

# Cross-Disability Experiences of Barriers to Health-Care Access

---

---

## *Consumer Perspectives*

Mari-Lynn Drainoni, Elizabeth Lee-Hood, Carol Tobias,  
and Sara S. Bachman, *Boston University School of Public Health*  
Jennifer Andrew, *Northeast Health Systems*  
Lisa Maisels, *Massachusetts Department of Public Health*

*In this article, we present the results of a series of focus groups with people with disabilities, in which we took a cross-disability, lifespan perspective of disability. Consumers were asked about a broad set of barriers, such as problems with communication, transportation, and insurance, as well as about barriers related to physical accessibility. We used the Institute of Medicine's framework to categorize barriers as either structural, financial, or personal/cultural. Our results suggest that individuals with disabilities experience multiple barriers to obtaining health care and that these barriers are more pronounced for some types of health care than others. In addition, regardless of disability type, consumers consistently spoke about similar barriers. The results underscore the importance of taking a broad perspective when making policy decisions and the need for continued change and improvement in this area.*

Access to health care is a prominent issue in the United States among consumers, advocacy groups, health-care providers, and policymakers. In February 2004, Americans ranked health care as the second most important matter for the government to address, citing costs as their most pressing health-care concern (44%; Kaiser Family Foundation [KFF], 2004). Amidst escalating costs, the number of uninsured Americans has been increasing, paralleling a reduction in the proportion of Americans with employer-sponsored insurance (U.S. Census Bureau, 2003). Top consumer priorities for specific health-care improvements include lowering health insurance costs, extending health insurance to more Americans, reducing the cost of prescription drugs, and helping families pay for long-term care (KFF, 2004). Access considerations, such as having a wide range of benefits and choice of doctors, are major concerns for Americans when choosing a health plan (Agency for Health Care Research and Quality [AHRQ] & KFF, 2000). At the same time, national efforts to reduce health disparities are focusing increased attention on the access experiences of particular groups, such as women, the elderly, racial and ethnic minorities, and the poor.

## **People With Disabilities as a Distinct Category of Health-Care Consumers**

Americans with disabilities, who constitute nearly 20% of the U.S. population (Centers for Disease Control and Prevention [CDC], 2001; DeJong et al., 2002; U.S. Census Bureau, 2000), are a diverse group and overlap with other demographic groups. Consequently, they are subject to a similarly broad range of health-care-access issues. Overall, however, they report more access problems than persons without disabilities, and these problems tend to be most pronounced for those with the poorest health and most severe disabilities (Beatty & Dhont, 2001; Beatty et al., 2003; Coughlin, Long, & Kendall, 2002; Fouts, Andersen, & Hagglund, 2000; Iezzoni, Davis, Soukup, & O'Day, 2000; Kennedy & Erb, 2002; Long, Coughlin, & Kendall, 2002). It is increasingly imperative that health-care policymakers, planners, and providers understand and address the needs of people with disabilities as a distinct category of health-care consumers. Reflecting this trend, the AHRQ agreed in 1999 to recognize Americans with disabilities as a "priority population" (AHRQ, 2000).

People with disabilities utilize a disproportionate amount of health-care services and constitute one of the largest groups of health-care consumers in the nation, accounting for hundreds of billions of dollars in health-care expenditures annually (CDC, 2001). Adults with functional limitations account for over a third of all physician visits, over 60% of all overnight hospital stays, and over 40% of all prescriptions and refills (DeJong et al., 2002). Given their high rate of health-care utilization, people with disabilities are disproportionately affected by existing access barriers.

People with disabilities also make special types of demands on the health-care system, as their health needs tend to be more complex and ongoing than those of the general population. Postacute and maintenance services are often crucially important to prevent functional decline and secondary health problems in this population, yet these types of care can be challenging to obtain in the American health-care system, as it is based to a great extent on an “acute-care model” (DeJong & Frieden, 2002, p. 7).

In terms of socioeconomic status, individuals with disabilities are less likely to be able to work, more likely to have low household incomes, and more likely to be dependent on federal and state-funded health insurance programs such as Medicare and Medicaid than those without disabilities (DeJong et al., 2002; KFF, 2003b). Although they are somewhat less likely to be uninsured than the general population (DeJong et al., 2002), they continue to experience significant gaps in coverage that cause them to delay or forgo needed care.

People with disabilities tend to be in poorer health and have greater medical vulnerability and a higher prevalence of secondary conditions than the general population (KFF, 2003b; Kinne, Patrick, & Doyle, 2004). Nevertheless, they tend to underutilize basic preventive services (Schopp, Sanford, Hagglund, Gay, & Coatney, 2001; Steinberg, Wiggins, Barmada, & Sullivan, 2002) and frequently use high-cost services such as emergency room care, in part due to worsening health problems resulting from unmet medical needs (Coughlin et al., 2002; Long et al., 2002). Lack of consistent health-care access has been associated with a higher risk of secondary conditions, especially for people with more severe disabilities (National Rehabilitation Hospital Center for Health and Disability Research [NRH-CHDR], 2002a). Because of their “thinner margin of health” (Institute of Medicine [IOM], 1991, p. 283), the medical, functional, and psychological consequences of not receiving appropriate health care in a timely fashion—and the practical implications for their level of independence and social and economic participation—are often considerably magnified (Coughlin et al., 2002; Neri & Kroll, 2003).

## **Health-Care Access and Barriers Since Passage of the Americans With Disabilities Act**

The Americans With Disabilities Act (ADA), signed into law in 1990, is the most significant civil rights legislation to date per-

taining to persons with disabilities, guaranteeing them equal opportunity in employment, state and local government services, public facilities, transportation, and telecommunications. Title II (Public Services) and Title III (Accommodations) of the ADA relate to services offered by health-care providers and to public accommodations, including accessibility of health-care facilities such as hospitals and professional offices, and prohibit discrimination by health-care providers against people with disabilities (Orlin, 1995; Walk, Ahn, Lampkin, Nabizadeh, & Edlich, 1993).

Some studies suggest that, since passage of the ADA, there has been progress in improving physical accessibility for people with mobility impairments and in the availability of accommodations such as Braille signage and text telephones (Kirby, O’Keefe, Neal, Bentrem, & Edlich, 1996; Pierce, 1998; Schopp et al., 2001; Thapar et al., 2004; Welner, 1998). However, a growing body of research suggests that a host of critical barriers to health-care access persist for people with disabilities (DeJong, 1997).

When examining health-care access and barriers, it is most useful to think broadly in terms of the relationship between patients’ functional abilities and health-care environments, rather than in terms of underlying medical diseases and diagnoses. When consumers attempt to access health-care services, their particular diagnoses have less relevance than does the way in which each patient “touches” the health-care system (e.g., in a wheelchair; without being able to see, hear, or speak). However, among numerous recent survey and qualitative studies, only a handful investigated access issues broadly across disabilities. Most were limited in focus to one or several disabilities/diagnoses and/or to specific age groups, services, or aspects of care.

In its 1993 publication, *Access to Health Care in America*, the Institute of Medicine set forth a conceptual framework for classifying barriers to health care that is useful for thinking about functional limitations and their relationship to such barriers. The IOM framework identified three broad categories of barriers: structural, financial, and personal/cultural. As noted by the authors, these three types of barriers are not mutually exclusive and often overlap and interact with one another.

Structural barriers are impediments to medical care directly related to the number, type, concentration, location, or organizational configuration of health care providers. Financial barriers may restrict access either by inhibiting the ability of patients to pay for needed medical services or by discouraging physicians and hospitals from treating patients of limited means. Personal and cultural barriers may inhibit people who need medical attention from seeking it or, once they obtain care, from following recommended posttreatment guidelines. (IOM, 1993, p. 39)

Research indicates that structural barriers related to insurance and health plans that exist for the general population

tend to be exacerbated for people with disabilities. Commonly reported areas of difficulty include navigating the health-care and insurance systems; finding knowledgeable providers; accessing specialists; obtaining approvals for rehabilitation services, durable medical equipment (DME), and repairs; and coordinating care. Such problems have been estimated in national surveys to significantly obstruct or delay access to needed care for 20% to 30% of children and 30% to 50% of adults with disabilities (Bingham & Beatty, 2003; Krauss, Gullely, Sciegaj, & Wells, 2003). Recent research suggests that these types of structural barriers tend to cut across health-plan types and be most significant for individuals with poorer health status and greater severity of disability (Beatty & Dhont, 2001; Bingham & Beatty, 2003; DeJong & Frieden, 2002; Hill & Wooldridge, 2002; Iezzoni et al., 2000; Krauss et al., 2003; Kroll & Neri, 2003; Long et al., 2002; NRH-CHDR, 2002). Transportation problems, also common among poor Americans and residents of rural areas, may pose substantial obstacles for many people with disabilities, who may have sensory, mobility, or cognitive limitations that impair their ability to effectively travel or find their way to their destination (Taylor & Taylor, 1996).

The literature also documents a number of additional structural barriers unique to persons with disabilities. Physical barriers include insufficient space for wheelchairs and a lack of accessible medical screening equipment essential for early diagnosis of serious diseases, such as breast and cervical cancer (Sanchez et al., 2000; Schopp et al., 2001). Communication barriers may result from a lack of alternative modalities to accommodate people with sensory impairments, such as American Sign Language (ASL) interpreters for the Deaf (Steinberg et al., 2002; Witte & Kuzel, 2000). For people with learning or cognitive disabilities, obstacles to effective care may occur when long wait times are required or providers do not allow enough time to make patients feel comfortable (Councilman, 1999; Lawrie, 1995).

Financial barriers to health-care access often overlap with structural ones; for example, insurance coverage restrictions may put certain services out of reach of lower-income consumers with disabilities (DeJong et al., 2002; KFF, 2003b). A disturbing proportion of people with disabilities report serious problems accessing prescription drugs (32%), dental care (29%), equipment (21%), mental health services (17%), and home care (16%) due to cost (Kennedy & Erb, 2002; KFF, 2003b; Schultz, Shenkin, & Horowitz, 1998). Financial barriers vary considerably by source of insurance coverage, being most pronounced for the uninsured and those with Medicare only. Cost barriers are especially a problem for the near-poor, who may not qualify for special government-sponsored health insurance programs (Broyles, McAuley, & Baird-Holmes, 1999; KFF, 2003b).

Personal and cultural barriers to health-care access that have been documented in the literature include providers' negative attitudes, misperceptions, and lack of knowledge. Providers typically perceive accessibility as a matter of physical access (Sanchez et al., 2000). Negative provider attitudes sometimes result in withholding of treatment or provision of infe-

rior treatment (Paris, 1993). Misconceptions and a focus on the disability rather than the whole person tend to lead to neglect of general and preventive care and failure to counsel patients on issues such as birth control and tobacco use (Burns et al., 1990; NRH-CHDR, 2002; Paris, 1993). For patients, negative experiences in the health-care system, including instances of insensitivity or disrespect, may give rise to distrust of health providers, failure to seek needed care, and reliance upon self-treatment (Steinberg et al., 2002).

## Study Objectives

The goal of the present study was to gain an in-depth understanding of the barriers to health-care access that confront consumers with disabilities, particularly in light of their functional abilities. Whereas previous work has tended to focus on particular groups of people with disabilities, the present study examines consumer experiences across a broad range of disabilities, age groups, and services. Efforts to increase health-care access for consumers with disabilities under the ADA have focused largely on physical access barriers, whereas the current study will highlight the significance of nonphysical barriers as well. Our primary objectives were to

1. document the major barriers to health-care access, including nonphysical access barriers, encountered by consumers across the lifespan and spectrum of functional disability using the IOM framework, and
2. ascertain the impact of those barriers on consumers with disabilities.

To this end, we conducted a series of focus groups with persons with disabilities in Massachusetts in 2000. Focus groups have the advantage of offering participants a "permissive environment" conducive to the expression of wide variety of experiences and opinions (Krueger & Casey, 2000). Participants' comments are allowed to determine the flow of the discussion, so that the ideas most important to the participants may emerge. Not restricted by a predetermined set of response options, the participants are free to raise issues and ideas unanticipated by the investigators.

The Massachusetts sample from this study presented a relatively positive picture of health-care access for people with disabilities. A fairly affluent state, Massachusetts has historically offered relatively generous health insurance programs for people with disabilities. In 2001–2003, it was among the approximately two thirds of states that extend Medicaid to people with disabilities and among the approximately one third of states that offer a Medicaid coverage expansion to those already receiving Medicare (KFF, 2001, 2003a). The state had a pioneering Medicaid buy-in program for people with disabilities, the CommonHealth program, which had no income limit for noninstitutionalized individuals with disabilities. In 2000, average annual Medicaid spending for enrollees with disabilities in the state was \$11,864, exceeding the national av-

erage by more than \$1,900 (KFF, 2000). As in most states, managed-care organizations played a prominent role in the Massachusetts Medicaid program, covering 64% of enrollees in 2002 (Centers for Medicare & Medicaid Services, 2002). However, the majority of Medicaid managed-care beneficiaries with disabilities in Massachusetts were enrolled in the state's fee-for-service Primary Care Clinician (PCC) program rather than HMOs.

## Method

### *Data Collection*

As previously stated, for this study we used a focus group methodology. The focus groups were selected to solicit the feedback of a broad spectrum of key stakeholders in the disability community. The individuals who participated were predominantly health-care consumers with disabilities but also included some proxies, such as parents, caregivers, and advocates. The selection criteria for the focus groups included having at least one permanent disability; showing Massachusetts residency; requiring health-care services within the state; and demonstrating the ability to participate in a focus group given assistance such as personal care, interpretation, or the help of a proxy.

To obtain focus group participants, we contacted organizations and advocacy groups serving persons with specific disabilities, such as Deaf, Inc., and an HIV/AIDS organization, as well as those serving persons with a broad range of disabilities, such as the state's Independent Living Centers. To obtain input from individuals who were unable to consent due to cognitive impairments or their young age, we also contacted a program for parents of children with special health-care needs and a group of nurses for individuals with developmental disabilities. To ensure that we included the full spectrum of ages, we also contacted some senior centers. The groups that we contacted then advertised the focus groups to their constituents. Focus group participants were offered a stipend of \$25 for participation, as well as reimbursement for travel and personal-care expenses, if needed. Spanish language and American Sign Language interpretation were available for the groups that required these services. All focus groups were held in locations that were fully accessible, and groups met in different areas of the state, on different days, and at different times of day. Some groups were held in the evenings, whereas others took place on weekends. In total, 87 people participated in the focus groups, including 64 people with disabilities and 23 proxies.

Eight focus groups were held at various locations throughout Massachusetts between January and May of 2000. Each focus group included between 6 and 15 individuals and was reflective of a different disability or of an age group with a broad range of disabilities. Six focus groups comprised consumers with disabilities, including adults with physical dis-

abilities, adults who were Deaf or hard of hearing, adults with developmental disabilities and their families, adults with psychiatric disabilities, adults with HIV/AIDS, and seniors with chronic medical conditions. A seventh focus group was made up of parents of children with disabilities, and the final group included nurse health-care advocates and care coordinators for people with severe developmental disabilities.

The focus groups were held in different parts of the state to include individuals living in urban, rural, and suburban areas. We estimate that roughly one third of the people with disabilities represented in the focus groups (directly or indirectly) were minorities. The group of seniors consisted entirely of Latino seniors and was conducted in Spanish. The HIV/AIDS group was made up of predominantly African American and Latino individuals and included Spanish translation. The majority of participants in the remaining groups were White. The group of Deaf and hard-of-hearing individuals included American Sign Language (ASL) translation. Gender representation among the participants with disabilities was fairly balanced.

Each focus group was led by two members of the research team and audiotaped with the participants' permission. A focus group interview guide provided a general framework for the conduct of each session. In response to participants' comments, the investigators sometimes used additional follow-up probes to obtain further information. One member of the research team took the lead in conducting each focus group. Each focus group lasted approximately 2 hours. The recordings of focus group content were transcribed for purposes of analysis.

### *Data Analysis*

Data from the focus groups were analyzed using the standard qualitative analytic techniques of grounded theory, which involves using a process-analytic framework and inductive logic to allow the categories of data to evolve throughout the analysis and from within. We utilized the Constant Comparative Method, described by Glaser and Strauss (1967), to begin our qualitative analysis. Under this framework, a set of conceptual categories was developed and applied to the initial focus group transcription on the basis of participant comments about the barriers they experienced. Then, as we examined transcriptions of the other focus groups, we either incorporated the new into the existing categories, revised the existing categories to allow for a better "fit" of the new data, or added new categories if needed. This method allowed us to capture all of the diverse commentary of the focus group participants in an organized manner.

The qualitative analysis revealed patterns in the types of barriers experienced by the focus group participants when they accessed, or attempted to access, health-care services. Then, to find a model to classify the responses that we found, we used the conceptual framework set forth by the Institute of



Medicine discussed above. Using the IOM framework, the barriers were organized into the IOM categories of structural, financial, and personal/cultural barriers to health care to provide an overall context, with the recognition that many of these experiences may fall into more than one type of barrier to health care.

## Results

The focus group participants described a variety of barriers to health care. The major types of access barriers reported and examples are summarized in Table 1. Structural barriers involved health-plan and insurance policies and procedures, transportation, the physical environment, communication with providers and staff, time constraints, and care coordination. Financial barriers included cost-related problems when accessing specific providers and services; prescription and over-the-counter medications; and equipment, repairs, and supplies. Personal and cultural barriers related to the care given by the provider included providers' insufficient knowledge, misconceptions about people with disabilities, instances of insensitivity and lack of respect, failure to take patients or their caregivers seriously, and reluctance or unwillingness to provide care, and also related to cultural gaps between patient and provider.

Although, overall, focus group participants reported that they were able to obtain many of the essential medical services they required, they frequently encountered delays and frustrations when they attempted to access care, and at times they did not receive the care they needed when they needed it. In some cases, repeated experiences with barriers led individuals to avoid seeking needed care.

### *Structural Barriers*

#### **Health-Plan and Insurance Policies and Procedures.**

Participants in several focus groups cited difficulties with Medicaid eligibility and the Medicaid service delivery system. The complicated issue of "spending down" to become financially eligible for Medicaid services caused confusion and resulted in overspending of personal assets in at least one case. Advocates and caregivers also described the bewildering system of fee-for-service (PCC) versus HMO options within Massachusetts' Medicaid managed-care program. Consumers' ability to navigate the system was made more difficult by what appeared to be sudden changes in health-plan type, approval requirements, and covered benefits. At times, it seemed that individuals were transferred without their consent from a PCC to an HMO; many consumers did not realize that if they did not choose the PCC plan or an HMO in advance, Medicaid administrators would assign them to a plan.

Insurance companies' policies limiting coverage to particular providers were cited as another barrier to care. Most in-

surance companies, particularly managed-care plans, have provider networks. Many participants expressed dismay at their insurance company's lack of understanding of their, or a family member's, disability and the medical services required to properly treat the condition. Many times a provider with whom a person with a disability had had a long-term, successful relationship was not in the provider network of a particular health plan. And, for low-incidence conditions, some health plans did not have providers with requisite areas of expertise. One parent described how, when her daughter with Down syndrome needed a specialist to conduct vision and hearing tests, the insurance company refused to refer the child to an appropriate specialist, insisting instead on sending her to an in-network provider without expertise in working with the disability.

Focus group participants reported significant delays in care due to lengthy insurance authorization procedures. An individual with HIV reported waiting months to obtain Medicaid approval for neuropsychological testing. The parent of a child with special health-care needs described the bureaucratic frustrations that families face: "We've found that the insurance company often denies things the first time. Then, you have to call back several times, every time getting a different person, and no one can actually help." Approval issues became even more complex when more than one potential payer was involved. One parent stated that her child had to wait over a year for a speech and language evaluation due to a dispute over whether the service would be covered by her health insurance company or the child's school system. These types of coverage disputes also led to reimbursement delays, causing financial hardship for some families.

**Transportation.** Individuals in almost all of the focus groups cited transportation problems as a barrier to accessing health care. Persons with disabilities living in geographic areas that lacked providers specializing in their specific condition often had to travel great distances for treatment. Several individuals living in the central or western part of the state reported having to travel to Boston to see many of their providers.

To travel these distances, patients often required special transportation accommodations in the form of The Ride and the Medicaid transit system, both publicly funded programs. Many participants reported problems with these transportation systems. Patients were frequently picked up or dropped off "a couple of hours early or late," which transformed medical visits into "a whole-day affair." Patients often missed appointments due to late rides, regardless of how much advance notice they provided to the transportation services. One Deaf participant recalled, "One time, I took The Ride . . . to sign language training. By the time they got me there, I was one-and-a-half hours late. No one was there. So, I got some money and took the bus home."

In addition to time delays, the eligibility requirements for publicly funded transportation for persons with disabilities prevented some individuals with disabilities from accessing

TABLE 1  
Barriers To Health-Care Access

Barrier	Examples of barriers for focus group participants
<b>Structural</b>	
Health plan and insurance	<ul style="list-style-type: none"> <li>• Confusion about financial eligibility for Medicaid and “spend-down” rules and about managed-care options and assignments</li> </ul>
Policies and procedures	<ul style="list-style-type: none"> <li>• Sudden changes in covered benefits and approval requirements, as well as in length of authorization procedures</li> <li>• Insurance companies’ lack of knowledge about disability and needed services</li> <li>• Conflicts over health insurance or school system coverage for services</li> </ul>
Transportation	<ul style="list-style-type: none"> <li>• Unreliable service and ineligibility</li> </ul>
Physical environment	<ul style="list-style-type: none"> <li>• Inaccessible equipment and lack of adaptive equipment</li> </ul>
Communication with providers	<ul style="list-style-type: none"> <li>• Inadequate accommodations for Deaf consumers</li> <li>• Office staff’s impatience with speech difficulties</li> <li>• Providers’ use of communication style that is inappropriate for patients’ comprehension level</li> </ul>
Time constraints	<ul style="list-style-type: none"> <li>• Insufficient time at visits to address complex needs</li> </ul>
Care coordination and continuity of care	<ul style="list-style-type: none"> <li>• Poor coordination within provider’s office and among different medical and other service providers</li> <li>• High provider and staff turnover</li> </ul>
<b>Financial</b>	
Providers and services	<ul style="list-style-type: none"> <li>• Lack of coverage for needed providers and services not considered “medically necessary” or “rehabilitative”</li> <li>• Few dentists accept Medicaid</li> </ul>
Medications	<ul style="list-style-type: none"> <li>• Limits to prescription coverage and high co-payments</li> <li>• Lack of insurance coverage for over-the-counter medications</li> </ul>
Equipment, repairs, and supplies	<ul style="list-style-type: none"> <li>• Prior approval process for coverage of needed equipment and supplies and lengthy coverage appeal processes</li> <li>• Unfair return policies for defective equipment</li> <li>• Inadequate coverage of equipment and supplies</li> </ul>
<b>Personal/Cultural</b>	
Insufficient knowledge	<ul style="list-style-type: none"> <li>• Physicians’ lack of knowledge about medical issues related to disability</li> <li>• Providers’ not using adaptations required for effective care</li> <li>• Providers’ being unaware of where to refer patients with disabilities</li> </ul>
Misconceptions about people with disabilities	<ul style="list-style-type: none"> <li>• Assumptions that patients with physical disabilities are cognitively impaired</li> <li>• Beliefs that patients with developmental disabilities (DD) do not feel pain and do not require anesthesia</li> </ul>
Insensitivity and disrespect	<ul style="list-style-type: none"> <li>• Segregation of patients with disabilities from general waiting area/other patients</li> <li>• Impatience with incontinence, vomiting, etc.</li> <li>• Staff/nurses preventing patients from communicating directly with doctors</li> </ul>
Failure to take patients/caregivers seriously	<ul style="list-style-type: none"> <li>• Assuming symptoms reported by patients with mental illness were psychosomatic</li> <li>• Ignoring parents’ warnings about child’s medication reaction</li> </ul>
Reluctance/unwillingness to provide care	<ul style="list-style-type: none"> <li>• Dentists’ reluctance to treat patients with certain disabilities, such as HIV or DD</li> <li>• Downplaying importance of gynecological care for patients with DD</li> <li>• Belief that MR/DD impacts quality of life so that surgery for advanced breast cancer is not necessary</li> </ul>

these services at all. Blind and Deaf individuals noted that Medicaid did not consider their disabilities to be “medical” conditions and therefore would not pay for them to use those transportation services.

**Physical Environment.** Some participants with mobility limitations reported that providers had trouble transferring them onto examination tables when they needed special tests, such as X-rays. They also reported having difficulty obtaining necessary adaptive equipment, such as nurse call bells and bed adjustment controls. One woman stated that when she goes to the doctor she needs a Personal Care Assistant (PCA) to assist with activities such as removing clothing, but she has difficulty paying for several hours of PCA services in addition to what she is approved for. Accessibility of dental services posed significant challenges for some individuals. One woman reported that she has been unable to find a dental provider because most dentists, even those at university-based dental schools, tell her they are unable to offer services unless she gets out of her wheelchair.

**Communication With Providers and Staff.** Many individuals with speech or hearing impairments described communication problems when they attempted to contact providers’ offices by telephone. Deaf individuals cited a lack of TTY machines or staff properly trained to use them in health-care settings. At times, rude or impatient staff further complicated patients’ attempts to reach their providers. A woman with a severe physical disability reported, “I speak a little slower, and people don’t understand me. I speak on a speakerphone, and if I’m not close enough, they can’t hear me.... I have my aide tell them to be patient. Sometimes, they get annoyed and hang up on me.” Several participants described difficulty using automated telephone answering systems, which caused delays as patients attempted to navigate through them, and were inadequate in urgent situations.

Deaf individuals cited difficulty obtaining ASL interpreters for medical visits on short notice and gaps in understanding caused by provider attempts at written communication. Furthermore, providers were sometimes unwilling to write out their findings or, if they did, used medical terminology that the patients did not understand.

These types of communication barriers had serious practical, emotional, and health consequences for some individuals. A Deaf participant described the terrifying experience of having to undergo surgery without knowing what was going on:

I needed a tonsillectomy. I went to the hospital and I was scared. I was sedated and anesthetized, and I woke up afterwards, scared and crying. I didn’t know what to expect or what was going on with the swelling. There was no interpreter there.

Inadequate communication occasionally had tragic results, as one participant related: “One [Deaf] man was given

anesthesia that he was allergic to—he tried to tell them—and he died.” Even in more routine situations, communication barriers often delayed patients’ medical visits or deterred them from seeking necessary care. Another Deaf individual noted that due to the problems they commonly encounter, “there are a lot of Deaf people who won’t go to the doctor” and instead perform self-care; when a health issue arises, they tend to take the attitude, “I’ll just bear with it until it goes away.”

Although not disability specific, communication barriers resulting from a lack of foreign language translators and providers’ communication styles were cited several times. Language barriers were particularly an issue for the participants in the elder Latino focus group. Some were forced to travel to provider offices to make all of their appointments in person so that they could find a staff member who spoke Spanish. One Latina participant stated that she never received reports on her health from her doctor, and another reported delaying surgery three times because the translator was unavailable. Some English-speaking participants reported communication barriers due to providers’ communication styles. A woman with a psychiatric disability said she believed that her providers deliberately “speak over her head” so that she is unable to understand them.

**Time Constraints.** Some focus group participants indicated that because of their complex issues and special needs, obtaining thorough and appropriate health care would generally take more time for them than for patients without disabilities. Given the short time allotted for medical appointments and many providers’ tendency to be in a rush, they often had trouble obtaining the care they needed. One mother described the difficulties she experienced in obtaining dental services for her son with developmental disabilities: “[We] can’t really get full care. It’s hard to find people with the patience to work with him, because he has to be given general anesthesia. When he was a child, he had to get caps put on his teeth, and this was a two-hour process.... Dentists don’t want to deal with the hassle.”

Participants pointed out that providers’ limited time with patients often compounded communication challenges. A Deaf woman who can read lips reported, “The doctor in the office is always in a hurry, talking too fast.” Providers do not always take the time to check patients’ understanding, as another Deaf participant related: “I’ve been given medications when I don’t understand what they’re for. It takes patience, and the doctors act like they have no time.”

**Care Coordination.** Members of several focus groups noted that their health-care providers often did not communicate with one another or did not do so effectively. Individuals with psychiatric problems cited a lack of coordination between their mental health providers and other specialists. Parents of children with special health-care needs commented on the lack of communication between their children’s health providers and school systems. One mother described her struggles to fill in the gaps in care coordination: “I spent a

whole year trying to integrate our psychiatrist's plan into the school system. The school system wouldn't work with the psychiatrist, and they kept putting up barriers, like saying they didn't have a speakerphone for conference calls or not responding to emails." Parents were frequently required to synthesize "bits and pieces" of information from different specialists and make ultimate decisions for their children themselves.

Some participants cited a lack of effective communication between providers and their staff, which led to difficulties with care coordination. For example, one woman described a lack of knowledge about providers' schedules among the staff at her physician's office, which meant that she had to seek out the doctor herself to make an appointment with him directly.

Care coordination challenges were particularly problematic for patients with speech or hearing impairments, and providers sometimes seemed unaware of this issue. As one Deaf participant described, "When [doctors] want me to see another specialist immediately, they say, 'Here's their phone number. Call them today.' The doctor doesn't even think about how the [specialist] doesn't have a TTY."

High turnover of providers and staff was described as an important obstacle to both care coordination and continuity of care. A nurse for individuals with mental retardation lamented that "as soon as you get to know a [provider], they leave." Nurse-advocates pointed out that providers' ability to become familiar with individual patients' issues and behaviors over time is particularly vital for individuals with cognitive impairments, who may be unable to articulate their experiences and needs verbally.

### *Financial Barriers*

**Providers and Services.** Given the high cost of health care, many focus group participants were limited by insurance restrictions in the types of health-care providers, services, and devices that they were able to access. Participants in five of the focus groups found dental care to be particularly difficult to obtain. At the time of the study, the Massachusetts Medicaid program provided reimbursement for some forms of dental care, but at very low rates; as a result, only a limited percentage of Massachusetts' dentists accepted Medicaid. This forced many people to travel to Boston for Medicaid-covered dental services, pay out of pocket for noncovered treatments, or go without services that they could not afford to pay for out of pocket. The shortage of Medicaid dentists caused problems with continuity of care, as patients had to switch providers if a previous provider was unavailable and they needed care. It also led to substantial service delays, with participants reporting waits for dental visits ranging from 3 months to over a year. Sometimes the challenges of accessing dental care were simply too great, as in the case of one individual with a psychiatric impairment who ended up forgoing care rather than paying a referral fee, arranging for transportation, and traveling several cities away from home to obtain services. Due to cost barriers, difficulties in obtaining routine care, and the worsening of patients' dental conditions, patients often ended up receiving

dental care in emergency rooms, where they could receive services free of charge.

Consumers also reported difficulties obtaining needed rehabilitation services. A parent of a child with autism spoke of paying \$90 per hour out of pocket for speech therapy because her insurer did not consider the service medically necessary. A Deaf participant reported that his insurer did not pay for ASL or Braille classes because the insurer did not consider them to be "rehabilitative." He questioned the insurance company's concept of rehabilitation, stating, "For someone who has lost their hearing [or blind] people, that's what rehabilitation means."

**Prescription and Over-the-Counter Medications.** Lack of coverage for medications, both prescription and over-the-counter, was a substantial financial barrier for a number of focus group participants, particularly those with psychiatric impairments or HIV/AIDS, parents of children with special health-care needs, and elders with chronic illness. Because Medicare does not have a prescription drug benefit, one woman with a psychiatric impairment who was insured by Medicare poignantly described how she had to apply directly to drug companies as "indigent" to obtain free medications and hope before each doctor's visit that the pharmaceutical representative had recently refreshed the provider's supply of free samples. Elders also raised this issue. An individual with HIV commented on a lack of coverage for lotions, even with a prescription, and time limits on coverage for certain types of medications. Each time his condition required medication, he was forced to begin the entire approval process all over again.

Parents of children with special health-care needs also experienced financial burdens due to a lack of coverage for over-the-counter medications. One woman cited the need to pay out of pocket for physician visits because only certain physicians would prescribe the drugs that worked best for her child. Another parent described the harsh reality of cost barriers to accessing potentially promising treatments for her child: "With an autistic child, I feel compelled to try all the kinds of possible treatments. But it's too hard and too expensive to do everything. New medications...for autism cost a lot of money. There is so much out there that you could buy if you had the money."

**Equipment, Repairs, and Supplies.** Some focus group participants reported difficulty obtaining coverage for devices critical to their health and basic functioning. One individual, following an accident in which he had lost his teeth and much of his hearing, was required to go through a prior approval process, a dispute, and a hearing with Medicaid before obtaining coverage for dentures. He also faced substantial obstacles when he tried to get appropriate hearing aids:

The woman told me I needed hearing aids which cost \$2,000 apiece. I bought them but could only hear the wind blowing. So, they adjusted them, and told me to try them for two more weeks, but they



kept falling out. Then they said it was past the period when I could return them and I couldn't get the money back. To appeal I had to have a second hearing test, but Medicaid wouldn't pay.

Individuals who require certain types of medical equipment or supplies often incur serious financial burdens due to inadequate reimbursement and lengthy waiting periods imposed by both public and private insurers. One parent reported paying approximately \$15,000 annually out of pocket for her child's health-care needs because her insurance would cover only specific brands of supplies, such as diapers to which her child was allergic. Another parent said that Medicaid would pay for only some of the supplies that her child's catheterization required, leaving her with the financial burden of covering the remaining costs.

Consumers with physical and developmental disabilities experienced major problems with Medicaid payments for equipment and supplies. Wheelchair users reported that their wheelchairs were eligible for repair only every 5 years. At times, they had to repair their chairs themselves, using materials such as duct tape. Coverage for repairs of other durable medical equipment, such as walkers and helmets, was also cited as problematic. Cases of improper body positioning and injuries due to faulty or self-repaired equipment were noted. One participant told of a woman who had broken her leg as a result of using an improperly repaired walker. Nurses caring for persons with developmental disabilities said that their clients are more likely to aspirate when improperly positioned in a faulty wheelchair. Given the problems in obtaining adequate supplies, patients sometimes rely on dangerous, unhygienic practices. As one participant described: "It's...hard to get G-tubes, drainage bags, nebulizers, catheters, leg bags, etc. When you're limited to a small number of these, you have to reuse products which are contaminated."

### *Personal and Cultural Provider-Related Barriers*

**Insufficient Knowledge About Disabilities.** Across nearly all of the focus groups, participants reported problems related to providers' insufficient knowledge about their patients' disabilities. The parent of a child with multiple disabilities reported that her daughter's pediatricians "were not even aware of what to do or where to send my daughter." A woman whose sister has Down syndrome described the dearth of medical knowledge about developmental disabilities in older persons, including issues pertinent to her sister's care, such as the interaction between Down syndrome and Alzheimer's. In situations of serious health crises, patients with disabilities were fortunate if they had a knowledgeable caregiver present to fill in gaps: "When my daughter was taken to [the hospital] during a seizure, I had to tell them what to do, because there was no neurologist available." Unable to count on providers' having adequate knowledge about disabilities, some parents felt as if they had to "become a 'parent professional,' knowing more

than the doctors."

Providers often seemed determined to stick to routine treatment approaches, even when this might be inappropriate for the individual patient. As the mother of a child with Down syndrome related, "My son had conjunctivitis, and the doctor kept trying to prescribe eye drops. But it's ridiculous to think we could get them in his eyes. And they kept refusing to give him oral antibiotics." The child eventually received medication in the appropriate form, but only, as the mother put it, "three visits, three co-pays, and three types of medications later."

Reliance upon providers with insufficient knowledge and expertise sometimes had serious consequences for patients. The parent of a child with autism related the following:

The speech therapist we got through school, we found out later, was not really qualified. When our son started regressing, we started to question it. We kept hearing that he was "too anxious to talk." When he was 6 years old, we started driving him to Boston [for therapy with a more qualified provider], but he had missed his critical learning period.

**Misconceptions.** Participants also expressed frustration with providers' preconceived ideas about their disabilities. A woman with a physical disability reported that her providers believed her to be cognitively impaired and therefore incapable of making her own decisions. Providers' misconceptions sometimes created dangerous situations for patients. For instance, one nurse reported that some emergency room doctors believe that patients with mental retardation do not feel pain and therefore do not need anesthesia. Indeed, the danger of such barriers to effective care in emergency room settings was a significant theme, as one advocate for patients with severe physical disabilities explained: "We hear frequently that people are terrified of going to the ER [emergency room], because their disabilities are misunderstood. People don't take the time to understand them and what they need. They're afraid of leaving the ER in worse shape than when they came in." As a consequence, some advocates believed that none of their clients should go to the emergency room unless accompanied by an advocate.

**Insensitivity and Lack of Respect.** Members of several focus groups described instances in which they felt that their health-care provider or the provider's staff treated them in a disrespectful or insensitive manner. A woman with a psychiatric disorder felt that at a certain large hospital, the front desk staff "have the attitude that we're all street people" and the providers "write us off as difficult." An individual with HIV reported being "yelled at" by nurse practitioners and "treated like a child." Two other participants with HIV stated that when they attempted to contact their physicians directly, nurse practitioners interceded and prevented the communication from taking place. This added layer of communication created yet another barrier to surmount when they attempted to access health services.

One participant with a severe physical disability characterized the treatment he received as an inpatient at one hospital as “abuse.” He stated that the providers “acted like everything that happened to me was my fault. If they came into my room and found a wet mess, they said, ‘Oh, you’re playing around.’” Another individual with a severe physical disability recounted an emergency room incident that was both humiliating and frightening: “One time I was real sick, and I couldn’t breathe. I threw up and they treated me real bad. They said that I made a mess, and they didn’t care if I aspirated. So, now I am afraid to go [to the ER].”

Families and nurses caring for persons with severe developmental disabilities related multiple experiences of patients’ being placed in separate rooms, away from the general waiting area, while waiting to see their doctors. The caregivers believed that this segregation was intended to “hide” the individuals with disabilities from other patients.

**Failure to Take Consumers or Their Caregivers Seriously.** Experiences of not being taken seriously by health-care providers were pervasive among the focus group participants with psychiatric disorders. One patient was accused by her provider of lying about her insurance coverage for her medications. Another reported that when she had trouble breathing due to an allergic reaction to penicillin, her provider initially ignored the problem, assuming that it was psychosomatic. Though she was eventually able to get help, she commented that “a person who is afraid to speak up would be in big trouble.” As a result of these types of experiences, some of the participants with psychiatric disabilities expressed reluctance to reveal their diagnoses to health-care providers for fear of stigmatization.

Several parents of children with special health-care needs reported problems arising from providers’ failure to take their input seriously. One mother of a child with autism related the following:

Once, my son had a piece of metal in his eye. We could see it there, but he didn’t feel it [because of his autism], so the doctor wanted us to go [home]. Another time, they wouldn’t listen to us when we told them our son had reactions to certain medications. They gave him the wrong medication, and he was knocked unconscious. He had nightmare and behavior problems for 2 or 3 months.

**Reluctance or Unwillingness to Provide Care.** In some cases, providers seemed reluctant or unwilling to treat individuals with certain types of disabilities. This was especially the case for the HIV-positive population and individuals with severe developmental disabilities. Some HIV-positive individuals described particular problems when they attempted to access dental care. One man with HIV said that he frequently observed dental staff drawing away from him when he revealed his HIV status. Others reported that their dental providers were reluctant to perform certain necessary procedures. Simi-

larly, family members and nurses caring for individuals with developmental disabilities said some providers conveyed the sense that “I don’t want to touch you, but I have to.”

Several focus group participants described what seemed to be indifference on the part of some health-care providers in the face of the challenges associated with treating patients with behavioral issues. A nurse for a woman with mental retardation who had difficulty undergoing gynecological exams reported that the woman’s doctor downplayed the importance of such exams for the woman, ostensibly because she was not sexually active.

Participants sometimes got the message from providers that individuals with disabilities were not worthy of receiving a high standard of care, particularly as the patients grew older. A woman with a sister in her 50s with developmental disabilities noted that her sister’s doctor suggested reducing the frequency of visits from every few months to once a year. When challenged, the doctor replied, “She’s lived a good life—once a year is fine.”

According to one focus group participant, in one particularly troubling instance, a provider’s value judgment about a patient with mental retardation led to a year-long delay in treatment for a life-threatening medical condition. The patient suffered from advanced breast cancer that required surgery, but her physician implied that due to her already low quality of life (owing to her disability), she did not merit the intervention, and her guardian did not want to make the decision to go forward without the physician’s support. This woman reportedly died within a year, and there was concern that her death may have been precipitated by the delay in surgery.

**Cultural Gaps Between Patients and Providers.** Understanding between provider and certain subgroups of people with disabilities was sometimes hindered by differences not only in language but also in culture and outlook. This issue was especially pronounced for members of the Deaf population. As one Deaf participant explained, “Even if there is an interpreter, [patient–provider interaction] might not work for the Deaf person for social reasons. There are big differences in levels of life experience and world knowledge between Deaf and hearing people. A lot of the conversation just goes over their heads.” Nurse-advocates noted that some individuals with disabilities from other countries may have “a cultural tendency to seek medical care only in emergencies,” despite their need for ongoing care to prevent secondary conditions and worsening of health status.

## Discussion

The results of the present focus group study, conducted in Massachusetts among individuals representing a wide range of disabilities and age groups, indicate that—despite gains since passage of the Americans with Disabilities Act—people with disabilities continue to face significant barriers to health-care

access. Consistent with the findings of other recent research on health-care access for people with disabilities in the United States, a wide range of barriers was reported. Access problems extended to settings across the continuum of care, including hospitals, emergency rooms, outpatient clinics, dentists' offices, and mental health and substance abuse treatment facilities. Although there were some reports of physical accessibility problems among persons with mobility limitations, the majority of barriers reported related to other aspects of the health-care delivery system and tended to affect persons across the spectrum of age and disability.

The Institute of Medicine framework classifying barriers into three broad categories—structural, financial, and personal/cultural—proved useful for defining the challenges to health-care access faced by our cross-disability sample. Prominent structural barriers included challenges and restrictions posed by health-plan and insurance policies and procedures, problems obtaining reliable transportation, inadequate care coordination, difficulty communicating with health-care providers, and providers' time constraints. Reports of physical accessibility problems focused less on issues of building access and more on such specific concerns as the availability of adaptive devices and equipment for special procedures and tests, as well as physical access to specific types of services, such as dental care. Financial barriers centered mainly on the problem of insufficient health-care coverage. Many individuals reported that for reasons of cost, they had been unable to access certain providers or services, with specialists, rehabilitation, and dental services posing the greatest difficulties. Similarly, many participants reported cost barriers to obtaining prescription and over-the-counter medications, as well as equipment, repairs, and supplies vital to their daily functioning and health maintenance. Finally, focus group participants reported a number of important personal/cultural barriers to health-care access, most of which centered on the providers' role. These included insufficient knowledge and misconceptions about people with disabilities, instances of insensitivity and lack of respect, failure to take patients seriously, and reluctance or unwillingness to provide care to members of certain populations. Cultural gaps between providers and patients, particularly Deaf and immigrant populations, were also noted.

This study provided important insights into the medical, functional, financial, and emotional consequences of barriers to health-care access for consumers with disabilities (see Table 2). Participants described instances of going without needed health care, as well as frequent delays in care that sometimes extended for months or longer. In certain cases, failure to obtain appropriate treatment or services in a timely fashion appeared to adversely affect patients' health, functional status, and even prospect of survival. Improperly repaired equipment sometimes resulted in mobility problems, poor body positioning, aspiration risk, and even serious injury. For some individuals, difficulty obtaining supplies led to dangerous practices, such as use of contaminated products, likely increasing their risks of infection and illness. Some participants reported ne-

glect of oral care as a result of problems accessing dental services. This finding is consistent with reports of an increased prevalence of dental problems among people with disabilities (Glassman & Miller, 2003) and is especially alarming given the growing appreciation of the importance of oral health to overall health and well-being.

Although some were forced to go without care due to access barriers, many focus group participants were eventually able to obtain most of the essential medical services they needed through effort and persistence. On the other hand, obstacles to health-care delivery and associated risks to patients' health were particularly acute for individuals with severe developmental disabilities. Families, nurses, and advocates indicated that, given these patients' complex medical, functional, and behavioral issues and often limited ability to express their needs, the challenges of coordinating multiple systems of care and the prejudices of health-care providers all too often combined to create situations wherein the patients' well-being might be seriously imperiled. Without advocates and caregivers, individuals with major cognitive impairment would be in great medical jeopardy.

Barriers to health-care access also gave rise to important nonmedical consequences. For a significant number of focus group participants, even those with some form of private or public health insurance, obtaining health care consumed substantial financial resources. Like people with disabilities in the United States generally, most of the individuals in our sample lived on limited incomes; the economic burden they bore in trying to meet their medical needs and obtain important medications, equipment, and supplies at times forced them and their families to make difficult financial choices. Furthermore, for many individuals, obtaining health care also consumed vast amounts of physical and emotional energy. Struggling to navigate complex insurance policies and procedures, battling with insurance companies to secure coverage for needed services, attempting to integrate information and care from multiple providers and specialists, locating accessible providers who would accommodate their needs, coordinating transportation to and from providers' offices, arranging for interpreters, and coping with providers who had limited knowledge or negative attitudes was described by participants as extremely draining and time-consuming, taking time away from other important activities.

Many individuals expressed feelings of frustration and anger resulting from the multiple barriers to care that they faced as well as instances of insensitivity, disrespect, and lack of understanding on the part of some providers. Some participants recounted episodes of what they considered humiliating and even abusive treatment. For some individuals, negative experiences in the health-care system created a sense of distrust in—and, in some cases, fear of—certain health providers and settings. This breakdown in patient-provider trust, in addition to posing a further obstacle to effective patient-provider interaction, led some individuals to avoid seeking needed medical care.

TABLE 2  
Consequences of Access Barriers

Consequence of barrier	Examples for focus group participants
Service delays/failure to receive needed care	<ul style="list-style-type: none"> <li>• Delays of more than 1 year for breast cancer surgery, neurological testing, and speech and language evaluation</li> <li>• Limited dental care, especially for Medicaid beneficiaries</li> <li>• Infrequent routine care and inadequate preventive care</li> <li>• Extended delay in surgery for advanced breast cancer</li> <li>• Late or missed appointments due to transportation problems</li> <li>• Delays in equipment repairs</li> <li>• Failure to receive adequate explanations of one's health status, medications, etc.</li> </ul>
Inadequate coordination and continuity of care	<ul style="list-style-type: none"> <li>• Unexpected transfers from fee-for-service to HMOs</li> <li>• Disruption of successful relationships with familiar providers</li> <li>• Forced to independently synthesize complicated information from multiple providers</li> </ul>
Additional time and effort	<ul style="list-style-type: none"> <li>• Need to travel long distances for dental and specialty care</li> <li>• Repeated contacts with multiple payers to get reimbursement</li> <li>• Numerous contacts with multiple providers to coordinate own care</li> <li>• Extensive advocacy to get health needs met and avoid dangerous medical errors</li> <li>• Time needed to apply to drug companies for free medications or rely upon providers' samples</li> </ul>
Financial burdens	<ul style="list-style-type: none"> <li>• Overspending personal assets in attempt to achieve Medicaid eligibility</li> <li>• Substantial out-of-pocket costs for medical care, equipment and supplies, transportation, and rehabilitation services not considered "medically necessary"</li> <li>• Difficulty obtaining reimbursement for covered services</li> </ul>
Emotional consequences	<ul style="list-style-type: none"> <li>• Anger, frustration, and humiliation due to barriers and insensitivity and disrespect</li> <li>• Fear for safety due to inadequate communication and confusion</li> </ul>
Damage to patient-provider relationship	<ul style="list-style-type: none"> <li>• Loss of trust in health-care providers</li> <li>• Reluctance to disclose diagnosis to providers for fear of stigmatization</li> </ul>
Avoidance of health system or providers	<ul style="list-style-type: none"> <li>• Failure to seek or delays in seeking care, leading to negative consequences</li> </ul>
Serious risks to health and well-being	<ul style="list-style-type: none"> <li>• Medication allergy initially dismissed by provider</li> <li>• Patient at risk of not receiving anesthesia when needed</li> <li>• Reuse of contaminated medical supplies</li> <li>• Attempts to self-treat for medical conditions or self-repair equipment</li> </ul>
Worsening of health and functional status	<ul style="list-style-type: none"> <li>• Exacerbation of health problems, leading to decrease in functional status</li> <li>• Medication errors with serious and fatal consequences</li> <li>• Decrease in functional abilities and increase in preventable injuries due to faulty equipment</li> <li>• Missed window of opportunity to treat certain aspects of developmental delay in children</li> </ul>

We believe that the experiences surrounding access to health care reported by our focus group participants in Massachusetts are reasonably representative of the experiences of people with disabilities in the United States in general, regarding a variety of factors: the diversity of our cross-disability sample in terms of gender, age, race, and geographic location; similarities in health-care financing and delivery systems and in the medical and financial circumstances of people with disabilities across the country; and the consistency between our findings and recent research conducted in other communities and nationwide. However, despite the severity of the barriers

faced here, we also believe that individuals with disabilities in other parts of the country may face even greater challenges than those reported here, in view of the relatively extensive and liberal programs for people with disabilities that were in place in Massachusetts at the time this research was conducted. Unfortunately, since completion of the study, state health programs for people with disabilities in Massachusetts and in many other states have undergone a number of significant cut-backs, including the elimination of coverage for certain services and products, the addition of new prior-approval requirements, and increases in cost sharing for Medicaid en-



rollees. Therefore, access problems for people with disabilities nationwide have likely been on the rise, particularly for persons with low incomes.

## Conclusion

Improving access to timely, effective, and compassionate health care for people with disabilities should be a high priority for United States health-care policymakers, planners, and providers. With regard to health care, people with disabilities as a group are among the nation's most vulnerable populations, given their special health-care needs as well as their lower financial status. Moreover, in terms of overall health-care utilization and expenditures, they represent one of the most important groups of health-care consumers in the United States. Nevertheless, to date, the American health-care system has in many respects failed to address the particular needs of this key group of stakeholders.

The structure of health-care financing and delivery in the United States is to a great extent based on an "acute-care model" that prioritizes coverage for acute and short-term medical needs over ongoing and preventive care, treats health issues largely as isolated problems or events, and defines concepts such as "rehabilitation" and "medical necessity" in terms of patients who are expected to resume prior health and functioning and are not at increased risk of medical complications. However, as we have seen through the experiences of our focus group participants, the health-care needs of individuals with disabilities are often complex and interrelated. Although the goal of full recovery is typically unrealistic, rehabilitation can be vital for gaining new functional modalities and maximizing functional abilities. In addition, ongoing preventive services, as well as access to equipment, timely repairs, and supplies, are critical for maintaining health and preventing secondary conditions, functional decline, and serious illness. The access issues of persons with disabilities highlight the need for reorganization of the health-care system to include components of a "chronic-care model." Such a system may dovetail in many respects with the health-care concerns of the elderly and, given the aging of the population, would likely prove increasingly relevant to the health needs of the nation as a whole.

Although the failure to adequately address the health insurance coverage and health-care programming needs of people with disabilities may seem inevitable given limited resources and spiraling health-care costs, it is not clear that the current approach is contributing to cost containment in the long run. On the contrary, there is evidence from the present study as well as other recent research (Coughlin et al., 2002; Long et al., 2002) that the shortcomings of the current system may be increasing overall health-care-utilization rates and, moreover, creating increased demand for high-cost care, such as emergency services and hospitalizations, by contributing to the development of secondary conditions and worsening health status among members of this population. In addition, financial barriers to obtaining routine care may be further affecting

health-care-utilization patterns by encouraging low-income patients to seek routine services in hospital and emergency room settings, where free care is available, thus increasing costs of care and placing greater strain on already overburdened free-care pools (Health Law Advocates, 2003).

Reorganizing health-care delivery so as to eliminate access barriers and meet the needs of people with disabilities in an effective and sustainable manner will require innovative thinking and input from those most intimately familiar with and affected by current barriers—consumers, families, and advocates. It will also require input from health-care providers, who are familiar with the structural, institutional, professional, and personal challenges of providing accessible and high-quality care to members of this population. Although the present study revealed substantial consumer perceptions of providers' personal/cultural barriers, such as lack of knowledge, insensitivity, and even bias, it would be valuable to investigate providers' perceptions of such issues, their accounts of similar incidents, and the barriers they experience in attempting to provide effective care. Providers themselves may in a sense be regarded as "victims" of a system that fails to offer them the training, preparation, facilities, time, and support that would enable them to provide optimum care to patients with disabilities.

Whatever strides are made toward improved health care for people with disabilities in the future, the present study has clearly shown that it is important for consumers to have strong self-advocacy skills and access to relevant information. Although individuals with disabilities, their families, and caregivers have demonstrated remarkable abilities and determination in their efforts to obtain needed care, much more can be done both to facilitate the process and to further empower these key health-care consumers.

Based on our present findings and analysis, the following recommendations are aimed at improving health-care access for persons with disabilities:

- establishment of consumer advisory boards and ombudspersons specifically for people with disabilities and their families within state Medicaid programs, managed-care plans, and health-care facilities.
- reexamination of the definition of *medical necessity* in terms of the ongoing needs of people with disabilities.
- streamlining policy and payment procedures in cases where there is more than one potential payer for services (e.g., insurers vs. school systems for children with special health-care needs).
- incentives for health plans that demonstrate improvements in the quality and accessibility of health-care services for people with disabilities.
- improved access to reliable, affordable, and accessible transportation.

- exploration of the feasibility and cost-effectiveness of alternatives to inpatient care.
- promotion of “disability literacy” and “disability competence” (DeJong et al., 2002; NRH-CHDR, 2001) among physicians and other health-care providers and staff, including mandatory training and professional development requirements.
- periodic rating of health plans on “disability-friendliness.”
- further research to investigate the economic and systemic implications, as well as the impact of barriers to health-care access on people with disabilities, and the potential for enhanced efficiency and cost savings through improved access.

Rising to the challenge of providing excellent and accessible health care to persons with disabilities is imperative as a matter of beneficence and equity. In the long run, it may even prove to be part of the solution for containing health-care costs. Furthermore, because people with disabilities are frequent users of the health-care system and tend to utilize a wide range of services across the continuum of care, their experiences may in some respects provide a good measure of the overall performance of the health-care system. Thus, in addition to benefiting members of this important and vulnerable population, improving health care for persons with disabilities may result in enhanced access to, and quality of, care for many other health-care consumers, as well.

#### ABOUT THE AUTHORS

**MARI-LYNN DRAINONI**, PhD, is a health research scientist at the Center for Health Quality, Outcomes, and Economic Research and associate professor at the Boston University School of Public Health. Her research and policy interests include disability, cross-disability issues, HIV/AIDS, substance abuse, and quality improvement. **ELIZABETH LEE-HOOD**, MS, MTS, is a senior project manager at the Center for Health Quality, Outcomes, and Economic Research and the Boston University School of Public Health. Her interests include health promotion and elimination of health disparities. **CAROL TOBIAS**, MMHS, is assistant professor at the Boston University School of Public Health. **SARA S. BACHMAN**, PhD, is assistant professor at the Boston University School of Social Work. **JENNIFER ANDREW**, MPH, works in the Education Department, Beverly Hospital, Northeast Health Systems. **LISA MAISELS**, MSW, MPH, was a disability specialist at the Massachusetts Dept. of Public Health. Ms Maisels passed away in July 2004. Address: Mari-Lynn Drainoni, Boston University School of Public Health, 200 Springs Road, Bedford, MA 01730; e-mail: drainoni@bu.edu

#### AUTHORS' NOTE

This research was funded by Grant H133A990014 from the National Institute on Disability and Rehabilitation Research (NIDRR). Institutional support and work space for the research was provided by the Department of Veterans Affairs, Veterans Health Administration, Health Services Research and Development Service. The views expressed in this article are those of the authors and do not necessarily represent the views of the NIDRR, the U.S. Department of Education, or the Department of Veterans Affairs.

#### REFERENCES

- Agency for Health Care Research and Quality, & Kaiser Family Foundation. (2000). *National survey on Americans as health care consumers: An update on the role of quality information*. Retrieved March 30, 2004, from <http://www.ahrq.gov/downloads/pdf/kffchartbk00.pdf>
- Beatty, P. W., & Dhont, K. R. (2001). Medicare health maintenance organizations and traditional coverage: Perceptions of health care among beneficiaries with disabilities. *Archives of Physical Medicine and Rehabilitation*, 82, 1009–1017.
- Beatty, P. W., Hagglund, K. J., Neri, M. T., Dhont, K. R., Clark, M. J., & Hilton, S. A. (2003). Access to health care services among people with chronic or disabling conditions: Patterns and predictors. *Archives of Physical Medicine and Rehabilitation*, 84, 1417–1425.
- Bingham, S. C., & Beatty, P. W. (2003). Rates of access to assistive equipment and medical rehabilitation services among people with disabilities. *Disability and Rehabilitation*, 25(9), 487–490.
- Broyles, R. W., McAuley, W. J., & Baird-Holmes, D. (1999). The medically vulnerable: Their health risks, health status, and use of physician care. *Journal of Health Care for the Poor and Underserved*, 10(2), 186–200.
- Burns, T. J., Batavia, A. I., Smith, Q. W., & DeJong, G. (1990). Primary health care needs of persons with physical disabilities: What are the research and service priorities? *Archives of Physical Medicine and Rehabilitation*, 71, 138–143.
- Centers for Disease Control and Prevention. (2001). Prevalence of disabilities and associated health conditions among adults—United States, 1999. *Journal of the American Medical Association*, 285(12), 1571–1572.
- Centers for Medicare & Medicaid Services. (2002). Medicaid Managed Care Penetration by State, June 30, 2002: National Summary Table. In *2002 Medicaid Managed Care Enrollment Report*. Retrieved March 30, 2004, from <http://www.cms.hhs.gov/medicaid/managedcare/mcsten02.pdf>
- Coughlin, T. A., Long, S. K., & Kendall, S. (2002). Health care access, use, and satisfaction among disabled Medicaid beneficiaries. *Health Care Financing Review*, 24(2), 115–136.
- Councilman, D. L. (1999). Caring for adults with mental disabilities. *Postgraduate Medicine*, 106(6), 181.
- DeJong, G. (1997). An overview of the problem. *American Journal of Physical Medicine & Rehabilitation*, 76(Suppl.), S2–S8.
- DeJong, G., & Frieden, L. (2002). It's not just managed care; it's the larger health care system say researchers. *National Rehabilitation Hospital Research Update, Spring* (Suppl.), 1, 4–7, 9.
- DeJong, G., Palsbo, S. E., Beatty, P. W., Jones, G. C., Kroll, T., & Neri, M. T. (2002). The organization and financing of health services for persons with disabilities. *The Milbank Quarterly*, 80(2), 261–301.
- Fouts, B. S., Andersen, E., & Hagglund, K. (2000). Disability and satisfaction with access to health care. *Journal of Epidemiology & Community Health*, 54, 770–771.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. New York: Aldine DeGruyter.
- Glassman, P., & Miller, C. E. (2003). Preventing dental disease for people with special needs: the need for practical preventive protocols for use in community settings. *Special Care in Dentistry*, 23(5), 165–167.
- Health Law Advocates. (2003). Written Testimony of Health Law Advocates and Health Care for All Joint Committee on Health Care Hearing on H. 3784, An Act to Restore Benefits for Adult MassHealth Beneficiaries. Supplementing oral testimony presented on 9/17/03. Retrieved April 27, 2004, from [http://www.hcfama.org/acrobat/HLA-HCFA\\_Testimony.pdf](http://www.hcfama.org/acrobat/HLA-HCFA_Testimony.pdf)
- Hill, S. C., & Wooldridge, J. (2002). Plan characteristics and SSI enrollees' access to and quality of care in four TennCare MCOs. *Health Services Research*, 37(5), 1197–1220.
- Iezzoni, L. I., Davis, R. B., Soukup, J., & O'Day, B. (2000). Satisfaction with quality and access to health care among people with disabling conditions. *International Journal for Quality in Health Care*, 14(5), 369–381.
- Institute of Medicine. (1991). *Disability in America: Toward a national agenda for prevention*, EDS. A. Pope and A. Tarlov. Washington, DC: National Academy Press.
- Institute of Medicine. (1993). *Access to health care in America*. Washington, DC: National Academy Press.

- Kaiser Family Foundation. (2000). Distribution of Medicaid spending per enrollee by enrollment group, FFY2000. In *State Health Facts Online*. Retrieved March 30, 2004, from <http://statehealthfacts.kff.org>
- Kaiser Family Foundation. (2001). Medicaid coverage expansions for Medicare beneficiaries. In *State Health Facts Online*. Retrieved April 12, 2004, from <http://statehealthfacts.kff.org>
- Kaiser Family Foundation. (2003a). Income eligibility levels for other Medicaid enrollment groups as a percent of federal poverty level, 2000, 2001, and 2003. In *State Health Facts Online*. Retrieved April 12, 2004, from <http://statehealthfacts.kff.org>
- Kaiser Family Foundation. (2003b). *Understanding the health-care needs and experiences of people with disabilities: Findings from a 2003 survey*. Retrieved March 30, 2004, from <http://www.kff.org/medicare/6106.cfm>
- Kaiser Family Foundation. (2004). Health care priorities. In *Kaiser Health Poll Report*. Retrieved April 14, 2004, from <http://www.kff.org/healthpollreport/CurrentEdition/about.cfm>
- Kennedy, J., & Erb, C. (2002). Prescription noncompliance due to cost among adults with disabilities in the United States. *American Journal of Public Health, 92*(7), 1120–1124.
- Kinne, S., Patrick, D. L., & Doyle, D. L. (2004). Prevalence of secondary conditions among people with disabilities. *American Journal of Public Health, 94*(3), 443–445.
- Kirby, D. L., O'Keefe, J. S., Neal, J. G., Bentrem, D. J., & Edlich, R. F. (1996). Does the architectural design of burn centers comply with the Americans with Disabilities Act? *The Journal of Burn Care & Rehabilitation, 17*, 156–160.
- Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41*(5), 329–339.
- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.
- Kroll, T., & Neri, M. T. (2003). Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury. *Disability and Rehabilitation, 25*(19), 1106–1114.
- Lawrie, K. (1995). Better health care for people with learning disabilities. *Nursing Times, 91*, 32–34.
- Long, S. K., Coughlin, T. A., & Kendall, S. J. (2002). Access to care among disabled adults on Medicaid. *Health Care Financing Review, 23*(4), 159–173.
- National Rehabilitation Hospital Center for Health & Disability Research. (2001, Fall). Researchers Report "Disability Literacy" Lacking Among Health Plans and Providers. *National Rehabilitation Hospital Research Update*, pp. 1–2. Retrieved March 30, 2004, from [http://www.nrhrehab.org/documents/Research/fall\\_2001.pdf](http://www.nrhrehab.org/documents/Research/fall_2001.pdf)
- National Rehabilitation Hospital Center for Health & Disability Research. (2002, Fall). Improved health care access may help prevent secondary conditions among people with disabilities. *National Rehabilitation Hospital Research Update*, p. 3. Retrieved March 30, 2004, from [http://www.nrhrehab.org/documents/Research/fall\\_2002.pdf](http://www.nrhrehab.org/documents/Research/fall_2002.pdf)
- Neri, M. T., & Kroll, T. (2003). Understanding the consequences of access barriers to health care: Experiences of adults with disabilities. *Disability and Rehabilitation, 25*(2), 85–96.
- Orlin, M. (1995). The Americans with Disabilities Act: Implications for social services. *Social Work, 40*(2), 233–239.
- Paris, M. J. (1993). Attitudes of medical students and health-care professionals toward people with disabilities. *Archives of Physical Medicine and Rehabilitation, 74*, 818–825.
- Pierce, L. L. (1998). Barriers to access: Frustrations of people who use a wheelchair for full-time mobility. *Rehabilitation Nursing, 23*(3), 120–125.
- Sanchez, J., Byfield, G., Brown, T. T., LaFavor, K., Murphy, D., & Laud, P. (2000). Perceived accessibility versus actual physical accessibility of healthcare facilities. *Rehabilitation Nursing, 25*(1), 6–9.
- Schopp, L. H., Sanford, T. C., Hagglund, K. J., Gay, J. W., & Coatney, M. A. (2001). Removing service barriers for women with physical disabilities: Promoting accessibility in the gynecologic care setting. *Journal of Midwifery & Women's Health, 47*(2), 74–79.
- Schultz, S. T., Shenkin, J. D., & Horowitz, A. M. (1998). Parental perceptions of unmet dental need and cost barriers to care for developmentally disabled children. *American Academy of Pediatric Dentistry, 20*(4), 321–325.
- Steinberg, A. G., Wiggins, E. A., Barmada, C. H., & Sullivan, V. J. (2002). Deaf women: Experiences and perceptions of healthcare system access. *Journal of Women's Health, 11*(8), 729–741.
- Taylor, B., & Taylor, A. (1996). Social work with transport disabled persons: A wayfinding perspective in health care. *Social Work in Health Care, 23*(4), 3–19.
- Thapar, N., Warner, G., Drainoni, M. L., Williams, S. R., Ditchfield, H., Wierbicky, J., et al. (2004, March). A pilot study of functional access to public buildings and facilities for persons with impairments. *Disability and Rehabilitation, 26*(5/4), 280–289.
- U.S. Census Bureau. (2003). *Health Insurance Coverage in the United States: 2002*. Issued September 2003. Retrieved March 30, 2004, from <http://www.census.gov/prod/2003pubs/p60-223.pdf>
- U.S. Census Bureau. (2000). Disability status: 2000. Table 1: Characteristics of the civilian noninstitutionalized population by age, disability status, and type of disability. In *Census 2000 Brief*. Last revised: May 14, 2003. Retrieved March 30, 2004, from <http://www.census.gov/hhes/www/disable/disablestat2K/table1.html>
- Walk, E. E., Ahn, H. C., Lampkin, P. M., Nabizadeh, S. A., & Edlich, R. F. (1993). Americans with Disabilities Act. *The Journal of Burn Care & Rehabilitation, 14*, 92–98.
- Welner, S. L. (1998). Screening issues in gynecologic malignancies for women with disabilities: Critical considerations. *Journal of Women's Health, 7*(3), 281–285.
- Witte, T. N., & Kuzel, A. J. (2000). Elderly deaf patients' health care experiences. *The Journal of the American Board of Family Practice, 13*(1), 17–22.

Copyright of Journal of Disability Policy Studies is the property of PRO-ED and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.