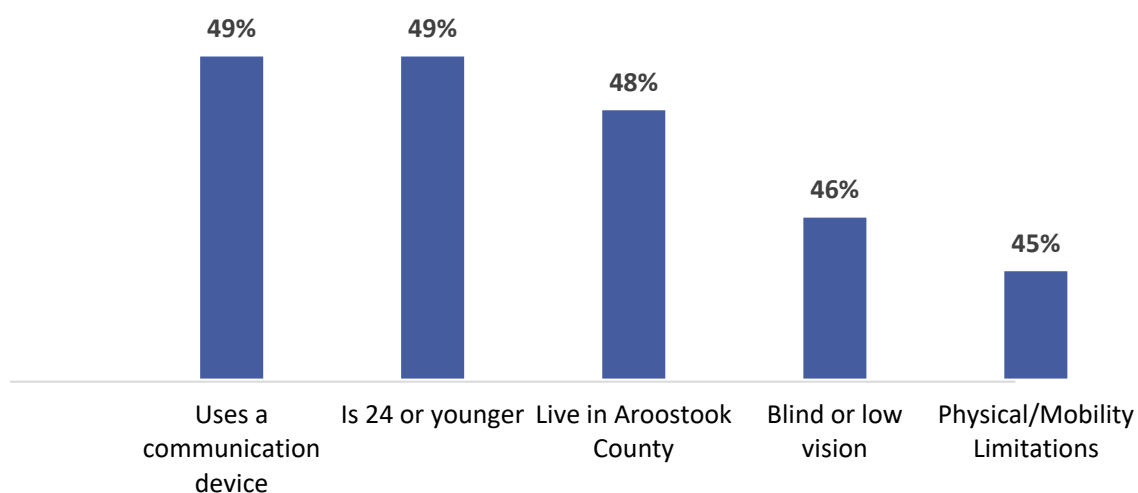
It is also crucial to highlight the significant incidence of trauma among individuals with disabilities, and the importance of utilizing a trauma-informed approach when providing treatment. Trauma—an experience or response that comes from an event, ongoing series of events, or circumstances that are physically or emotionally harmful or life-threatening to a person—can have lasting effects on mental, physical, social, and spiritual well-being and functioning.^{52,53} The trauma-informed care approach recognizes that some individuals, including people with disabilities, are at a higher risk of experiencing trauma due to various factors, such as social isolation, discrimination, and power disparities in relationships. This approach also recognizes the need to fully integrate knowledge of trauma and its impacts into policies and practices. The primary objective of trauma-informed care is to promote a culture of trust and safety between the provider and patient, where the unique experiences and needs of the patient are acknowledged and respected.⁵⁴

Key findings

Clinical Knowledge

Approximately 38% (n=203) of Health Care Access Survey respondents reported that they did not think doctors and medical staff were adequately trained and prepared to treat them in medical settings. Looking across survey results, percentages were highest among younger people, individuals in Aroostook County, and those with certain disability types or characteristics (Figure 6).

Figure 6: Percent of Survey Respondents Reporting They Did Not Think Medical Staff Were Properly Trained and Prepared to Treat Them



Participants in the focus groups and survey conveyed encounters that demonstrated how health care providers, particularly primary care practitioners, lacked clinical education and practical experience in treating those with disabilities. Participants acknowledged that this lack of education was often unintentional by providers, but nevertheless, expressed frustration with the providers' inadequate understanding of even the fundamental aspects of their care.

Participants in focus groups and the Health Care Access Survey expressed the need to continually educate their primary care providers about the specific nuances and details of their disabilities or chronic illnesses. Many participants reported encountering frequent provider turnover, resulting in the need for repetitive and ongoing education. One participant mentioned that their provider "barely knew more than what a basic Google search would tell them." Several individuals conveyed that the frequent turnover of physicians dissuaded them from attending their appointments. They experienced a sense of discouragement as soon as they started developing a level of comfort with a provider, only to have them depart, thereby necessitating the initiation of the process anew with a different provider.

A significant number of participants expressed the perception that providers held preconceived notions about their body or health condition solely based on their disability, even prior to meeting or conducting a thorough examination. While these assumptions were not meant to be malicious, they felt dismissive, and participants felt this was coming from a lack of understanding or awareness. Participants described situations where they felt "pigeonholed" based on their disability. Participants also said that getting an accurate diagnosis for their symptoms was often a long process.

The participants' comments in the focus groups and survey consistently highlighted instances where their doctors expressed a lack of knowledge about their medical condition or were unfamiliar with necessary treatments. People with disabilities often reported feeling like their providers were talking down to them and not listening.

"The constant dismissal of my concerns as if I am not the one living in this body is incredibly frustrating. I want to be treated as at least somewhat of an expert on my experiences. I deserve to have my concern matched as well. If I'm worried about something and am met with a noncommittal response, that is stressful and disrespectful, in my opinion. I want to be treated as though I understand what is going on."
– Health Care Access Survey respondent

Numerous participants in the focus groups highlighted instances where providers exhibited reluctance to engage in a collaborative relationship. They expressed concerns about providers not allocating sufficient time to listen to their needs and preferences, failing to present options, and disregarding their input in treatment decisions. Participants conveyed a sense that providers sought expedient solutions or answers, avoiding thorough investigation and inquiry into complex issues. Focus group participants felt providers treated patients like they were all the same. Similarly, survey respondents frequently stated they felt their providers were not reading their charts to understand what diagnoses, disabilities, or chronic health issues they had and that they overly relied on specialists for any discussion of chronic health conditions. One survey respondent expressed frustration with their primary care provider, saying, "My primary care provider not only had no idea of how to diagnose me,

but also had no idea of how to treat my symptoms. Now that I have a specialist, they don't even talk to me about my disease even though it is important in my regular care."

"It would be really nice if more providers were required to have education on brain injuries and other disabilities. There are a lot of providers who know nothing about brain injuries. Some [providers] dismissiveness is not malicious. It's just that they do not know."

– Focus Group participant

"My PCP is good at listening, but they can't answer a lot of questions because I have very specialized needs related to my injury. I'm scared about having a serious event happen where I need care, and more generalist providers may not understand my very specific needs."

– Focus Group participant

"I have been through the gamut. I've experienced it all. Most places have no idea what to do when a Deaf person walks in. Some places are compassionate, and some places have no idea. They need so much education. If the shoe was on the other foot, imagine how they would feel, relying on lip reading or writing everything out - especially with medical terminology. For me as a mother, it's already a stressful dynamic there, with my son. A lot of providers don't understand disabilities in general. Of course, there are access issues being Deaf, but when you have added other disabilities, that lack of awareness on the part of the provider is really difficult. It's tenfold when you have additional disabilities."

– Focus Group participant

Yet another concern raised repeatedly was that of health care providers not believing people with psychiatric labels or diagnoses. Individuals reported that providers often dismissed physical health issues and focused solely on their psychiatric label. Participants frequently mentioned that they felt that their mental health or substance use label was prioritized over any physical issues they were experiencing. One survey respondent summed up numerous participants' feelings when they stated, "The separation of body and mind treatments create worsening mental health and physical health problems."

Participants also reported that providers often made assumptions about their limitations and ability to comprehend information. For example, three focus group participants described experiences where their doctors did not provide information about their diagnoses, why they were prescribing certain medications, or what possible side effects of medication might be. One focus group participant mentioned feeling like a "guinea pig" regarding medication, not knowing how they would react to side effects. Participants often shared that they were recommending testing and treatment to their physicians.

One survey respondent stated the need for health care providers to have more education and experience working with historically marginalized populations, including people of color and immigrants, saying that this lack of understanding, "can lead to misdiagnosis because there is no knowledge of the important cultural practices (e.g., lack of eye contact is interpreted as a mental health condition or

there is little understanding of the way that non-white bodies grow and develop)." A conversation with an organization that addresses the needs of individuals living with HIV/AIDS further illuminated the need to address issues of cultural competency in health care, as culture plays a significant role in shaping individuals' beliefs, attitudes, and expressions of pain. An extensive body of research supports the belief that there are substantial disparities in health care access and outcomes by racial and ethnic groups.⁵⁵

"Health care in Maine is shaped by a culture steeped in white Puritanical patriarchy. It's very much a culture of "get outside, drink some water" and bootstraps. There's a constant barrier to getting care when providers lack even basic information, and worse, curiosity, about their client's condition(s). The cultural expectation here remains one of 'we don't talk about things that make folks uncomfortable.' And if you're not white, getting appropriate and compassionate and inquisitive care here must be like navigating hell. There is a dearth of trauma-informed care, and care is stingy and withholding to anyone lacking economic resources. Maine overall, from its lack of infrastructure, its inherent ruralness, and its aging architecture, is inaccessible to most of its aging and poor population."

– Health Care Access Survey respondent

Cultural Competency

Approximately 27% (n=140) of the Health Care Access Survey respondents reported that health care providers do not respect them. When asked to elaborate on the reasons, 18% (n=105) said that providers do not consider their needs and experiences, and 16% (n=96) said they do not listen to or take their concerns seriously. The focus group attendees echoed the sentiments expressed by the survey participants. Many participants shared that in addition to a lack of knowledge on how to treat people with disabilities clinically, health care providers made little effort to comprehend their experiences. Participants suggested that providers engage more directly with people with disabilities to enhance their cultural competency and understanding.

"The problem is not always about access to care – it's competent care."

– Focus Group participant

Focus group participants frequently expressed the belief that health care providers, and the health care system as a whole, view people with disabilities as being less than a "whole person." Participants mentioned feeling like their providers were uncomfortable providing a complete examination and were

resistant to touching or moving their bodies. One survey respondent said that providers seem afraid of their disability and chronic health issues. Both survey and focus group participants also reported that health care providers often belittle or dismiss their concerns. The issue was particularly significant for individuals with mental health diagnoses or labels and individuals with intellectual or developmental diagnoses or labels, who said that health care providers used their diagnoses to disregard their concerns. Further, several participants raised concerns about the presence of fatphobia within the healthcare system, and described instances where providers perceived obesity as a moral failing rather than recognizing it as a medical condition.

“As a fat person, I routinely feel like I have to convince doctors – of all kinds – that my pain is real and not always related to my weight.”

– Focus Group participant

“They [providers] see me as an anxious patient, and they don't listen to me. It's the most irritating thing I've ever experienced. I have alopecia, and my hair falls out – they haven't been able to pinpoint why that is. It has taken three years of me advocating for support and not getting that support. I asked to see a specialist, and they said I couldn't. They blame everything on my mental health, and that I'm anxious.”

– Focus Group participant

Focus group participants expressed the need for more health care providers to adopt a trauma-informed care approach, particularly for people with disabilities. Recognizing and acknowledging that many people with disabilities have experienced discrimination and trauma from health care providers and other “trusted” individuals is crucial in providing culturally competent care. The desire for trauma-informed care and a demonstrated understanding of how post-traumatic stress disorder (PTSD) can affect people within a clinical setting was expressed repeatedly.

Additionally, multiple participants mention a need for gender-responsive and trans-competent health care. The importance of providing care that treats the whole person, including their many identities, cannot be understated.

To provide care using a trauma-informed approach, providers and administrators should ensure the following six principles, as defined by the Substance Abuse and Mental Health Services Administration (SAMHSA), are in place within their practice:

1. **Safety:** ensure that physical and psychological safety is a priority;
2. **Trustworthiness and Transparency:** provide transparency in the operations and decisions made at all levels of the organization or practice;
3. **Peer Support:** establish opportunities for individuals to connect with others who have a shared lived experience;
4. **Collaboration and Mutuality:** recognize the power imbalance between staff and patients or clients and provide meaningful opportunities to share power in the decision-making process;

5. **Empowerment, Voice, and Choice:** provide opportunities for patients to have a say in all levels of care;

6. **Cultural, Historical, and Gender Issues:** as a practice, recognize stereotypes and biases that have historically impacted the work, work towards addressing the biases, offer access to cultural- and gender-responsive care, and develop policies, processes, and procedures that address systemic and historical inequity.⁵⁶

"They [providers] do not understand or provide trauma-informed care. They make assumptions and generalizations that do not apply to me."

– Health Care Access Survey respondent

"I've faced such chronic shame that if I go to a medical professional and feel like they are shaming me in any way, I will not return. As a trans person, I have to find care that is trauma-informed and competent."

– Focus Group participant

Recommendations

Recommendation	Potential Strategies
Ensure that individuals with disabilities are represented as decision-makers and subject matter experts in spaces where education and training curricula are established.	Establish guidance for hospital systems to include people with disabilities within their Diversity, Equity, and Inclusion efforts and patient and family advisory boards.
Train health care personnel to provide comprehensive and high-quality care to patients with all types of disabilities.	Implement licensing requirements that include ongoing provider education about providing care to individuals with disabilities.
	Embed requirements for direct service/practice experiences with individuals with disabilities in health care training and continuing education programs.
	Require that didactic education in health care fields include content on a range of disabling conditions and human responses.
	Continuing education on working with people with disabilities should be available and encouraged.
Increase the number of individuals with disabilities employed in health care settings.	Pilot programs that support individuals with disabilities to enter the healthcare workforce.
Improve the quality of care for people with disabilities.	Require that health care organizations provide disability specific training on an annual basis.
	Require that health care providers complete all routine aspects of care for people with disabilities (e.g., asking about mental health, substance use, and sexual health).
	Incorporate trauma-informed care approaches at all points of contact.

Priority Area 3: Structural and Systemic Barriers to Care

Background

Systemic barriers can make it difficult, or even impossible, for people with disabilities to access care. This section will discuss systemic barriers related to the costs of care and health insurance, the complex nature of the American health care system, and transportation.

People with disabilities often face economic disadvantages, due to discrimination in the workplace and other areas of life, that make it challenging to find and keep jobs. Policy failures have resulted in inadequate affordable housing and transportation options, difficulty accessing education and training, and health issues that may interfere with work.^{57,58} In Maine, the unemployment rate for people with disabilities is 11%, more than double that of those without disabilities (4%). The median household income for people with disabilities is \$36,000 compared to \$62,000 for people without disabilities.

People with disabilities are nearly three times more likely to live in poverty than people without disabilities.⁵⁹ A contributing factor to this is the intersection between employment and health insurance. With lower employment, fewer people with disabilities can access employer-sponsored health plans. In addition, many people with disabilities require ongoing access to certain services necessary to live independently in the community, typically only available through MaineCare, Maine's version of the federal Medicaid program. MaineCare is a needs-based program with various income and asset limitations that impact eligibility. While MaineCare does offer the MaineCare for Working People with Disabilities, this too has income and asset limitations.⁶⁰ For people with disabilities who require MaineCare services to live independently and in their community, they must maintain eligibility for necessary services not offered through Medicare or private health insurance plans. This does not have to be the case. Maine could change the MaineCare for Workers with Disabilities option to encourage participation by more individuals. Better yet, insurance plans offered by Medicare and private insurers could be structured and designed to provide benefits that individuals with disabilities need to work and live independently.

The economic difficulties faced by people with disabilities are relevant because cost barriers to care are significant and can prevent people with disabilities from accessing the care they need. Approximately 27% of people with disabilities in the United States report not receiving needed medical care compared to 12% of people without disabilities.⁶¹ People with disabilities may require more frequent medical visits, assistive devices, or home care services, resulting in higher out-of-pocket expenses. These costs can be especially burdensome for people with disabilities who may have limited income or rely on government benefits.⁶²

People with disabilities face barriers to obtaining health insurance due to many factors. Beyond high out-of-pocket costs and co-pays, some health insurance plans may not provide adequate coverage for services necessary for people with disabilities, including durable medical equipment, assistive technology, or home modifications. This can result in high costs or individuals needing help accessing these services.⁶³ Insurance plans may also have limited networks of health care providers, which can

make it difficult for people with disabilities to find providers who are knowledgeable about their specific health needs.⁶⁴ Though Medicaid and Medicare are essential sources of health care coverage for people with disabilities, not all are eligible for these programs. Additionally, eligibility requirements and coverage limitations may make accessing the care they need difficult for some individuals.⁶⁵

Many people with disabilities also face transportation barriers that prevent them from accessing care when and where they need it. For those without personal vehicles or the ability to drive, transportation costs can be a significant financial burden, especially for those who require specialized transportation services (e.g., wheelchair-accessible vans) or accommodations.⁶⁶ Many public transportation services, despite the A.D.A., are not always accessible to people with disabilities, such as buses or trains that do not have wheelchair ramps or lifts.⁶⁷ In rural locations, public transportation services may not be available or can be challenging to find.⁶⁸ Many health care facilities do not have enough accessible parking spaces for people with disabilities.⁶⁹ This can make it difficult for people with mobility impairments to reach the facility's entrance.

The fragmented health care system places an undue burden on patients to try and coordinate services across organizations and providers which is often the case for people with disabilities.

The American health care system is highly fragmented, which is felt acutely by many people with disabilities, who may require more complex health care services beyond traditional primary care. A fragmented health care system can have several negative consequences. For instance, people may receive care from multiple providers who need to be connected, leading to duplication of care, poor

coordination of services, and increased costs. This can result in dangerous situations, such as doctors prescribing treatments that interact dangerously with other medications that a patient is taking.⁷⁰

Key Findings

Cost and Insurance

Over half (57%, n=300) of survey respondents reported a time in the past five years when they needed health care but couldn't get it. Among these respondents, 21% (n=126) said care was too expensive, or insurance did not cover the service. Some participants lacked health insurance because the income restrictions for accessing MaineCare meant they made too much money, yet could not access private insurance through their employer or by purchasing it through CoverME.gov, Maine's health care marketplace.⁷¹

Focus group and survey respondents repeatedly identified a need for improved access to dental care, and a lack of oral health care providers that will accept MaineCare. According to the U.S. Department of Health and Human Services, more than 370,000 Mainers live in regions with dental provider shortages, and 15 of the state's 16 counties have a dentist shortage.⁷² The number of participants who mentioned their inability to access oral health care due to a lack of availability or a refusal by dental providers to accept MaineCare was numerous, and spoke to the need for a better network of oral health care providers, particularly in rural areas of the state.

One focus group participant reported that when they finally found a dentist who accepted their insurance, they were still unable to be seen, and the office was booked for the foreseeable future.

Participants in both the survey and focus groups mentioned time and time again that they could not access medication or treatment because of insurance coverage. The high cost of prescription medications, regardless of whether they are covered by insurance, meant that participants could not accept or purchase their medicine. Another survey respondent stated they hesitated to use health care services because a simple visit could be too expensive. Survey participants felt disconnected from their health care providers, saying their providers did not know what it was like to be poor and needed to consider the financial implications of treatment options. Another participant reiterated this when they stated, "Providers don't think about the obstacles associated with being disabled and poor." One survey respondent shared their experience of receiving a diagnosis of Multiple Sclerosis while on private insurance and then having to switch to MaineCare, saying, "I felt care really changed for the worse after the switch. Many providers didn't seem to care about quality of life or have empathy for diagnoses". Another survey respondent shared their experience, saying MaineCare only covered their general care and immediate needs but did not support treatments that would address the underlying problem or provide resources for long-term therapies.

"I wish it was more affordable to all in this country, as many people, myself included, are hesitant to use these services as they cost so much, even for a simple visit to answer a question or get a DX (diagnosis)."
– Health Care Access Survey respondent

"It [the health care system] is extremely classist. The specialist I need to see - I have to pay 100% of the costs for the visit and medicine. These are Drs that keep me alive, not extra support specialists. And these are the only people in Maine who can treat me. If I didn't have money and good insurance from my well-off family, I would probably die. In my experience, Maine greatly lacks in diversity of doctors, quality of care, Dr knowledge, and accessible low-cost options."
– Health Care Access Survey respondent

Participants highlighted various limitations on health services coverage, particularly concerning MaineCare (Medicaid) and the frequency at which certain services were covered. They expressed frustration that standard health insurance plans did not include dental, hearing, or vision services coverage. Participants also raised questions about the decision-making process employed by insurance providers, specifically regarding treatments, diagnostic tests, or services that fell outside the coverage provided by their plans. This desire for transparency and clarity reflected their concerns about how insurance coverage decisions influenced their health care options. The frustration surrounding providers being "out of network" was a recurring theme among focus groups and survey participants. Given the limited number of health care providers in Maine, finding providers who were accepting new patients and could offer timely appointments took time and effort. Consequently, many participants mentioned the need to travel out of state, often to Boston, to access specialized care, which created additional barriers.

"In terms of finding occupational therapists, it's been a nightmare to find one that takes my insurance. They really need to find some really good people to do all of these services up here in Aroostook County. I'm not giving up, but it's been a nightmare to find [providers that take] my insurance. People should try to take as many insurances as they can - there are many people who need help, and they need treatment."

– Focus Group participant

"Insurance doesn't cover a lot. I haven't had glasses for a long time – it's so hard to find a place that will take MaineCare for doing actual vision tests."

– Focus Group participant

Navigation

In addition to facing obstacles related to health insurance and costs, individuals encountered many problems navigating the health care system that hindered their access to health care. Of those who reported being unable to receive care in the past five years, 27% (n=159) cited long wait times as the primary barrier. Survey and focus group participants also highlighted the difficulty of navigating a complex healthcare system without sufficient support and needing more case managers and supportive services. As focus groups and survey participants noted, insurance does not always cover case management. This challenge is particularly significant for people with disabilities who may need to manage care across multiple specialists, making assistance with navigating care systems essential. For people experiencing homelessness, the additional barriers of a lack of a stable address, phone or internet access, and transportation mean it is exponentially more difficult to access care or coordinate care.

Participants shared their experiences of providers failing to communicate effectively across different care types and organizations, leading to exacerbated medical issues and delays in critical care. They highlighted instances where providers lacked coordination, resulting in fragmented care and a lack of continuity. Survey respondents expressed their awareness that, as patients, they often bore the responsibility of sharing new information with their doctors or following up on necessary actions after appointments with specialists. This lack of communication between providers led to different health care professionals holding varying opinions or treatment ideas without effectively sharing them, leaving the patient as the sole source of information. Moreover, participants mentioned instances where providers promised referrals but failed to follow through unless prompted by the patient. These experiences underscored the need for improved communication and a stronger sense of continuity of care among health care providers.

Additionally, participants felt providers need to be more knowledgeable about the different services and alternative options available within a local area, region, or even statewide. Some survey respondents said they did not know where to go for help. A survey respondent noted that the "availability of resources (i.e., reimbursement for rides to appointments) is information that all services providers have and should be relayed as a matter of course whenever a provider sees a patient." Similarly, participants in the Blind and Low Vision and Brain Injury focus groups expressed a desire to have been connected to

support groups or services that could have been beneficial when they experienced their injuries or received their diagnoses.

"The delays are hard. It takes so long to get in to see someone right now. For my son, he lives in a group home. And then, with the turnover in his Direct Support staff, there will be all these mistakes. Like, my son will miss his specialist appointment. They were supposed to bring him, but with the turnover, someone doesn't tell someone else, and they don't bring him. They were supposed to bring him. And we waited six months for that appointment! So then he has to just start over and wait all over again."

– Focus group participant

Transportation

According to the Health Care Access Survey, 11% (n=68) of respondents reported being unable to access health care in the last five years due to transportation issues. This barrier was even more pronounced among individuals with visual impairments, with 24% (n=24) reporting transportation as a barrier. In focus groups, many participants who lacked personal vehicles or could not drive expressed similar concerns, citing the scarcity of affordable and accessible public transportation options. In many areas of the state, particularly rural northern and western Maine, there is no public transportation, including taxi or ride-share services. A 2016 study of transportation barriers for chronically ill older adults in Bangor and the surrounding Penobscot County area found that 67% of patients wanted or needed public transportation services to get to care. In the same study, 80% of schedulers and social workers in medical offices reported difficulties in assisting patients who required transportation, and 40% said that appointment cancellations due to lack of transportation occurred at least once per week in their facility.⁷³

Multiple survey respondents reinforced the importance of transportation to accessing health care. There are transportation

"If you do not drive, you are unable to access health care."

–Health Care Access Survey respondent

options for individuals insured through MaineCare (Medicare), though there are requirements that may prohibit its use. Typically, the service can only be used for non-emergent MaineCare-covered appointments and requires a request to be submitted at least two business days before the appointment.⁷⁴ In August 2013, Maine underwent a significant transformation of its MaineCare transportation program to align with federal Medicaid regulations. This overhaul transitioned from utilizing local nonprofits to organize and provide transportation services to a broker-based model involving ride coordination in eight designated regions. However, this change introduced logistical challenges, leading to many patients reporting missed rides, consequently impacting their ability to attend crucial appointments.⁷⁵

"[There are] lots of public transportation problems for disabled people. It's not right. They don't understand that if you don't get the care you need, it could be serious."

– Focus Group participant

Recommendations

Recommendations	Potential Strategies
<p>Increase opportunities to access funding, resources, and technical assistance to better care for people with disabilities.</p>	<p>Expand efforts that identify Health Professional Shortage Areas (HPSAs) to include urgent care, specialty care, and home health services, which would allow centers to expand specialized services.</p> <p>Designate people with disabilities as a medically underserved population through the Health Resources and Service Administration (HRSA) to increase opportunities to access funding and technical assistance support at federally qualified health centers through a Governor’s Designation.⁷⁶</p>
<p>Provide navigation and supportive services to people with disabilities and their families/caregivers.</p>	<p>Nurture peer navigation and support programs that pair individuals with disabilities with peers who have expertise and experience successfully navigating the health system.</p> <p>Explore opportunities to offer or expand case management and care coordination services for individuals with disabilities with both public and private insurance plans.</p> <p>Advocate for supportive services for parents and caregivers of children with disabilities.</p> <p>Incentivize partnerships between health care providers and community-based organizations to address common barriers to care (e.g., transportation barriers).</p>
<p>Explore mechanisms to improve timelier access to care.</p>	<p>Expand after-hours and weekend care at primary care practices, including federally qualified health centers.</p> <p>Use telehealth technologies, such as virtual visits and remote consultations, to deliver health care services to patients in remote or underserved areas to reduce travel time and costs, and enhance access to care for individuals with limited mobility or transportation options.</p> <p>Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.</p>

Priority Area 4: Communication

Background

Communication issues between health care providers and people with disabilities affect the quality of care received by people with disabilities and may lead to adverse health outcomes. Research shows that people with disabilities are more likely to report communication difficulties with health care providers than those without disabilities (28% vs.10%).⁷⁷

Health care providers may have limited time to communicate with patients, leading to rushed conversations or a lack of clarity in the information provided.⁷⁸ The average primary care visit is 18 minutes long in the United States.⁷⁹ One study found that the average talk time between patients and physicians during appointments was only 5 minutes each.⁸⁰ Although this is a challenge facing all patients in our current health care system, it has particular equity implications for people with disabilities. For people who communicate differently, need more time for comprehension, utilize communication devices or require an interpreter, or have complex medical needs, the short time allotted for examination, questions, and discussion is even more limiting on their care.

Providers often use complex medical terminology that may be difficult for people with disabilities to understand.⁸¹ Studies show that medical terminology also poses specific challenges for Deaf individuals who use American Sign Language and are at high risk for low reading levels, health terminology recognition, and health literacy.^{82,83} Providers must speak in terms that allow individuals to understand diagnoses, treatment options and plans, directions, and medical advice.

People with disabilities also report difficulties obtaining accommodations from health care providers that would improve communication, such as captioning discussions, sign language interpreters, visual aids, and other communication aids and services. Providers that do not have education, training, or experience about the ways to communicate with individuals with disabilities may overlook the need for communication accommodations, such as the use of assistive devices, communication boards, captions, or interpreters.

Providers may also make incorrect assumptions about the patient's abilities and default to communicating with others in the room (such as family, caregivers, or support staff) rather than the patient directly. Many individuals with disabilities report that providers infantilize them by speaking to others in the room instead of speaking with them.

Key Findings

Approximately 44% (n=231) of survey respondents reported that it was challenging to communicate with their health care providers. When asked to provide additional context about their experiences, 20% (n=121) of individuals who reported difficulties said that providers did not listen to them or believe them, 13% (n=80) said providers did not speak directly to them, and 7% (n=40) said they were not

provided the accommodations they needed to communicate (e.g., interpreters, captions, or other aids or services). Focus group and survey participants expanded on these experiences, saying they felt their health care providers:

- Do not believe them;
- Dismiss their concerns;
- Do not include them in the decision-making process;
- Do not think they are capable of making decisions;
- Talk to their family members, guardian, companion, or staff member who are with them, rather than directly to them;
- Say things in the exam room and then do not follow up;
- Do not explain things well or use terminology they don't understand;
- Do not take the time to ensure understanding;
- Lack empathy and/or;
- Focus on their laptops rather than making eye contact.

Over a fifth (21%, n=103) of Health Care Access Survey respondents said doctors and staff do not listen carefully to their concerns and symptoms. Many reported on the rushed nature of health care appointments and the impacts this has on their ability to express concerns, ask questions, and discuss options for treatment and services:

22% (n=105)

**of survey respondents said
doctors and staff do not
explain what they think about
their condition**

22% (n=105)

**of survey respondents
said doctors and staff do
not answer all of their
questions**

23% (n=121)

**of survey respondents said
health care providers do not
involve them in decisions
about their health care**

Participants described times when they felt their health care providers made assumptions about what they could do or comprehend. One participant said, "Providers make hasty assumptions about me in all directions. I am extremely intellectually capable but have trouble with auditory processing and emotional regulation, so sometimes it takes a while for me to understand things when people assume I should get things quicker. Alternatively, people see "autism" and assume I am intellectually disabled, which I am not. I am always over- or under-estimated.

Just speak to me directly, and I'll let you know where I am at and what I need!"

"I would like people to take more time to talk to me. Doctors sometimes talk to the person with me instead of directly to me."

–Focus Group participant

Other survey and focus group participants described similar experiences where providers spoke to them in patronizing tones. Alternatively, participants reported that providers use "doctor talk" and do not take the time to clarify specific medical terminology or explain things thoroughly.

Participants in focus groups and Health Care Access Survey respondents also reported that communication issues could occur at every point and throughout the process – from scheduling, arrival, and check-in to appointments, services, and follow-up. For example, some individuals reported that pre-appointment forms and questionnaires are dense, difficult to understand, or inaccessible formats they cannot complete. For people who are blind or have low vision, this could mean online patient portals that are not screen-reader friendly or paper forms that are not provided ahead of time, meaning the patient needs assistance to complete the form in the waiting room before their appointment.

"They (providers) often treat me in an infantilizing way. They sometimes are unable or unwilling to assist with paperwork that they hand me at the office."

–Health Care Access Survey respondent

"What's hard for me when making an appointment is going through all of the automated stuff - trying to figure out the insurance stuff and the paperwork. I don't know what that means because I struggle with steps due to my autism. It's really hard - the way they word certain stuff. What is easier for me is when I have my mom or someone with me to explain what they mean. I feel like they should word things in a simpler way. People like me who have a harder time understanding these types of words could better understand what I need to do and what I need to sign."

–Focus group participant

Individuals who are Deaf or hard of hearing face especially significant barriers in communicating effectively with their health care providers. Focus group and survey participants who are deaf and hard of hearing expressed that health care providers often overlook or ignore their need for communication accommodations, making it difficult to understand their health care and navigate the health system. Participants described providers needing to be more receptive to using captioning or sign language interpreter services, needing to be made aware of how to obtain such services for appointments, or stating they could not provide them. Participants reported that they felt the need to explain how to communicate with providers continuously and perceived that the providers did not retain information. Many providers assume that lip reading is universal or innate, while only a small subset of individuals can communicate this way (with limited accuracy). Participants also shared that during COVID-19, most providers did not wear or supply transparent masks, which further hampered communication by eliminating the ability to read facial expressions and mouth movements, both essential in American

Sign Language (ASL). Communication before and after appointments was also a concern. One focus group participant shared that when he needed to discuss urgent test results with a provider, the office had no way of communicating these results to him except by phone call, which he could not hear; the provider shared the results with his spouse instead, and he was unable to ask questions.

Deaf focus group participants who used American Sign Language described many concerns and barriers related to the need for interpreter services. Participants reported experiencing delays in their care because many health care facilities needed more, or minimal, ability to provide in-person sign language interpreters for urgent or last-minute needs. One survey participant stated that health care providers and their staff needed training on how to work with interpreters, saying that providers talk to the interpreter instead of the patient.

The number of issues reported with Video Remote Interpreting (VRI) services, in particular, was high. VRI provides an ASL interpreter pulled on-demand from a virtual pool of interpreters nationwide. Individuals reported experiencing frequent malfunctions of the VRI service and equipment that prevented effective communication. Individuals also reported frustrations with the "random" nature of VRI. Participants described trying to navigate communication

“Most places want you to use VRI and it’s a problem. I don’t want VRI. They say, ‘I don’t care.’ That response – it’s so upsetting. Medical care, medical events, it’s important. Like, if I have a heart attack, I could die. That’s scary. They should have it set up so that I can get the interpreting services I need the way I know I need it. VRI is very hard – you need to be able to see it, you need to have it set up right, and staff need to know how to use it. But it doesn’t always happen right, and you are left there stuck.”

–Focus Group participant

through VRI interpreters who were not from Maine and, therefore, unfamiliar with regional signs, or inexperienced interpreters that they struggled to understand in high-stakes situations. Many survey and focus group participants described cases where the VRI was delivered on small devices like phones or tablets, which were difficult to see, or where the system kept freezing, making it difficult or impossible to communicate back and forth with health care providers. Participants also described feeling anxiety and stress when providers presented them with VRI, particularly when an on-site interpreter had been requested well in advance.

"On-site interpreters make communication faster. If I have the same interpreter or two for a five-day hospital stay, they have the context. They can just interpret the questions being asked by the doctor, interpret my answers. Simple. If it's a VRI interpreter, the communication takes forever. The interpreter is random, someone different each time. They have to ask so many questions of me, of the doctor, to understand the context, what has happened already, what conversation they are jumping into, the terms being used—the schema. Our prior knowledge of the situation – our communication relies on that. The doctor has it, and I have it. But the interpreter needs to have it too. And the VRI interpreters don't."

– Focus Group participant

Regarding preferred communication methods, the sentiment expressed by one focus group participant resonated with others: "I don't know if I've ever been asked by a provider's office what is the best way [to communicate]." This remark highlighted a shared experience where individuals felt their communication preferences were not acknowledged or respected by health care providers. A survey participant shared an incident where their audiologist did not utilize a clear mask during their interaction despite being aware of the participant's reliance on lip-reading. This lack of accommodation reflected a misconception among providers that speaking alone was sufficient for clear communication, disregarding the specific needs of individuals who required visual cues. In addition, several focus group participants expressed the added challenge of background noise impeding their ability to understand their health care providers. Whether it was background music, conversations between others, white noise machines, or other noise sources, these external factors further burdened their communication experience with health care professionals.

"I'm a very easy-going person, and I know my providers well enough that I can lip-read. I use text-to-speech, but sometimes it's not perfect because I can swear like a sailor. But it does help at some points. The thing is that certain providers [differ]. It's interesting for an audiologist [to wear] a mask - a solid mask. Why? It's just like - use that common sense. So my experience has been mixed. And some providers who don't provide sign language and interpreters on behalf of a client could be doing more."
–Focus Group participant

One survey respondent did express hope for the future, saying, "I am encouraged that the younger physicians seem to "get it" more quickly, and many – even specialists – often have better communication skills than one might expect."

Recommendations

Recommendations	Potential Strategies
Equip health care personnel with the necessary knowledge and tools to interact positively with patients with disabilities.	Require that all health care personnel, from administrative staff to physicians, receive formal training on effective methods for communicating with patients with disabilities. Conduct training on legal obligations providers have when interacting with patients with disabilities. Develop provider educational materials (e.g., guides, toolkits, checklists) that providers and staff can use to ensure accessibility during appointments.
Individuals with disabilities must be represented in decision-making bodies to ensure that communication needs are addressed sufficiently.	Require that hospital Patient Advisory Councils include people with disabilities to solicit and encourage improvements related to effective communication and patient access.
Inform individuals with disabilities of the rights afforded to them.	Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available to them.
Communication devices and technologies should always be working and available for use.	Examine the accessibility of health care technologies (e.g., kiosks, patient portals, telephone systems, video conferencing, websites) prior to implementation.

	<p>Ensure that health care facilities have contracts for on-site and video interpreters in place before a request for interpreters is received.</p> <p>Develop and implement state-level guidelines for using ASL Video Remote Interpreting in medical settings.</p>
<p>All communications (e.g., forms, questionnaires, educational materials, instructions) should be accessible, easy to complete, and representative of people with disabilities.</p>	<p>Offer patients the opportunity to fill out all forms (electronically or in hard copy) prior to their appointment.</p> <p>Require that all materials distributed to patients during the visit are audited for accessibility.</p> <p>Ensure that all online data and information are provided in formats that can be interpreted by screen readers.</p> <p>Ensure the facility and providers have the ability to offer large-print versions of all printed materials (font size 18 pt or larger).</p> <p>Include images of people with disabilities in all educational and promotional materials.</p>
<p>Consider communication needs and privacy concerns when interacting with patients in health care facilities.</p>	<p>Implement more discrete communication strategies that do not rely on hearing a person's name called (e.g., distributing pagers instead of calling names in a waiting room).</p> <p>In places where masking is required and implemented, ensure all staff has easy access to clear masks and communicate that patients can ask for staff to wear them.</p> <p>Schedule longer appointments for patients with disabilities to accommodate diverse communication needs, styles, cognition levels, and use of interpreters/communication devices.</p> <p>Explore opportunities to be more flexible in allowing for longer patient visits.</p>

Priority Area 5: Physical Spaces

Background

Physical barriers in health care settings can make it difficult or impossible for people with disabilities to access health care services or receive appropriate care. The Americans With Disabilities Act was signed into law in 1990, over 30 years ago, providing the minimum requirements that employers, government agencies, services, public facilities, transportation, and telecommunications must provide to ensure accessibility for people with disabilities.⁸⁴ While this legislation was a significant step forward for people with disabilities, inaccessible buildings and building features are still a common problem.⁸⁵ There are also gaps regarding mandatory standards for accessible medical and diagnostic equipment. In 2010, the Patient Protection and Affordable Care Act (ACA) added an amendment to Section 510 of the Rehabilitation Act where accessibility standards for medical diagnostic equipment were developed.⁸⁶

Health care facilities are often not designed to accommodate people with physical disabilities, such as those who use wheelchairs. For example, inaccessible entrances, narrow doorways, stairs without handrails, and lack of accessible restrooms can impede people's ability to navigate the facility safely.⁸⁷ People struggle to access care in these spaces. A study published in the *Journal of Rural Health* found that people with disabilities in rural areas have limited access to health care facilities that are equipped to accommodate their needs, which suggests that inaccessible medical equipment may be more prevalent in rural areas due to the lack of resources and infrastructure and more limited options available in these regions.⁸⁸ The 2022 research study by Lagu et al. found that all physicians participating had physical barriers to providing health care, including inaccessible buildings and equipment (such as height-adjustable exam tables).⁸⁹ Some physicians even reported sending their patients to supermarkets, grain elevators, zoos, and cattle processing plants to obtain a weight when they did not have an accessible scale.⁹⁰

Inaccessible medical equipment can delay the diagnosis of disease and treatment and affect the quality of care provided. Health care equipment is not designed to accommodate people with disabilities, such as adjustable examination tables, weight scales, and imaging machines. For example, some imaging machines may require patients to remain still for extended periods, which can be challenging for people with mobility impairments.⁹¹ A study published in the *Journal of General Internal Medicine* found that more than half of primary care clinics surveyed in the United States did not have accessible weight scales, which can hinder the monitoring of critical health conditions such as obesity and diabetes.⁹² Research has also shown that people with disabilities are less likely to receive diagnostic medical examinations due to inaccessible medical equipment. For example, reported cervical cancer screening rates for women with disabilities ranged from 60-80%, compared to 80% screening rates for women without disabilities. The percentage of women with disabilities between 50 and 74 years of age who had a mammogram was between 61% to 68%, compared with 74% of women of the same age without disabilities.⁹³

A 2013 study evaluated health care administrators' knowledge of accessible equipment available for medical practices. Less than half knew accessible equipment existed, and only a fourth could describe the equipment. Less than half of the study participants reported ever purchasing equipment, and only a third said that the number of patients with disabilities could justify the cost of such equipment.⁹⁴

Finally, many health care facilities are not designed to accommodate individuals with sensory issues, and specific facility types, such as emergency rooms and dental offices, can be unpredictable and overstimulating. Exposure to these environments can have physical and psychological effects that trigger adverse reactions.⁹⁵

Key Findings

Nearly a fifth (18%, n=93) of Health Care Access Survey respondents reported that the spaces they receive care do not feel accessible or safe. The highest percentage of individuals reporting that spaces were not accessible or safe were those with physical disabilities or mobility issues, those who use communication devices, and individuals with intellectual or developmental diagnoses or labels (21%).

Focus group participants and Health Care Access Survey respondents shared numerous experiences detailing the difficulties they faced, including:

- Not enough designated accessible parking spots or even street parking only;
- Narrow or tiny hallways that did not allow enough space for wheelchairs, rollators, or walkers;
- No automatic door openers or inaccessible handles on doors too heavy to open;
- No elevators within the building;
- Inaccessible chairs in waiting rooms and exam rooms;
- A lack of accessible equipment or tools in the exam rooms, such as height-adjustable exam tables;
- Atmospheres that were triggering or overwhelming with too much noise or bright lights;
- Background noise that made it hard to understand people talking, such as music, other people talking, and white noise machines;
- A lack of appropriate placement for pediatric psychiatric patients in emergency room settings;
- Bathrooms that were not large enough to accommodate power wheelchairs and have soap and paper towel dispensers that are out of reach to someone using a wheelchair.

Several respondents shared difficulties in gaining entry into the facilities where they were to receive care and navigating the space:

"ADA [Americans with Disabilities Act] scrapes the bottom of the barrel. Doors are always too narrow, getting through is hard; there are too many chairs to park a wheelchair. There are no spaces to park in the waiting room. There's an awkward dance with people. This includes parking lots and maintenance of pathways which aren't safe or accessible. Exam rooms are usually too small to move my chair around."

—Focus Group participant

Participants also described experiences where they were explicitly told by health care providers that they could not receive the diagnostic treatments for which they were scheduled.

"Another issue sometimes is getting up onto tables. It's not easy for somebody in a wheelchair to get up on a table- it takes three people to get me up onto a table. That is one reason why one time I didn't have a full bone scan because they couldn't get me up on the table to have the bone scan. Those tables are very difficult. I've been having to bring my sliding board with me lately to get from the chair to the table. Those tables can be hard to get up to. When my mom started coming with me, she could help me get up onto the table - one time, they only did a bone scan on my wrist because they couldn't get me up. One time they had to x-ray me in my chair."

–Focus Group participant

Focus group participants and Health Care Access Survey respondents also reported that some physical spaces do not protect the privacy of their names and personal information.

"The front desk staff who assist with filling out forms want to do it in the waiting area surrounded by other patients who can easily hear the whole thing."

–Health Care Access Survey respondent

"Sometimes [I have to meet] with doctors in the hallway where there's no privacy; the doctors just want to speak quickly, like they have no time, and just get the meeting done in the hallway instead of taking the time to properly meet."

–Focus Group participant

Recommendations

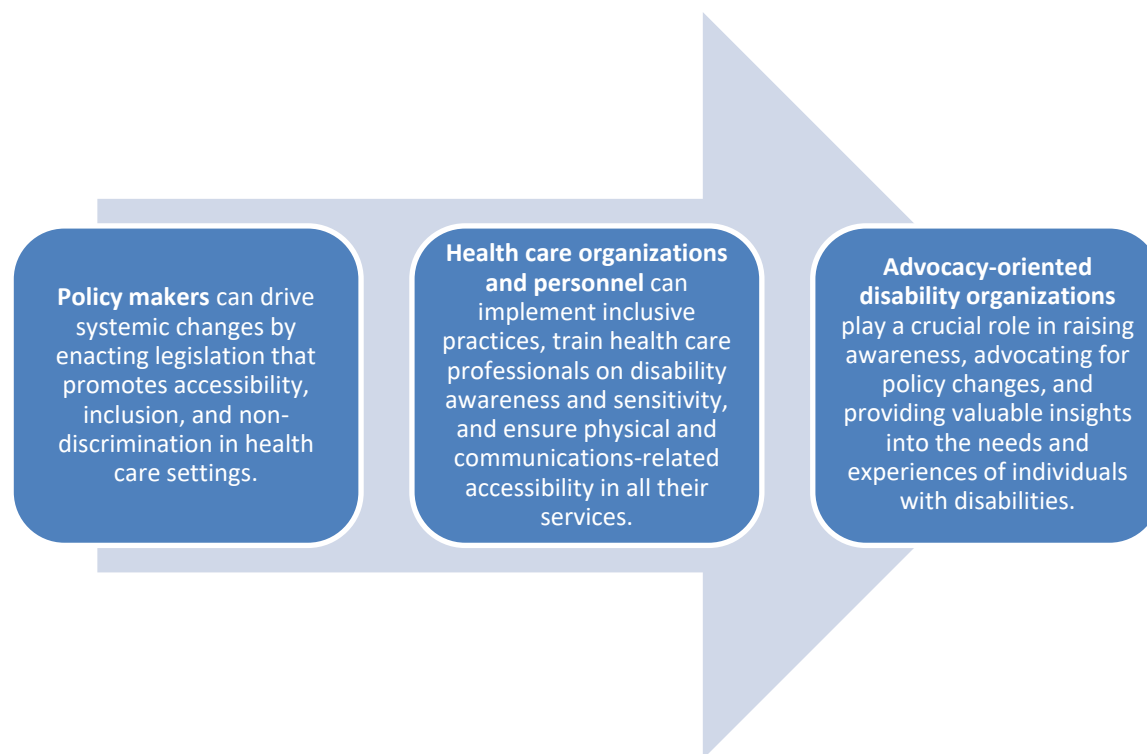
Recommendations	Potential Strategies
Create, implement, and improve mechanisms for notifying providers and staff of patient accommodations and needs.	Embed questions about accommodation needs at first contact (scheduling, registration, triage, etc.) Proactively communicate with patients ahead of health care visits to assess potential accessibility needs and accommodations for individuals with disabilities. Clearly and prominently identify patient accommodation needs in Electronic Health Records. Enable Electronic Health Record pop-up notifications at log-in, advising of accommodation needs (including whether an interpreter is needed), and that require an action such as clicking an acknowledgment button to dismiss the pop-up. Provide regular reports to administrative staff and providers that identify upcoming patient appointments where accommodations or accessible equipment is needed.
Equip all health care organizations with tools, assistive devices, medical equipment, and personnel that allow for	Ensure that an on-site "Access Coordinator" is appointed and available at all times. This person should be on-the-ground and responsible for

<p>universal access to all recommended screening and diagnostic tests and treatments.</p>	<p>providing immediate assistance to staff to locate and implement communication aids and services, schedule interpreters, and assist/troubleshoot issues.</p>
<p>Create accessibility guidelines that go beyond the basic minimum requirements and provide additional access whenever the needs of the population go beyond those minimum standards.</p>	<p>Require that healthcare organizations routinely assess and report on the accessibility of their building (e.g., parking lots, waiting areas, exam rooms).</p>
	<p>Increase the number of accessible parking spaces at health care facilities, rather than meeting ADA minimum requirements.⁹⁶</p>
	<p>Increase availability of accessible medical equipment (e.g., height adjustable examination tables, accessible mammography equipment, accessible weight scales, and lift equipment).⁹⁷</p>
<p>Ensure that patients are fully aware of the accessibility-related services available to them.</p>	<p>Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available.</p>

Conclusion

As highlighted throughout this report, the first of its kind in Maine, individuals with disabilities face significant barriers when seeking health care services, often resulting in disparities and inequities in their health outcomes. The challenges surrounding equitable access to health care for individuals with disabilities are intricate and multifaceted, demanding sustained dedication and collaborative endeavors from diverse stakeholders.

We recognize that transforming existing structures and practices requires careful planning, coordination, and consideration of diverse perspectives. However, the situation's urgency demands swift action to ensure that individuals with disabilities can access quality health care on an equal footing. While policy changes may take time, there are ample opportunities for organizations, policymakers, advocates, and health care organizations to collaborate and make meaningful strides toward improving equitable access to care for people with disabilities. By fostering partnerships and working together, different entities have specific opportunities to identify and address the challenges faced by Mainers with disabilities.



Collaboration between advocacy-oriented disability organizations and other groups can result in the development of innovative programs and services tailored to the unique needs of people with disabilities. DRM hopes that the insights presented in this report will serve as a valuable resource to establish new partnerships or reinforce existing ones with clinical and community-based organizations. These collaborations are essential for effectively addressing the recommendations and exploring potential strategies outlined in the report. By leveraging the expertise and resources of various stakeholders, we can create a collective force that drives positive change and dismantles the systems

force that drives positive change and dismantles the systems that hinder health equity and access for people with disabilities.

Through collaboration, persistence, and a shared commitment to social justice, we can foster a health care system that treats all individuals with the respect, dignity, and equitable care they deserve. While the road ahead may be challenging, the potential to create lasting change is within our grasp. Let us seize this opportunity to work together and build a society that ensures equitable access to health care for all, regardless of ability.

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APPENDIX A

1. HEALTH CARE ACCESS SURVEY
2. SURVEY FINDINGS
3. DIRECT QUOTES FROM OPEN RESPONSES

Health Care Access and Equity for Individuals with Disabilities in Maine

Survey for Individuals with Disabilities in Maine

Page exit logic: Skip / Disqualify Logic

IF: #1 Question "Do you live in Maine?" is one of the following answers ("NO") **THEN:** Disqualify and display:

We appreciate your interest in this survey, however, it is intended only for individuals with a disability(ies) in the state of Maine. If you have questions, please contact Jennifer Battis at jbattis@drme.org or (207)626-2774

1. Do you live in Maine? *

- YES
- NO

Page entry logic:

This page will show when: #1 Question "Do you live in Maine?" is one of the following answers ("YES")

2. Are you deaf or do you have difficulty hearing? *

- YES
- NO

3. Are you blind, have low-vision, or have serious difficulty seeing even when wearing glasses? *

- YES
- NO

4. Do you have a mental health condition or been given one of these labels? This may include anxiety, depression, post-traumatic stress disorder (PTSD), bipolar disorder, schizoaffective disorder, substance use disorder or other conditions.

*

YES

NO

5. Do you have a developmental disability or been given one of these labels? This may include Intellectual Disability, Down Syndrome, Autism, Cerebral Palsy or others. *

YES

NO

6. Do you have a brain injury or related condition? This may include brain tumor, stroke, impacts from loss of oxygen to the brain, traumatic brain injury, or others. *

YES

NO

7. Do you have a physical or mobility disability? This may include spinal cord injury, cerebral palsy, limb or body structure disabilities, muscular dystrophy, multiple sclerosis, or other conditions. *

YES

NO

8. Do you have any other serious health problem or condition expected to last for six months or more? This may include auto-immune disorders, cancer, digestive disorders, diabetes, epilepsy, long-term disease or illness, or others. *

- YES
- NO

9. Do you have difficulty, concentrating, remembering, or making decisions? *

- YES
- NO

10. Do you use a communication device or communicate alternatively? This may include letter or word boards, eye gaze, gesturing, text to speech apps, and others. *

- YES
- NO

11. Do you have serious difficulty walking, climbing stairs, using your hands or fingers, or doing other physical activities? *

- YES
- NO

12. Do you use a wheelchair or other device for mobility?

*

- YES
- NO

Experiences with Health Care Providers

LOGIC Show/hide trigger exists.

13. Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room.

- YES
- NO

LOGIC Hidden unless: #13 Question "Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room." is one of the following answers ("YES")

14. Does your doctor and staff listen carefully to your concerns and symptoms?

- YES
- NO

LOGIC Hidden unless: #13 Question "Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room." is one of the following answers ("YES")

15. Does your doctor and staff examine you the way you think you should be examined?

- YES
- NO

LOGIC Hidden unless: #13 Question "Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room." is one of the following answers ("YES")

16. Does your doctor and staff explain to you what they thought about your health or medical condition?

- YES
- NO

LOGIC Hidden unless: #13 Question "Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room." is one of the following answers ("YES")

17. Does your doctor and staff answer all of your questions?

- YES
- NO

LOGIC Hidden unless: #13 Question "Do you have a health care provider that you see regularly? For this question, when we say healthcare provider, we mean a doctor, nurse practitioner, or someone similar you see for ongoing care. We do not mean a doctor you may have seen at an emergency room." is one of the following answers ("YES")

18. Think about your most recent primary care visit. Did your doctor ask you about the following? Check all that apply.

- Getting screenings for cancers. This might include screenings for cervical, breast, colon, or prostate cancer (age and gender appropriate).
- Making sure you are up-to-date in vaccinations. This includes your Flu and COVID-19 vaccinations.
- Your exercise habits or weight control.
- Tobacco use.
- Alcohol and other drug use.
- Sexual practices.
- Safety risks such as guns, seatbelt use, and helmets.
- Whether your mood is okay or if you feel sad or anxious? Does your doctor ask you if you have ever thought about hurting yourself?

LOGIC Show/hide trigger exists.

19. In the past year, have you gone to an Emergency Room?

- YES
- NO

LOGIC Hidden unless: #19 Question "In the past year, have you gone to an Emergency Room?" is one of the following answers ("YES")

20. Why did you go to the Emergency Room? Check all that apply.

- I do not have a primary care provider.
- My primary care provider told me to go to the Emergency Room.
- I was not able to see my primary care provider.
- It felt like it could not wait.
- Other - Write In (Required)

*

LOGIC Hidden unless: #19 Question "In the past year, have you gone to an Emergency Room?" is one of the following answers ("YES")

21. In the Emergency Room, did the doctors and nurses listen carefully to your concerns and symptoms?

- YES
- NO

LOGIC Hidden unless: #19 Question "In the past year, have you gone to an Emergency Room?" is one of the following answers ("YES")

22. In the Emergency Room, did the doctors and nurses examine you the way you think you should be examined?

- YES
- NO

LOGIC Hidden unless: #19 Question "In the past year, have you gone to an Emergency Room?" is one of the following answers ("YES")

23. In the Emergency Room, did the doctors and nurses explain to you what they thought about your health or medical condition?

- YES
- NO

LOGIC Hidden unless: #19 Question "In the past year, have you gone to an Emergency Room?" is one of the following answers ("YES")

24. In the Emergency Room, did the doctor and nurses answer all of your questions?

- YES
- NO

LOGIC Show/hide trigger exists.

25. Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.

- YES
- NO

LOGIC Hidden unless: #25 Question "Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else." is one of the following answers ("YES")

26. What type of care were you not able to access? Choose all that apply.

- Primary care
- Oral/dental health care
- Mental/behavioral health care
- Substance use care
- Emergency care
- Urgent care
- Home health care/Personal care services
- Other - Write In (Required)

*

LOGIC Hidden unless: #25 Question "Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else." is one of the following answers ("YES")

27. For the times you were not able to access care, what was the reason? Check all that apply. Was there a time in the past five years where you needed to see a health care provider, but you were not able? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.

- The wait was too long.
- I had no way to get there.
- It was too expensive or my insurance did not cover it.
- The provider hung up on me or did not call me back.
- The provider did not provide the accommodations I needed (e.g., ASL interpretation, accessible medical equipment, allowing me to bring a support person).
- The provider did not feel able to meet my needs.
- I did not know how to find a provider.
- Other - Write In (Required)

*

LOGIC Show/hide trigger exists.

28. Are health care providers properly trained and prepared to treat you?

- YES
- NO

LOGIC Hidden unless: #28 Question "Are health care providers properly trained and prepared to treat you?" is one of the following answers ("NO")

29. What makes you feel that way?

30. Do health care providers involve you in decisions about your healthcare?

- YES
- NO

LOGIC Show/hide trigger exists.

31. Is it difficult to communicate with your health care providers?

- YES
- NO

LOGIC Hidden unless: #31 Question "Is it difficult to communicate with your health care providers?" is one of the following answers ("YES")

32. What experiences have you had? Choose all that apply.

- They do not know how to communicate with me.
- They do not provide accommodations that I need (e.g., captions, interpreters).
- They do not speak directly to me.
- They do not listen to me or believe me.
- They do not make sure I understand.
- Other - Write In (Required)

*

LOGIC Show/hide trigger exists.

33. Do health care providers respect you?

- YES
- NO

LOGIC Hidden unless: #33 Question "Do health care providers respect you?" is one of the following answers ("NO")

34. What experiences have you had? Check all that apply.

- Providers do not listen to me or do not take my concerns seriously.
- Providers talk to the people with me and not to me directly.
- Providers do not consider my needs and experiences.
- Providers are rude or hostile to me.
- Other - Write In (Required)

*

LOGIC Show/hide trigger exists.

35.

Think about the spaces where you receive care. For example, clinicians or doctors' offices, waiting rooms, hospital rooms, and other places. Are these spaces accessible and do they feel safe?

- YES
- NO

LOGIC Hidden unless: #35 Question "

Think about the spaces where you receive care. For example, clinicians or doctors' offices, waiting rooms, hospital rooms, and other places. Are these spaces accessible and do they feel safe?

" is one of the following answers ("NO")

36. What makes the spaces inaccessible or feel unsafe? Choose all that apply.

- Parking lot does not have appropriate parking.
- I cannot get into the building.
- Staff are not trained to handle my body in a safe way.
- The medical equipment is inaccessible. For example, there are no height-adjustable table, no accessible scale, no accessible MRI or mammogram, or something else.
- The staff were not trauma informed.
- Other - Write In (Required)

*

37. How do you typically get health information? Check all that apply.

- Friends and/or family.
- Medical providers.
- Residential or group home support staff.
- Television or internet (e.g., television news, social media, WebMD, Mayo Clinic website).
- I do not have access to health information.
- Other - Write In (Required)

*

Health Care Experiences

LOGIC Show/hide trigger exists.

38. Have you received primary care services sometime in the past 5 years?

- YES
- NO

LOGIC Hidden unless: #38 Question "**Have you received primary care services sometime in the past 5 years?**" is one of the following answers ("YES")

39. How did you feel about the quality of the primary care services that you received, on a scale of very unhappy to very happy.

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

40.

Have you received mental/behavioral health care services sometime in the past five years?

- YES
- NO

LOGIC Hidden unless: #40 Question "

Have you received mental/behavioral health care services sometime in the past five years?

" is one of the following answers ("YES")

41. How did you feel about the quality of the mental/behavioral health services that you received, on a scale of very unhappy to very happy.

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

42. Have you received oral/dental health services sometime in the past 5 years?

- YES
- NO

LOGIC Hidden unless: #42 Question "**Have you received oral/dental health services sometime in the past 5 years?**" is one of the following answers ("YES")

43. How did you feel about the quality of the oral health/dental care services that you received, on a scale of very unhappy to very happy.

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

44. Have you received emergency care services sometime within the past 5 years?

- YES
- NO

LOGIC Hidden unless: #44 Question "**Have you received emergency care services sometime within the past 5 years?**" is one of the following answers ("YES")

45. How did you feel about the quality of the emergency care services that you received, on a scale of very unhappy to very happy.

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

46. Have you received home health care services sometime in the past 5 years?

- YES
- NO

LOGIC Hidden unless: #46 Question "**Have you received home health care services sometime in the past 5 years?**" is one of the following answers ("YES")

47. How did you feel about the quality of the home health care services that you received, on a scale of very unhappy to very happy.

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

LOGIC Show/hide trigger exists.

48. Have you received specialty care services sometime in the past 5 years? For example - occupational therapy, physical therapy, audiology, or something else.

- YES
- NO

LOGIC Hidden unless: #48 Question "Have you received specialty care services sometime in the past 5 years? For example - occupational therapy, physical therapy, audiology, or something else." is one of the following answers ("YES")

49. How did you feel about the quality of the specialty care services that you received, on a scale of very unhappy to very happy.

- Very unhappy
- Unhappy
- Neutral
- Happy
- Very happy

50. Is there anything else you would like to share about your experiences with the health care system?

Demographics

51. What is your age?

- Under 18
- 18-24
- 25-44
- 45-64
- 65-74
- 75-84
- 85 and older
- I prefer not to answer

52.

Which of these groups best represents your race? Choose all that apply. You will have space to enter ethnicity in the next question.

- Asian
- Native Hawaiian or Other Pacific Islander
- Black/African-American
- White
- American Indian/Alaska Native
- I prefer not to answer
- I prefer to self describe

*

53. What is your ethnicity?

54. Do you identify as Hispanic/Latino(a)?

- YES
- NO
- I prefer not to answer

55. What is your primary language?

56. What type(s) of health insurance do you have? Check all that apply.

- Private insurance (for example, insurance provided through current employer or union, or purchased directly from an insurance company)
- Medicare
- MaineCare/Medicaid
- TRICARE or other military healthcare
- VA (enrolled for VA health care)
- Indian Health Service
- Other health insurance/health coverage plan:
- I do not have health insurance
- I prefer not to answer

*

57. What best describes your current housing situation?

- I live in my own home.
- I live with my parents or family members.
- I live in a group home.
- I live in an institution.
- I am experiencing homelessness.
- I prefer not to answer

58. What best describes your current gender identity?

- Genderqueer or gender non-conforming
- Man
- Transgender man
- Transgender woman
- Woman
- I prefer to self describe
- I prefer not to answer

59. What best describes your sexual orientation?

- Asexual
- Bisexual
- Gay or lesbian
- Straight/heterosexual
- I prefer to self describe

- I prefer not to answer

60. What was your total income last year, before taxes?

- Less than \$20,000
- Between \$20,001 and \$40,000
- Between \$40,001 and \$60,000
- Between \$60,001 to \$80,000
- Between \$80,001 to \$100,000
- Over \$100,000
- I prefer not to answer

61. What county do you live in?

- Androscoggin
- Aroostook
- Cumberland
- Franklin
- Hancock
- Kennebec
- Knox
- Lincoln
- Oxford
- Penobscot
- Piscataquis
- Sagadahoc
- Somerset
- Waldo
- Washington
- York
- I don't know
- I prefer not to answer

Full Sample Frequencies		
Question	N	%
Do you have a health care provider that you see regularly?		
NO	52	9.68
YES	485	90.32
Does your doctor and staff listen carefully to your concerns and symptoms?		
NO	103	21.46
YES	377	78.54
Does your doctor and staff examine you the way you think you should be examined?		
NO	121	25.10
YES	361	74.90
Does your doctor and staff explain to you what they thought about your health or medical condition?		
NO	105	21.74
YES	378	78.26
Does your doctor and staff answer all of your questions?		
NO	105	21.78
YES	377	78.22
Think about your most recent primary care visit. Did your doctor ask you about the following? Check all that apply.		
Getting screenings for cancers	190	31.77
Making sure you are up-to-date in vaccinations	350	58.53
Your exercise habits or weight control	279	46.66
Tobacco use	249	41.64
Alcohol and other drug use	233	38.96
Sexual practices	114	19.06
Safety risks such as guns, seatbelt use, and helmets	107	17.89
Whether your mood is okay or if you feel sad or anxious? Does your doctor ask you if you have ever thought about hurting yourself?	282	47.16
In the past year, have you gone to an Emergency Room?		
NO	269	50.75
YES	261	49.25
Why did you go to the Emergency Room?		
I do not have a primary care provider	9	1.51
My primary care provider told me to go to the Emergency Room	58	9.70
I was not able to see my primary care provider	58	9.70
It felt like it could not wait	129	21.57
Other	69	11.54
In the Emergency Room, did the doctors and nurses listen carefully to your concerns and symptoms?		
NO	84	32.68
YES	173	67.32
In the Emergency Room, did the doctors and nurses examine you the way you think you should be examined?		
NO	89	34.63
YES	168	65.37

In the Emergency Room, did the doctors and nurses explain to you what they thought about your health or medical condition?		
NO	85	33.20
YES	171	66.80
In the Emergency Room, did the doctor and nurses answer all of your questions?		
NO	104	40.31
YES	154	59.69
Was there a time in the past five years where you needed to see a health care provider, but you were not able to? This could mean you needed to see your doctor, dentist, specialist, therapist, home healthcare, or something else.		
NO	231	43.50
YES	300	56.50
What type of care were you not able to access? Choose all that apply.		
Primary care	153	25.59
Oral/dental health care	154	25.75
Mental/behavioral health care	134	22.41
Substance use care	23	3.85
Emergency care	29	4.85
Urgent care	33	5.52
Home health care/Personal care services	39	6.52
Other	52	8.70
For the times you were not able to access care, what was the reason? Check all that apply.		
The wait was too long	159	26.59
I had no way to get there	68	11.37
It was too expensive or my insurance did not cover it	126	21.07
The provider hung up on me or did not call me back	52	8.70
The provider did not provide the accommodations I needed (e.g., ASL interpretation, accessible medical equipment, allowing me to bring a support person)	33	5.52
The provider did not feel able to meet my needs	54	9.03
I did not know how to find a provider	37	6.19
Other	42	7.02
Are health care providers properly trained and prepared to treat you?		
NO	203	38.09
YES	330	61.91
Do health care providers involve you in decisions about your healthcare?		
NO	121	22.79
YES	410	77.21
Is it difficult to communicate with your health care providers?		
NO	297	56.25
YES	231	43.75
What experiences have you had? Choose all that apply.		
They do not know how to communicate with me	89	14.88

They do not provide accommodations that I need (e.g., captions, interpreters)	40	6.69
They do not speak directly to me	80	13.38
They do not listen to me or believe me	121	20.23
They do not make sure I understand	82	13.71
Other	81	13.55
Do health care providers respect you?		
NO	140	26.77
YES	383	73.23
What experiences have you had? Check all that apply.		
Providers do not listen to me or do not take my concerns seriously.	96	16.05
Providers talk to the people with me and not to me directly	55	9.20
Providers do not consider my needs and experiences	105	17.56
Providers are rude or hostile to me	63	10.54
Other	28	4.68
Think about the spaces where you receive care. For example, clinicians or doctor's offices, waiting rooms, hospital rooms, and other places. Are these spaces accessible and do they feel safe?		
NO	93	17.71
YES	432	82.29
What makes the spaces inaccessible or feel unsafe? Choose all that apply.		
Parking lot does not have appropriate parking	23	3.85
I cannot get into the building	12	2.01
Staff are not trained to handle my body in a safe way	28	4.68
The medical equipment is inaccessible. For example, there are no height-adjustable table, no accessible scale, no accessible MRI or mammogram, or something else	13	2.17
The staff were not trauma informed	43	7.19
Other	47	7.86
How do you typically get health information? Check all that apply.		
Friends and/or family	246	41.14
Medical providers	392	65.55
Residential or group home support staff	99	16.56
Television or internet (e.g., television news, social media, WebMD, Mayo Clinic website)	250	41.81
I do not have access to health information	19	3.18
Other	67	11.20
Have you received primary care services sometime in the past 5 years?		
NO	17	3.23
YES	509	96.77
Have you received mental/behavioral health care services sometime in the past five years?		
NO	163	31.11
YES	361	68.89
Have you received oral/dental health services sometime in the past 5 years?		

NO	108	20.69
YES	414	79.31
Have you received emergency care services sometime within the past 5 years?		
NO	169	32.31
YES	354	67.69
Have you received home health care services sometime in the past 5 years?		
NO	405	77.29
YES	119	22.71
Have you received specialty care services sometime in the past 5 years? For example - occupational therapy, physical therapy, audiology, or something else.		
NO	245	46.76
YES	279	53.24

Provider Education and Cultural Competency

Open-ended responses to “Are providers properly trained and prepared to treat you? If no, what makes you feel that way?” All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • Because they mixed up the chart and diagnosis and a Parent had to straighten it out
<ul style="list-style-type: none"> • I have significant gastro issues. My former NP and gastroenterologist failed to work with me to figure out I am dairy sensitive. I made my own appointment with a specialist, and she figured it out in one meeting. I suffered for 10 years. A gastroenterologist couldn't figure it out????
<ul style="list-style-type: none"> • Too little time and only want to deal with simple issues.
<ul style="list-style-type: none"> • Many providers did not understand my brain disorder.
<ul style="list-style-type: none"> • they keep changing and new ones come in who don't know what they are doing
<ul style="list-style-type: none"> • Often "basic" providers like PHPs are Jack of all trades, master of none. They rely on specialists that have literal years long waits in order to make decisions about critical health issues and rarely do more than a google search on a condition they aren't familiar with. It's extremely rare for them to update themselves on new research and information in their field.
<ul style="list-style-type: none"> • Current medical education programs do not include intellectual and developmental disabilities, including autism as part of the mandatory education academically, nor in their day today clinic experiences. Understanding that someone can have alternative methods of communication, or in fact, have an intellectual disability, and yet still deserve the same preventive healthcare, urgent, healthcare, and acute care that everyone else needs is essential. Secondly, it is important for providers and their entire staff to be able to build in the time to learn how to communicate with someone spend the time necessary for someone to process information to change communication, language, style, and comprehension levels when speaking with an individual. Third providers need to take into account that some people with ADD need a health partner whether that's a staff member a family member or a trusted friend the same way in the geriatric population someone brings a spouse an adult child, or a personal care assistant. An example is the primary care doctor and staff don't inquire about mental health issues that affect daily functioning and emotional status and ability to engage with other people other than offering an SSRI, which have been an effective a primary care provider is unable to make a reasonable referral to a psychiatrist is there a virtually none with experience an ID in the state of Maine.
<ul style="list-style-type: none"> • Because I feel like they don't believe me.
<ul style="list-style-type: none"> • They just don't care, why would they have to care, there's no whistle-blowers in Maine.
<ul style="list-style-type: none"> • Some of them are uncomfortable or not familiar with services
<ul style="list-style-type: none"> • Brain injury is largely invisible. Even with a service dog, I often have to remind practitioners about my disability and its effects.
<ul style="list-style-type: none"> • no way to help transfer out of wheelchair
<ul style="list-style-type: none"> • They don't seem to know a lot about brain injury and understand the before and after life of living with it
<ul style="list-style-type: none"> • Many doctors do not understand my condition and tell me so. Since I have an autonomic condition I need multiple specialists for related problems and conditons it becomes very

<p>difficult when my specialists do not understand my primary condition (POTS) and thus do not give the best recommendations for whatever secondary issues I am seeing them for. I wind up reading a lot of research articles and lectures from medical conferences to inform my medical decisions and what testing/treatment I ask my doctor for. It makes me feel like I have to be my own doctor or medical case worker or what have you.</p>
<ul style="list-style-type: none"> • Dr. Says one thing in the exam room and then doesn't ever follow up
<ul style="list-style-type: none"> • When I contacted my provider about ongoing pain and fatigue, she said it was simply from being a mom and dismissed all of my concerns when my blood work was normal.
<ul style="list-style-type: none"> • I have had some ongoing health concerns and I often have to suggest ideas re: dx , testing, & treatment
<ul style="list-style-type: none"> • I have a neurological condition that required me to go out of state to see the right kind of specialist that understands myoclonus.
<ul style="list-style-type: none"> • I had one doctor ask why I had morphine in my system (when I take codiene which gives a pos morphine)... I had to research this myself. Should a dr. know that?... Also, when I voiced my concerns, she said it was inappropriate.
<ul style="list-style-type: none"> • they speak as if i am a child
<ul style="list-style-type: none"> • Always seeing an FNP or PA when feel should be with an MD due to chronic conditions.
<ul style="list-style-type: none"> • They often talk about me to Guardian/Parent not to me. They also act like they are afraid to touch me in order to give me a real examination. Usually it it in and out in 15 minutes.
<ul style="list-style-type: none"> • Due to my MS and aging issues I am regularly sent home from ER with no support. A am a victim if hospital violence everytime I go to an ER and advocate for myself. I do not feel safe, heard or respected at the ER...leaving me trauma informed everytime pretty much.
<ul style="list-style-type: none"> • They make assumptions about what is going on with me without taking the time to ask. They do not have the time to check things out nor ask the right kinds of questions. They write notes in my health portal that are frequently inaccurate and these notes are then re-written by other doctors at shift change and this causes ineffective treatment. They often assume if you've been there before - that you are having the same issues when that is not always the case.... And a big one: If I go to the ER for a mental health emergency - they ignore and/or refuse to treat the physical issued including severe pain, infection symptoms, - like no reclining chairs with headrest or anyway to elevate legs, inappropriate hospital beds (no head and foot adjustments and very painful to sleep on beds, nor pain medication (that ARE prescribed by PCP and are listed). The separation of body and mind treatments create worsening mental health and physical health problems.
<ul style="list-style-type: none"> • has no clue what to do with deaf people
<ul style="list-style-type: none"> • I can't find a regular PCP so am seeing Drs at a Residency program. It's not adequate, integrated or comprehensive.
<ul style="list-style-type: none"> • Don't seem very educated on psych illnesses Also understanding of obesity is fat-phobic and moral failing view instead of medical view
<ul style="list-style-type: none"> • Can't answer questions
<ul style="list-style-type: none"> • I have a rare condition not well understood and treatment options are limited.
<ul style="list-style-type: none"> • Providers make incorrect assumptions about my disability and my capabilities. They often treat me in an infantilizing way. They sometimes are unable or unwilling to provide assistance with paperwork that they hand me at the office. When I bring my children to see their health care

<p>providers, the providers assume that I am either not their parent or that I am unable to make decisions on my minor children's behalf because of my disability.</p>
<ul style="list-style-type: none"> • I feel like they lack the knowledge on treating someone who is transgender and has mental illnesses. They don't seem to know when to differentiate mental health symptoms with physical symptoms that need to be looked into and not blamed on mental illness without looking into it.
<ul style="list-style-type: none"> • They don't understand autoimmune conditions and their complications well. I often have to explain them and teach them about certain things. Also, sometimes they push antibiotics for wound care instead of just treating a wound or sending you to a specialist.
<ul style="list-style-type: none"> • Lack of accessible communication tools, provider training and poor care
<ul style="list-style-type: none"> • The psychiatric system did not listen about who I was or my individual experiences. Kept giving medication, took over a year and a half for a proper diagnosis.
<ul style="list-style-type: none"> • Not enough physicians take mental health issues seriously. Was told to get a grip when I, due to PTSD, asked for someone else. Had double kidney infection, could not keep even H2O down and given incorrect oral meds to take. Was back in ER less than 8 hours later where I was admitted by a knowledgeable physician
<ul style="list-style-type: none"> • I was referred to a pulmonologist that had no clue what an 8th thoracic vertebrae was. My situation was a total cluster. The ER doctor just dismissed me (I had 2 breaks in my back, a deflated lung, a damaged diaphragm, and a severe traumatic head injury), plus I had to call an ambulance because I couldn't drive myself.
<ul style="list-style-type: none"> • My PCP doesn't really understand my condition, Paralytic Polio. However, on my own, I have found specialists who do understand, but wait times have been long.
<ul style="list-style-type: none"> • Their focus is on data entry for insurance coverage, prescribing drugs that cost \$10K+ a year even with disability Medicare. And, most recently, reduced or nonexistent COVID mitigation practices such as masking. I am at high risk for severe disease and physical therapy practice was surprised when I left their crowded waiting room with no one wearing a mask.
<ul style="list-style-type: none"> • I love my PCP but he admits to not being an expert on multiple sclerosis. I have not been happy with the neurologists I have seen so I prefer to stick with my PCP.
<ul style="list-style-type: none"> • Half the time do not even take my vitals
<ul style="list-style-type: none"> • The support staff are always quick to make judgmental comments, are dismissive, and do not treat with dignity. My PCP tries but she is overworked and under supported in her rural office and all follow up care has to be done elsewhere which is exhausting. Most importantly, the lack of care shown by staff in taking serious COVID mitigations means I have had to delay care (one-way masking, inappropriate masking, no masking.) Additionally, our dental practice closed for six months in 2020 so we had to delay care because of that absolutely reasonable and necessary mitigation effort.
<ul style="list-style-type: none"> • They do not understand my triggers and don't take the time needed to understand my reactions.
<ul style="list-style-type: none"> • Helping me to format my thoughts and feelings in a constructive way that makes sense to them.
<ul style="list-style-type: none"> • A lot of rural doctors don't know how to manage patients with spinal cord injuries. Likely due to no experience.
<ul style="list-style-type: none"> • Many of my conditions aren't discussed at all in most medical schools, and many doctors recommend harmful "treatments" that have been disproven. I often find myself being the one explaining my medical conditions to doctors.

<ul style="list-style-type: none"> • Most know very little about the complex health problems I deal with daily
<ul style="list-style-type: none"> • It seems that only specialists these days have any intimate knowledge of any specific condition or idea. PCPs (or more likely, nurse practitioners) seem like they are only checking very basic things and missing the nuance that doctors understood in the past.
<ul style="list-style-type: none"> • PCP is great! The issue with almost every other is with providing an in-person ASL live interp
<ul style="list-style-type: none"> • They have limited knowledge of alternative options for all aspects of care. They are also prone to bringing in their own preconceived notions and assumptions of what is going on with us (the patient) prior to even meeting with us and examining us.
<ul style="list-style-type: none"> • He doesn't do a complete exam. I think it is because he is uncomfortable doing it with me.
<ul style="list-style-type: none"> • They spend their time looking at their laptop and rarely looking at or talking directly to me. The patient doctor relationship has vastly disintegrated.
<ul style="list-style-type: none"> • I do not feel heard. My concerns are brushed off or dismissed. I get told to go to a specialist who has a months long waiting list, they spend a few minutes with me, only looking at paperwork and say I should see a different specialist. I gave up when my Mainecare didn't get renewed after months of no resolution/diagnosis.
<ul style="list-style-type: none"> • Focus only when I present symptoms. I expect preventive care to happen as opposed to Wellness. Telehealth is useless.
<ul style="list-style-type: none"> • Many do not get training on interacting with autistic clients. As well as mental health and it is common to be treated as a "psych patient" the minute you have a mental health diagnosis in your chart. You then receive inadequate or no care. They also are not trained in how to help other conditions without defaulting to weight- which has been proven to rarely be a health factor in chronic conditions.
<ul style="list-style-type: none"> • Lack of knowledge by many providers of the ins and outside of brain injury.
<ul style="list-style-type: none"> • My child has autism and most medical providers we have encountered have limited knowledge on this disorder unless they specialize in the behavioral health field.
<ul style="list-style-type: none"> • Mental health care really does not exist. Not enough providers or support people or any medical people trained to help with mental health..very sad
<ul style="list-style-type: none"> • They don't seem to be willing to do what it takes physically to examine me.
<ul style="list-style-type: none"> • I was psychotic due to a misdiagnosis from major depressive disorder which was actually bipolar disorder. I was on the max dose of zoloft and put on prednisone because my primary care provider at the time didn't notice. The emergency room doctors laughed at me, mocked me, sent me home with no transportation and dead phone so I had a panic attack outside northern light's emergency room. I remember being heartbroken that I knew I was in danger and not even a hospital would help me. I could have ended my life. I had a nurse say "we have real emergencies to deal with. This is a free country you can go". I had a doctor tell me I was a waste of an emergency bed, and to keep "barking up trees" when I had an ovarian cyst rupture and was psychotic. He gave me sedatives that weren't need to shut me up. They let me go without ever having seen a psychiatrist. I tapered myself off medication incorrectly as I wasn't receiving the help I desperately needed. I have never felt like less of a human. It was disgusting display of humanity and I will never trust health care "Professionals" again.
<ul style="list-style-type: none"> • therapists are not equipped to deal with development disabilities and cognitive disabilities
<ul style="list-style-type: none"> • They know much less than I do about dinner if my illnesses. They dismiss or minimize the symptoms that I report. They chalk physical symptoms up to mental health issues and refuse to

<p>address them except for a referral to mental health. They only treat one system/specialty and are not able to appropriately address the complex, multi system issues I have.</p>
<ul style="list-style-type: none"> • They are not paralyzed like I am so they do not understand the pain or spasms I'm having. It's been 8 years and they still do not know the right treatment or why I continue to have out of control spasms. They can't help me and don't have answers.
<ul style="list-style-type: none"> • #1 this is NOT a 'feeling.' I have multiple rare conditions and long covid. They aren't even trained in long covid so I've been working on ensuring it. Maybe also because i was told that if I didn't start a treatment I would risk my life and I looked at teh provider knowing that if I did start the treatment I would risk my life and then was later backed up by providers educated in diseases and long covid.
<ul style="list-style-type: none"> • They only focus on their "specialties" they don't treat me as a whole person.
<ul style="list-style-type: none"> • patience and distance
<ul style="list-style-type: none"> • I have been mistreated in emergency rooms because I have a mental health diagnosis. My physical symptoms are often ignored, downplayed or belittled because I have a mental health diagnosis.
<ul style="list-style-type: none"> • It's gotten better but I feel they could still use more training when working with adults w/disabilities. Especcially about treating me like everyone elseand I'm an adult
<ul style="list-style-type: none"> • I feel rushed and too many patients crammed in one day. Don't always listen to me. Doctors don't talk to one antoher about treatment and disagree on treatement and leaves me confused
<ul style="list-style-type: none"> • They use "doctor" talk and I cna;t understand them. They talk to me like I was 2 years old and talked in "riddles".
<ul style="list-style-type: none"> • Sometimes may not completely understand about a specific disability and how to treat and talk to
<ul style="list-style-type: none"> • Could use more training and don't feel like the nurses and the doctors always talk to each other. I had health cnocners and couldn;t get in and I ended up having cancer!
<ul style="list-style-type: none"> • I don't have one
<ul style="list-style-type: none"> • They do not understand or provide trauma informed care. They make assumptions and generlizations that do not apply to me about my weight and mental health and don't believe me when I provide accurate information about my body like about A1C Levels, cholesterol , my diet, and lack of blood pressure issues.
<ul style="list-style-type: none"> • Need more training for trauma informed care - seem to just want to get you and get you out without really hearing concerns and trying to fix it
<ul style="list-style-type: none"> • I had a stroke and I have a benign brain tumor so I get MRIs every year. Usually I go to Augusta but one time I went to [redacted] and there were two girls who could not get the needle in my arm for the dye. The two girls were young and lack experience. So I told them to stop. When I talked to the doctor later, I asked if the MRI was good without the dy and they said yes, they still got a good MRI. I don't like [redacted], but it is a lot better than my experience in [redacted]. They usually give me warm blankets during the MRI and they did that in [redacted] too, but they wrapped me up like a burrito so I couldn't move. I did not like that either.
<ul style="list-style-type: none"> • Physically: It is standardly minimalistic, meaning that unless I appear to be dying, they often only provide the bare minimum care. Mentally: I'm treated with professional bias even though the vast majority of mental health issues can only be solved on a case by case basis.
<ul style="list-style-type: none"> • Need more training or such in empathy. Pay more attention to me, not my condition.

<ul style="list-style-type: none"> • I shouldn't have to explain how I feel.
<ul style="list-style-type: none"> • Asked to see doctors about physical stuff (like fast heartbeat; thought it was a heart attack) but was taken to a psych ward
<ul style="list-style-type: none"> • Don't explain things well
<ul style="list-style-type: none"> • Few of the rural pediatricians or dentists or MD's have experience working with Down Syndrome.
<ul style="list-style-type: none"> • I've had to instruct them how to do simple things like measure BP (I don't let them do it electronically) a lot of them can't take a manual BP
<ul style="list-style-type: none"> • I have chronic pain. They always blame/say its my Fibromyalgia. NO IT IS NOT!! I have spinal stenosis, degenerative bone disease etc. They never look into my charts The list goes on.
<ul style="list-style-type: none"> • I have chronic pain along with Fibromyalgia. What they dont look into are my spinal stenosis, degenerative bone disease. Sick and tired of them saying its your fibromyalgia all the time. When it is NOT just fibr
<ul style="list-style-type: none"> • It took seven years to find a doctor who would listen and look past lab results.
<ul style="list-style-type: none"> • It's not that I "feel that way," it's that they've told me that.
<ul style="list-style-type: none"> • Providers continually advised that best treatment was [redacted] but because wait was too long prescribed multiple pharmaceuticals with significant side effects and no impact on overall symptom burden. Providers said to take more medication and to "try harder" while waiting for BHH.
<ul style="list-style-type: none"> • I'm often dismissed due to perception of and assumptions based on mental health condition.
<ul style="list-style-type: none"> • They don't understand my disability
<ul style="list-style-type: none"> • When you have a mental health diagnosis in your chart your physical issues are often ignored. Also you are not treated well or with respect.
<ul style="list-style-type: none"> • I have a colostomy and hernia and chones and the doctors had to send me out of state for medical needs
<ul style="list-style-type: none"> • With all the issues I have had for 14 years. Not once have they been able to give me a good answer for why my body is trying to destroy itself. Whenever I have gone to the doctors for anything all I ever get is everything looks fine your blood work is normal. So I leave and have no answers once again. Frustrating now I don't see a doctor unless I am in really bad shape. Just not worth the time and co-pays sadly.
<ul style="list-style-type: none"> • Even their handicap accessible rooms do not have a way for you to be weighed. Because my arms are so spastic, they don't have a way to properly take my blood pressure without causing me to be bruised
<ul style="list-style-type: none"> • Thye dont' talk to me - just staff need go listen and understand me they try to get me to take meds that I don't want to take
<ul style="list-style-type: none"> • thye could do better and need more training
<ul style="list-style-type: none"> • we have a hard time understanding each other they don't call back and don't tell me things they don't always believe me my cas emanager stopped me from getting counseling
<ul style="list-style-type: none"> • more training
<ul style="list-style-type: none"> • need to learn more about me/disabilities learn how to communicate with me better learn hoe to treat me better

<ul style="list-style-type: none"> • They are not trans competent, they discriminate based on my mental health conditions and memory issues
<ul style="list-style-type: none"> • I have had multiple medical professionals look me in the face and tell me they don't know how to help me. Doctors don't listen to me when I tell them I am dealing with a certain issue, they will try to diagnose me with something else.
<ul style="list-style-type: none"> • There's a lot of misinformation about my conditions out there and it does carry over into the medical/mental health field and they were not properly educated on my conditions, i was constantly having to correct them or explain things about my disorders that i would expect a healthcare provider to know already.
<ul style="list-style-type: none"> • They don't seem trauma informed or I needed a higher level of care then they were trained for.
<ul style="list-style-type: none"> • Disgusted with PCP
<ul style="list-style-type: none"> • They don'y understand PTSD and how it affects/effects people in a clinical setting.
<ul style="list-style-type: none"> • Don't tell me what is going on. Have a blood disease but no one will tell you what it is.
<ul style="list-style-type: none"> • Not the eye doctor
<ul style="list-style-type: none"> • Not my psychiatrist - not able to meet my needs
<ul style="list-style-type: none"> • When the doctor asked questions, they assumed the answers. They didn't try to get more information and rushed through it. They just "threw meds at the problem" and did not explore other options.
<ul style="list-style-type: none"> • big barrier is communication
<ul style="list-style-type: none"> • communicatin could be better
<ul style="list-style-type: none"> • somtimes they "skip a page" and I don't understand or they don't explain things, espeically new people. They don't always understand my communicatin needs. Need more training on getting to know people better & get people's info
<ul style="list-style-type: none"> • There isn't an ENT with the qualifications to help me.
<ul style="list-style-type: none"> • They don't talk with me they talk with everyone else about me.
<ul style="list-style-type: none"> • Sometimes I'm not taken seriously, since it's all "in my head," and often I'm told it's growing pains. I didn't realize I was being abused because nobody asked me about my home life except to say "things are good, right?"
<ul style="list-style-type: none"> • I feel like they don't listen to me or believe I am in pain
<ul style="list-style-type: none"> • I don't get the care I need.
<ul style="list-style-type: none"> • I feel as though most healthcare workers, especially in the age of covid are trying to get patients in and out as quickly as they can
<ul style="list-style-type: none"> • Not being listened to about my symptoms and concerns due to their biases.
<ul style="list-style-type: none"> • I'm answering all my questions for my PCP and not my specialists. My PCP not only had no idea of how to diagnose me but also no idea of how to treat my symptoms. Now that I have a specialist she doesn't even talk to me about my disease even though it's important in my regular care.
<ul style="list-style-type: none"> • I have had bad expiriences with doctors' knowledge in queer health
<ul style="list-style-type: none"> • I feel like there are many situations where a healthcare provider is so wonderful to me, but there are so many more times that I have to explain so clearly what my needs are and just hope they're met.
<ul style="list-style-type: none"> • lack of practial knowledge in patient care

<ul style="list-style-type: none"> Autism is a huge barrier in receiving care. For example I have anorexia and have left school twice for inpatient treatment. While I was there, both times, I was not accommodated, insurance cut me, and I ended up losing weight. I've reached a point where health providers' ignorance has actually worsened my state so I just try my best to eat and keep myself alive on my own. Similarly I have PTSD and health providers' lack of trauma-informed care is a barrier.
<ul style="list-style-type: none"> Many professionals are not prepared for neurodivergent clients and often do not understand common autistic problems nor do many offer realistic changes for the poor. Often the provider will offer an idea that would help however they wouldn't help me understand what the cost or how I would fund it if insurance denied me.
<ul style="list-style-type: none"> Many are not well equipped for neurodivergent clients and will oppose their care if the client challenges their authority and ethics (such as denying someone surgery for a clear issue bc of believing they may not have money, despite being bound by ethics to help all)
<ul style="list-style-type: none"> My primary care is good. We have a long, established relationship. Other specialists you have to explain how to communicate to someone with hearing loss.
<ul style="list-style-type: none"> I think they don't have a full understanding of the medications I take and their side effects. They don't have an understanding of the degree to which my mental health challenges impact my life or the resources to help. They assume other providers are meeting my needs.
<ul style="list-style-type: none"> Providers change too often...when you finally get comfortable with a Dr..they leave and you have to start over with someone else..which makes you not want to go
<ul style="list-style-type: none"> No idea how to be personal. Nurse had a business attitude - no patient interest. "Just get on a scale for weight." No nice greeting. New doctor is 35 years old, seems to have no idea about anxiety, etc. Non-personal attitude, no interest in my losing my past doctor. 1st meeting with new PCP was a real disgrace and embarrassment for me. Can't switch as no doctor is taking new patients.
<ul style="list-style-type: none"> mental health makes most health providers treat me like trash
<ul style="list-style-type: none"> Because of the assessment in the ED I didn't get the attention that I needed. I fired just about everybody at that facility, and found drs at another location. Just to be clear: I finally discovered (purely by chance) that I had a significant break in my back, head trauma/concussion, a deflated lung, damage to my diaphragm. All this was "discovered" piece meal and dismissed. I now have a new team at a different facility.
<ul style="list-style-type: none"> I am still trying to find provider who has experience with TBI's
<ul style="list-style-type: none"> Most of them, especially my primary doctor at the moment, seem afraid of my disability and chronic health issues.
<ul style="list-style-type: none"> they are now, but it took a while for them to understand me and for me to feel comfortable talking with them.
<ul style="list-style-type: none"> Depends on where I go; lack of empathy; don't care about people's pain levels
<ul style="list-style-type: none"> not well equipped to deal with mental health disabilities, especially PCP
<ul style="list-style-type: none"> I have very rare diseases and tumors and a specialist in these areas are far and few between.
<ul style="list-style-type: none"> Need education about deaf-blind people
<ul style="list-style-type: none"> poor quality of care - feel like some of them don't care they hurt me and didn't care
<ul style="list-style-type: none"> Need better positive bedside manner feel like a burden feel like I'm being rushed
<ul style="list-style-type: none"> need to work with people in their specific needs talk to my daughter more than me

<ul style="list-style-type: none"> • I feel they are prepared but I don't know when. I want them to tell me when.
<ul style="list-style-type: none"> • Providers do not believe or listen to me. They utilize restraint too quickly. They do not include me in planning.
<ul style="list-style-type: none"> • They only saw me quickly.
<ul style="list-style-type: none"> • could do better at taking the time for better communication
<ul style="list-style-type: none"> • not sure - just better
<ul style="list-style-type: none"> • sometimes they rush through
<ul style="list-style-type: none"> • I am feeling hurried because of the time peramiters.
<ul style="list-style-type: none"> • I feel like some of my providers are able to assist and willing to assist but ultimately they don't have enough experience working with individuals with spinal cord injuries
<ul style="list-style-type: none"> • need more understanding about my specific needs/treatments need to stop using languag/terms I don't understand
<ul style="list-style-type: none"> • I have inner knowledge
<ul style="list-style-type: none"> • Sometimes. They are so limited by the rules and guidelines of the State and others, that it is sometimes impossible for them to accomodate their patients with the help they need.
<ul style="list-style-type: none"> • It depends on what their specialty is buy my main doctor does not know mental health stuff that well so I keep my mental health matters for my mental health providers at Acadia. I wish them to coordinate, so I sign released for them to talk to each other about me.
<ul style="list-style-type: none"> • I feel like a lot of providers are there for a paycheck. They don't listen to what I need, they just kept pushing meds at me.
<ul style="list-style-type: none"> • Because of what I need. What I'm dealing with, the injuries I have sustained.
<ul style="list-style-type: none"> • The staf here at [redacted] isn't always agreeable and caring towards me in particular at all! I have Bipolar Disorder Type II which means I have a mostly depressive illness. My speech is rampant at times because of my disability too.
<ul style="list-style-type: none"> • [Redacted] views me as a woman who is bipolar.
<ul style="list-style-type: none"> • Some do not treat those with disabilities like they are valued equal to normal people. They do not look into options for scans to rule out things. They assume the patient will give them all the history, but forget that some clients cannot tell all, sense all, feel all that could be happening. Some have had conditions go unfound due to delay into looking deeper.
<ul style="list-style-type: none"> • Lack of understanding about mental illness and multiple sclerosis
<ul style="list-style-type: none"> • PCP didn't pursue medical treatment or exams for diabetes despite having a family history of diabetes and showing symptoms. It took going to the ER to get the exams done and to be diagnosed with diabetes
<ul style="list-style-type: none"> • [Redacted] said "I don't know what a pro-drug is, I just use my DSM-V for everything."
<ul style="list-style-type: none"> • CNAs, NPs, RNs, have communication barriers; push medications even if I don't want them. they prioritize medication over other preferences of treatment
<ul style="list-style-type: none"> • In Maine, health care providers do not have as much experience with communities of color, immigrants, and underrepresented minority groups. This can lead to misdiagnosis because there is no knowledge of important cultural practices (e.g. lack of eye contact in interpreted as a mental condition or there is little understanding of the way that non-white bodies grow and develop.

<ul style="list-style-type: none"> • -Knowledge base lacks when people rely too heavily on automation. Didn't know how to do manual blood pressure. - Passing knowledge from those medical professionals - who have been here for years down to the newbies, 15 minutes per patient may not be adequate
<ul style="list-style-type: none"> • They understand things like "diabetes" but don't understand my need to self harm and hating myself.
<ul style="list-style-type: none"> • My PCP can't weigh me. They don't have a wheelchair scale. The electric blood pressure cuff doesn't work well with my spasms. I've been seeing this doctor for 17 years. My specialist has a wheelchair scale. That's how I get weighed and they tell my PCP.
<ul style="list-style-type: none"> • Mostly yes, but missing empathy.
<ul style="list-style-type: none"> • My new PCP scrapped my skin in two places for skin cancer leaving me very scared. NOT for her to do, should send me to a specialist.
<ul style="list-style-type: none"> • For the most part, yes, although recent experiences made me feel uncomfortable.
<ul style="list-style-type: none"> • they don't understand that blindness doesn't automatically limit the ability to do certain things. Most don't even know how to do sighted guide. The front desk staff who assist with filling out forms want to do it in the waiting area surrounded by other patients who can easily hear the whole thing.
<ul style="list-style-type: none"> • They referral to a place without explaining what they provided and I ended up stuck with expenses that does not fit my expectation. I wish my referral person explain more of what they actually do in their practice.
<ul style="list-style-type: none"> • Ok, after first coronavirus shot with ASL, then I requested ASL for second shot, never happened, then again third one, no ASL, the nurse was not friendly. I was damn innocent. The nurse brought vrs with terrible Wi-Fi. Of course, I reported on vrs "öÿ'ž".
<ul style="list-style-type: none"> • Today I am calm because the sunny weather.
<ul style="list-style-type: none"> • They were not efficient with the VRI provided
<ul style="list-style-type: none"> • No, I had to ask live ASL interpreter, but changed to VRI without my knowledge
<ul style="list-style-type: none"> • No one spends time in knowing me

Open-ended responses to "Do healthcare providers respect you? If no, what experiences have you had?" All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • Not all providers disrespect me but older white male doctors certainly do it at a higher frequency
<ul style="list-style-type: none"> • Provider tried to provide parenting advice when I was very ill with COVID. I was the patient, not my child.
<ul style="list-style-type: none"> • Providers have made jokes about disability symptoms
<ul style="list-style-type: none"> • Not properly trained people in mental health care
<ul style="list-style-type: none"> • Emergency room providers made assumptions based on my mental health diagnosis and ignored my physical symptoms.
<ul style="list-style-type: none"> • Denied knee surgery because of weight. I experienced a lack of understanding of trauma informed care including Assault by police officers who were called to the ER because I didn't give the nurses my keys. There was absolutely no aggression on my part and had communicated that I was experiencing trauma related dissociation for the reason for going to the ER.

<ul style="list-style-type: none"> • What Family Practice, have their patients, swab their own Vagina for a yeast infection, put the swab on a paper towel & not in a tube?? I sat in the room to see how long it would take for them to come and put the swab in the tube. I waited 5-7 minutes. And, left the room, as I was asked to after I swabbed my va jay jay. I am still quite disturbed by this.
<ul style="list-style-type: none"> • it was assumed that I was drug seeking when in fact I had a fractured neck! I had to go to two different doctors to get a diagnosis.
<ul style="list-style-type: none"> • I have had healthcare providers ignore my physical needs. I have had doctors mock me as well
<ul style="list-style-type: none"> • They have no idea what it's like to be disabled and poor, and can't seem to even fathom the obstacles I face
<ul style="list-style-type: none"> • didn't try hard to find problem
<ul style="list-style-type: none"> • Providers make hasty assumptions about me in all directions. I am extremely intellectually capable but have trouble with auditory processing and emotional regulation so sometimes it takes a while for me to understand things when people assume I should get things quicker. Alternatively people see "autism" and assume I am intellectually disabled, which I am not. I am always over- or under-estimated. Just speak to me directly and I'll let you know where I am at and what I need!
<ul style="list-style-type: none"> • some are better than others!

Open-ended responses to “Is there anything else you would like to share about your experiences with the healthcare system?” that relate to provider education and/or cultural competency. All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • I have found that in the ED the providers see that I have received psychiatric care and I am treated much differently I think than others. They think physical complaints are related to mental illness.
<ul style="list-style-type: none"> • The constant dismissal of my concerns as if I am not the one living in this body is incredibly frustrating. I want to be treated as at least somewhat of an expert on my experiences. I deserve to have my concern matched as well, if I am very worried about something and am met with noncommittal response that's stressful and often disrespectful in my opinion. I want to be treated as though I understand what is going on.
<ul style="list-style-type: none"> • We need to have more accessible ready for deaf patients with no stress involved like in staff interpreter (s)at hospitals . Drs office, hospitals staff need trainings on deaf etc more often due to high volume of staff turnovers.
<ul style="list-style-type: none"> • [Redacted] Is very knowledgeable, patient, and responsive. I have a rare airway condition and he said we would find a way to treat my apnea, considering my: 1. Airway sensitivity 2. Violent night terrors
<ul style="list-style-type: none"> • Above questions are misleading. Very happy with current dental, fired last one. Some mental health professionals have been good some poor. Etc. My rankings do not necessarily refer to current, but any I have received over past 5 years.
<ul style="list-style-type: none"> • I sometimes feel like my issues are not getting addressed enough just because their test comes back negative. They do not try to peruse why then do I feel like this?? Instead I am made to feel like it is in my head until I ask them for something else. Then I feel like I am diagnosis searching Instead of just trying to figure out what is making me feel like this? Like now I am going to ask for allergy testing.

<ul style="list-style-type: none"> • While my current medical team is amazing, it took me years to find providers that wouldnt ignore my health problems and brush them off as mental health. I feel a lot of people with mental health problems get ignored by their medical team when it comes to physical illnesses and physical symptoms.
<ul style="list-style-type: none"> • Specialists need to take a more "whole body" approach and not just narrow in on their area. For instance the thyroid can effect other systems of the body and the endocrinologist needs to be able to focus on more than just the endocrine system when it effects more than that. But they tend to only go as far as their specialty area.
<ul style="list-style-type: none"> • No facility has a public toilet that is accessible to me! Even the hospitals. All I need is a modern version of an outhouse seat (a smooth wide hole in a board). This is what I use at home. See www.handicaptipsfordailylife.net
<ul style="list-style-type: none"> • Medical professionals MUST become more trauma informed and social workers must be available for us to talk with!!!
<ul style="list-style-type: none"> • I am grateful every day I went to [redacted]. They finally diagnosed me with catatonia as I turned 18. I suffered for a year and a half with the wrong diagnoses.
<ul style="list-style-type: none"> • Health care needs to be healthy care. Not enough providers or knowledgeable staff to be able to help. Stop cookie cutter medicine. Not all patients are the same. All health care Staff need to be trained for mental health care to better understand mental health issues in patients
<ul style="list-style-type: none"> • Mental health services are hard to access. Once I receive the services they are sometimes very helpful and sometimes not very helpful. I have an extremely hard time opening up to providers, partly because I'm not sure what the result of talking about "serious" issues like, for example, suicidal thoughts will be.
<ul style="list-style-type: none"> • The health care system treats mentally ill adults like meaningless scum.
<ul style="list-style-type: none"> • I've had 6 heart attacks in my lifetime and no medical doctor that takes me seriously. No RX prescription medications were ever prescribed for the attacks and no medications prescribed for my chronic A-fib that I suffer from. Also, my penis and testicles were found inside my pelvic cavity during a routine ultra sound and still no referral to a surgeon who can surgically make my male reproductive normal (on the outside) like any normal man.
<ul style="list-style-type: none"> • I've been blessed to have competent providers who make me feel good and meet my needs. I feel like oral dental care is to expensive and hard to access if you do not have proper insurance.
<ul style="list-style-type: none"> • Doctors sometimes do not respect my questions and answer them impatiently without verifying that they actually answered the question I had. The tone is "I'm the expert so what I already said is relevant and if you are asking about something else, it is irrelevant/wasting my time."
<ul style="list-style-type: none"> • Organizing my care, scheduling appointments, following up with doctors about things they said they would do, and advocating for my needs with doctors takes a huge toll on my mental and physical health. It feels like a full time job, and it's very frustrating and stressful.
<ul style="list-style-type: none"> • They do not care about chronically ill and/or medically complex individuals. They want quick and easy answers.
<ul style="list-style-type: none"> • There is a large knowledge gap for brain injury- PCP or neurologists. I have experienced MULTIPLE providers that made unsafe medication recommendations, didn't return phone calls/emails, or simply said they couldn't help me.
<ul style="list-style-type: none"> • They feel that they do understand what they're going through.
<ul style="list-style-type: none"> • I am grateful every day I went to [redacted]. They finally diagnosed me with catatonia as I turned 18. I suffered for a year and a half with the wrong diagnoses.
<ul style="list-style-type: none"> • Was medically abused as a child repeatedly and avoided medical system for several years to avoid further harm. It took a lot of trial and error to find providers who would not perpetuate

<p>harm and would actually listen to me. Particularly as a non-binary disabled person, this was doubly difficult to find inclusive practices. Additionally, weight stigma and anti-fat bias made it challenging to seek treatment for eating disorders, which were often exacerbated by medical providers. Several times medical providers affirmed disordered exercise and eating and penalized me when I stopped those behaviors.</p>
<ul style="list-style-type: none"> • I am encouraged to take way too many medications. I am encouraged to undergo way too many tests and scans that ultimately do not change course of treatment. I am always secondary to the computer screen from check in to time with provider to check out.
<ul style="list-style-type: none"> • Healthcare in Maine is shaped by a culture steeped in white Puritanical patriarchy. It's very much a culture of "get outside, drink some water" and bootstraps. There's a constant barrier to getting care when providers lack even basic information, and worse, curiosity, about their client's condition(s). The cultural expectation here remains one of "we don't talk about things that make folks uncomfortable." And if you're not white, getting appropriate and compassionate and inquisitive care here must be like navigating hell. There is a dearth of trauma informed care and care is stingy and withholding to anyone lacking economic resources. Maine overall, from its lack of infrastructure, its inherent ruralness, and its aging architecture, is inaccessible to most of its aging and poor population. Maine, frankly, for all its "the way life should be", is hostile to anyone who doesn't embody the LL Bean model of health.
<ul style="list-style-type: none"> • A doctor insisting that they're 45min college lecture makes them more qualified than me, with 40 years of experience with a disease, is unacceptable. Decades of medical gaslighting/abuse had led to severe medical trauma. Even a simple PCP appt sends me into a tailspin due to the trauma and fear it will happen again.
<ul style="list-style-type: none"> • it is broken. There is no room for a doctor to spend an adequate amount of time with you due to the hierarchy in which they work. We as patients feel like a number, or even a fraction.
<ul style="list-style-type: none"> • I have had difficulty with providers both for physical an mental health needs not having knowledge about alternative therapies and when the do the do not know how I could access what they are suggesting unless I can pay for them out of my pocket which I am unable to afford. So , I have been forced into more invasive treatments for conditions such as ECT, injections, surgeries, and medications when alternative approaches have been proven to be more effective and less invasive. Such as bio- feedback, hormone therapy for a hormonal imbalance, massage therapy, acupuncture for pain management, and meditation classes. None of these things are accessible to the poor and these services are cheaper, preventative, and work better to support a sustainable wellness than more invasive options that are paid for by mainecare.
<ul style="list-style-type: none"> • Stop treating homeless people like sub-standard people. I didn't decide to be homeless.
<ul style="list-style-type: none"> • medications are hard to discuss or to scribe some pain or mental needs
<ul style="list-style-type: none"> • No. I hate doctors.
<ul style="list-style-type: none"> • Wish felt more care or love or supported by doctors, staff, guardians, and peers; wish I had more friends, to be safe.
<ul style="list-style-type: none"> • Not enough doctors; have to work with nurse practitioners. They are too by-the-book and don't listen to what works for you in the past.
<ul style="list-style-type: none"> • I would not recommend anyone go there because staff need more training!
<ul style="list-style-type: none"> • I don't like the fact that I have to fight so hard to get into a mental health hospital. I've been turned away several times and it's not right.
<ul style="list-style-type: none"> • Health care providers, in general, seem to have very little training on how to assist people who are blind...I'm often treated like anelderly person who has lost thier sight later in life rather than

<p>someone who has lived with blindness for years. The few times I've been to the emergency room, my cane is folded up and since I don't look blind, i have to explain to all the different people who come into the room that I am blind. This also happens when i have to undergo some type of testing.</p>
<ul style="list-style-type: none"> • It is not safe to go to an emergency room by yourself. It is best to go with someone you trust and have them stay with you.
<ul style="list-style-type: none"> • If my health care provider didn't respect me, I would go somewhere else. I really like my PCP. They are right in my neighborhood, which is a great thing because I don't drive. They listen well as well. Mental health/med. management/some pharmaceutical stuff: not so good. My provider is far away so I need to rely on [redacted] to get there and back. At least one local pharmacy is so strict about when people with prescriptions for controlled substances can get them filled that I have had to go without medicine because of a lack of public transportation on Sundays.
<ul style="list-style-type: none"> • I think they are doing a good job.
<ul style="list-style-type: none"> • My health care provier is funny and gives lots of information
<ul style="list-style-type: none"> • No, I am happy with my doctor.
<ul style="list-style-type: none"> • I see a muscle doctor for my muscles and a pediatricist. I wish my muscle doctor did primary care! They are the best. I know when we were dealing with COVID, they should let my caregiver assist me. I had to speak with my PCP and he talked to [redacted] and they apologized and were good in the future, but I should not have had to do that. They should have known better in the first place.
<ul style="list-style-type: none"> • When I had mental health episode, I was brought to [redacted], where they didn't know me. I was kept in the emergency room and released either too early or simply monitored. I needed to go in-patient at [redacted]. I needed medications changed and observed. I finally went in-patient at [redacted] in the next couple of years. Had I been brought by [redacted] to the place sooner, as I said in my crisis plan, I would have had fewer hospital/emergency room visits.
<ul style="list-style-type: none"> • I am upset about the psych rooms in hospitals and the staff. They make you feel like an animal in a cage and hygiene doesn't seem important.
<ul style="list-style-type: none"> • [Redacted] does not see me in person. He does not ask enough questions. My PCP does not ask me if I'm eating, how I am getting my food.
<ul style="list-style-type: none"> • My doctor (PCP) in [redacted] is at [redacted]. He is neglected to gain access to speak directly to him personally about my brother's interests concerning me at this group home! Guardianship, he didn't want to grant to me! I don't need a payee either!
<ul style="list-style-type: none"> • I would like [redacted] to listen to my childhood trauma.
<ul style="list-style-type: none"> • We often see specialists that do not take the time to address ailments, often seeming to treat the person as if because they have a developmental disability they do not deserve all the time they should get. Like they are not equal in value of care. We have had ICU doctors reluctant to take all avenues to save a person because they implied it was not worth it. Regardless of the expected outcome, all avenues that are basic should at least be tried.
<ul style="list-style-type: none"> • All my professional doctors, therapists, and social workers have always been prompt, well prepared, and helpful to all my needs: mental, physical, and emotional. I appreciate Maine very much for all they have done for my mental health, physical health, and emotional health. Please give everyone my thanks. I have almost everything I need thanks to Maine.
<ul style="list-style-type: none"> • Receive MS diagnosis with good insurance then switched to MaineCare/MediCare. Feld care really changed for the worse after the switch. Many providers didnt' seem to care about quality of life or have empathy for diagnoses.

<ul style="list-style-type: none"> • I like when they interact w/ the patient to diagnosis. For diabetes they go over the weight and A1C. Never feels judged about diabetes.
<ul style="list-style-type: none"> • Entered ER they dismissed concerns of frontal lobe injury.
<ul style="list-style-type: none"> • My urologist is very easy to speak to and helpful but I find my primary care service providers to be less educated on my needs due to my disability
<ul style="list-style-type: none"> • I've noticed a difference in how I'm treated by docs and etc. since I've stopped talknig about any current or past mental health stuff, and since I've requested labels to be taken off records. I only go to PCP and gynocologist when I have to. I interact as little as possible with the "health" care system. And my (not recent) experience and experience from working in EDs, I've seen how a patient is treated differently depending on why the person is there (in the ED).
<ul style="list-style-type: none"> • I am treated with a lot of respect each time.
<ul style="list-style-type: none"> • Sept - went to primary care in fort kent; didn't feel safe sharing personal info, scared of being committed
<ul style="list-style-type: none"> • no empathy at er primary care is amazing therapist is amazing
<ul style="list-style-type: none"> • there could be improvement more trauma-informed staff @ group homes and doctor's offices
<ul style="list-style-type: none"> • don't feel like i am seeing the person who has the best knowledge about my condition
<ul style="list-style-type: none"> • Re: Q12 on paper version: The people at this group home bought a wheelchair for me but won't let me use it. Q29. I do not know how hold I am but not 61 years old Q38. Someone won't let me know my income I was "diagnosed" as a "paranoid schizophrenic" after a 6 week long drugging and gang rapes without having an exam. The "diagnosis" was called into [redacted] before I even arrived there. First time I was ever put in any psych hospital. This keeps happening to me everywhere I go from ME to Washington, D.C. and from Mass. to the State of Washington. Someone keeps badmouthing me.
<ul style="list-style-type: none"> • I've been advocating since I was 12 and am mid-40's. I don't have enough spoons and this survey is too long for spoonies who have limited energy. I'm surprised this was not considered.
<ul style="list-style-type: none"> • I have experienced many forms of care over the last 5 years but the lack of training and judgements people made about me in emergency rooms resulted in my physical issue being totally ignored while I had a focus being made towards a false belief I was suicidal because the pain I was experiencing made me teary. My physical pain not only was ignored by emergency room notes but the false belief I was suicidal notes followed me so when I sought care in the next emergency room, again my physical issue was ignored and the focus was put on a mental health concern. I had to go to a 3rd emergency room who finally ran the correct test on me physically to discover the true issue I had that needed to be fixed. The events of those visits cost me over \$7500.00 because I had no health insurance at the time. I am still paying because some admitting nurse made a false judgement based about me because my chart had a diagnosis of a mental health issue and I was teary upon arrival in pain from my stomach issue.
<ul style="list-style-type: none"> • fellowship, together, proper care, due care 100 percent
<ul style="list-style-type: none"> • I see a psychiatrist [redacted] for medication management for schizophrenia. He has help me a lot.
<ul style="list-style-type: none"> • Before finding our primary care doctor two years ago, most doctors were completely useless and actually make things worse.
<ul style="list-style-type: none"> • There needs to be alternative testing available for diagnosing Alzheimer's/Dementia for people with developmental Disorder (Down Syndrome) and are non-verbal. The testing methods are impossible to complete for this population.
<ul style="list-style-type: none"> • I've been blessed with the best care I think I can get. I've been very happy with all my doctors, nurses, and all staff. I'm so grateful to have these people in my life. When my PCP moved from a

<p>Primary care facility in my town even though I'm legally blind and have to get rides I chose to follow her even given I'm legally blind to a much further facility out than I am, and to be seen at a "clinic" because she listens completely to me and we discuss everything together. Dr. Amanda Powell is awesome! I would highly recommend her to anyone. I'm very grateful for her and her staff and would highly recommend her to anyone I know.</p>
<ul style="list-style-type: none"> • [Redacted] did a horrendous job upon my entry with a physical issue. The nurse assumed I was having a mental health issue because I was crying and in pain. I was labeled suicidal despite never having been suicidal in my life. I did not get the care I needed
<ul style="list-style-type: none"> • I'm astonished by how good this system is sometimes, and then they throw me into a "play later" kind of situation. I need the demands that I need.
<ul style="list-style-type: none"> • I have had good experiences.
<ul style="list-style-type: none"> • Just wish they would be more educated in Autoimmune diseases and Tick borne illnesses
<ul style="list-style-type: none"> • I'm my own guardian and I don't bring stadd with me. Overall they listen to me and talk to me like an adult. After my day surgery staff sent a card that everyone signed - I felt appreciated.
<ul style="list-style-type: none"> • They could do better for sure, especailly working with people with disabilities
<ul style="list-style-type: none"> • My dentist hurt me and didn't seem to care
<ul style="list-style-type: none"> • they could do better and need more training
<ul style="list-style-type: none"> • I like them but needs improvement
<ul style="list-style-type: none"> • Most doctors are ableist, transphobic, homophobic, racist and/or saneist towards me and many people I know.
<ul style="list-style-type: none"> • Mental health professionals don't understand transgender identities. Multiple times I have been referred to as an it by doctors in the ER when I was in a mental health crisis.
<ul style="list-style-type: none"> • I am not one the best patients in the world but my primary care doctors and physical therapists have been a lot of help.most of my mental health care has been through [redacted], and the change over is just too much. I get very overwhelmed by the amount of times I have had to describe my life and what I have had to deal to a new person, it sets my mental health back even further. Most of the doctors at [redacted] are great, but I have felt a few doctors didn't care about what was going on. I felt neglected and had to wait a very long time to get help. I have had to tell a couple if they weren't going to help me then sign me out and give me the slip of paper that need for a taxi home. And twice in my life I have had a hospital doctor not give me the correct x-ray, or refused to give me telling me my ankle wasn't broken just sprained. My primary care dog was livid, and my ankle never healed correctly.
<ul style="list-style-type: none"> • I was turned away many times because of being transgender until I found the right doctor
<ul style="list-style-type: none"> • I am thankful and they put time and effort to help me. They are doing it for my best interest.
<ul style="list-style-type: none"> • They look out for the rich people. When they see me coming, it's all down hill.
<ul style="list-style-type: none"> • Very unhappy with health care system in Maine. I am treated differently because of my disability. I was kicked out of [redacted]. I feel no better after 22 years in Maine. They shouldn't discriminate because I am mentally and physically disabled.
<ul style="list-style-type: none"> • Have a lot of confidence in it.
<ul style="list-style-type: none"> • Although I was happy overall with the care I received, I feel my diagnosis of substance use disorder is still used as a label and I am viewed through that lens first rather than a person. It determines certain treatments offered. I've also seen the phrase "patient is an addict" on a medical/dental chart before. That bothers me and stuck with me.
<ul style="list-style-type: none"> • [Redacted] used racial comments at one of my appointments.

<ul style="list-style-type: none"> As a fat person, I routinely feel like I have to convince doctors - of all kinds (dentists, etc) that my pain is real and not always related to my weight. And sometimes, doctors make assumptions about me because I have PTSD - also that I might be making things up or my pain isn't real. It's very frustrating and I have to advocate for myself every time I'm in a medical professional's office to be taken seriously.
<ul style="list-style-type: none"> I am fat. I eat healthily, I do moderate exercise, yet anytime I complain about symptoms or speak about my concerns, health care providers advise me to lose weight.
<ul style="list-style-type: none"> Have found very few providers who are even have baseline understanding of the difference in cognition between neurotypical and autistic clients.
<ul style="list-style-type: none"> yearly wellness exam is poorly designed. no unclothed thorough exam, and no labs or tests prior to visit so results can be discussed. obviously designed to make money for insurance companies. also great need for urgent care clinics in rural areas to stop over use of E.R.s.
<ul style="list-style-type: none"> I was diagnosed with Hashimoto disease and also was diagnosed with Sensory integration disfunction as a child which I have mostly grown out of but still have many autistic tendencies and was told I could definitely be autistic but my mom didn't want to get the studies fully done because we were doing just fine with me having sensory and didn't need to have full label for my few issues. I have just expressed I on on the spectrum since when I was diagnosed with Sensory it was part of the autism spectrum in the year 2001 and my doctor made sure to mention that to my mother. I don't obviously know for sure all of it but I just believe I am a high function person with autistic tendencies. This was the first big medical issue to happen to me I am of course okay and doing a lot better but trying to adjust and not knowing what was wrong and all the blood testing was definitely a very hard time for me. I do live in NH but I have been living at [redacted] since August of this year and so I have needed to get medical care in Maine it was very sufficient which is why I still felt that my feedback could still be beneficial for your research. Thank you for listening to my story and if you have any questions feel free to email me at [redacted].
<ul style="list-style-type: none"> Super not trauma informed! Very trauma inducing! Especially emergency settings.
<ul style="list-style-type: none"> My provider is trauma-informed, and I am very lucky in that. If they weren't, it would be much less accessible.
<ul style="list-style-type: none"> My current primary care physician is amazing, she is respectful and kind and a good communicator. I feel comfortable with her. In the past however that was not the case. Before I saw her I saw a few other providers and some specialist who were pretty awful. One ignored my complaints about my hearing and said I had "teenaged selective hearing". Turns out I have hearing loss and needed hearing aids. I stopped seeing that doctor after that. The doctor I saw after her was aware of some trauma I had that made certain examinations difficult for me and was not as empathetic about it as I would have liked. She made me feel like I was making a poor choice choosing not to do certain screenings due to my PTSD and very recent trauma. (My current doctor is very different about that subject and has encouraged me not to do anything I feel would be damaging to me mental health wise and not to go through with procedures like that unless I feel ready to do so). The specialist who was awful I saw was for "womens health" and she just did not listen to me at all. She ignored everything I said and just made me feel uncomfortable. It felt like she didn't want to hear about my symptoms. I never saw her again and when I told my current primary (the good one) about her and the experience she apologized and asked if I wanted to be refered somewhere else. I ended up just choosing not to see anyone after that and tried to deal with the issue with just my primary and not a specialist since she was the only one I was comfortable with and actually listened to me. I feel very lucky

that my primary is so wonderful because outside of her I don't feel seen or cared for all that much.

- I'm almost 27 & have never been asked about getting a mammogram before. I've not asked myself because I'm scared
- I've had interactions with 2 different facilities, so the questions are a little difficult to answer. I can't say that I had any positive treatment at the 1st one; the 2nd one was so much better! I truly believe I'd be at a much better place had I been treated appropriately at the 1st ED. Instead I was dismissed and sent home. I'm still dealing with the aftermath.
- have had fine experiences

Structural and Systemic Barriers to Care

Open-ended responses to “Is there anything else you would like to share about your experiences with the healthcare system?” that relate to systemic barriers. All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • Losing one's license due to a medical cause even though no accidents. Statutes are punitive.
<ul style="list-style-type: none"> • I think it is very important to expand sufficient health care programs for everyone, regardless of income, medical background, and/or other factors such as race, sex, religion, etc. It is very disappointing to see the domino effect of not providing safe and fair working conditions to providers (as well as other medical staff) while CEOs and hospital admin made record profits during the height of COVID. The cascading effect translates to tangible diminishment in care throughout Maine. Many providers have left or are leaving Maine (high provider turnover), medical professionals offer insufficient care due to disturbingly high patient-to-provider case loads that increase stress across the board, and then add how already marginalized groups receive a lesser quality of care on top of that.
<ul style="list-style-type: none"> • I think the health care system is severely lacking. Doctors do not look at you; you don't undress so they can check for skin tags, etc. I believe this current health care system is awful, and the primary reason is insurances. Years ago, I had a 45-minute appointment for my annual physical. No stone went unturned. Now, you are lucky to see a provider for 15 minutes. The communication is severely lacking. Doctors dismiss symptoms if they cannot explain it with a lab test. I feel like they just phone it in and don't really care about patients.
<ul style="list-style-type: none"> • Transportation is my biggest barrier, since I do not drive.
<ul style="list-style-type: none"> • Patient would not have been able to navigate health care over the past five years (given multiple medical conditions and acquired intellectual disability resulting from a lifetime of epilepsy) without a family member in the capacity of family caregiver.
<ul style="list-style-type: none"> • My mother is my healthcare advocate. She works with my group home to make sure appointments are scheduled. She also goes with me to all of my appointments. Sometimes my [redacted] staff also attends.
<ul style="list-style-type: none"> • It is horrid! Doctors don't stay. Hospital is substandard...
<ul style="list-style-type: none"> • Had insurance purchased through Obamacare and was kicked out three times. They accused me having double insurances. While I was working part time with SSDI. They forced me to buy part B with SSA but it cost double than my Obamacare plans. Obamacare plans are far better than SSDI coverages. So I went without the insurance and no Doctors to see. Even have health problems or dental care that I needed badly.
<ul style="list-style-type: none"> • Finances limit my access to proper dental care. Finances limit my access to adequate eyeglasses. My glasses are about \$900 cheapest at Walmart and much higher elsewhere. That is almost one month's income.
<ul style="list-style-type: none"> • Psychiatric care, mental health therapy, DSP support staff, medical care (primary, neurology), dental care and eye care are all so separated. Lack of providers who are comfortable with patients who have IDD and mental illness is the main problem. Systems are not flexible for people who have difficulty communicating under pressure.
<ul style="list-style-type: none"> • I have access to private insurance and to a living wage so healthcare is at a baseline more accessible for me.
<ul style="list-style-type: none"> • There needs to be better options for dental, hearing and sight. It should be included in general health and covered by insurances and mainecare and medicare

<ul style="list-style-type: none"> • [Redacted] is the hardest to deal with if you have non geriatric conditions I was constantly told "idk all my other patients on this/wirh this are 90". While ageism is certainly a problem it seems that there is an inverse issue of younger disabled people getting subpar care. I had to transfer my speciality care to southern maine/out of state
<ul style="list-style-type: none"> • There are no dbt therapy in-person groups avaiable, theres only one intensive outpatient program accepting clients and the wait is long, also I've been waiting for a neuropsychology evaluation for 2 years. Due to the trouble with not being able to access services, [redacted] couldn't hold my spot, and I am unable to get the help I need. So. I cannot work and be independent. :(
<ul style="list-style-type: none"> • I wish it was more affordable to all in this country as many people myself included are hesitant to use these services as they cost so much, even for a simple visit to answer a question or get a DX.
<ul style="list-style-type: none"> • these people need to be trauma informed and need to stop pushing treatments that make them money vs. helping people... also why does mainecare cover \$200 inserts but not \$15 eye drops? And why is the mainecare pharmacy so unwilling to help?
<ul style="list-style-type: none"> • Thank God for IPS and being a ME CIPSS navigating this broken for profit clinical healthcare system where lived experiences and ability to advocate for myself protects me to some degree when life "requires" an ER visit that never fails to leave me trauma informed pretty much everytime. Been to ER about 30 times in last 5 years I'm guessing
<ul style="list-style-type: none"> • I need help getting back on SSDI I couldn't do paperwork to stay on it and they stopped my benefits. I have no help or transportation and I am feeling hopeless because I have a hard time knowing how to get help.
<ul style="list-style-type: none"> • Difficulty in availability of appointments with my physician
<ul style="list-style-type: none"> • I have given up on the public health care system , and have switched to naturopath and homeopath , defitenly a chunk out of my pocket despite having insurance but private care is what works for me and not the big public system. For my PCP I fought for a year to get a live interpreter after a failed traumatic expiereince with a new provider (former one closed) then once i finally got a terp, they cancelled on my twice. I have. dropped them and will be finding a new private provider who gives a damn. My phoen will work for both naturopath and homeopath, but it does not work for my provider. Blood work and X rays are also very traumatic because you have to go through multiple people. So I switched to using a private labin and out easy... had that this morning, the person is used to me ONE person and not 9 , person new how to gesture and communicate with me and never spoke a word. :) . My family has a lot of medical and autoimmune issues , so I do fear that I will inherit one of these and be stuck with whatever I get and no access to the information I need for now, will stick with homeopath and naturapath who take the time to listen and explain, and also schedule me for extra time as needed. Looking forward to the new provider in january who also emailed me a lengthy email explaining how she does things :O) . Referrals from Physicans or dentist never happen
<ul style="list-style-type: none"> • It's hard to get prescriptions filled. Offices say they will do things like referrals but they don't.
<ul style="list-style-type: none"> • Case management is not covered by MaineCare Quimby. It def should be.
<ul style="list-style-type: none"> • Emergency room waits are too long. I was sick with cushions for six years and undiagnosed. I was in the emergency room once a month during those years and would be left very ill in a chair for up to 5 hours and then released my treatment there was horrible. The wait time to get into see primary care is too long, and the wait to see a specialist can take months.
<ul style="list-style-type: none"> • Answers would be different if focused on assisting a client with obtaining healthcare.

<ul style="list-style-type: none"> • I am currently struggling to find an appropriate medical care provider to treat my provisionally diagnosed ADHD. This has been causing me problems in other areas of my life.
<ul style="list-style-type: none"> • Chronically ill patients should not have to fight with insurance companies to get the care they need and deserve!
<ul style="list-style-type: none"> • I'm 53 yo female and my lived experience has been largely disregarded/ignored by most medical providers. Systems designed for efficiency and profits do not recognize the unique or specific experiences of disabled people.
<ul style="list-style-type: none"> • There was no box for what I didn't have access to, I am on a waitlist for mental health care neuro psychologist and general counseling.
<ul style="list-style-type: none"> • There are several barriers to receive care for my child, such as long wait lists, few providers available for section 28 services, case management, and play therapy, etc. The changes happening with CDS is affecting my child's ability to maintain services there. We needed to wait several months to get an appointment to get an autism diagnosis that delayed services for my son.
<ul style="list-style-type: none"> • Aetna Insurance - doesn't cover a lot of health services I need because it's out of range. Dental - I need more work on my teeth than just a cleaning and insurance won't cover so I have to pay out of pocket. I am very happy with dental services but insurance doesn't cover it. Pain Management through [redacted] - Won't take me because of my drug use in the past and my doctors referred me to them because there is nothing else they can do. :(
<ul style="list-style-type: none"> • A disabled caregiver is afforded no accommodation or leeway to help them care for their charges. Example: I, with a sleep disorder, cannot always get my mom with a brain injury up for day care. No attempt at accommodating me was made and I was treated as though asking was ludicrous on its face.
<ul style="list-style-type: none"> • Not enough home health care workers. It pays too little
<ul style="list-style-type: none"> • Insufficient providers in rural areas...
<ul style="list-style-type: none"> • need more access to quicker treatment options for substance use disorder and mental health challenges; need more access to quicker treatment for dental care; more options for cost effective dental and eye care, prescription costs
<ul style="list-style-type: none"> • Medicare directs our health
<ul style="list-style-type: none"> • My PCP is closing her office and it will take months to get set up with a new provider. There are limits on how many patients who have Medicare for insurance that providers will take. It took month to find the doctor who is closing and I was only with her for 6 months, and now need to seek new care.
<ul style="list-style-type: none"> • Access to specialists in rural communities
<ul style="list-style-type: none"> • I am not sure that I qualify for a handicap card for my car, but some days my MS makes a walk just exhausting. I would like to understand at what point will I qualify.
<ul style="list-style-type: none"> • I'm learning that Medicare Advantage plans do are not adequate if one has a chronic or disabling condition. For example: My [redacted] plan denied my new orthotics because I was out of network. There are also co-pays for every OT and PT service which do add up.
<ul style="list-style-type: none"> • Very confusing knowing what provider to see that my insurance will cover.
<ul style="list-style-type: none"> • It takes way too long to get an appointment and especially if it is a specialty doctor - it takes months. Then there are different opinions of treatment, without talking to each other, Should be a care team approach
<ul style="list-style-type: none"> • Transportation is an S.O.B. My OT was great, but they closed and I had to go somewhere else and it was bad. Medication: I am legally blind and take a lot of medications. It's up to me to get my medications. I get them from [redacted] and they put it in a square, see-through

<p>envelope which i like. It's been easier because I don't have to pick it up, they mail it to me. But every month I have some left over so it concerns me that I might be getting more than I need. Also, when they mail it, the Post Office or whoever is delivering it to me just leave it with the rest of the packages. They don't put it in my mailbox. They leave it with the packages in my apartment building's entry way. I don't want it just hanging around. It's a 9" round box and I don't want people to steal it. Can they do something else? I called the pharmacy this morning and they said they will label it so it says "put in mail box" so we will see if that changes anything. From my own brain injury from my stroke, I was paralyzed for 3 weeks until I had surgery. Now i have a lack of focus and concentrating can make me tired. I could use more support.</p>
<ul style="list-style-type: none"> • I lost my MaineCare and food stamps. I find the lack of a primary/personal care worker has lead to a severe lack of willingness to provide me care. I can't even find out my own blood type, for example. I've been diagnosed with ADHD, ADD, OCD, ODD, Chronic or Recurring Manic Depression and I haven't been able to get my meds for 12 years (since becoming an adult and homeless back in April 2010).
<ul style="list-style-type: none"> • Why is everything so expensive
<ul style="list-style-type: none"> • Insurance companies don't trust the PCP and won't approve the claim
<ul style="list-style-type: none"> • We have asked for referrals to mental health providers for anxiety. As her mom, I have contacted numerous providers who weren't taking new patients. The only person who had room in her practice , we will be seeing next week. This is a wait of over 5 years.
<ul style="list-style-type: none"> • Need more mental healthcare such as PET/CT Scans because of brain injury. Dentist drilled tooth but have not removed it and other wisdom teeth - it is a lot of pain and scheduled way in the future
<ul style="list-style-type: none"> • Availability of resources (i.e. reimbursement for rides to appointments) is information that should be information all services providers have and should be relayed as a matter of course whenever a provider sees a patient.
<ul style="list-style-type: none"> • I could not afford my prescriptions so I ended up in the hospital. I was also told I could not have a therapist or case manager when I moved to Maine 5 weeks ago. I had both and psychiatrist in New Hampshire where I am from.
<ul style="list-style-type: none"> • We are looking for a dentist.
<ul style="list-style-type: none"> • I don't have stable housing, which makes it hard to find providers. I am homeless, and sleep wherever I can find all over the state. Providers won't accept me if I don't live in their area.
<ul style="list-style-type: none"> • I blame the current medical system for my dissatisfaction with my primary care, as seeing more patients and making more money is seen as more important than providing quality care.
<ul style="list-style-type: none"> • Feel like I'm not treated the same as people with good insurance because I have MaineCare
<ul style="list-style-type: none"> • Providers don't accept MaineCare; can't get treatment. Providers treating me like a dollar sign. MaineCare only covers general care, but not necessarily specialty care or specialty referrals. No intensive outpatient programs or rehabs that accept MaineCare. Get mental health treatment for immediate needs, but no resources for long-term treatment. Psychiatrists treat people with substance use disorder different, as "med seeking" or like they have other motives. The State is doing nothing to address the underlying problem; just putting in solutions that look good at face value, but don't do anything. It's a vicious cycle
<ul style="list-style-type: none"> • I am lost within the mental health system. Before COVID, I was attended with a mental health system once a week. Now I am told that I have to wait 6 months and I feel so defeated. No one to guide me - give me medications. I am here in Maine - single - no family - senior citizen and I truly feel I am all alone. I am now at the Peer Support in [redacted] and have a place to

<p>go instead of going to a "bridge". Why is the mental health system so limited? It takes a "shooting" before any action is taken. So sad - so disappointing - so inadequate.</p>
<ul style="list-style-type: none"> • The health care system is bureaucratic and broken. National and local rules on vaccination and masks have driven doctors, nurses and therapists away from their profession, leading to shortages of caregivers. Inefficient and confusing billing and reimbursement leads to patient stress and higher costs.
<ul style="list-style-type: none"> • Medication is very expensive
<ul style="list-style-type: none"> • I did not have a primary care provider prior to hospitalization @ [redacted]
<ul style="list-style-type: none"> • 2 year waitlist for dental services
<ul style="list-style-type: none"> • There is high turnover in my PCP office. This has resulted in staff not knowing me and this is a barrier to accessing my PCP.
<ul style="list-style-type: none"> • It tends to work for me. I have had trouble filling a prescription when I was out of state. When I have had a problem (prescriptions) it has been due to MaineCare.
<ul style="list-style-type: none"> • Sometimes hard to get services.
<ul style="list-style-type: none"> • It is hard to find healthcare in the Houlton area. My doctors are kind and polite. I have been working with home staff for a while.
<ul style="list-style-type: none"> • There isn't currently a dentist in [redacted]. There isn't any public transportation in [redacted]- not even a taxi
<ul style="list-style-type: none"> • Dental care had long waits
<ul style="list-style-type: none"> • VA is useless for receiving help when you need it; access to their services is impossible. VA has a lot of people working from home. Hard to get through to a provider.
<ul style="list-style-type: none"> • Having a long waiting list for dental care really stinks. I have 3 broken teeth that need to be pulled and I am still waiting to be seen.
<ul style="list-style-type: none"> • While it doesn't impact me, there are many people with mental and physical health problems that are unable to access a provider due to long wait times or unavailability.
<ul style="list-style-type: none"> • It's broken. We need to move away from for-profit driven system of care to a system that actually wants people to be well!
<ul style="list-style-type: none"> • Yes, I have been in jail for 3 years awaiting trial. The jail has denied me health care and dental services even though my teeth were knocked out in jail. I almost lost both my legs (twice) too diabetes (necrotising fasciatis) while in jail. The skin was gone from my legs! I was also with covid19 delta for 6 weeks and was told I needed to go to the hospital since I was coughing up blood and could barely breath, but the jail had no staff to take me and they left me to die! Expect a huge law suit!
<ul style="list-style-type: none"> • I feel stuck working a job that is difficult for me to maintain in order for my to have insurance/access to healthcare
<ul style="list-style-type: none"> • Excellent care; good systems. PCP's are overbooked. Especially in summer. Sometimes getting a ride is tricky.
<ul style="list-style-type: none"> • I haven't gotten in th the dentist and I don't feel they can accomodate my sensory needs. It can be hard to get an appt.w/my promary care and it is diffucult for me to wear a mask so I'm unable to go in person most of the time. Need better seating
<ul style="list-style-type: none"> • Very happy with my primary care but there were times I could not access health care in person, which was difficult for me. I also had issues with long wait times to ge my meds from the pharmacy and had insurance issues.
<ul style="list-style-type: none"> • The home health care system fails people on MaineCare or with disabilities. The home health care system is not coordinated with the health services offered while patient is within the public school system. A person with disabilities who needs SPEECH !!!! The school system is

offering one or two 30 minute session per week, when the person likely needs an hour daily
â€” outside MaineCare services are not available outside of school hours. The local school system is hiring a speech therapist IN [redacted] to serve students in the school system in [redacted]

- Children with mental health conditions and their families are a neglected, underfunded and underserved component of health care. The 2020 pandemic caused irreversible trauma in children and their families who were already struggling with a mental health condition. The pandemic postponed appropriate, timely, care and interventions for children with mental health conditions. It provided no additional support for families and parents on how to best navigate this time without support and caused significant lag time in accessing the appropriate care. Public Schools have continued to have the same expectations for students during and after the pandemic. They have continued education as if these children have experienced no change or lack of social/emotional support and development as well as trying to make up for "lost time" by forcing their academic demands over social and emotional well-being in the classroom. Schools have not adequately supported their staff to be trained in social and emotional health as well as accommodating children who need alternative learning styles, settings or teachers. Educators have continued to see through a narrow scope in how they assess learning. They cannot think outside of the box to integrate different approaches to learning to engage all students. They lack the ability to engage and understand neuro atypical learners when the can't "see" the disability. The ER is not a place to hold a child and their family over and over again when the child continues to need and cannot access services that can PREVENT the ER visit in the first place. The wait time to see a Psychiatrist, therapist, HCT (Homecare team) and OT is totally unacceptable and dangerous. Any other chronic or acute illness requiring a 2 week long hospitalization would never make a patient wait months to get a home care support team. Accessing Mainecare and trying to communicate with DHHS is impossible. We speak English, have a college education and work in healthcare and it felt hopeless, confusing, frustrating and exhausting. Applying for Maine Care, accessing a case manager, finding a therapist, OT provider and psychiatrist for our 8 year old son was a full time job. Maintaining safety, keeping him engaged in a school curriculum (though very difficult due to the lack of school support, delayed IEP assessments and poor staffing), and accessing healthcare for him was not sustainable for a working parent. We had to transition to one income while still not having the services we needed for his mental health for over 7 months. The only reason we received HCT was because his mother called DRM, and DHHS almost daily to access support. Police were in our home multiple times a week when our son was suicidal, dysregulated and unable to communicate his needs. While the police department became very familiar and fond of our son and family, they did not have the training to respond to his mental health needs. Our son was admitted to a mental health hospital during the week of Christmas last year for SI. Because of Covid we could not visit him. He was 7 years old and it was the first time he had ever been away from his family. When he came home he shared with us all the video games and iPad time he had in his room (unsupervised, without parent consent and with games that were violent and not age appropriate). He also explained the screen time was because of "not enough staff". He came home with sores all over his feet because of wearing shoes without socks and getting blisters, his skin was raw on his toes and he had a skin infection from poor skin care. He lost weight due to not having his dietary needs met. Although the hospitalization was to establish safety and initiate a medication regimen, we felt horrified as parents knowing the care he received was inadequate and the communication to his parents was negligent. He received care as if it was a glorified babysitter at [redacted]. Once we did receive HCT and a case manager 7

months after his hospitalization, we knew it would be the missing piece of the puzzle to support him and our family. The mental health needs of our child affect the entire family unit and our healthcare system does not support the needs of the family unit. HCT has been hard work and exhausting for our son and our family but it has provided us all with structure, behavior modification support, healthcare addressing real-time problems and needs in our family, a working relationship that is patient and family centered. Our mental health system for children needs more support. We need more staff, research based clinicians and training, trauma informed care, age appropriate treatment, better access to outpatient services, improved outreach to families and patients with new mental health and chronic diagnosis, increased awareness and funding for programs to support families like the GEAR parent network, increased education and training for schools, parents and caregivers of those with mental health conditions, emergency support services to families in crisis such as meals, and providing services in the home, reducing the barriers to accessing Maine care and communicating with DHHS to complete forms or inquiring with questions, increasing the ER response for children and keeping them in a safe, age appropriate unit.

- Long waits for BHH caused a significant and life threatening decline. When trying to access support continual messages of "more meds" and "try harder" pushed our son to suicidal behavior. It wasn't until a 30 day stay in the ER that we were finally able to get help. This has been traumatic for our entire family. We have lost income, experienced financial hardship, and our family will forever be changed by this horrific experience. Our son is recovering but there is no way to know what the long term impact will be on his life.

- I am in [redacted] and there are very few providers to choose from and most are too quick and don't listen to me. I haven't had a therapist for a long time because I am on the waiting list everywhere but no one wants to take me as a patient because of my disability.

- there is no availability of mental health counseling through mainecare. i have been on a [redacted] wait list for a year.

- I am not able to receive any health care due to my income exceed for MaineCare.

- [Redacted] needs more dentists - it's hard to get in to see one

- I find the quality and availability much worse in Central Maine then when I lived in the Portland area.

- There is not enough mental health providers in the state of Maine that are familiar with DID (Dissociative Identity Disorder) specifically, i have been desperately trying to find one that takes mainecare. There is just honestly a huge lack of mental health services in general that are accessible but for people with more complex disorders it is even harder to find help, a lot of therapists i have seen are not able to meet my needs or are unsure of how to treat me due to lack of experience treating my disorders.

- With Maine Care, I get lower quality of care than people with other insurances. I don't have many options. If I don't feel comfortable or trust a specialty doctor, I don't have a choice to go to another doctor because they are the only ones who take my insurance. The mental/behavioral health services are the worst. Especially with my insurance. No good quality provider takes Maine Care. They are in private practices or only take "real" insurance. I get the scraps. I need trauma therapy and no one takes my insurance. I've been on a years long waiting list for over a year, and got nowhere. I'm still waiting, twiddling my thumbs, needing it to get on with my life. My access to good quality health care services is cut short because of my insurance. It shouldn't be that way, but I feel discriminated against because of the insurance I have due to my being disabled.

- Triaged and waited 14-16 hours so I left.

<ul style="list-style-type: none"> • transportation psychiatrist - case manager - no help
<ul style="list-style-type: none"> • no transportation to get to certain health care such as physical therapy, cortizone shots...
<ul style="list-style-type: none"> • I moved to Maine from Vermont last year, and I feel like I'm in a healthcare desert when it comes to specialists.
<ul style="list-style-type: none"> • It is literally impossible to find dental care that takes mainecare. There is a one year wait, except they call and cancel and you wait another year. The [redacted] clinic is the only option and it's students experimenting on you with treatments you don't want to get to the treatments you need, one root canal took 5 meetings, 4 hours each, and 2 hours drive (1 hour each way) and I have so many cavities to fill back from 4 years ago that will need root canals eventually because no one will fix them. It's not my fault during pregnancy my calcium levels were so low, I had a difficult and dangerous pregnancy and a bunch of stuff happened including my teeth rotting. I haven't developed new cavities since then on X-rays. I can't afford a regular dentist but why should I have to lose my teeth? They should make regular dentists take mainecare or a certain amount of mainecare patients a year. I'm a high honors premed student, single mom to an autistic child, and I'm currently doing undergrad research myself. You shouldn't have to deserve healthcare but if you did I think I'd qualify. How am I going to do med school interviews missing teeth?
<ul style="list-style-type: none"> • I have been struggling to get the right care for my disabilities for over 15 years. I almost died multiple times from being denied care at [redacted] ER triage. However, it is [redacted] that has saved my life. In addition it has been very hard to get MaineCare or food stamps when I was homeless because I couldn't work due to mental illness.
<ul style="list-style-type: none"> • It has been impossible to find a dental care provider that takes Mainecare, because of this I have not had dental care in over 10 years, This includes the recent changes of the state helping more providers take mainecare- there are no providers available.
<ul style="list-style-type: none"> • The healthcare system is not designed for anyone with a long term illness or disability. It's only designed for quick checkups on healthy people. When you aren't an easy fix, you will be shamed and gaslit, and ignored. This is my experience going from abled to disabled. It is extremely classist, the specialist I need to see I have to pay 100% of the costs for the visit and medicine. These are Drs that keep me alive, not extra support specialists. And these are the only people in Maine who can treat me. If I didn't have money and good insurance from my well off family I would probably die. In my experience, Maine greatly lacks in diversity of drs, quality of care, Dr knowledge, and accessible low cost options.
<ul style="list-style-type: none"> • The access to dental care has been atrocious as nearly every dental facility I have search for will NOT accept Mainecare as an insurance provider. This has lead me to have a sever abscess for well over two years as a result of not being capable to pay out of pocket
<ul style="list-style-type: none"> • cost/lack of Mainecare coverage for services/lack of providers accepting Mainecare and limited provider availability make finding dental and mental health care extremely difficult. I was able to get counseling and psychiatric support through USM's counseling services, but now that I have graduated I will no longer have access.
<ul style="list-style-type: none"> • I spend a great deal of time navigating the health care system as a patient with a complex ultra-rare primary immune deficiency.

Communication

Open-ended responses to “Is it difficult to communicate with your provider?” All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • Telemedicine via phone call with no caption service/audiologist wearing opaque mask and needing lip reading for verbal communication
<ul style="list-style-type: none"> • They do not take the time for me to process questions and offer a response. Because it takes a long time, they keep changing the questions, causing anxiety, and I can't answer. They don't offer time for my health partner/companion
<ul style="list-style-type: none"> • I was under stress when video remote interpreting constantly frozen that caused me to lose track of my thoughts and more stress for me.
<ul style="list-style-type: none"> • They do not make themselves available for communication
<ul style="list-style-type: none"> • Some doctors are blatantly sexist and will instantly go to anxiety that said I have learned how to deal with these providers to not get subpar healthcare but it requires more work.
<ul style="list-style-type: none"> • I have not had any doctors, on the list to get some help.
<ul style="list-style-type: none"> • They say I am difficult and inappropriate when I advocate for myself
<ul style="list-style-type: none"> • They only want info through their portal/online
<ul style="list-style-type: none"> • They do not touch me.
<ul style="list-style-type: none"> • They do not include me in decisions and send me home too often than not.
<ul style="list-style-type: none"> • Inaccurate speech-to-text apps delay things. Using the Notes app on iPhone 11 since seems almost as good as \$ apps.
<ul style="list-style-type: none"> • I need to read lips or ability to use my caution on my phone in their office space it does not always work. I was told by a specialist once when I told them I could not hear but read like well. He said well if you expect me to remove my mask I'm not
<ul style="list-style-type: none"> • No timely answer to questions.
<ul style="list-style-type: none"> • Not enough support staff
<ul style="list-style-type: none"> • They don't want to hear about the individual when it comes to mental health care. They have a checklist response and don't listen to you as an individual. Some do but most don't. Worse with mental health. to
<ul style="list-style-type: none"> • Don't listen and treated as infants
<ul style="list-style-type: none"> • History of eating disorders and doctors' internalized weight stigma frequently steamroll over my concerns about relapses and often make ED behaviors worse
<ul style="list-style-type: none"> • The solution for every symptom is yet another prescription, nothing else.
<ul style="list-style-type: none"> • They will not wear respirator masks while treating everyone, including high-risk individuals
<ul style="list-style-type: none"> • confirm what I had said.
<ul style="list-style-type: none"> • They do not let me make the full decision about my health needs but rather encourage alternate pieces of equipment.
<ul style="list-style-type: none"> • They belittle me for the symptoms I have and tell me it's all in my head
<ul style="list-style-type: none"> • They do not respond to phone calls, emails, etc.
<ul style="list-style-type: none"> • unavailable/too busy
<ul style="list-style-type: none"> • I have PTSD and it is difficult to advocate for myself, especially with brusque/dismissive doctors.
<ul style="list-style-type: none"> • They gaslight, they don't track my illnesses

<ul style="list-style-type: none"> • Jail did not provide access
<ul style="list-style-type: none"> • can't talk to doctor directly
<ul style="list-style-type: none"> • They patronize me and assume I am under educated speaking in small words. They also seem to conclude that all my problems have to do with my weight or mental health.
<ul style="list-style-type: none"> • They try to "railroad" me the majority of visits, portraying a "I know best" attitude with a lack of considering my personal experiences and variance
<ul style="list-style-type: none"> • They speak to my mother my guardian, as I have speech delay
<ul style="list-style-type: none"> • Trying to contact over the phone is impossible
<ul style="list-style-type: none"> • Clear masks should be mandatory. Since the pandemic, noone would get or wear one!
<ul style="list-style-type: none"> • Clear masks ARE a must for the HOH/Deaf!
<ul style="list-style-type: none"> • They use language that I dont understand and they do not explain it. They just don't listen to me.
<ul style="list-style-type: none"> • they don't return phone calls or emails
<ul style="list-style-type: none"> • I bring my mother in with me --I need her to help me understand and she is my guardian, but in the past they have said that they won't speak to her and make her leave.
<ul style="list-style-type: none"> • Make assumptions and judgements based on diagnosis
<ul style="list-style-type: none"> • Too many layers. you have to leave a message with a receptionist, the receptionist tells the medical assistant, the medical assistant tells the nurse, the nurse tells the doctor by the time the doctor gets the message, it's been interpreted differently than the original meaning
<ul style="list-style-type: none"> • I leave messages through the portal and they do not respond. They mix up medications and do not follow threw from one facility doctors to the others to know what is and isn't available
<ul style="list-style-type: none"> • They are busy
<ul style="list-style-type: none"> • They are usually very quick to dismiss whatever med you may mention to them to possibly try.
<ul style="list-style-type: none"> • can't always understand what they mean
<ul style="list-style-type: none"> • At [redacted] a doctor did not listen or believe me when I told him that though my shoulder blade was injured in a fall that I was concerned for my neck. So instead of x-raying my that has cervical disk disease, and has a crushed vertebrates, he x-rayed my shoulder blade instead. We had agreed before hand that my shoulder should be fine, and I just needed a sling for it.
<ul style="list-style-type: none"> • they make assumptions - jump to conclusions
<ul style="list-style-type: none"> • rushed
<ul style="list-style-type: none"> • They don't understand my condition
<ul style="list-style-type: none"> • I have experienced medical gaslighting for years with my chronic health conditions and mental health.
<ul style="list-style-type: none"> • They use checklists surveys and rattle off questions instead of understanding conversations
<ul style="list-style-type: none"> • They don't offer help that I ask for
<ul style="list-style-type: none"> • They don't seem to care - too young - I too old.
<ul style="list-style-type: none"> • I have aphasia
<ul style="list-style-type: none"> • They often believe in false claims by public health officials
<ul style="list-style-type: none"> • I can't get out of my head what's going on inside me
<ul style="list-style-type: none"> • It is hard to reach out
<ul style="list-style-type: none"> • Speech impediment
<ul style="list-style-type: none"> • Don't listen to personal experience; don't spend enough time with patients
<ul style="list-style-type: none"> • they do not understand the way I communicate

<ul style="list-style-type: none"> • rather tell staff
<ul style="list-style-type: none"> • gave me weightloss tips and diagnosed me with anorexia all in the same meeting. Told me she doesn't believe in bipolar disorder even though that is my diagnosis.
<ul style="list-style-type: none"> • I'm treated like a hypochondriac
<ul style="list-style-type: none"> • "If you can talk you can hear" Not true! In hospital they made decision to have surgery, didn't ask me. Because I can talk, they assume I can hear.
<ul style="list-style-type: none"> • not individualized care
<ul style="list-style-type: none"> • Sometimes my head gets tired when talking to my doctors
<ul style="list-style-type: none"> • do not include in decision making
<ul style="list-style-type: none"> • Not making sure I understand is a big one.
<ul style="list-style-type: none"> • the wait can be difficult
<ul style="list-style-type: none"> • i don't comprehend well.
<ul style="list-style-type: none"> • you can't get ahold of them
<ul style="list-style-type: none"> • Some treat patients as if they are too busy to treat them properly.
<ul style="list-style-type: none"> • they're overloaded with work and can't give enough time to me
<ul style="list-style-type: none"> • They sometimes make it extremely difficult to get in contact with them (i.e. long hold times, days before getting a call back, etc.)
<ul style="list-style-type: none"> • My mental health care is new
<ul style="list-style-type: none"> • They speak to staff
<ul style="list-style-type: none"> • sometimes they yell at me
<ul style="list-style-type: none"> • They speak to my staff
<ul style="list-style-type: none"> • don't care
<ul style="list-style-type: none"> • VRI sometimes freeze. Caused communication misunderstanding. I want to talk more.
<ul style="list-style-type: none"> • Doctors need to review patients charts and make sure what is then entered is accurate. Please use names. They are in the chart.
<ul style="list-style-type: none"> • I have communicated with my doctor via the patient portal about health needs that need to be explored more deeply and received a negative response. I also advocate for holistic care and continue to receive a negative response. The doctors are only worried about the symptoms and not the root cause of the issues.
<ul style="list-style-type: none"> • We need to have more accessible ready for deaf patients with no stress involved like in staff interpreter (s)at hospitals . Drs office, hospitals staff need trainings on deaf etc more often due to high volume of staff turnovers.
<ul style="list-style-type: none"> • It is frustrating to continually remind people about my audio processing issues and ask them to slow down or ask only one question at a time. However, I have been fortunate to be able to assemble a team of providers that are caring competent, and responsive. I am encouraged that the younger physicians seem to "get it" more quickly and many -even specialists- often have better communication skills than one might expect.
<ul style="list-style-type: none"> • I have TBI but look fine on the outside. Even when providers are told I cannot read and find a lot of communication hard to understand they don't seem to care and never follow up
<ul style="list-style-type: none"> • We have changed primary care doctors because of the lack of communication and feeling that needs were not being met. We were very clear with new primary care of what expectations were, and it was okay for the first two visits and then started going down hill. Now care is the same as before. No communication to me directly, and no physical examination or testing beyond bloodwork.

- most of difficulty is with making appointments or dealing with automated online stuff, and poor captions. Had to drive 5 hours each way to make first appointment with [redacted]. Once get face to face with a health person, they have been very accommodating and patient. Note that hearing went from severe to profound during this time. Difficulties have increased since hearing aids became mostly useless in past 6 months. cochlear implant not viable - did get tested for that during this time.
- I am happy with my current provider. About 4 years ago, I left a provider who continually "forgot" to speak slowly and clearly, facing me. I reminded them several times.. Then I changed medical offices.

Open-ended responses to “Do healthcare providers respect you? If no, what experiences have you had?” All responses are presented as written, with identifying information redacted.

- I HAD to have dirty work to contact nurse for ASL interpreter.
- [Redacted] just views me as a woman who is bipolar. I don't think [redacted] listens to my childhood traumas.
- Demeaning and condescending
- no empathy; just getting to the next person
- 85% of time they talk to the interpreter, not me.
- talk to me like a child
- talk down to me
- The people who run their offices are rude and don't even know the correct policies for what is being done right now with Covid, masking
- Talk to my family members, not me
- Some providers are great but others do bot make it comfortable to communicate and don't give my health partner/companion time to facilitate successful conversation
- I HAD to have dirty work to contact nurse for ASL interpreter.

Open-ended responses to “Is there anything else you would like to share about your experiences with the healthcare system?” that relate to communication. All responses are presented as written, with identifying information redacted.

- I would like to have 2 or 3 consistence interpreter for appointments. Not just random interpreter it does effect my progress of becoming healthier.
- Overall my experience with health care has been good. Sometimes it has been hard to get an appointment if Dr office is full. Really wish that hearing aid manufactures would bring back analog hearing aids ad the digital ones do not work as well for me.
- Nope interpreting for er Not like vri
- VRI shouldn't be used in ER, X-ray, etc. Sometimes VRI in doctor's office or ER freeze and I had no way to express more of my health issues, I prefer to express my words in ASL rather than writing notes. [Redacted] rescheduled my appointment because they forgot to request an interpreter. [Redacted] has contract with [redacted] interpreter agency. I was not happy with ASL interpreter (from [redacted] interpreter agency) who is not qualified. Same thing happened at [redacted] with same interpreter when my son was sick. This interpreter sometimes had difficult understanding what I said. I had to repeat.

<ul style="list-style-type: none"> • I can do zoom video
<ul style="list-style-type: none"> • The way nurses call patients to the room is not accessible. Should give out # and display them like they do at DMV
<ul style="list-style-type: none"> • I feel that there SHOULD provide ASL Medicare book annually. I know it's too much to ask, but deaf people deserve to understand PRETTY much!
<ul style="list-style-type: none"> • My family makes decisions for me and communicate with me after doctors office.
<ul style="list-style-type: none"> • problems with interpreters
<ul style="list-style-type: none"> • My provider and my sister does the communicating with medical provider, and share with me when is needed. Interpreter has always been provided, along with CDI as well.
<ul style="list-style-type: none"> • I do have communication issue with my health care provider, but they do provide appropriate service.
<ul style="list-style-type: none"> • I depend on lip reading to understand speech. When I went to the emergency room for COVID, the doctor and nurses noted my hearing loss and wore a clear shield in place of a face mask.
<ul style="list-style-type: none"> • I have learned more to advocate for needs and be open to share what I feel needs to be shared.
<ul style="list-style-type: none"> • Doctors need to learn to listen to patients because no one knows your body better than you. PCP treats me differently because of mental health diagnosis; they talk down to me, are condescending, and treat me like I don't know what I'm talking about
<ul style="list-style-type: none"> • I feel like I am treated better than people with MaineCare and that I have access to better providers than people with MaineCare. When in the ER, staff don't watch what they say around patients. While I was in the ER in [redacted], I was kept in the hall for hours and was not given a private room. People there for physical medical issues could have their cellphone, but because I was there for mental health, I was not allowed to have mine. While I was there, staff made the comment "Of course she's here for crisis. It's Halloween, what do you expect." I felt very offended and disrespected; like she wasn't taking me seriously.
<ul style="list-style-type: none"> • A patient with patience makes the best patient.
<ul style="list-style-type: none"> • MyChart is not private because staff can see it. PCP and psychiatrist appointments: staff attend and the person [patient] is ignored.
<ul style="list-style-type: none"> • Communication problems, but new girl is good
<ul style="list-style-type: none"> • Fight to get interpreter, long time waiting
<ul style="list-style-type: none"> • Lots of problems with audiologists, had to switch due to MaineCare. Would be nice if they had people with expertise working with deaf people. Stop imposing VRI. Heard in community many problems with VRI. Need in-person interpreters. If use VRI, need better interpreters. New interpreters can't handle problems. In state of Maine, 95% of deaf people hate VRI. Story: I was living in NH taking care of my son. My mom was there. My son was hit by a pickup truck. We went to the hospital, he was screaming. There were no interpreters. I had no idea what was happening. Can you imagine that?! For example, if I help my dad go to the doctor, they won't get an interpreter for me.
<ul style="list-style-type: none"> • communication skills could be better - speak "above me or below me" treat me better as a veteran
<ul style="list-style-type: none"> • I feel rushed, the wait time is ver long as well They don't listen and tell you what you want to hear to get you our
<ul style="list-style-type: none"> • Wants more personal care. Easier ways to communicate with providers and more consistency in care given.
<ul style="list-style-type: none"> • I am very outspoken to them

<ul style="list-style-type: none"> • The system seems to be too hurried and too busy. My doctor doesn't remember me (understandable considering the workload) but does not review my records before seeing me. Part of the visit is him getting up to speed. It is as if I have a new visit every time. And no communication between specialists and my doctor. He gets the reports but never, never reads them before seeing me.
<ul style="list-style-type: none"> • Masks have made communication access challenging.
<ul style="list-style-type: none"> • In speciality care services - I had one incredible doctor and many that were disrespectful - refusing to speak to me, ignoring my concerns. I was at the hospital getting tests done for a diagnosis and a doctor, insensitively, looked at me and said, "The good news is it's DEFINITELY not what you thought it was." Which ended up being untrue.
<ul style="list-style-type: none"> • Need more training with communication, especially specialty doctors like urologist. Need to take more time and care. Some people have different pain tolerance than others
<ul style="list-style-type: none"> • They need help in understanding about "life information - need to get the whole picture of a person and review all of the information. Sometimes I feel rushed
<ul style="list-style-type: none"> • I always have to make sure to request an ASL interpreter when I make an appointment. I can't make an assumption that they will automatically schedule one. I had to share my frustrations with one medical provider site as they were not prepared for communicating with me even though I clearly explained my communication needs when I made an appointment for COVID testing. When I scheduled a sleep study evaluation, a medical provider suggested VRI. I explained that it was not going to work due to the nature of the appointment and requested in-person interpreter. They did comply with my request. There were times where I had to educate the medical staff about using ASL interpreters. Also, it is very hard to be 6 feet away from the front desk trying to "check in" for an appointment - it is hard to see VRI when one is 6 feet away from the window.
<ul style="list-style-type: none"> • Frustrated with medical provider not aware of providing interpreter service, Video Relay Service is not reliable and keeps freezing.
<ul style="list-style-type: none"> • My Doctor is good keeping up to make sure that I had communication access, but there were several times where they forgot to schedule interpreters, so they resorted to using VRI which was not favorable.
<ul style="list-style-type: none"> • [Redacted] wanted to know why staff is asking him these questions and not the doctors.
<ul style="list-style-type: none"> • I do feel my healthcare provider can be patient when I don't understand things
<ul style="list-style-type: none"> • I think the ER People at [redacted] need to be trained in patient rights. When I was seen in the ER last Monday, they prohibited me from calling my patient advocate. I think it adversely affected the quality of my care because the doctors didn't understand me and I didn't understand them. My advocate could have helped explain things.
<ul style="list-style-type: none"> • [Redacted] asked why there were so many questions that didn't make sense to her.

Physical Spaces

Open-ended responses to “What makes the spaces where you receive care feel inaccessible or feel unsafe?” All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • Hospital was so full beds are in the hallway and unsafe , hours go by before someone realizes your there.
<ul style="list-style-type: none"> • tiny rooms with no space for wheelchair
<ul style="list-style-type: none"> • Having to fight almost every single visit in order to get my appointments charged appropriately. They refuse to bill MaineCare on multiple items for my child as well.
<ul style="list-style-type: none"> • Literally in a hallway for ER
<ul style="list-style-type: none"> • I go to ER by ambulance. Have difficulties finding rides home and rides to follow up appts
<ul style="list-style-type: none"> • Bathrooms are not large enough to accomodate my power wheelchair. I have to go very far down the hall to fit in one (or leave the door open to handicap stalls as the chair won't fit. OR in some buildings there is not grab bar by the toilet - even though the rest of the bathroom is accessbile (button on door, sink okay.) Some places have the papertowel and soap too far out of reach for the wheelchair with legs on it. Some healthcare buidlings (dentist, mental health, PCP buildings and bathrooms have the old round doorknobs and heavy spring doors that are impossible to open when in wheelchair or using walker to get into the building or bathroom).
<ul style="list-style-type: none"> • have to go through multiple people to get to the doctors office (registration of hospital, registration of x ray, registration etc) Communication is hindered
<ul style="list-style-type: none"> • There is not an expectation that psychiatric spaces have a warm comforting feeling like general medicL care. Mental health care is medical care. System does not behave that way.
<ul style="list-style-type: none"> • Not masking
<ul style="list-style-type: none"> • Again, a lack of serious Covid mitigations like respirator mask wearing, social distancing, ventilation, are all problems with accessing safe care while high risk.
<ul style="list-style-type: none"> • The exam rooms are always tiny, so it's hard to fit my rollator or maneuver my wheelchair
<ul style="list-style-type: none"> • Everything is good
<ul style="list-style-type: none"> • Just because a person looks ok..doesn't mean they are..mental illness cannot be seen with the naked eye..and people just assume they are dine because they look fine..their illness cannot be seen
<ul style="list-style-type: none"> • I was psychotic and put into a room with staff lockers, a bathroom, and people in a locked up unit screaming a door away. While psychotic, this was terrifying and not comforting in the slightest.
<ul style="list-style-type: none"> • When you have a drug problem you get treated like shit.
<ul style="list-style-type: none"> • Have you been to the lab at [redacted]? You make it down a longggg hallway and then there is no accessible door. I was using a walker and couldn't get in. 1/2 the doors in that building are inaccessible. That's just one.
<ul style="list-style-type: none"> • Staff is not respectful or well trained and often make snap judgements
<ul style="list-style-type: none"> • chairs aren't accessible
<ul style="list-style-type: none"> • there were stairs to see dr.
<ul style="list-style-type: none"> • There have been times when I felt it was more like a jail than a medical facility.
<ul style="list-style-type: none"> • I'm homeless, they treat me like a leper.
<ul style="list-style-type: none"> • city downtown locations with no private parking; only parking is public street parking or parking garages; too far away from the offices, can't walk that far

<ul style="list-style-type: none"> • Lack of appropriate placement for pediatric psychiatric patients in an ER setting. [Redacted] places all psychiatric pediatric patients in the same ER as adult psychiatric patients. It feels scary, dangerous, unpredictable, and the staff is not appropriately trained to support pediatric patients.
<ul style="list-style-type: none"> • no access to therapy or visitors in ER while waiting 30 days for inpatient psychiatry. Minimal access to windows or sunlight. Some inflammatory staff though most were compassionate. Lots of restraints.
<ul style="list-style-type: none"> • not well trained lots of assumptions
<ul style="list-style-type: none"> • Inadequate or nonexistent COVID mitigation measures
<ul style="list-style-type: none"> • need more handicapp spots
<ul style="list-style-type: none"> • security
<ul style="list-style-type: none"> • need more handicap spots
<ul style="list-style-type: none"> • Emotionally after the medical trauma I've experienced, going into a medical setting is extremely triggering for me
<ul style="list-style-type: none"> • the atmosphere is incredibly triggering towards my sensory needs.
<ul style="list-style-type: none"> • I have sensory difficulties and the lights in doctors offices and exam rooms are unbearable
<ul style="list-style-type: none"> • Autism, ADHD, and trauma make expectations and waiting very very difficult. If my appointment is at 2pm I expect to be seen between 2 and 2:15. Sometimes they won't call me up for an hour after my appointment and even then I get put into a room to wait even longer. It's exhausting and by the time they come to examine me I am all out of spoons and sometimes become nonverbal from the distress.
<ul style="list-style-type: none"> • Too much back ground noise. Music, general noise, white noise.
<ul style="list-style-type: none"> • Poor public transportation and agoraphobia
<ul style="list-style-type: none"> • They are too busy treating me disrespectfully, because someone calls up before I get to an appointment.
<ul style="list-style-type: none"> • Intercom systems to enter the building, I can't hear. Wait forever to be let in
<ul style="list-style-type: none"> • Any medical/clinician, because they can commit you
<ul style="list-style-type: none"> • need more handicap spots
<ul style="list-style-type: none"> • rooms are too small for wheelchair
<ul style="list-style-type: none"> • need more handicap spaces
<ul style="list-style-type: none"> • trauma on top of trauma. strip searched in the ER
<ul style="list-style-type: none"> • My need to hurt myself
<ul style="list-style-type: none"> • I was there all night before they were done with me.
<ul style="list-style-type: none"> • violation of HIPPA in waiting room

Open-ended responses to “Is there anything else you would like to share about your experiences with the healthcare system?” that relate to physical spaces. All responses are presented as written, with identifying information redacted.

<ul style="list-style-type: none"> • Don't always use walker at doctor becasue hard to get around
<ul style="list-style-type: none"> • Not every providers office space is accessible as it might be.

APPENDIX B

FOCUS GROUP GUIDE

DRM Focus Group Guide

- The facilitator and co-facilitator introduce themselves
 - Tell participants about the assessment; why it's happening, what kind of information we're looking for in the focus group, and what will be done with it
 - Disability Rights Maine is undertaking this effort to better understand health equity and access issues for individuals with disabilities across the state of Maine
 - The project includes a survey, focus groups, open forums, and gathering any and all data to help characterize the population and health outcomes/disparities
 - This focus group allows us to understand better the experiences of individuals who have particular disability types
 - Set ground rules for the conversation
 - This is an open discussion
 - All views are accepted
 - Listen and speak in equal measure
 - Be open to learning about situations beyond your personal experiences
 - Quick round of introductions by participants, if they're comfortable
-

Question 1: We want to start by asking about your experiences getting the health care that you need - health care includes not just primary care, but also mental health, substance use, dental care, urgent care, etc. How easy is it for you to make an appointment, or get the care that you needed?

Probes: What sort of care is easiest to get? What is most difficult?
If it was easy – what sorts of things made it easy?
If it was difficult – what barriers did you face?

Question 2: We want to know about what it's like to communicate with your health care providers. How easy or difficult is it to communicate with them – about your needs/concerns, about your condition, etc.?

Question 3: What about the physical spaces where you receive care – is it easy and comfortable for you to be in those spaces?

Question 4: Do you feel treated with respect when you interact with the healthcare system?

Probe for specific examples of what makes them feel respected AND disrespected

Question 5: Is there anything else you'd like to share about your experience with the health care system?

Probes: Is there something you wish providers would/could do to create a more positive experience?
If you had a magic wand, what's the one thing you wish to change about the healthcare system?

APPENDIX C

RECOMMENDATIONS BY
RESPONSIBLE ENTITY

State and Federal Policymakers

Recommendation	Potential Strategies
<p>Make disability status a standard demographic indicator in data collection and surveillance efforts.</p>	<p>Establish rules and guidelines for all state-funded grants and surveillance efforts to include disability as a demographic indicator.</p>
	<p>Require self-reported disability status as part of standard demographic information collected in electronic health records.</p>
	<p>Tie state Medicaid and block grant funding to substantive evidence of health equity for people with disabilities.¹</p>
	<p>Improve the quality of disability data through cross-agency collaboration on data collection/sharing to include standardized questions on disability.</p>
<p>Individuals with disabilities must be represented in public health surveillance efforts.</p>	<p>Ensure that individuals with disabilities are represented statewide and on state-level advisory councils to direct statewide guidance related to health care planning, health equity, and assessment processes.</p>
	<p>Advocate for better representation of people with disabilities in national surveillance efforts, such as the Behavioral Risk Factor Surveillance System (BRFSS) and the American Community Survey (ACS).</p>
	<p>Require that surveillance efforts engage individuals with disabilities residing in group homes or other institutional placements.</p>
<p>Increase opportunities to access funding, resources, and technical assistance to better care for people with disabilities.</p>	<p>Expand efforts that identify Health Professional Shortage Areas (HPSAs) to include urgent care, specialty care, and home health services, which would give centers the ability to expand specialized services.</p>
	<p>Designate people with disabilities as a medically underserved population through the Health Resources and Service Administration (HRSA) to increase opportunities to access funding and technical assistance support at federally qualified health centers through a Governor’s Designation.²</p>
<p>Communication devices and technologies should always be working and available for use.</p>	<p>Develop and implement state-level guidelines for the use of ASL Video Remote Interpreting in medical settings.</p>
<p>Create accessibility guidelines that go beyond the basic minimum requirements and provide additional access whenever the needs of the population go beyond those minimum standards.</p>	<p>Require that healthcare organizations routinely assess and report on the accessibility of their building (e.g., parking lots, waiting areas, exam rooms).</p>

Health Care Policy Organizations, Health Systems, Providers, and Personnel

Recommendation	Potential Strategies
Ensure that individuals with disabilities are represented as decision-makers and subject matter experts in spaces where education and training curricula are established.	Establish guidance for hospital systems to include people with disabilities within their Diversity, Equity, and Inclusion efforts and patient and family advisory boards.
Train health care personnel to provide comprehensive and high-quality care to patients with all types of disabilities.	Implement licensing requirements that include ongoing provider education about providing care to individuals with disabilities.
	Embed requirements for direct service/practice experiences with individuals with disabilities in health care training and continuing education programs.
	Require that didactic education in health care fields include content on a range of disabling conditions and human responses.
	Continuing education on working with people with disabilities should be available and encouraged.
Increase the number of individuals with disabilities employed in health care settings.	Pilot programs that support individuals with disabilities to enter the healthcare workforce.
Improve the quality of care for people with disabilities.	Require that health care organizations provide disability specific training on an annual basis.
	Require that health care providers complete all routine aspects of care for people with disabilities (e.g., asking about mental health, substance use, and sexual health).
	Incorporate trauma-informed care approaches at all points of contact.
Provide navigation and supportive services to people with disabilities and their families/caregivers.	Nurture peer navigation and support programs that pair individuals with disabilities with peers who have expertise and experience successfully navigating the health system.
	Explore opportunities to offer or expand case management and care coordination services for individuals with disabilities with both public and private insurance plans.
	Advocate for supportive services for parents and caregivers of children with disabilities.
	Incentivize partnerships between health care providers and community-based organizations to address common barriers to care (e.g., transportation barriers).
Explore mechanisms to improve timelier access to care.	Expand after-hours and weekend care at primary care practices, including federally qualified health centers.
	Use telehealth technologies, such as virtual visits and remote consultations, to deliver health care services to patients in remote or underserved areas to reduce travel time and costs, and enhance access to care for individuals with limited mobility or transportation options.
	Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.

Equip health care personnel with the necessary knowledge and tools to have positive interactions with patients with disabilities.	Require that all health care personnel, from administrative staff to physicians, receive formal training on effective methods for communicating with patients with disabilities.
	Conduct training on legal obligations providers have when interacting with patients with disabilities.
	Develop provider educational materials (e.g., guides, toolkits, checklists) that providers and staff can use to ensure accessibility during appointments.
Individuals with disabilities must be represented in decision-making bodies to ensure communication needs are addressed sufficiently.	Require that hospital Patient Advisory Councils include people with disabilities, to solicit and encourage improvements related to effective communication and patient access.
Inform individuals with disabilities of the rights afforded to them.	Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available to them.
Communication devices and technologies should always be working and available for use.	Examine the accessibility of health care technologies (e.g., kiosks, patient portals, telephone systems, video conferencing, websites) prior to implementation.
	Ensure that health care facilities have contracts for on-site and video interpreters in place before a request for interpreters is received.
	Develop and implement state-level guidelines for the use of ASL Video Remote Interpreting in medical settings.
All communications (e.g., forms, questionnaires, educational materials, instructions) should be accessible, easy to complete, and representative of people with disabilities.	Offer patients the opportunity to fill out all forms (electronically or in hard copy) prior to their appointment.
	Require that all materials distributed to patients during the visit are audited for accessibility.
	Ensure that all online data and information are provided in formats that can be interpreted by screen readers.
	Ensure the facility and providers have the ability to offer large-print versions of all printed materials (font size 18 pt or larger).
	Include images of people with disabilities in all educational and promotional materials.
Consider communication needs and privacy concerns when interacting with patients in health care facilities.	Implement more discrete communication strategies that do not rely on hearing a person's name called (e.g., distributing pagers instead of calling names in a waiting room).
	In places where masking is required and implemented, ensure all staff has easy access to clear masks and communicate that patients can ask for staff to wear them.
	Schedule longer appointments for patients with disabilities to accommodate diverse communication needs, styles, cognition levels, and use of interpreters/communication devices.
	Explore opportunities to be more flexible in allowing for longer patient visits.
Create, implement, and improve mechanisms for notifying providers and staff of patient accommodations and needs.	Embed questions about accommodation needs at the point of first contact (scheduling, registration, triage, etc.).
	Proactively communicate with patients ahead of health care visits to assess potential accessibility needs and accommodations for individuals with disabilities.
	Clearly and prominently identify patient accommodation needs in Electronic Health Records.

	<p>Enable Electronic Health Record pop-up notifications at log-in, advising of accommodation needs (including whether an interpreter is needed), and that require an action such as clicking an acknowledgment button to dismiss the pop-up.</p>
	<p>Provide regular reports to administrative staff and providers that identify upcoming patient appointments where accommodations or accessible equipment is needed.</p>
<p>Equip all health care organizations with tools, assistive devices, medical equipment, and personnel that allow for universal access to all recommended screening and diagnostic tests and treatments.</p>	<p>Ensure that an on-site “Access Coordinator” is appointed and available at all times. This person should be on-the-ground and responsible for providing immediate assistance to staff to locate and implement communication aids and services, schedule interpreters, and assist/troubleshoot issues.</p>
<p>Create accessibility guidelines that go beyond the basic minimum requirements and provide additional access whenever the needs of the population go beyond those minimum standards.</p>	<p>Require that healthcare organizations routinely assess and report on the accessibility of their building (e.g., parking lots, waiting areas, exam rooms).</p>
	<p>Increase the number of accessible parking spaces at health care facilities, rather than meeting ADA minimum requirements.³</p>
	<p>Increase availability of accessible medical equipment (e.g., height adjustable examination tables, accessible mammography equipment, accessible weight scales, and lift equipment).⁴</p>
<p>Ensure that patients are fully aware of the accessibility-related services available to them.</p>	<p>Provide civil rights notice to patients when admitted to hospitals and a list of communication aids and services available.</p>

Other Stakeholders (e.g., Community Organizations, Councils on Aging, etc.)

Recommendations	Potential Strategies
Provide navigation and supportive services to people with disabilities and their families/caregivers.	<p>Nurture peer navigation and support programs that pair individuals with disabilities with peers who have expertise and experience successfully navigating the health system.</p> <p>Explore opportunities to offer or expand case management and care coordination services for individuals with disabilities with both public and private insurance plans.</p> <p>Advocate for supportive services for parents and caregivers of children with disabilities.</p> <p>Incentivize partnerships between health care providers and community-based organizations to address common barriers to care (e.g., transportation barriers)</p>
Explore mechanisms to improve timelier access to care.	<p>Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.</p> <p>Use telehealth technologies, such as virtual visits and remote consultations, to deliver services to patients in remote or underserved areas to reduce travel time and costs, and enhance access to care for individuals with limited mobility or transportation options.</p> <p>Explore partnerships with community-based organizations to expand transportation options for medical and supportive visits.</p>

¹ Fong, M. "Mind the Gap: A White Paper on Maine's Missing COVID-19 Surveillance Data, How They Perpetuate Health Disparities of Maine's Citizens with Disabilities, and What Can Be Done to Increase Maine's Public Health Data & Service Equity." University of Maine Center for Community Inclusion and Disability Studies, 2023. Accessed via <https://ccids.umaine.edu/resource/mind-the-gap-a-white-paper-on-maines-missing-covid-19-surveillance-data/>.

² U.S. Department of Health and Human Services, "HPSA and MUAP Shortage Designation Types," <https://www.hhs.gov/guidance/document/hpsa-and-muap-shortage-designation-types>.

³ U.S. Department of Justice. 2010 ADA Standards for Accessible Design. <https://www.ada.gov/law-and-regs/design-standards/2010-stds/>

⁴ National Council on Disability. Health Equity Framework for People with Disabilities. 2022. Retrieved from https://ncd.gov/sites/default/files/NCD_Health_Equity_Framework.pdf