

Key Issues for Disabled Health Care Consumers

I am fifty-seven and I didn't have a mammogram until last year, because my doctor never referred me. I guess he didn't think it was important for someone in a wheelchair. This isn't good, since my mother died of breast cancer, which I wrote on all the forms. -Disabled focus group participant

In order to challenge the barriers to health care access, disabled consumers and their allies must understand the range of barriers to quality health care in the current health care system. Priority concerns for quality care and full access are addressed below, with quotes from disabled people and providers helping to illustrate the concepts. Your job as a trainer and supporter is to understand these concerns and be able to present effective strategies for overcoming them.

Consumers with Disabilities Have Greater Health Care Needs

She came in with a folder of a dozen forms for me to complete. She said she needed them right away. I told her, "I can't do that now." She left my office. My rationalization was that she's not coming to see me, she just wants a signature. I'm a doctor, not her secretary. -Physician focus group participant



People with disabilities utilize health care resources at a higher rate than people without disabilities, despite the challenges they face in getting those services.[6] Impairments are one reason why many people with disabilities need to make more frequent visits to their medical providers. However, often other non-medical reasons require people with disabilities to see physicians, such as getting certified as "disabled" in order to receive Social Security benefits, Medicaid, wheelchair transportation, personal care attendant benefits, or other services. Physicians sometimes resent bureaucratic intrusions and don't fully comprehend the hoops disabled people have to jump through in order to get the benefits and community resources they need for survival.

Furthermore, some physicians don't accept patients covered by public health insurance programs like Medicaid. Because many people with disabilities are low-income, they are six times more likely to be covered by Medicaid than non-disabled people,[7] and thus the only available form of medical insurance to many becomes a barrier to health access. Recent changes in health care law mean that over the next several years, the health care system will gradually change. Hopefully, these changes will alleviate financial barriers to medical access, but the impact of these changes remains to be seen. [Click here](#) to read more about how health care reform is changing health care for people with disabilities.

Barriers to Physical Access

I've never been to a pediatrician's office with my kid where I could fit with my wheelchair. They don't expect anybody in a wheelchair to have children, which I find not only offensive, but also inconvenient. Disabled people do have children. -Disabled focus group participant

Barriers to physical access, also known as structural barriers, are caused by the way buildings and their surroundings are designed. Barriers to physical access are things you encounter on your way to a specific location that hinder or prevent you from reaching your destination. Barriers to physical access can be outside or inside. Parking areas, passenger drop-off and loading zones, ramps, grates, access lifts, entrances, paths, walkways, sidewalks, or stairs can all turn out to be outside barriers to physical access. For example, if you use a wheelchair and arrive by car at a hospital for a checkup and discover there is no curb ramp that allows you to safely approach the building, you have encountered an outside barrier. A building's exits, elevators, stairs, restrooms, or inaccessible diagnostic equipment can be inside structural barriers.[8] For example, if you have a mobility impairment and your doctor's office is on the fourth floor of a building that does not have an elevator that is accessible to you, you have encountered an inside barrier. Many facilities do not have adjustable exam tables and mammography equipment that enable better access for individuals with mobility disabilities.

Barriers to Program Access



Barriers to program access, also known as programmatic barriers, are caused by the policies and practices that health care providers use. Barriers to program access limit the ways in which information, programs, and services are presented and delivered, preventing disabled individuals from interacting with and fully benefiting from them. Printed and oral information and

instructions, medical equipment, computer systems and programs, and telephone devices can all be barriers to program access. For instance, if you have a hearing loss and the information you need is only presented with a video without captions, you have encountered a barrier to program access.

Need for Cultural Competence

He would ask my sister in front of me, “How is she doing?” Hello! I am your patient. I am an adult, old enough to describe how I feel. I need assistance in the exam room, but I told my sister to wait outside, so I can get the doctor to talk to me. -Disabled focus group participant

Health care services must be provided in ways that

- treat disabled patients with dignity and respect, without uninformed assumptions;
- make access a priority;
- accept disabled individuals as knowledgeable about their own conditions;
- treat disabled patients as partners in their own health care through sharing of information and decision-making.

However, the reality is that people with disabilities often view health care providers as barriers to good health care rather than facilitators.

Medical professionals often have general and diagnostic knowledge about medical conditions that affect people with disabilities, but lack the cultural competence and sensitivity to effectively deliver that care. Discriminatory attitudes can prevent physicians and patients from understanding each other well enough for adequate diagnosis and treatment. Some medical providers regard people with disabilities as passive, childlike recipients of health care. Others believe society’s prejudices regarding disabled people.

These stereotypical attitudes are especially marked when medical providers work with disabled women^[9] and people from racial, ethnic, and socioeconomic backgrounds other than their own.^[10] As a result, both groups are often underserved, misdiagnosed, ineffectively treated, or even put at risk during medical procedures.

I’m a member of the Navaho Tribe, so we’re training ground for their interns coming in from some other place, there for maybe a few months, then they leave and somebody else new comes in and we have to start all over. –Disabled focus group participant

When treating disabled people who are from minority racial and ethnic background and/or are women, health care providers may tend to focus on specific symptoms, ignoring how the broader social context and other health circumstances not directly linked to their disabilities affect the lives of their patients. Discriminatory attitudes may also limit providers’ attention to concerns such as sexuality and mental health.

Medical Service Provider Knowledge of Community Resources

The main insurance I have is Medicaid. Unfortunately many doctors do not take Medicaid. There are many procedures and many prescriptions that are not covered by Medicaid. A lot of durable medical equipment that I need is not covered. –Disabled focus group participant

Up-to-date knowledge and willingness to learn from patients are key factors in the delivery of quality medical care. In the course of developing its training materials, WID conducted focus groups with sixty-five medical professionals to research providers' attitudes towards and knowledge of disability and disability issues and found that many medical providers lacked accurate information about disability and disabled people. Some of the participating physicians made comments like, "I'm impressed to realize that blind people can use computers," while others complained about the high cost of interpreters for deaf people, with no understanding of their necessity for clear communication.[11]

Health care professionals also displayed a lack of knowledge about the numerous community services that have been created *by and for* people with disabilities. Many did not understand what these services offer and do not refer their patients to them when appropriate.

Lack of Attention to Disability in Medical School

I heard about the ADA in med school. It was described as something to work around, expensive and burdensome. It wasn't until I came here for my residency in rehab medicine that I began to appreciate its purpose. -Physician focus group participant



Fifty-four million disabled individuals live in the United States,[12] yet physicians and medical education programs still don't seem to recognize the importance of learning more about disability issues, the ADA, and cultural competency. They place little emphasis on dealing with disability and offer inadequate clinical experience to prepare medical students and working professionals to provide comprehensive and culturally competent care for people with disabilities. The result is that physicians feel ill-prepared to deal with disabled patients. Furthermore, even when the ADA is addressed in medical education, it is sometimes done in a negative light.

[6] Harris Survey of Americans with Disabilities, 2000, National Organization on Disability.

[7] The 2008 Disability Status Report Rollout. Cornell University, ILR School Employment and Disability School. Ithaca, NY. <http://www.ilr.cornell.edu/edi/DisabilityStatistics/resources/Rollout2008DisabilityStatusReport.pdf> Accessed on May 21, 2010

[8] "Blocked." Lisa Iezzoni, MD. *Health Affairs*, 27, no.1 (2008) 203-209, doi: 10.1377/hlthaff.27.203

[9] Krotowski, D., Nosek, M. & Turk, M., (Eds.) *Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being*. Baltimore: Paul H. Brookes, 1998.

[10] National Healthcare Disparities Report 2003, Agency for Healthcare Research and Quality 540 Gaither Road Rockville, MD 20850 Telephone: (301) 427-1364 <http://www.ahrq.gov/qual/nhdr03/fullreport/priorit2.htm#disabilities>

[11] *Treating People with Disabilities Report to the Center for Health Care Strategies*, World Institute on Disability 2005.

[12] *Americans with Disabilities 2005*. US Census Bureau. <http://www.census.gov/prod/2008pubs/p70-117.pdf> Accessed September 9, 2009.