

The ADA and Changing Perspectives

Training Self-Advocates to Improve Their Medical Care

A lot of polio survivors have clueless doctors. I went to a doctor and he said, “Well, no pain, no gain.” That’s the opposite of what polio survivors should be doing. You’re supposed to listen to your body. -Disabled focus group participant

MAP to Access provides health care advocacy resources and tools to people with physical, sensory, cognitive, and emotional disabilities and their family members and allies. With MAP resources and tools, they can become educated and knowledgeable about their own disability health care access needs and aware of the requirements of the ADA for accessible facilities; learn to ask pertinent questions; and use information and community resources to optimize their own health. Yet most disabled individuals and their family members and allies will want additional training so that they can become effective health care advocates who can inform their medical providers about the concerns and laws that affect people with disabilities.

Therefore, MAP to Access also aims to reach the estimated 25,000 organizations and groups in the U.S. that serve people with disabilities,[1] including centers for independent living, rehabilitation centers, disability rights and services organizations, developmental disabilities centers, networks of group homes, disability support groups, self-advocacy organizations, organizations of parents of disabled children, and disabled student programs. These organizations need to tell individuals with disabilities and their families and friends about MAP and use it to train them to advocate for better health care access. That is why this section of MAP is dedicated to trainers, so that you can get more detailed information and educational tools to help health care consumers review, monitor, and improve the care they are currently receiving.



People with Disabilities and the ADA

The Census Bureau estimates that 18.7% of Americans have disabilities, making this population the single largest minority group in the country.[2] Disability cuts across all socioeconomic backgrounds, geographic areas, and demographic characteristics, including 28 million working-age Americans (ages 21-64).[3] To ensure that the tens of millions of Americans with disabilities have their rights respected and be treated as equals, the United States Congress passed the Americans with Disabilities Act (ADA) in 1990.

The ADA and Health Care

The medical profession, and society in general, wants it to be an either/or situation; you're either healthy or you're sick, disabled or not. My experience being disabled is that my health and well-being is on a continuum, not because I'm disabled, but because I'm a human being. -Disabled focus group participant

The ADA requires the health care system, including both medical care providers and facilities, to respond to the needs of disabled people. Thus, medical professionals must understand that disability is more than physical, sensory, cognitive, or emotional dysfunction. Indeed, environmental, architectural, logistical, societal, and cultural influences all define and impact the health and wellness of disabled individuals at least as much as their biological impairments do.[4]

In this context, health care providers must become aware that appropriate, culturally sensitive care at the outset can avoid unnecessary emergency-room visits, costly case mismanagement, and dangerous secondary conditions down the road. Moreover, they must realize that people with disabilities are not passive and powerless recipients of health care services, nor are they "victims" of their impairments. The ADA and the disability rights movement have raised the bar: disabled people must be viewed as active partners by their health care providers and get access, respect, and quality care.

Changing Perspectives

This new perspective on disability is the result of four decades of research and advocacy rooted in the disability rights and independent living communities, leading to tremendous growth in the provision of community resources by and for people with disabilities. Today, disabled individuals are increasingly empowered and ready to be leaders for change. Health care professionals need to respect this empowerment and become knowledgeable about the expanding range of community resources, including peer counseling, mutual support groups, independent living centers, advocacy groups, and recreational services.[5]

[1] The Complete Directory for People with Disabilities, 2008 Edition, Greyhouse Publishing.

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

[3] Ibid.

[4] Institute of Medicine, Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C.: National Academy Press, 2001.

[5] Healthy People 2010 Disability and Secondary Conditions Conference Report, Sponsored by the CDC and NIDRR, Sept. 20-21, 2002.