

Access to Health Care for People with Disabilities in Massachusetts: Key Results of a Focus Group Study



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From January through May 2000, the Health and Disability Working Group (formerly the Medicaid Working Group) at the Boston University School of Public Health conducted a series of focus groups on access to health care for people with disabilities. The goal of these focus groups was to get some first-hand information from a wide range of people with disabilities about their experiences with the health care system and health care providers. We hoped to use the information we obtained to create consumer and provider surveys for a study of access to health care for people in Massachusetts funded by the National Institute on Disability Research and Rehabilitation (NIDRR).

The focus groups included people with a wide range of disabilities and covered access to the full continuum of health care services, from outpatient dental visits to inpatient psychiatric care. They were conducted in eastern, western, and central Massachusetts, with people from a variety of ethnic backgrounds. One group was conducted entirely in Spanish; a second was conducted in English with Spanish translation. The groups included individuals with Medicaid, Medicare and private insurance. Although the focus groups included a broad cross-section of people, they were a convenience sample, and therefore representative only of themselves.

Focus groups were conducted with seven different groups of consumers:

- Adults with severe physical disabilities;
- Adults with developmental disabilities and their families;
- Seniors with chronic health conditions;
- Adults who are deaf or hard of hearing;
- Parents of children with special health care needs;
- Adults with psychiatric disabilities; and
- Adults with HIV/AIDS.

We also conducted an eighth focus group with nurses who work as health care advocates and coordinate care for people with severe developmental disabilities who live in the community.

The survey results demonstrated there were many barriers that were common across different groups of people with disabilities. There were other barriers specific to people with certain types of disabilities. This report summarizes the major barriers to health care described by the focus group members.

Barriers common across disability groups

Insufficient health care coverage was a barrier to accessing providers, medicines, and medical equipment.

People with psychiatric disabilities found that they were limited to community mental health centers or major teaching hospitals because psychiatrists in private practice would not accept Medicaid or Medicare. Poor treatment by providers and staff felt particularly oppressive because they could not seek care elsewhere.

Because Medicaid reimburses dental services at a low rate, members of many groups reported costly and time-consuming travel to dental schools in Boston to find dentists who would accept Medicaid. The care available closer to home was often inadequate. People with HIV in central Massachusetts reported that dental clinics that accepted Medicaid in their area were so busy that patients had to wait two weeks after their first appointment to call to schedule their next appointment.

One woman on Medicare poignantly described the impact of her lack of prescription drug coverage. She had to apply directly to drug companies as "indigent" to get free medicines, hope before each doctor visit that the pharmacy representative had stopped by recently with free samples, and try to ensure that the doctors liked her so that they would give her free samples.

Inadequate reimbursement by Medicaid and Medicare led to problems with medical equipment and supplies. People with physical disabilities and developmental disabilities reported that wheelchairs could only be replaced every five years. Sometimes they held their wheelchairs together with duct tape. People who were using inadequately repaired wheelchairs were more likely to fall out and injure themselves. Repairs were also difficult to get because of low rates of reimbursement.

Lack of reimbursement was also a problem for many other kinds of equipment, such as beds, walkers, and oxygen, and medical supplies, such as supplements, catheters, and skin and wound care supplies. For example, one woman reported that although Medicaid would reimburse for 200 catheters per month, they would only reimburse for 50 pairs of sterile gloves, so she had to pay for the rest out-of-pocket.

Deaf and hard of hearing adults had difficulty getting reimbursed by Medicaid for certain types of hearing aids. For people who become deaf as adults, and for families who need to learn sign language to communicate with their children, sign language classes are a form of rehabilitation. However, participants reported that Medicaid did not reimburse for these classes.

Members of many groups reported difficulty navigating the health care system and managing their health insurance.

In the HIV group, two people reported that they had difficulty getting their prescriptions because the pharmacy did not charge the correct co-pay. Another person who had to spend down to become eligible for Medicaid incorrectly paid over \$1,000 out-of-pocket because he did not have the correct information about the spend-down rules.

Other members of the HIV group said that when they went to a nearby emergency room, they were transferred to the emergency room at a different hospital because they had Medicaid.

The focus group of nurses reported that their clients with developmental disabilities who were on Medicaid sometimes seemed to be switched from a fee-for-service system to an HMO without notification. Or maybe their clients received a letter in the mail but did not understand it. These nurses frequently tried to advocate for their patients with Medicaid, but one nurse commented, "every time I have to call Medicaid, I cringe."

Parents of children with special health care needs reported unending, draining battles with private insurance companies over payment of claims. They also reported a problem particular to children: because many health-related services are provided to children through their school, parents reported frequent battles over whether the school or their health insurance plan was responsible for funding certain tests or services. These battles could delay services or an evaluation for up to a year.

A senior with chronic illness said he had not been notified when his doctor left his clinic. At his next visit to the clinic, he discovered that he had been switched to another doctor. His records were not transferred for months.

Members of every focus group reported experiencing **stigma and disrespect**.

Members of the HIV focus group felt they had experienced prejudice during surgical procedures, in doctors' offices, and in the emergency department. "I can see them drawing back from me," said one member. People with HIV found that many dentists who accepted Medicaid would not perform certain procedures on them because of fear of infection. The members of this group also felt that front desk staff were often rude on the telephone or in person and sometimes presented barriers to speaking directly with the doctor. However, they did not necessarily attribute this to their HIV status.

Stigma was also an important issue for the people with psychiatric disabilities. They commented that sometimes clinic staff, "have the attitude that we're all street people," and treated them disrespectfully. One person who sought treatment for an adverse reaction to antibiotics did not receive appropriate treatment because the provider assumed her symptoms were psychiatric in origin.

People with physical and developmental disabilities also felt stigmatized. Members of the focus group on physical disability reported that providers often thought they were cognitively disabled as well.

One family member of a person with a developmental disability described providers' attitudes as, "I don't want to touch you but I have to." The nurses described people with severe developmental disabilities being put in separate rooms to wait to see the doctor in order to hide them from the other patients. The nurses also reported that their patients received less aggressive care because their lives were viewed as less valuable. For example, one patient waited a whole year

for breast cancer surgery because her guardian and her doctor felt her quality of life was too poor to warrant such intervention, although her residential staff vehemently disagreed.

Stigma, disrespect, provider ignorance, and the urgency of the setting combined in the emergency room to make it the most dangerous and frightening health care setting for many people with disabilities.

A woman with severe cerebral palsy described being in the emergency room when she vomited. She reported that the staff refused to clean her up and said they did not care if she aspirated the vomit. "So now I am afraid to go to the ER," she said. Other people with severe physical disabilities shared her fear.

The focus group of nurses reported that some patients with severe developmental disabilities were not given anesthesia because providers thought they did not experience the same levels of pain as other people.

Deaf people were reluctant to seek emergency care because they were unlikely to be able to communicate effectively with the emergency room staff.

Parents of children with special health care needs said that providers often did not listen to them when they explained how to approach their child. As a result, the children became upset, their behavior was difficult to control, and sometimes it was impossible to give them appropriate treatment. Advocates for people with developmental disabilities reported similar problems. Providers often would not listen to them when they explained how to approach the person they were advocating for. Sometimes providers refused to let advocates accompany patients.

Difficulty finding knowledgeable providers was a problem for people with developmental disabilities and others with complex medical conditions, particularly when they did not live in the Boston area.

People with developmental disabilities had difficulty finding providers who understood their medical condition or disability. One nurse reported that providers often said, "You brought these people in here, and I don't know a thing about mental retardation." The family member of a woman with Down's syndrome and Alzheimer's disease reported that physicians knew very little about the interaction of these two conditions.

One parent of a child with special health care needs reported that she had given up on finding someone who could test her child's hearing or vision. Another parent explained that by the time she realized her son's speech therapist did not have proper training, he had passed out of the critical period for language acquisition.

People also spoke about having to make long trips into Boston to find providers who were knowledgeable about their or their children's disabilities.

Disability-specific barriers

For people with **severe physical disabilities**, transportation and physical access were major problems. For people whose physical disability also affected their speech, communication was a barrier.

Because public transportation is often not physically accessible, many people in the Boston area had to depend upon The Ride, a paratransit system, to get to medical appointments. Focus group participants reported waiting for hours to be taken to their appointment or to be picked up afterwards. They sometimes waited outside in cold or rainy weather. Often they were late for appointments, and a single appointment could take all day.

Lack of physical access made it difficult for people with physical disabilities to see the dentist, receive medical services, and receive mental health and substance abuse treatment. People who could not transfer easily out of their wheelchairs had trouble finding dentists who would examine them in their wheelchairs. If the dentist's equipment could not reach the wheelchair, or if the wheelchair did not recline, a complete examination could not be performed.

People with physical disabilities said they often could not get the help they needed to undress at medical offices. Sometimes the staff did not know how to use the medical equipment with them. For example, technicians often did not know how to transfer them to the table for an x-ray. Members of this focus group also said that when they were in the hospital it was difficult to get a call button they could control.

Access to mental health and substance abuse services was also a barrier for this population. Most psychiatrists' offices were not large enough to accommodate a gurney, or the provider was unwilling to move the furniture to accommodate the patient. For inpatient mental health or detoxification services, a major barrier was access to personal care. People who needed help with toileting, feeding, or bathing could not use inpatient services when this assistance was not provided.

People who had difficulty with speech said that providers and staff often did not take the time to try to understand them on the phone or in person. One woman reported that providers asked her, "Why didn't you bring someone with you?" as if she were not competent to speak for herself.

For people with **severe developmental disabilities**, a combination of physical and cognitive disabilities, complex medical conditions, systems issues, and stigma were major barriers to getting dental and gynecological care.

Consumers with developmental disabilities who also had physical disabilities sometimes needed to be seen in their wheelchairs. Some people with significant cognitive disabilities required sedation when undergoing dental procedures. If general anesthesia was required, the dental procedure had to be performed in an operating room. Because few dentists have access to operating rooms, the wait for elective procedures could be long. In some cases, a guardianship process had to be completed to give consent for the procedure. The nurses' focus group reported that these factors sometimes delayed dental work for so long that patients were exposed to serious risks, such as septicemia.

Gynecological care posed similar challenges. In addition, people with developmental disabilities had trouble understanding why they needed to undergo such an invasive exam. They had difficulty lying still and sometimes needed sedation.

The nurses reported that appropriate dental services and other medical services were available to people with developmental disabilities at specialized facilities. These were often former state institutions. These facilities were sometimes the most efficient way to provide health care that people with developmental disabilities needed. However, the disability rights movement has been firmly against segregation. Use of the specialized facilities was seen as providing segregated care, so the agencies that care for people with developmental disabilities were discouraged from using them.

Communicating with providers was the most serious problem for people who did not speak English or were deaf or hard of hearing.

Seniors w/chronic illnesses who did not speak English said that communication severely limited their access to health care. Often, these seniors did not use the phone to make appointments, but instead went in person to the hospital or clinic. However, they also had difficulty finding their way on public transportation. In addition, they had a hard time finding interpreters, particularly in the smaller clinics; completing paperwork; and finding providers' offices.

For **people who are deaf and hard of hearing**, communication was the central barrier to health care. Telephone communication with providers was difficult because many providers did not have or did not know how to use a TTY. As a result, deaf people sometimes went in person to a medical office to make an appointment. A deaf man reported that it was not until a few years ago that he realized one could call a doctor's office to receive medical advice.

Focus groups members said that accessing interpreters was very difficult. Providers did not know how to request or schedule an interpreter. Interpreters often were not available even when scheduled in advance or when urgent care was needed. Some focus group members sign but are not fluent in American Sign

Language (ASL). They required not only an ASL interpreter but also a second interpreter who could translate between their signs and ASL.

Focus group members reported that writing was not an adequate substitute for verbal communication because much less information was conveyed. They described providers as unwilling to take the time to write down all the information they would convey verbally. Members also said that when providers wrote, they often used medical language that members could not understand. Although models and illustrations were extremely helpful, most providers did not have them or were unwilling to take the time to use them. Some focus group members said they delayed seeking health care because communication was so difficult.

Conclusion

From the focus groups we found the following key points:

- Most people with disabilities obtain the essential medical services they need;
- Inadequate health insurance, lack of accommodation, and disrespect make accessing health care frustrating and humiliating;
- Many people with disabilities must expend an enormous amount of energy and time in order to receive adequate health care; and
- Delays in receiving appropriate health care limit functioning.

Most participants eventually got most of the essential medical services they needed. The one exception was people with severe developmental disabilities. Sometimes the health care they needed was delayed for so long, because of prejudice, complex medical needs, and the difficulty of coordinating systems, that their health was threatened.

Participants frequently reported feeling angry, frustrated, and humiliated by inadequate health insurance, lack of accommodation, and disrespect. For example, inadequate health insurance benefits meant that one woman had to depend on a provider's goodwill for her medication. Lack of accommodation for people with severe physical disabilities meant that they were sometimes transferred roughly or unsafely from their wheelchair to a table for an exam or x-ray. Parents of children with special health care needs were frustrated when providers would not listen to them explain what their child needed. People with HIV and psychiatric disabilities felt that providers and staff often treated them like second-class citizens.

For many participants, getting the health care they needed consumed vast amounts of physical and emotional energy. Battling with their health insurance plan, coordinating transportation, finding accessible providers, and organizing interpreters meant they did not have the time to pursue other important goals in their lives.

Delays in getting health care and difficulty in getting the appropriate health care services limited people's functioning. For example, when people with physical disabilities could not get timely wheelchair repairs, they could not leave their home.

People of all abilities need accessible, responsive health care. For people with disabilities, lack of funding, prejudice, ignorance, and poorly designed and coordinated systems make getting health care services unnecessarily difficult, demeaning, and exhausting. Creating more accessible health care will require the input of all stakeholders: policymakers, purchasers, providers, and consumers. Comprehensive consumer input is crucial to identify the limitations of the current system and the changes that are needed.