What do the structural and systemic barriers to care look like?

Systemic and structural barriers make it difficult or impossible for people with disabilities to access care. People with disabilities often face disadvantages, due to discrimination in the workplace and other areas of life, that make it challenging to find and keep jobs.

- In Maine, the unemployment rate for people with disabilities is 11%, more than double those without (4%).
- With lower employment, fewer people can access employer-sponsored health insurance. MaineCare has income and asset limitations that impact eligibility.

About 27% of people with disabilities in the U.S. reported not receiving needed medical care, compared to 12% of people without disabilities.

- Some insurance plans do not provide adequate coverage for needed services such as assistive technology, home modifications, and durable medical equipment.

Transportation barriers prevent people with disabilities from accessing care when and where they need it.

The fragmented health care system means people receive care from many providers. This causes:

- risk of duplication of care,
- poor coordination of services, and
- extra costs.
Cost and Insurance

57% of survey respondents reported a time in the past five years where they needed health care but could not get it.

- 21% of those survey respondents said care was too expensive or insurance did not cover the service.
- Some people don’t have insurance because they earn too much to qualify for MaineCare, but also cannot obtain private insurance through their employer or CoverME.gov.

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.

- More than 370,000 Mainers live in regions with dental provider shortages.

The high cost of prescription medications, regardless of insurance coverage, means many cannot purchase their medicine.

Standard insurance plans do not include dental, hearing, or vision services coverage.

Participants raised questions about the decision-making process used by insurance providers, specifically regarding treatments, diagnostic tests, or services that fell outside the coverage provided by their plans.

- A desire for transparency and clarity reflects concerns about how insurance coverage decisions influence health care options.

“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 too much, even for a simple visit to answer a question or get a diagnosis.”

SURVEY RESPONDENT
Navigation

Participants reported many problems navigating the health care system. Of those who reported being unable to receive care in the past 5 years, 27% cited long wait times as the primary barriers.

- Survey and focus group participants also described difficulty navigating the complex healthcare system without sufficient support.
  - Insurance does not always cover care 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 stable address, phone or internet access, and transportation, make it exponentially more difficult to access or coordinate care.
  - When providers lack coordination, care is fragmented or lacks continuity which can exacerbate medical issues and delay care.

Participants felt providers should be more aware of the services and options available within their local area, region, or statewide.

- Participants 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.
Transportation

11% of survey respondents reported being unable to access health care in the last five years due to transportation issues.

- This barrier was even higher among individuals who are blind or low vision, with 24% reporting transportation as a barrier.

Participants without cars or who could not drive were concerned about the scarcity of affordable and accessible public transportation.

- In many areas of Maine there is no public transportation, taxis, or ride share services.

While MaineCare does provide transportation options, the service can typically only be used for non-emergent MaineCare-covered appointments and requires a request to be submitted at least two business days before the appointment.\(^4\)

- Due to changes made in 2013, logistical challenges have lead patients to report missed rides, negatively impacting their ability to get to important appointments.\(^5\)

"[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

1. Increase opportunities to access funding, resources, and technical assistance to better care for people with disabilities.

2. Provide navigation and supportive services to people with disabilities and their families/caregivers.

3. Explore mechanisms to improve timelier access to care.

References:


2. Maine Health Insurance Marketplace (coverme.org)


4. Maine Department of Health and Human Services, “Member Transportation Resources,” https://www.maine.gov/dhhs/oms/member-resources/transportation