**“I Don’t Get the Care I Need”:**

**Equitable Access to Health Care for Mainers with Disabilities**

Plain Language Summary

## Why did we do this project?

Disability Rights Maine (DRM) knows it is very important for people with disabilities to access health care. In the past, DRM has received many calls and handled cases where people could not get the health care they needed. Recently, the number of these calls and cases has been increasing. This shows that people with disabilities in Maine don’t always have the same opportunities for good health care and wellness as others. Unfortunately, this is often not considered a violation of their rights.

In 2020, the COVID-19 pandemic made these inequalities even more clear. People with disabilities had a hard time getting tested, treated, and vaccinated for COVID-19. Sometimes, people with disabilities were not given the life-saving care they needed simply because of their disability or other health conditions.

In 2022, DRM created a Health Equity workgroup. The goal of this group was to find ways to remove barriers in health care and make it easier for people with disabilities to get the care they need all across Maine. But there was a problem. We did not have enough information about Mainers with disabilities and the challenges they face when they try to get health care. DRM’s Health Equity work group received funding from the Maine Health Access Foundation to conduct a project to get this information. The goal of this project was to collect data and create a report on the barriers to health care for people with disabilities in Maine.

Many research studies have looked at the obstacles and problems from the health care provider’s perspective. Health care providers include doctors, dentists, therapists, and others. Very few research studies have focused on the experiences of individuals with disabilities. DRM hired John Snow, Inc to lead a Health Equity and Disability research project. This research project collected information from people with disabilities about their experiences with health care. John Snow, Inc is a public health consulting company. They help organizations to address health-related issues or problems. The goal of the report is to make meaningful change for people with disabilities by:

* Increasing access to health care;
* Increasing choice in health care; and
* Increasing quality of health care.

## How did we do the research?

We used different ways to learn about the problems that make it hard for Mainers with disabilities to get health care. We looked at what statistics are available. We asked people questions in a survey and had over 600 responses. We had group discussions with about 90 people to understand what is going on. We also looked at information from research articles and reports to get more background information.

## What did we learn?

We grouped what we learned in this project into five topic areas.

### Data Collection

#### What did we learn?

* People with disabilities are not often included in official statistics at the national and state level.
* It is hard to agree on what disability means, so different people ask about it in different ways. This makes the numbers and results different too.
* In Maine, about 16% of people have a disability and in the whole United States, it is about 13%. We need to make sure people with disabilities are counted and represented in statistics.

#### What should we do?

* People should always ask about disability when they collect information in surveys or other formats for statistics or research.
* The statistics about people with disabilities should be kept updated and available for everyone to look at.
* People with disabilities must be included in making decisions and understanding information about public health.

### Provider Education

#### What did we learn?

* Doctors and nurses don’t receive enough training about disabilities, or working with people with disabilities. This can lead to mistakes in diagnosing, delays in getting the right treatments, and other problems for patients with disabilities.
* Recent studies have shown that doctors themselves have concerns, biases, and are hesitant to take care of people with disabilities. [[1]](#footnote-1)
* About 38% of people who took our survey said that doctors and medical staff do not have the right training to treat them properly. 38% is around 200 people.
* In group discussions, people shared how health care providers are not educated and prepared to treat people with disabilities. This includes doctors, nurses, assistants, and staff at the front desk and people who handle administrative tasks.

#### What should we do?

* Doctors and nurses should be trained to give good care to people with all kinds of disabilities.
* People with disabilities must be involved in curriculum development for medical schools. That means they have a say about what is taught in schools and training programs for doctors, nurses, dentists and other people who work in health care.
* We should have more people with disabilities working in health care.
* We need to make sure that the care given to people with disabilities is really good.

### Structural and Systemic Barriers to Care

#### What did we learn?

* More than half of the people who took our survey said in the past five years, there was a time when they needed health care but could not get it.
* About 20% of people who said they could not get health care said it was because the cost was too much or their insurance would not cover the treatment they needed.
* The health care system is made up of many separate parts, which can make it hard for people with complex health care needs. Some people in the group discussions talked about how their health care providers do not communicate well with each other. This communication problem causes them delays and confusion in getting care.
* Some people do not have good options for public transportation. It might not be available or it might not be accessible for them to use. Transportation problems came up in every group discussion.

#### What should we do?

* We should have more money, help, information, and advice available to give better care to people with disabilities.
* People with disabilities and their families or caregivers should have support and help to find their way through the health care system.
* We need to find ways to make it easier and faster for people with disabilities to get the care they need. This includes better communication between doctors, easier insurance processes, and more ways to get from one place to another (like cars or buses).

### Communication

#### What did we learn?

* Almost half of the people (44%) who took our survey said it was hard to talk to their doctors. Common problems included:
  + - Feeling unheard or not believed;
    - Not being spoken to directly; and
    - A lack of accommodations to communicate effectively. Examples of these accommodations might include masks with a see-through window, longer appointments, and online portals that can be used with a screen reader.
* More than 20% of people who took our survey said providers do not:
  + - Listen to what is worrying them;
    - Explain their diagnosis or condition;
    - Answer their questions; and
    - Involve them in making choices about their health.
* Communication issues were talked about a lot in every group discussion.
  + - Many people thought this was because doctors do not know how to talk to people with disabilities.
    - Many people said they feel rushed during appointments and do not have enough time to talk about everything they want to talk about.
    - Deaf and Hard of Hearing ASL signers shared they are not getting the interpretation services they needed.

#### What should we do?

* Doctors and nurses should learn how to talk respectfully and patiently to patients with disabilities.
* People with disabilities should be part of the groups that make decisions about policies and rules so that their communication needs are understood.
* People with disabilities should know their rights and what to do if their rights are violated.
* All of the things we use to talk and share information, like forms and instructions, should be easy for everyone to understand and use.
* When health care workers talk to patients, they must think about how to communicate clearly and keep information private.

### Physical Space

#### What did we learn?

* About one out of every five people who took our survey said the places where they go to get health care are not accessible or safe.
* Many people said it is hard for them to get into buildings and find their way around the different rooms and areas.
* Some people in the group discussions said they could not get the tests or treatments they needed because the medical equipment was not made for people with disabilities. This was especially true for people with physical disabilities.
* People in the group discussions who have mental health diagnoses or labels or are blind or low vision talked about privacy issues. They said:
  + - The places where they have exams are not private.
    - They have to fill out forms where others can see or hear their answers to the questions while someone reads the questions.
    - Their doctors talk to them in hallways instead of private spaces.

#### What should we do?

* Create and improve ways for patients to tell doctors and staff the accommodations they need.
* Make sure all health care organizations have the tools, assistive devices, and accessible medical equipment they need to make sure everyone can have access to all health screenings, test, and treatments.
* Make sure medical offices, their parking lots, exam rooms, and medical equipment are useable by people with disabilities. This may mean making some new accessibility requirements that are better and stronger than the Americans with Disabilities Act (ADA). [[2]](#footnote-2) Tell patients about the services within the health care organization that can help them with accessibility.

## What happens next?

In this report, we learned that people with disabilities in Maine face many challenges when trying to get health care. This can make their health outcomes worse compared to others. Fixing these problems is not easy. It requires a lot of people to work together.

Changing the way things are done takes time and planning. But we need to act quickly to make sure people with disabilities can get good health care like everyone else. While it may take time, there are things that different groups can do right now to improve access and fairness in health care for people with disabilities.

Health care organizations and workers can make changes like training their staff to understand and help people with disabilities. They can also make sure their buildings and communication methods are accessible to everyone. Health care organizations and groups that advocate for people with disabilities can work together to create new programs and services that meet the specific needs of people with disabilities. Organizations serving people with disabilities can raise awareness, push for changes, and give important information about what people with disabilities need and experience. Lawmakers can make new rules that make health care places accessible, inclusive, and fair for everyone.

Disability Rights Maine hopes this report will lead to change. We hope those working inside and outside the health care system follow the suggestions and find new ways to break down barriers and improve health care for people with disabilities.

We need to keep working together. We need to never give up. We need to make sure that everyone gets the same chance to have good and respectful health care. It may not be easy, but it is possible. Let’s join hands and build a system where everyone, no matter their abilities, can access the health care they need, with dignity and fairness.

1. Lagu, T., Haywood, C., Reimold, K., DeJong, C., Walker Sterling, R., & Iezzoni, L. I. (2022). ‘I Am Not The Doctor For You’: Physicians’ Attitudes About Caring For People With Disabilities: Study examines physician attitudes about caring for people with disabilities. *Health Affairs*, *41*(10), 1387-1395. [↑](#footnote-ref-1)
2. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 (1990). <https://www.ada.gov/pubs/adastatute08.htm> [↑](#footnote-ref-2)