

It takes more than ramps

to solve the crisis
of healthcare
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with disabilities.

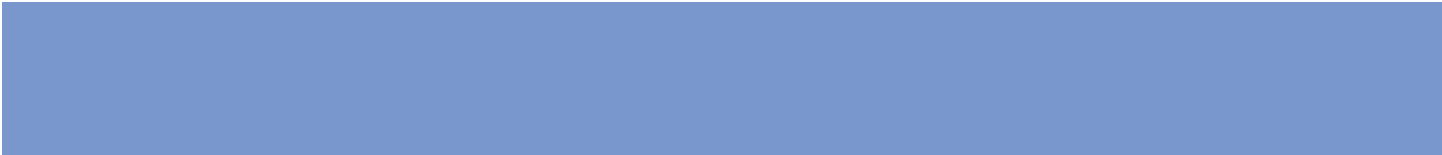
SEPTEMBER 2004

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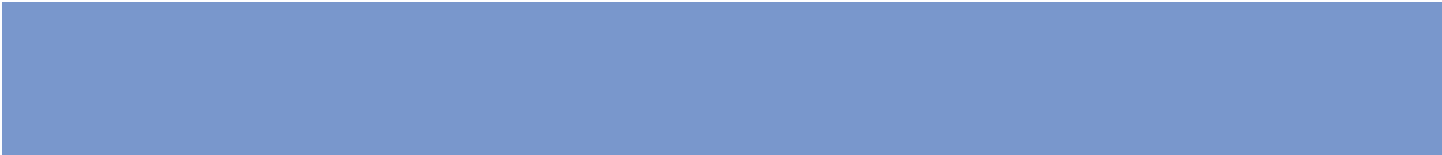
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Chicago, Berkeley, and Boston, August 2004

JPR / MLB / LII / KKK



The Rehabilitation Institute of Chicago (RIC) is dedicated to helping people with all levels and types of physical disabilities regain or improve their physical functions and to empowering people with disabilities to participate more fully in family, social, vocational, and leisure pursuits. *U.S. News & World Report* has ranked the Rehabilitation Institute of Chicago “The Best Rehabilitation Hospital” every year since 1991.

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The Rehabilitation Institute of Chicago’s Health Resource Center for Women with Disabilities (HRCWD) is a community-based program of the Rehabilitation Institute of Chicago. Established in 1991, the Center is the nation’s first community-based health center run by and for women with disabilities. The Center serves the health needs of women and teenage girls with disabilities in the Chicago area. Through its programs, the Center helps women with disabilities to achieve physical and emotional wellness, combat social isolation, and practice self-determination. The Center offers accessible medical services, conducts research in disabled women’s health issues, and provides educational and support resources for women and teenage girls with disabilities and their health care providers.

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The Rehabilitation Institute of Chicago’s Center for the Study of Disability Ethics (CSDE) is dedicated to creating confidential, academic, interdisciplinary forums for intellectual activities within RIC and the Chicago disability community. The Center is dedicated to breaking down the barriers and prejudices that hinder people with disabilities from reaching their full potential. CSDE works closely with a board of community representatives on current issues of importance to people with disabilities.

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The Robert Wood Johnson Foundation (RWJF) initiated the **Robert Wood Johnson Community Health Leadership Program (CHLP)** in 1991 to recognize individuals' contributions to improving health and healthcare in their communities. Through \$100,000 awards to their organizations, CHLP honors unsung and unusually resourceful people working in communities across the country to improve access to healthcare and the health and local health conditions of often disenfranchised populations.

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“Health care is an essential safeguard of human life and dignity and there is an obligation for society to ensure that every person be able to realize this right.”

– *Joseph Cardinal Bernadin, Pastoral Letter on Health Care*
 October 1995

We often think about healthcare access in terms of financial access—and, indeed, none of us who works in healthcare would dispute that egregious inequities exist in this arena, especially when one views the disturbing trends of those who are still without any or adequate access to health insurance. But that is not what this report is about. This report focuses on other types of access barriers—those that prevent people with disabilities from securing healthcare services. For people with disabilities, the access barriers are often much more concrete—getting in the door or onto an examination table, for example—while at the same time they are also ephemeral. Attitudes that place the person with a disability in the position of asking for accommodation rather than just expecting it, as an able-bodied patient would, still exist in many delivery systems and are held by many professionals. These are the stories that we hear every day, for our focus is that ever-growing minority group—persons with disabilities.

This report provides a comprehensive overview of these access issues, highlighting their impact on patient safety and patient-centered care. While there is significant emphasis on the legal and regulatory environment in the report (reflecting the important roles of the Americans with Disabilities Act and the Joint Commission on Accreditation of Healthcare Organizations in systems changes), that is not necessarily where the emphasis should be placed. Indeed, rather than a legal or regulatory mandate, the impetus to open our healthcare environments to *all our citizens regardless of disability* should be a moral mandate, no different from moral mandates related to race, creed, religious preference, and related broad, ethical issues.

If we assume that our desired outcome is full acceptance of all patients by our systems of care and by those who work in them, then we might ask the question, what are the structural variables that must be extant to allow this to occur. Before focusing on the easy answers (resources, people, staffing, physical plants), we should take heed of the teachings of Avedis Donabedian, a brilliant scholar and someone with whom I was lucky enough to study at the University of Michigan, who would frequently remind his students that the process-outcome relationship must be strengthened first, since it is more powerful than the structure-outcome relationship. So, how might we do this?

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One approach is through community benefit planning. My colleague and another great thinker in our field, Bob Sigmond (currently senior adviser to the dean, School of Public Health at Drexel University), has written extensively about hospitals and healthcare organizations participating in a process of community benefit planning as a way of clarifying their mission and defining the communities they serve. A community benefit model would encourage healthcare institutions to come together—*on a voluntary basis*—to create the foundations for planning how best to meet the needs of their physical and population-specific community. Sigmond reminds us that including representative groups and stakeholders in the needs analysis, problem identification, and resolution processes is a necessary and critical factor if the system is to meet the latent and overt healthcare requirements of the populations we are striving to serve.

Community benefit planning—whether you are a rehabilitation hospital or an acute care hospital, a mammography facility or a surgery clinic—needs to take people with disabilities into account. People with disabilities make up about 20 percent of the population, encompass all ages, and are increasingly prevalent as the population ages. All healthcare settings need to be knowledgeable, accessible, and attentive to the psychosocial and physical care needs of people with disabilities as they plan their organization’s resources.

At the Rehabilitation Institute of Chicago, we are proud to be working with the Robert Wood Johnson Community Health Leadership Program to bring national attention to the healthcare access needs of people with disabilities. After all, that is what our mission states we should do...focus on the fullest assimilation of people with disabilities into all aspects of society.... In other words, we strive to achieve societal equality for those we serve, making sure that people with disabilities are fully integrated into the texture and fabric of our society. Thus, in closing, I would like to take the liberty of slightly modifying Cardinal Bernardin’s sentiments as a reminder for all of us:

Health care is an essential safeguard of human life and dignity and there is an obligation for hospitals, health care professionals and society to ensure that every person, *including those with disabilities*, is able to realize this right.

It Takes More than Ramps to Solve the Crisis of Healthcare for People with Disabilities explores the extent to which people with disabilities experience problems and barriers receiving healthcare services and analyzes their root causes. In addition, this report aims to create a better understanding of how the 1990 Americans with Disabilities Act (ADA), which calls for architectural accessibility in healthcare settings, also serves as a guide for providing safe, patient-centered, culturally competent healthcare for people with disabilities. The report makes extensive recommendations for key stakeholder groups in order to spark reforms in the current inadequate approach to healthcare delivery for people with disabilities.

It Takes More than Ramps contains an introduction to disability definitions and demographics; an overview of access-to-care issues, the nature and scope of quality-of-care problems, and the need for structural reforms; an analysis of disability civil rights laws and their applicability to healthcare; an examination of the role of accreditation agencies such as JCAHO and CARF; and a call for healthcare providers to embrace the core principles of the ADA—equality of opportunity, access, fair treatment, and self-determination—as a model. *It Takes More than Ramps* lists promising programs and best practices and includes extensive resources in areas that range from research to equipment to advocacy.

An estimated 19.3 percent of the U.S. population, or 49.7 million Americans, live with disabilities. If the age-specific prevalence of major chronic conditions remains unchanged, the absolute number of Americans with functional limitations will rise by more than 300 percent by 2049. With this increasing population as a backdrop, *It Takes More than Ramps* draws three fundamental conclusions:

1. People with disabilities use healthcare services at a significantly higher rate than people without disabilities, yet commonly express dissatisfaction with their healthcare services, are particularly susceptible to disparities in healthcare, and experience widespread lack of appropriate accommodations.
2. The roots of these quality-of-care and safety shortfalls include inadequate training of clinicians and other healthcare professionals, poor executive oversight to enforce the ADA, limited funds and few financial incentives for upgrading equipment and hiring and training support staff members to assist patients, and misperceptions and stereotypes about disability.
3. Healthcare institutions have the moral as well as the legal responsibility to take actions to improve the healthcare delivery system for people with disabilities in a way that is safe, patient-centered, and culturally competent.

Evidence supports the proposition that the healthcare system in the United States is fundamentally unable to recognize, respect, and respond to the basic needs of individuals with disabilities. The failure to provide safe and competent services is rooted in the American healthcare culture and structure, which, according to the Institute of Medicine, has floundered in its ability to provide consistently high quality care to all Americans. For people with disabilities, equity concerns are particularly pressing, because this population often receives inferior care to that provided to nondisabled persons. This unequal treatment diminishes opportunities for longer productive lives for people with disabilities and can compromise the quality of those lives.

Finding solutions to these quality shortfalls, therefore, not only makes sense for the healthcare system overall but is also a matter of basic human and civil rights. The ADA establishes fundamental principles that apply to healthcare providers and set the stage for examining and reshaping the way healthcare is delivered. To ensure the delivery of safe, culturally competent healthcare services will require structural and systemic shifts in the healthcare system.



Research and extensive personal reports support the proposition that the healthcare delivery system in the United States is not structured to provide safe, patient-centered care to persons with disabilities. This premise establishes the foundation for our report on healthcare access for people with disabilities: failing to accommodate persons with disabilities represents a fundamental breach of the principles of patient-centered care at their most basic levels. The purpose of this report, therefore, is threefold:

- To highlight the gap between safe, patient-centered care and the reality of healthcare experiences for countless persons with disabilities
- To explore the role and relationship of the 1990 Americans with Disabilities Act (ADA) to improving access to care
- To recommend ways to bridge the gaps

Unfortunately, it is easy to identify numerous examples of unsafe, ineffective, inefficient, or discriminatory healthcare. We open with an exemplary and egregious case. For eighteen years, John Lonberg, a patient in his early sixties with quadriplegia from a spinal cord injury, urged his healthcare clinic to install an accessible examining table. Accessible tables automatically lower to wheelchair height, which would allow him to transfer easily from his wheelchair for complete physical examinations. But the clinic refused. Often no one was available to lift him onto the standard-height table; his clinicians frequently performed cursory examinations while Mr. Lonberg sat in his wheelchair. “They take the easy way out and do everything while I sit in the chair,” noted Mr. Lonberg. “But they miss things.” In particular, his clinicians missed the pressure ulcer developing on his buttocks. When they finally examined him perhaps a year after it began, the pressure ulcer had become infected and required surgery. Not only was Mr. Lonberg seriously injured by inadequate care, he also felt invisible: “You almost feel like you’ve disappeared. You’ve fallen off their radar screen. You don’t matter.” In addition to the damage—physical and psychological—to Mr. Lonberg, this situation produced a preventable medical condition that was far more costly to treat than it would have been to prevent.

John Lonberg’s experience as a healthcare consumer illustrates our contention that the healthcare delivery system in the United States is not structured to provide safe or effective care to persons with disabilities. Here, we use the word *structure* as did the late University of Michigan Professor of Health Management and Policy healthcare quality expert, Avedis Donabedian, who nearly thirty years ago articulated an enduring, three-part framework for assessing healthcare quality—the structure-process-outcome triad. *Process*, or what clinicians do for patients, and *outcomes*, or the results of care, generally attract the most attention. Certainly, the process of care (an inadequate physical examination) that Mr. Lonberg received produced its unacceptable outcome (an undetected pressure ulcer). However, the structure, or the healthcare environment, allowed this to happen. Typically, observers often limit structure to such “bricks and mortar” topics as addressing fire codes and public health regulations. However, Donabedian conceived *structure* much more broadly as the following:

the relatively stable characteristics of the providers of care, of the tools and resources they have at their disposal, and of the physical and organizational settings in which they work. [It] includes the human, physical, and financial resources that are needed to

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provide medical care...[and] the number, distribution, size, equipment, and geographic disposition of hospitals and other facilities. But the concept also goes beyond the factors of production to include the ways that the financing and delivery of health services are organized, both formally and informally.²

Mr. Lonberg's story exemplifies a commonplace but counterintuitive aspect of our health-care delivery system: the failure to provide safe and accessible care to those who have most frequent need of it—persons with disabilities. This failure has deep roots, reaching into the culture and structure of healthcare in the United States. Mr. Lonberg had health insurance, so his problems were not rooted in financial access, as is the case for more than 43.6 million Americans.³ Indeed, he belonged to Kaiser Permanente of California, long hailed as a visionary organization dedicated to maintaining its members' health. Instead, his experiences resulted from the fundamental inability of the healthcare system to recognize, respect, and respond to basic needs of individuals with disabilities. These failures produced disastrous consequences, both for Mr. Lonberg and for the healthcare system that now needed to expend resources (for example, costs of surgery, lengthy post-operative care, and so on) to redress its error.

Finding solutions to these quality shortfalls not only makes financial sense for the health-care system overall but is also a matter of basic human and civil rights as articulated by the ADA. As we describe later, Mr. Lonberg did find some solutions through the ADA: he and two other wheelchair users sued Kaiser Permanente, arguing that the healthcare giant failed to provide equitable and adequate care to persons with physical disabilities. The landmark settlement, reached in March 2001, offers a roadmap to other facilities for improving healthcare access.⁴

This report focuses primarily on general, acute care hospitals, their associated outpatient facilities, and clinics that provide routine care—the kinds of settings where people like John Lonberg get much of their primary and specialty care—and to a lesser degree on the experiences of people with disabilities who receive care in private medical offices. Of almost 880.5 million outpatient office visits in the United States in 2001, roughly 10.7 percent (over 94 million) occurred in clinics, outpatient facilities, health maintenance organizations, or other health center settings, while the remaining 89.3 percent took place in private practices.⁵

For a situation such as Mr. Lonberg's, it might appear that the problem could be narrowly defined as inaccessible examining tables. But an expansive view encompasses a much larger systemic picture: inadequate training of clinicians and clinic managers; poor executive oversight to enforce ADA compliance; and limited funds for upgrading equipment and for clinic staff members to assist patients to mount examining tables.

In light of this foundation, we cover the following topics in this report:

- The population of persons with disabilities
- The scope and nature of quality healthcare problems confronting persons with disabilities

- An overview of the impact and effectiveness of federal disability rights laws in the healthcare context
- The role of healthcare regulatory and oversight bodies
- Recommendations for closing healthcare gaps for persons with disabilities
- Examples of promising programs and best practices

DEFINING DISABILITY

The phrase *persons with disabilities* conjures many images—reasonably so, because physical and mental variations, including impairments, are as diverse as the human condition. Potentially impairing conditions differ in their causes, nature, timing, pace, and societal implications. Some are congenital, others acquired. Some occur suddenly, with injury or accident; others arise slowly, with progressive debility. Some gradually limit but do not threaten life; others hurry death. Some are visible to outsiders; others remain hidden. In recent years, we have come to understand that people with a range of physical and mental impairments often experience denial or limitation of opportunities resulting from societal barriers, including negative stereotypes and architectural and communication barriers. *Disability*, therefore, is not simply the implication for or impact of an impairment on the individual, but also results from the interaction between an individual’s impairment and the social, economic, and built environment. This newer, more expansive understanding of disability has come to be known as the *social model* because it recognizes the impact on individuals with disabilities of prejudice, discrimination, and inaccessible architectural surroundings.

No single consensus definition of disability yet exists that suits all purposes. Indeed, different goals may require different definitions. Historically, most national disability policy has translated into programs that are based on medical and rehabilitation models. For example, the Social Security Administration defines disability in terms of functional limitations as they affect employability: “the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.” In contrast, the ADA not only defines disability from the perspective of physical or mental impairment but also recognizes that societal barriers, including negative stereotypes and architectural and communication barriers, or the failure to provide reasonable accommodation, can give rise to the denial or limitation of opportunities. Thus, the first two “prongs” of the definition of disability in the ADA are intended to cover individuals who have current physical or mental impairments or a record of such impairments, whereas the third prong covers individuals whose impairments are not substantially limiting but are treated as though they are. The ADA defines an individual with a disability as someone who has “(a) a physical or mental impairment that substantially limits one or more of the major life activities, (b) a record of such an impairment, or (c) who is regarded as having such an impairment.”⁶ Delineating exactly who is considered disabled under the ADA continues to evolve with Supreme Court rulings.⁷

In its International Classification of Functioning, Disability and Health (ICF), the World Health Organization also took an expansive view by recognizing that factors outside the

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individual—for example, environmental barriers, such as inaccessible examining tables—contribute to disability. The ICF calls disability an “umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s functioning and disability... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors,” including environmental and personal attributes. In contrast to administrative definitions, which typically must decide whether or not persons are eligible for some benefit, the ICF aims to shift the disability paradigm to universality, encompassing everyone:

Heretofore, disability has been construed as an all or none phenomenon: a distinct category to which an individual either belonged or not. The ICF, on the other hand, presents disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives. Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition.... Over the lifespan, [disability is] a universal phenomena [sic].¹¹

This report takes the broad view: that disabling conditions are nearly universal, relevant to almost all persons at some point in their lives. However, we also recognize that self-identifying as “disabled” is a personal choice with critical implications for clinician-patient communication. Efforts to foster patient-centered care must recognize this. Kate, for example, “was born to a Deaf family—I’m third generation Deaf. So I’ve been signing [speaking American Sign Language or ASL] since day one.” When going out in the hearing world, as she daily must, Kate views herself as a linguistic minority, subject to similar vicissitudes confronting other foreigners. She does not view herself as disabled, but she thinks that most clinicians do:

The medical community has a pathologic view of Deaf people. There’s a cultural view of Deaf people that these providers do not hold. They don’t see us as a linguistic minority. I don’t identify myself as a disabled person. There’s a certain kind of pity on us as Deaf people.¹²

These attitudes and inadequate communication make Kate unwilling to seek healthcare services. Nevertheless, Kate, who is young and vigorous, does need routine screening and preventive care, as everyone does, to maintain her excellent health. She does not have a primary care clinician. Thus, differences in underlying concepts of disability between clinicians and patients can fundamentally affect communication, relationships, and even perhaps the nature and quality of the healthcare services that patients receive.

POPULATION PREVALENCE OF DISABILITY

According to the U.S. Census of 2000, an estimated 49.7 million persons (19.3 percent) aged five and older and living in communities rather than institutions report disability. At younger ages (five to fifteen years), males generally have higher rates of disability than females, while the reverse occurs over the age of sixty-four years. Physical disabilities are more common than sensory or mental health disabilities. White persons typically have lower disability rates than do African Americans and Native Americans. (See Tables 1 and 2.)

Persons aged sixty-five and older are much more likely than younger individuals to report any disability—41.9 percent compared to 18.6 percent—and the numbers of older persons are expected to grow substantially in coming decades.¹³ By 2030, the number of persons aged sixty-five years and older will rise to 69.4 million (20 percent of the population) from 34.7 million (12.6 percent) in 2000.¹⁵ Over the next fifty years, persons aged eighty-five years and older will become the most rapidly growing segment of the population, rising from 4.3 million (1.6 percent) in 2000 to 18.2 million (4.6 percent) in 2050.

TABLE 1 Population by Age, Gender and Disability

CHARACTERISTIC	Total Number	Total %	Male Number	Male %	Female Number	Female %
Population 5 and older	257,167,527	100.0	124,636,825	100.0	132,530,702	100.0
With any disability	9,746,248	19.3	24,439,531	19.6	25,306,717	19.1
Population 5 to 15	45,133,667	100.0	23,125,324	100.0	22,008,343	100.0
With any disability	2,614,919	5.8	1,666,230	7.2	948,689	4.3
Sensory	442,894	1.0	242,706	1.0	200,188	0.9
Physical	455,461	1.0	251,852	1.1	203,609	0.9
Mental	2,078,502	4.6	1,387,393	6.0	691,109	3.1
Self-care	419,018	0.9	244,824	1.1	174,194	0.8
Population 16 to 64	178,687,234	100.0	87,570,583	100.0	91,116,651	100.0
With any disability	33,153,211	18.6	17,139,019	9.6	16,014,192	17.6
Sensory	4,123,902	2.3	2,388,121	2.7	1,735,781	1.9
Physical	11,150,365	6.2	5,279,731	6.0	5,870,634	6.4
Mental	6,764,439	3.8	3,434,631	3.9	3,329,808	3.7
Self-care	3,149,875	1.8	1,463,184	1.7	1,686,691	1.9
Difficulty going outside the home	11,414,508	6.4	5,569,362	6.4	5,845,146	6.4
Employment disability	21,287,570	11.9	11,373,786	13.0	9,913,784	10.9
Population 65 and older	33,346,626	100.0	13,940,918	100.0	19,405,708	100.0
With any disability	13,978,118	41.9	5,634,282	40.4	8,343,836	43.0
Sensory	4,738,479	14.2	2,177,216	15.6	2,561,263	13.2
Physical	9,545,680	28.6	3,590,139	25.8	5,955,541	30.7
Mental	3,592,912	10.8	1,380,060	9.9	2,212,852	11.4
Self-care	3,183,840	9.5	1,044,910	7.5	2,138,930	11.0
Difficulty going outside the home	6,795,517	20.4	2,339,128	16.8	4,456,389	23.0

Source: U.S. Census Bureau, Census 2000 Summary File 3¹⁵

Available at <http://www.census.gov/hhes/www.disable/disablestat2K/table1.htm>

This growth reflects lengthening life expectancies even in recent decades. Decreasing death rates from heart disease have substantially prolonged longevity, increasing the numbers of people living with chronic, nonfatal, but disabling conditions. Persons with significant physical disabilities are also living longer, largely because of fundamental medical

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breakthroughs such as advances in antibiotics. For instance, according to the National Spinal Cord Injury Statistical Center, persons who become paraplegic at age forty and survive one year following injury can expect to live another twenty-nine years, compared to thirty-eight years for persons without spinal cord injury.¹⁶

Aging does not invariably produce disability, at least not until persons are near death. Recent reports suggest that rates of serious functional deficits have declined among older individuals, although evidence about the most severe disabilities is contradictory.¹⁷ Multiple factors likely underlie improvements in functional abilities among older persons, including new medical therapies and healthy lifestyle changes such as decreased smoking.

Arthritis, the leading cause of disability among adults, affected 70 million people in 2001, including 60 percent of persons aged sixty-five and older.¹⁸ If current rates of arthritis prevalence remain unchanged, the number of persons over age sixty-five with arthritis will double by 2030. Obesity among adult Americans is also increasing, from 12 percent in 1991 to 20.9 percent, or 44.3 million persons, in 2001.¹⁹ Apart from being disabling itself, obesity contributes to other potentially debilitating conditions, including diabetes, arthritis, high blood pressure, and asthma. In coming years, many more persons will therefore have multiple coexisting, chronic, disabling conditions.

TABLE 2 Population by Race and Disability

Race and Hispanic or Latino Origin	Total population	% with a disability			
	aged 5 and older	5 and older	5 to 15	16 to 64	65 and older
Total	257,167,527	19.3	5.8	18.6	41.9
White alone	195,100,538	18.5	5.6	16.8	40.6
Black or African American alone	30,297,703	24.3	7.0	26.4	52.8
American Indian and Alaska Native alone	2,187,507	24.3	7.7	27.0	57.6
Asian alone	9,455,058	16.6	2.9	6.9	40.8
Native Hawaiian and Other Pacific Islander alone	337,996	19.0	5.1	21.0	48.5
Some other race alone	13,581,921	19.9	5.2	23.5	50.4
Two or more races	6,206,804	21.7	7.1	25.1	51.8
Hispanic or Latino (of any race)	31,041,269	20.9	5.4	24.0	48.5
White alone, not Hispanic or Latino	180,151,084	18.3	5.7	16.2	40.9

Source: U.S. Census Bureau, Census 2000 Summary File 3²⁰

Available at <http://www.census.gov/hhes/www/disable/disabstat2k/table2.html>

ACCESS TO CARE

Even with health insurance, persons with disabilities are often unable to get the care they need. In the spring of 2000, a nationwide survey commissioned by the National Organization on Disability of persons aged sixteen and older with and without disabilities found worrisome disparities. Fully 28 percent of insured people with disabilities reported that they needed particular therapies, equipment, or medications that were not covered by their health plans, compared to 7 percent of those without disabilities. Compared to 6 percent of nondisabled persons, 19 percent of disabled persons reported that they needed medical care within the previous year but did not get it. Persons with disabilities attributed these failures to a variety of factors, including lack of insurance coverage (35 percent), high costs (31 percent), difficulties or disagreements with doctors (8 percent), problems getting to doctors' offices or clinics (7 percent), and inadequate transportation (4 percent).²¹

It is ironic that access to healthcare is so problematic for a population that is in frequent need of healthcare services. According to Gerben DeJong, PhD, former director of the National Rehabilitation Hospital Research Center in Washington, DC and currently with the University of Florida, within the working age population, the 14 percent who have disabilities create about 64 percent of healthcare expenditures.²² He notes that people with disabilities typically have a “thinner margin of health” due to their impairments and functional limitations, fewer opportunities for health maintenance and preventive healthcare, earlier onset of chronic health conditions, susceptibility to secondary functional losses and, not uncommonly, a need for complicated and prolonged treatments.²³ According to the National Medical Expenditure Survey in 1987, 22 percent of respondents indicated knowledge of legal obligations regarding Deaf patients, but only 2.6 percent indicated specific awareness of the ADA. In addition, 41 percent of the respondents did not know whether interpreters were available to them.²⁴

Anecdotes reported to the authors by wheelchair users seeking patient services:

I'm sorry, but unless you can stand, we can't do a mammogram.

Didn't you bring someone to transfer you? If you can't get yourself on the examination table, we cannot do the colonoscopy. Our staff are not trained to do that.

Research on the experiences of women with disabilities, who comprise more than 50 percent of disabled Americans, reveals fundamental flaws in the healthcare system for healthcare access. The Center for Research on Women with Disabilities has found that a substantial proportion of primary care physicians' offices are not in compliance with ADA requirements²⁵ and that nearly a third of women with physical disabilities are denied services at a doctor's office solely because of their disability.²⁶ A survey of disabled women who had given birth in hospitals indicated that 56 percent of the respondents reported that the hospital was ill prepared to accommodate their disability-specific needs.²⁷

In the United States, access to healthcare requires either health insurance or substantial economic resources—both of which persons with disabilities frequently lack. National surveys such as the 1994–1995 National Health Interview Survey Disability

Supplement find that persons with physical, sensory, and psychiatric disabilities are substantially more likely than other persons to report attributes reflecting social and health disadvantages. These disadvantages include poverty, unemployment, tobacco use, obesity, and poor health. Moreover, these individuals are also more likely than the nondisabled

population to live alone, have only a high school education or less, and feel frequently depressed or anxious. Because of social “safety net” programs, notably Medicare for persons with disabilities who are under age sixty-five and Medicaid, they are equally as likely as others to have health insurance, but more likely to seek and use services.

Even with health insurance, the needs of people with disabilities for health-related items and services—for example, extensive prescription drug regimens and assistive technologies—often outstrip benefits. Services such as routine transportation to medical appointments, home modifications to improve accessibility, and personal care assistance often fall outside standard health insurance benefit packages. These very services, however, may be essential to enable persons to live independently while maintaining quality of life.

SCOPE AND NATURE OF QUALITY-OF-CARE PROBLEMS

Alarm about substandard quality of care extends across the healthcare delivery system. In its seminal report *Crossing the Quality Chasm*, the Institute of Medicine of the National Academies in Washington, DC noted the irony of these worries:

At no time in the history of medicine has the growth in knowledge and technology been so profound.... Genomics and other new technologies on the horizon offer the promise of further increasing longevity, improving health and functioning, and alleviating pain and suffering. Advances in rehabilitation, cell restoration, and prosthetic devices hold potential for improving the health and functioning of many with disabilities.²⁸

As medical science and technology have advanced at a rapid pace, however, the healthcare delivery system has floundered in its ability to provide consistently high-quality care to all Americans.²⁹

Persons with chronic conditions are particularly susceptible to substandard care. The sources of quality shortfalls run the gamut, from errors in filling medication prescriptions to faulty communication between clinicians and patients. Even persons with common medical conditions frequently do not receive routine services. One study found that Americans receive, on average, roughly half of recommended healthcare services: for example, only 57.3 percent of persons with osteoarthritis get recommended care, as do 45.4 percent of persons with diabetes and 22.8 percent of those with hip fractures.²⁹

Anecdotes reported to the authors by women who use wheelchairs:

You don't have to worry about osteoporosis because you cannot walk.

There is no reason for some one like you to be tested for AIDS; the test should be administered to those who really need it (people who are sexually active).

Taking a public health perspective, *Healthy People 2010*, a report by the U.S. Department of Health and Human Services, the agency that sets national health priorities, notes explicitly that persons with disabilities are often left behind. In particular, misconceptions about people with disabilities contribute to troubling disparities in the services they receive, especially an “underemphasis on health promotion and disease prevention activities.”³⁰

For example, persons with severe difficulty walking receive significantly fewer screening and preventive services such as

mammograms, Papanicolaou smears, and tobacco queries than other individuals.³¹ Fewer than 1 percent of persons with arthritis receive public health interventions, such as community-based exercise programs, that could improve or maintain their function.³² Thus, “as a potentially underserved group, people with disabilities would be expected to experience disadvantages in health and well-being compared with the general population.”³³

Medicare beneficiaries who have disabilities generally report greater dissatisfaction with their care than do others.³⁴ Most persons with disabilities do generally perceive their physicians as competent and well trained. Nonetheless, even after accounting for various confounding factors, people with disabilities were significantly more likely than those without to report other problems, including incomplete understanding of clinical histories and conditions, lack of thoroughness, and inadequate communication. These findings held across disabling conditions. People with disabilities were much less likely than others to have confidence in their doctors.

Another study involving Medicare beneficiaries showed that as the number of activity limitations reported by respondents increased, so did dissatisfaction with care.³⁵ The proportion dissatisfied was especially high for follow-up care, availability of specialists, ease of getting to doctors and other providers, and getting help during off-hours. Also noteworthy were concerns that physicians were more interested in isolated symptoms or diseases than patients’ overall health.

NEED FOR FUNDAMENTAL RESTRUCTURING

The Institute of Medicine believes that only fundamental restructuring can rectify the myriad shortfalls of today’s healthcare delivery system and argues that healthcare should incorporate major changes so that healthcare delivery can be accurately designated with the following attributes:

- Safe, avoids injuring patients
- Effective, based on scientific evidence of benefit
- Patient-centered, respectful of patients’ preferences, needs, and values
- Timely, reduces waits and harmful delays
- Efficient, avoids waste of equipment, supplies, ideas, and energy
- Equitable, equal quality regardless of patients’ personal characteristics³⁶

Each of these aims holds special resonance for persons with disabilities.³⁷ The first place to start is patient-centeredness—the primacy of “the experience of patients, their loved ones, and the communities in which they live,” seeing “the experience of patients as the fundamental source of the definition of *quality*.”³⁸ Many people with disabilities are accustomed to having others evaluate and circumscribe their lives and opportunities. Stereotypic and stigmatizing views of living with disabilities erect barriers to comprehensive care, such as limiting discussions of mental health or sexuality, and overemphasizing isolated symptoms and diagnoses rather than overall health.

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Clearly, the healthcare system must accommodate people with disabilities. Failure to do so, thus limiting or even shutting out a large number of healthcare consumers, betrays the goal of healthcare providers to dispense safe, patient-centered care. As described below, however, patient-centeredness fits squarely within the growing movement to provide culturally competent care.

The other five aims also carry particular relevance for persons with disabilities. People with complex diagnoses or multiple coexisting conditions face greater safety risks. For example, they often use more medications, experience more invasive procedures, and spend more time within the healthcare system. Like Mr. Lonberg, they can suffer from neglect (for example, developing pressure ulcers, having depression left untreated). Furthermore, persons with disabilities are typically excluded from the randomized clinical trials that assess the efficacy and effectiveness of therapeutic interventions, such as new medications or surgical procedures. Therefore, minimal evidence exists about “people like them” that could support evidence-based care. The evidence base for assistive technologies and rehabilitation services to prevent or delay functional declines, for example, remains fairly modest.

Delays and waits affect everybody. At the most basic level, for example, persons depending on over-booked and financially strapped paratransit systems often miss appointments or arrive late. This frustrates both patients and clinicians. At a more profound level, as already noted, certain persons with disabilities are significantly less likely than others to receive selected screening and preventive services. Without screening tests, serious diagnoses (such as breast, cervical, or colon cancer) may be delayed, resulting in detection at later, less treatable stages of disease.

Avoiding waste, especially of energy, is highly relevant for persons with physical impairments that limit their activities. Ironically, however, with short appointment times, persons with disabilities may need to make multiple trips to the doctor to address their healthcare concerns fully.³⁹ Traveling to multiple settings to see multiple providers is exhausting. One study found that people with disabilities are significantly more likely than others to be dissatisfied with getting “all their medical needs taken care of at the same location.”

Finally, equity concerns are particularly pressing. As noted throughout this report, persons with disabilities often receive inferior care to that provided to nondisabled persons. This unequal treatment diminishes their opportunities for longer, productive lives and can compromise the quality of those lives.

SUMMARY

An estimated 19.3 percent of the U.S. population, or 49.7 million Americans, report having disabilities. If the age-specific prevalence of major chronic conditions remains unchanged, the absolute number of Americans with functional limitations will rise by more than 300 percent by 2049. Recent studies and government reports indicate that people with disabilities share these characteristics:

- Significant high use of healthcare services
- Frequent expressions of dissatisfaction with their care
- Particular susceptibility to disparities in care that can result from a failure to provide safe and accessible services
- Experiences of widespread lack of appropriate accommodations

The failure to provide safe and competent services is rooted in the American healthcare culture and structure, which according to the Institute of Medicine has floundered in its ability to provide consistently high-quality care to all Americans. Solving the shortfalls in the quality of healthcare that are experienced by individuals with disabilities will ultimately not only prove to be cost effective, but is a matter of basic civil rights. Solutions will entail a fundamental restructuring of the healthcare delivery system: this restructuring must build on the principles of cultural competency, safety, and patient-centeredness.

DISABILITY CIVIL RIGHTS LAWS AND HEALTHCARE

During the past twenty-five years, federal and state disability anti-discrimination laws and policies have begun to challenge and reverse the historic practices of exclusion, segregation, and isolation of people with disabilities from all spheres of community life, including healthcare services. In this section of *It Takes More than Ramps*, we report how two federal laws are helping to increase and improve access to healthcare and how their central principles can guide healthcare providers toward the goal of providing safe, culturally competent care for people with disabilities.

The landmark 1990 Americans with Disabilities Act (ADA)⁴⁰ and its predecessor law, Section 504 of the Rehabilitation Act of 1973,⁴¹ create a comprehensive national mandate that prohibits disability-based discrimination. Taken together, these laws call for public and private healthcare services, programs, and providers to treat people with disabilities in a nondiscriminatory and integrated manner and to ensure that they have an equal opportunity to participate in and benefit from healthcare services.

While enacting the ADA, Congress established a powerful legislative record that documents the breadth of disability discrimination, including in the provision of healthcare services. A 1986 report by the U.S. Commission on Civil Rights, cited by the House Committee on Education and Labor, stated that “Despite some improvements... [discrimination] persists in such critical areas as education, employment, institutionalization, *medical treatment*, involuntary sterilization, architectural barriers, and transportation.”⁴² (Emphasis added.)

Since its enactment, the ADA has undeniably had an extraordinary impact on American society, particularly by increasing both access to the built environment, which is illustrated by the ubiquitous accessibility symbol on public restrooms, parking places, and entryways, and by generally increasing community awareness of disability. The ADA’s requirement for accessibility in newly constructed and altered buildings continually increases the number of medical facilities that people with certain disabilities can enter and use. Unfortunately, however, many older facilities that have not undergone recent renovations—including many private offices of medical practitioners—remain largely inaccessible, although the ADA also requires some accessibility for these facilities under certain circumstances. The potential and intent of the ADA, however, goes far beyond bricks and mortar. The law’s core principles—nondiscrimination, inclusion, and accommodation—set the stage for examining and reshaping the way healthcare is delivered.

The extent to which healthcare providers voluntarily implement the ADA can be debated. By many accounts federal enforcement of the law, combined with the impact of some successful private litigation, has generated the greatest degree of compliance to date by sending the message to healthcare providers that they must offer nondiscriminatory services to patients with disabilities. This message is also beginning to make its way into the policies and practices of private insurers that offer healthcare plans for Medicaid patients, many of whom are people with disabilities. In recent years, these insurers have come under increasing pressure to find ways to serve such patients appropriately by, among other things, applying the core principles of the ADA to their products and services.

In light of these developments, this section illustrates various ways the principles of the ADA can be used as a tool—indeed as a model—to advance the goal of safe, patient-centered care. We approach the topic from two perspectives. First, we illustrate changes that have come about within healthcare delivery settings such as hospitals and offices of medical practitioners in response to government enforcement of the ADA and private litigation. Second, we discuss changes in products and services offered by insurers who provide healthcare services to people with disabilities under the Medicaid program. This section presents the following information and analyses:

- The basic requirements of the ADA as they apply to health providers
- Trends and outcomes from federal enforcement of the ADA and private litigation
- Examples of responses to the ADA by some insurers that provide healthcare services to Medicaid beneficiaries with disabilities
- Opportunities and limitations of civil rights law as a tool for resolving problems that remain systemic throughout the healthcare industry for people with disabilities

THE ADA AND HEALTHCARE PROVIDERS

Since its enactment, the ADA has been used to challenge a wide variety of discriminatory practices involving healthcare decision making, rationing of limited resources,⁴³ the exclusionary policies of the long-term care industry, and institutionalization of people with disabilities by states.⁴⁴ It has also been invoked in the debate about physician-assisted suicide. While these are critical and interlocking areas of concern, our report focuses on the extent to which the ADA has provided the impetus for increasing and improving access to safe, effective healthcare services for people with disabilities.

This report cannot fully cover the content of the ADA. Rather, we provide a short overview that outlines the basic principles of the law. These principles form a coherent structure that, if adopted, can inform and guide the development of some critical reforms for people with disabilities.

All healthcare providers, regardless of the size of the facility or office, or the number of employees, are required to comply with the ADA. Hospitals, nursing homes, psychiatric and psychological services, offices of private physicians, dentists, health maintenance organizations (HMOs), diagnostic centers, physical therapy and other allied health settings, and health clinics are included among the healthcare providers covered by the ADA. All healthcare providers are considered “public accommodations” under the ADA and are therefore covered by Title III.⁴⁵ Healthcare services provided by state or local governments either directly or through contractual arrangements are also covered by Title II of the ADA.⁴⁶

The ADA establishes fundamental principles that apply to covered entities, including healthcare providers. First, at the heart of the law is its nondiscrimination mandate.

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While the drafters of the ADA specifically intended to prohibit discrimination arising from prejudice, they also recognized that discrimination can be the outcome of benign neglect. Thus, the ADA prohibits both intentional and unintentional discrimination. Second, recognizing that people with disabilities had been historically excluded from schools, jobs, and community life, the ADA calls for the integration of people with disabilities into all programs and activities to the maximum extent possible. Third, the ADA establishes the principle of *reasonable accommodation*. When this requirement applies to patient care by healthcare providers, it is referred to as reasonable modification. Thus, discrimination can be defined as the failure to reasonably modify policies, practices, or procedures when they are required to afford people with disabilities access to such things as goods, services, facilities, privileges, and advantages offered to the public. Finally, the ADA calls for accessibility of buildings, facilities, and communication. Greater levels of accessibility are required in newly constructed facilities than in altered ones, though altered facilities are still subject to significant accessibility requirements.

Congress also balanced the rights of people with disabilities to be free of discrimination with business interests and the cost concerns of public entities. For example, accessibility alteration to existing facilities such as the private offices of physicians and other medical personnel is required if doing so is “readily achievable.” That is, it is required if doing so is “easily accomplishable and able to be carried out without much difficulty or expense.”⁴⁷ In existing healthcare facilities operated by state or local governments, programs must be readily accessible to and usable by people with disabilities when they are viewed in their entirety. A provider can avoid complying by showing that a modification would result in an “undue burden” or a “fundamental alteration” of the service or program.⁴⁸

Under the ADA individuals can seek remedies to discrimination by filing a complaint with the healthcare provider if a state or local government operates it, or with one of several federal agencies, or by going to court.⁴⁹ In the following section, we present representative examples of healthcare cases that have been reported by the U.S. Department of Justice (DOJ) and some examples of outcomes from private litigation. This discussion is not intended to be exhaustive. Rather, its purpose is to illustrate the range of problems people with disabilities face in obtaining healthcare services and the extent to which the ADA has been effective, not only in remedying these problems for the individuals and groups involved, but also in affecting larger service centers such as hospitals.

DOJ has the primary enforcement authority for the ADA, as it does for other civil rights laws. The United States Department of Health and Human Services (HHS) also enforces the ADA and Section 504 in healthcare contexts. These agencies set enforcement priorities, investigate discrimination allegations, and file or join lawsuits when necessary against covered entities, including healthcare providers. Following the enactment of the ADA, DOJ established two healthcare priority areas for enforcement: (a) ensuring that hospitals provide auxiliary aids and services such as sign language interpreters for Deaf individuals and (b) ensuring that services are provided to individuals in integrated settings.

A review of quarterly ADA “Status Reports” published by DOJ between April 1994 and March 2003 reveals that 114 healthcare-related cases involving accessibility to facilities and

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equipment, effective communication, and denial of service were resolved either through litigation or through another dispute resolution mechanism.⁵⁰ Of the 114 reported cases, the largest number (sixty-five) involved the provision of auxiliary aids and services required to ensure effective communication for individuals who are Deaf or hard of hearing. In most cases, healthcare providers were not providing qualified sign language interpreters, text telephones (TTYs), or other communication devices. Thirty-four of these incidences of discrimination took place in the offices of a physician, dentist, or other medical professional. Twenty-five took place in hospitals or medical centers, and six took place in service settings such as radiology offices or in clinics.

TABLE 3 **Instances of Discrimination**

CASE TYPE/ISSUE	Office Setting	Hospital Setting	Clinic or Service Center Setting	TOTAL
Deaf or Hard of Hearing (effective communication)	34	25	6	65
Mobility Access	27	4	4	35
HIV Status	5	1	2	8
Blind/Low Vision	2			2
Access to Examination Tables	0	1	2	3
Intellectual Disabilities			1	1
TOTALS	68	32	14	114

Source: US Department of Justice Status Reports – April 1994 – March 2003

Thirty-five cases involved architectural access to medical offices and facilities. These cases involved barriers such as inaccessible parking, lack of basic entry access, bathrooms that were not accessible to wheelchair users, and inaccessible elements within physicians' offices and laboratories, including corridors, doorways, and examination rooms. Three additional cases concerned access to examination tables, one involving hospitals and two involving radiology practices.

Eight cases involved denial of service to individuals with a positive HIV status, including five in the offices of physicians, dentists, or other medical professionals. One incident took place in a hospital and two in a clinic or other service setting. Two cases involved accommodations for blind or visually impaired individuals, both in office settings. One case involved denial of service because of intellectual disability status. (See Table 3.)

Auxiliary Aids and Services for Effective Communication

DOJ joined a lawsuit in Connecticut against ten acute care hospitals for allegedly failing to provide sign language and oral interpreters for persons who are Deaf or hard of hearing. DOJ and approximately twenty-five hospitals in Connecticut entered into a consent agreement in which the hospitals agreed to provide sign language or oral interpreters to patients and companions of patients who are Deaf, when necessary for effective communication,

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within one to two hours after receiving notice of the need for such interpreters. The hospitals also agreed to provide necessary assistive devices and technology, including telecommunication devices for the Deaf (TDDs), for Deaf or hard of hearing patients or their companions. Each hospital also agreed to establish an information office with a TDD telephone line and to designate a full-time program administrator to ensure effective implementation of its communication policy. Finally, the hospitals agreed to pay \$217,000 in compensation to the plaintiffs in the case, and to train emergency, psychiatric, and social work personnel concerning the communication needs and preferences of individuals who are Deaf or hard of hearing.⁵¹ The Department has used this model for enforcement in other states and communities across the nation.⁵²

The following examples illustrate similar outcomes in other cases:

- The U.S. Attorney's Office for the District of Arizona entered into a settlement agreement to resolve a complaint against Mezona Orthopedic Professional Association, Inc. Mezona allegedly repeatedly refused to provide sign language interpreters for a Deaf patient. To settle the complaint, Mezona agreed to the following provisions:
 1. To provide auxiliary aids and services, including qualified sign language interpreters where necessary, to ensure effective communication, at no cost to the patient
 2. To provide a detailed written explanation if Mezona staff members determine either that an interpreter is not necessary to ensure effective communication or that providing one would pose an undue burden
 3. To post a sign giving notice that auxiliary aids and services are available
 4. To train its employees on the requirements of the ADA
 5. To pay the complainant and her daughter \$500 each in damages and a civil penalty of \$1,000 to the United States⁵³
- A Deaf individual charged that a Texas hospital did not ensure effective communication for persons who are Deaf or hard of hearing. The hospital made the following changes:
 1. Entered into a new contract for sign language interpretation services
 2. Purchased six new TTYs
 3. Changed the hospital's patient guide to inform patients and their companions of the services available to persons with hearing and speech impairments
 4. Updated its policies on providing auxiliary aids and services in order to ensure effective communication⁵⁴
- The U.S. Attorney's Office for the Eastern District of California, in conjunction with the Office of Civil Rights of the U.S. Department of Health and Human Services, entered into an agreement with Oroville Hospital (part of the Golden Valley Health Network) to implement major changes in the hospital's treatment

of patients who are Deaf or hard of hearing. Additionally, physicians and staff members will receive ongoing training on the healthcare needs of persons who are Deaf and hard of hearing. The hospital also agreed to pay \$20,000 in damages to the complainant and \$10,000 in civil penalties.⁵⁵

Removal of Architectural Barriers

Similarly, DOJ has achieved reforms with some individual health providers and medical facilities when it pursues claims of discrimination on behalf of individuals with mobility impairments. In almost every case, the individual health provider or institution has modified inaccessible architectural features such as parking lots, walkways and building entrances, bathrooms, hallways, and the like. The following examples illustrate some of the details of these settlements:

- In Pennsylvania, a wheelchair user charged that a building owner refused to construct a ramp to provide access to a dental office in the building. The owner constructed the ramp.⁵⁶
- In Mississippi, an individual charged that a medical laboratory was inaccessible and that it conducted outpatient lab work in the waiting room in front of other patients. The hospital that owns the laboratory agreed to alter a room to provide accessible private and confidential laboratory services to patients who use wheelchairs.⁵⁷

Inaccessible Diagnostic Equipment and Examination Tables

The following summaries describe cases involving discrimination based on the failure of a medical provider to offer appropriate services to a person with a disability because either an examination table or diagnostic equipment was inaccessible:

- A Virginia medical center allegedly refused to treat a woman who uses a wheelchair during her scheduled appointment because they said they could not lift her on to the examining table. The medical center completed a survey of current examination tables and developed a capital budget and a timeline to purchase motorized examination tables. It also provided training to staff members on ADA requirements.⁵⁸
- A Washington, DC radiology practice allegedly failed to provide adequate assistance to a woman who uses a wheelchair to help her transfer from her wheelchair to an examination table. The practice purchased an additional height-adjustable examination table and designated three lead medical assistants as ADA patient advocates to help patients with mobility disabilities receive services as quickly and efficiently as possible.⁵⁹
- Georgetown University Hospital allegedly failed to offer reasonable accommodations to a woman who uses a wheelchair by providing assistance to help her transfer from her wheelchair to an examination table for a gynecological examination in its obstetrics and gynecology clinic. Georgetown agreed to pay the plaintiff \$15,000. Additionally, they paid the United States a civil penalty in the amount of \$10,000, and according to a DOJ official, they agreed to undertake a facility-wide review of related accommodation and accessibility problems.⁶⁰

Denial of Care Based on HIV Status

The following example involves denial of service to an individual who is HIV-positive:

- A South Florida dentist allegedly denied dental services to a patient who is HIV-positive. The dentist agreed to provide sensitivity training to his staff, publicize the availability of services to patients who are HIV positive, and post notices concerning his office's desire to treat all patients in a nondiscriminatory manner.⁶¹

Accommodation of People Who Have Vision Disabilities

The following example involves accommodations for blind or visually impaired individuals:

- In New York, a dentist's office staff allegedly refused to assist a blind couple to complete consent forms while informing the patient that treatment would be denied unless the forms were completed. The settlement requires the dentist to provide assistance to blind patients to complete forms, provide ADA training to her staff, comply with the other provisions of the ADA, and pay compensatory damages.

PRIVATE LITIGATION—AUXILIARY AIDS, ACCESSIBILITY, AND HIV STATUS

This section discusses to what extent private lawsuits have succeeded in protecting the rights of individuals with disabilities from discrimination by healthcare providers. We focus primarily on trends in the courts concerning auxiliary aids that ensure effective communication for people who are Deaf, lack of access for people with mobility disabilities, and denial of service based on HIV-positive status.

While DOJ has shown good results in cases concerning auxiliary aids and services, the results of similar private claims in the courts have had mixed results. These are attributed to the limits both the ADA and Section 504 place on the type of remedy that is available when an individual files a lawsuit against a medical professional. Specifically, injunctive relief is the primary remedy available under the ADA and Section 504. Some monetary damages are available under both laws, but not when the claim is against a private healthcare provider. Because the incident of discrimination has already taken place when the lawsuit is filed, many plaintiffs have found it difficult to show to the courts' satisfaction that they face a real and immediate threat—one of the tests to obtain an injunction—if the healthcare provider does not provide the auxiliary aid or service, or take other actions. Consequently, they are unable to meet the legal requirements to obtain an injunction, even though they have experienced discrimination that is prohibited by both the ADA and Section 504.

For example, a hospital allegedly refused several times to provide a sign language interpreter for a man who is Deaf while he was being treated for injuries acquired in a motorcycle accident. These refusals took place when doctors were discussing the need to amputate his leg and when hospital staff sought his signature on a consent form. He filed suit after being discharged. The court held that the man could not ask for injunctive relief because he could not show that it was likely that he would personally experience future discrimination by the hospital.⁶²

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In October 2003, the American Medical Association's Florida delegation passed a resolution calling for the repeal of the requirement that medical professionals pay for sign language interpreters in order to communicate effectively with Deaf and hard of hearing patients.⁶³ While cost concerns are legitimate, alternative solutions to repealing the requirement for effective communication with Deaf patients were not explored.

These same constraints also cause mixed outcomes when individuals seek remedies in the courts for healthcare providers' failure to remove architectural barriers or provide accommodations when examination facilities and equipment are inaccessible. For example, a woman who uses a wheelchair and her husband brought a suit under the ADA to compel a hospital to make the birthing center wheelchair-accessible in anticipation of a future pregnancy. The district court ruled that the couple could not sue because they could not prove that they would be harmed in the future.⁶⁴

On the other hand, litigation involving denial of service based on HIV-positive status has generated good outcomes. *U.S. v. Castle*⁶⁵ produced the first AIDS-related ADA settlement with a dental service. A Houston dental office paid \$100,000 in damages and penalties for allegedly refusing to treat a patient who revealed he was infected with HIV. Castle Dental Center, a large chain of dental offices in the Houston area, paid \$80,000 in compensatory damages to the patient. In addition, the owner of the center and its management company each paid a \$10,000 civil penalty to the federal government. The defendants were also required to provide full and equal services to persons with HIV or AIDS and to train their staff members in nondiscriminatory treatment of persons with HIV or AIDS.

In a well-publicized case, *Abbott v. Bragdon*,⁶⁶ a dentist refused to treat a patient in his office based on her HIV-positive status. The U.S. Supreme Court ruled that asymptomatic HIV status falls within the ADA's definition of disability and sent the case back to the lower court. Relying on the specific facts of the case, the 1993 Dentistry Guidelines of the Centers for Disease Control and Prevention (CDC), and the 1991 American Dental Association Policy on HIV, the lower court ruled that the patient's HIV status posed no direct threat and, therefore, the dentist must treat her.

In November 2003, four former patients with disabilities filed a lawsuit against Washington Hospital Center in Washington, DC, alleging that they could not receive routine medical care because of inaccessible examination equipment as well as other equipment and facilities. This and other similar suits use the ADA to challenge inadequate care rather than outright denial of service.⁶⁷

Landmark Lawsuit against Kaiser Permanente

In 2000, three wheelchair users sued Kaiser Permanente, the nation's largest nonprofit health maintenance organization. Based in Northern California, Kaiser operates thirty hospitals in nine states and the District of Columbia and has 8.2 million members. The lawsuit alleged that the healthcare giant failed to provide equal and adequate care for patients with physical disabilities, citing pervasive barriers as well as a lack of specially equipped examination tables and weight scales at scores of Kaiser facilities throughout California. Of Kaiser's nearly 6 million patients statewide, more than 100,000 are

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individuals with disabilities, and 40,000 use wheelchairs, according to Disability Rights Advocates, attorneys for the plaintiffs.

In addition to John Lonberg, who developed a pressure ulcer that went undetected, became infected, and eventually required surgery, a second Kaiser patient, also a wheelchair user, was told to weigh herself on a set of truck scales because clinic operators did not have a scale that was usable. The third Kaiser patient who joined the lawsuit said she felt like a prisoner, not of her wheelchair, but of her healthcare provider. “This isn’t about doctors,” said the Hayward, California, resident, aged sixty-three. “It’s about the system. When you’re disabled, you take what they hand you until you can get something better. That’s what this lawsuit is all about. Getting something better.”⁶⁸

The lawsuit was the first of its kind in the country. A landmark settlement was reached in March of 2001. The comprehensive settlement agreement and subsequent plan to review and reform Kaiser’s facilities and policies provide a model for the healthcare industry as a whole about how to provide safe, patient-centered medical care for people with disabilities. The broad settlement requires Kaiser to resolve a range of access barriers present in Kaiser facilities throughout the state, including architectural barriers, inaccessible medical equipment, and discriminatory Kaiser policies and procedures for patients with disabilities.⁶⁹ As part of its settlement, Kaiser not only had to install accessible medical equipment, but also was required to remove architectural barriers and to commit to staff training. A review of the patient complaint system and policies was also required to ensure that the healthcare system meets the needs of all people, with or without disabilities.

Among the innovations that stemmed from the Kaiser suit was a height-adjustable examination table that, for the first time, takes the needs of people with a wide range of disabilities into account. The table, created by a medical equipment manufacturer and rehabilitation design engineers at the request of the parties in the lawsuit, lowers farther than previous tables that claimed to be accessible, and features contouring and attachments that people with certain disabilities require for access, safety, and comfort. These tables will be deployed throughout the Kaiser Permanente system.

The Kaiser litigation has broken new ground by demonstrating that ADA litigation can be effective when it is used strategically on behalf of a class of individuals who have ongoing problems with a healthcare institution. Furthermore, the lawsuit and subsequent settlement have sent an important message to disability rights advocates and healthcare providers alike. By remedying substandard healthcare, providers not only meet the intent of the law but also take important steps toward creating a safe, patient-centered healthcare environment for people with disabilities.

Using the Law from a Patient’s Perspective

No civil rights law, including the ADA, is self-executing. When covered entities do not act proactively to comply with the law, enforcement can only be triggered if people with disabilities are aware of their legal rights and act on that information. They must be willing and able to bring the problem to the attention of the medical practitioner and, if necessary, to file a complaint with the enforcement agency or to bring litigation against healthcare

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providers and institutions. Realistically, however, people with disabilities are frequently deterred from taking action:

- Patients who are in a vulnerable position fear they might anger their healthcare provider, or that the provider will penalize them in some way.
- Internalized oppression could lead some people with disabilities to believe that care inevitably and unavoidably will be inferior simply because they have a disability that makes it difficult for them to use standard examination facilities and equipment. Consequently, they place the burden of responsibility for solving the problem on themselves rather than on the healthcare professional or institution.
- People with disabilities who are ill and in need of immediate medical attention are rarely in a position to raise problems regarding accessibility in an assertive manner, or even to request an accommodation.
- It can take months to obtain a resolution from an administrative complaint. Private litigation can also be time-consuming, slow, and potentially costly. While these tools can effectively achieve long-term change under certain circumstances, they rarely provide a solution that solves the individual's immediate problem.

In light of these disincentives, it becomes increasingly important for healthcare providers to embrace the goals and operational principles of the ADA.

THE ADA AND MEDICAID HEALTHCARE INSURERS

Of the 41 million low-income people Medicaid covers, nearly seven million beneficiaries qualified in 1997 based on disability.⁷⁰ States contract for healthcare services for Medicaid beneficiaries through a variety of mechanisms, including fee-for-service, managed care, or other targeted care. In 1998, about one in four (1.6 million) non-elderly persons with disabilities who were eligible for Medicaid were enrolled in Medicaid managed care plans. This trend has spurred concern about the quality of care patients receive and the impact of capitation and other cost-saving steps on people with special needs, including people with disabilities. Thus, the principles of the ADA and Section 504 have become an especially important tool for shaping the way care is delivered by health plans that have entered into contracts with states.

Its limited application to insurance carriers represents one striking weakness of the ADA. It does not disrupt the current nature of insurance underwriting, for example.⁷¹ However, the law does play a specific and important role with respect to the obligation of states under Title II that relates directly to insurers: when states contract for service with health plans on behalf of Medicaid beneficiaries, they must ensure that those plans comply with the ADA.

While implementation of the ADA by health plans appears limited, a few plans have taken steps to fulfill at least some of their ADA obligations. This fact suggests that combined state and federal ADA implementation efforts, community advocacy that has led to development of model projects, and some successful litigation have provided the necessary impetus to capture the attention of insurers. Some have attempted to incorporate specific services and features into Medicaid plans that acknowledge the range of needs of beneficiaries with

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disabilities, thus beginning a process of improving care. Others have experimented with specialized and innovative care strategies that serve the dual purposes of containing costs while improving preventive care.

The U.S. Department of Health and Human Services (HHS) has provided important guidance. In October 1998, the HHS Center for Medicaid and State Operations of the Health Care Financing Administration (HCFA), published “Key Approaches to the Use of Managed Care Systems for Persons With Special Health Care Needs.” This nonbinding guidance was intended to “serve as a valuable resource to State Medicaid agencies as well as a broad statement of HCFA’s goals for care delivery systems intended to serve persons with special healthcare needs.”⁷²

The document expressly states, “while the guidance is written from the standpoint of service delivery within a managed care setting, the vast majority of the guidance is appropriate regardless of the service delivery model being employed by a State.”⁷³ Among many important quality-of-care topics, the guidance specifically addresses the obligation of states to require their healthcare contractors to comply with the ADA. In a section entitled “Access and Quality,” the guidance states, “Of fundamental importance to any healthcare service delivery system is the ability of enrollees to access appropriate services in a timely manner.” It goes on to state, “Issues that impact on access include . . . steps the State is taking to comply with relevant Federal statutes regarding persons with disabilities (e.g., the Americans with Disabilities Act) when designing, implementing and monitoring its care delivery systems.” The document also identifies issues that should be given serious consideration in order to ensure access to services for persons with special health needs.⁷⁴ The core principles of the ADA, which equate with quality healthcare delivery for people with disabilities, are incorporated throughout. These include the following:

- Enrollment materials should be made available for persons with sight or hearing impairments or for people who do not speak English. In addition, the establishment of thresholds for these materials should be considered by the state. These individuals need to be identified by the state prior to initiating the enrollment process.
- Multilanguage materials (written and audiovisual) should be made available at an appropriate comprehension level (based on community standards).
- Assurances should be provided that services (to aid in enrollment) are available for persons with cognitive impairments (or their guardians) during the MCO [managed care organization] selection process.
- Outreach materials and intake services should be made available at locations that are especially convenient to persons with special healthcare needs.
- Patient confidentiality must be ensured throughout the enrollment, disenrollment, default assignment, and care delivery processes, and penalties should be associated with breaches of privacy or confidentiality. Communications with MCO enrollees must be consistent with the ADA prohibition on unnecessary inquiries into the existence of a disability.⁷⁵

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The following examples illustrate how the ADA and the movement for quality care have spurred actions by some states and health plans to meet the needs of Medicaid patients with disabilities.

In 1997, New York's Office of Medicaid Managed Care published "Guidelines for Medicaid MCO [Managed Care Organization] Compliance with the Americans with Disabilities Act (ADA)." The guide includes standards and suggested methods for compliance and requirements for documentation.⁷⁶ New York led the way by attempting to use the principles of the ADA as a tool for change within managed care.

In California, the Department of Health Services (CDHS) requires compliance with the ADA in its contract for Medicaid (Medi-Cal) services with managed care providers.⁷⁷ Plans have developed various programmatic responses to CDHS's ADA contract requirements:

- Some plans have a staffing unit to help providers and members locate accessible services when access is an issue.
- In conjunction with an outside consulting disability organization, one plan produces a provider directory that rates physical accessibility of provider settings.
- Several plans report including American Sign Language in their linguistic and cultural programs.⁷⁸

Some plans have initiated specific programs aimed at achieving cultural competency. Examples include the following:

- Coordination and reimbursement for non-emergency transportation, provision of in-home durable medical equipment assessment, and home-based wheelchair repair.
- Care coordinators and case managers to serve as advocates and the primary points of contact for patients with disabilities.
- Design of provider arrangements that include higher rate structures for members with disabilities, bonuses, and carving members with disabilities out of the capitation rate.⁷⁹

Several innovative programs build on the idea of creating novel strategies to address specific healthcare needs. The Community Medical Alliance (CMA) provides one example. A division of the Massachusetts Neighborhood Health Plan (NHP), CMA is a nonprofit managed care organization founded specifically to meet the needs of Medicaid enrollees with complex and costly conditions. Initially, the plan served people with quadriplegia, and CMA then added people with HIV/AIDS. A team philosophy of primary care focuses on the following:

- Organizing to respond 24/7
- Fostering a highly personalized patient relationship
- Empowering providers to order services rather than request them
- Integrating case management into care delivery
- Establishing new locations of medical decision making⁸⁰

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Nurse practitioners provide primary care along with specialists on the care team. Clinical care is frequently provided in the patient's home or place of employment (74 percent in the patient's home or office as compared with 26 percent in the physician's office for primary care). This approach has stabilized costs, reduced acute hospitalizations, and improved quality of life for enrollees, who require fewer stays in the hospital.⁸¹ Patients consistently report high levels of satisfaction with the program.⁸²

Similarly, Axis Healthcare offers Minnesota Disability Health Options (MnDHO), a managed care plan serving people with physical disabilities aged eighteen to sixty-four who are eligible for Medicaid and who reside in four target counties. The Minnesota Department of Human Services (MnDHS), in collaboration with two rehabilitation organizations in the state, designed this program to combine physician, hospital, home care, nursing home care, home- and community-based services, and other care into one coordinated care system.⁸³

People with disabilities, who helped plan MnDHO, identified the following needs:

- Healthcare and support services that focus on the whole person
- More control and choice in healthcare and support services
- Providers who are experienced in working with people who have physical disabilities
- Healthcare and support services that are accessible to people with different disabilities
- Help coordinating care among doctors, home care providers, equipment vendors, and other healthcare workers

Forty individuals with disabilities participated in the pilot project. It is anticipated that several hundred people will eventually be enrolled in the plan.

SUMMARY

Federal and state implementation and enforcement of the ADA and Section 504, in addition to private litigation, have spurred important but modest reforms in healthcare service delivery for people with disabilities. These reforms fall into two broad categories. First, remedies have been secured for some individuals who have been directly refused treatment; some large hospitals now provide auxiliary aids such as sign language interpreters for individuals who are Deaf or hearing impaired; and new or altered medical facilities afford basic architectural accessibility.⁸⁴ Second, some Medicaid healthcare plans, primarily in the managed care sector, have begun to respond to the particular needs of patients with disabilities by developing specialized services. Systemic reforms are expected within the managed care giant Kaiser Permanente when the settlement agreement in the lawsuit has been completely implemented.

While this progress is not insignificant, many serious problems remain. Most hospitals and large healthcare facilities simply have not gone beyond providing architectural accessibility to embrace a holistic, integrated approach to providing quality care. Such institutions appear to accept and initiate changes called for by the ADA. However, the real intent of the law in the healthcare context—to ensure that people with disabilities have a truly equal opportunity to benefit from available services—remains largely misunderstood, ignored or worse, challenged by some institutions.

Other than some architectural access that has been triggered either by new construction or alterations, most offices of medical providers remain relatively untouched by the ADA. Although DOJ has actively sought and won remedies on behalf of some individuals for ADA violations that took place in the offices of a provider, these cases have not had a meaningful ripple effect. On the whole, medical providers who serve patients in private offices appear to have little awareness of the ADA, particularly of their obligation to determine if a patient with a disability requires an accommodation and to provide that accommodation if possible.

Still, the message is clear: by ignoring the intent of the ADA, medical providers and institutions risk significant liability. More important, patients can become or remain ill, suffer, and die because care is inadequate. Healthcare institutions, therefore, have the moral as well as legal responsibility to take action.

THE ROLE OF THE JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS (JCAHO) AND THE COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES (CARF)

Two key agencies play central roles through accreditation and related services in improving the safety and quality of healthcare provided to the public. The major accreditation body for hospitals and care facilities is the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which evaluates and accredits more than 16,000 healthcare organizations and programs in the United States. The Commission on Accreditation of Rehabilitation Facilities (CARF) reviews and accredits rehabilitation and human services providers. Currently, more than 38,000 services have earned CARF accreditation. In 2003, CARF merged with the Continuing Care Accreditation Commission (CCAC), an agency that accredits aging services, including continuing care retirement communities.

The most important benefit that accreditation offers is the assurance that healthcare service is safe and of high quality. Furthermore, the accreditation imprimatur serves to enhance a facility's relationship with financial partners such as managed care contractors and third party payers, while reassuring the community that the organization is committed to providing safe, effective, and professional healthcare services.

As the leading healthcare accreditation bodies in the United States, JCAHO and CARF are uniquely positioned to play a significant role in improving healthcare service delivery and access for individuals with disabilities.

JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS (JCAHO)

JCAHO thus far appears to limit its role to referencing the ADA as a legal mandate in accreditation materials: "The hospital's responsibility to provide access to care is governed by the Americans with Disabilities Act (ADA) and other applicable law and regulation."⁸⁵

JCAHO lists in its 2001 accreditation manual only three types of specific actions or steps hospitals are expected to have taken to meet ADA requirements. The following actions appear in references to effective communication and are likely included because of DOJ's emphasis on cases involving auxiliary aids and services:⁸⁶

- The hospital has access to translators or translation services when necessary.
- The hospital's switchboard has TDD access.
- Telephones in patient rooms are supplied with voice amplification devices as appropriate.
- Patient information is available in Braille or on audiocassette.

In a footnote, the manual also refers to ADA requirements concerning professional criteria for hospital medical staff:⁸⁷ "The professional criteria at least pertain to evidence of current licensure, relevant training or experience, current competence, and ability to perform the privileges requested."⁸⁸

THE ROLE OF THE JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS (JCAHO) AND THE COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES (CARF)

The JCAHO manual makes an oblique reference to the built environment in one sentence: “The hospital plans and provides for other environmental concerns.”⁸⁹ Describing its intent, the JCAHO manual states, “The built environment supports the development and maintenance of the patient’s interests, skills, and opportunities for personal growth.”⁹⁰

The manual gives the following example: “Furnishings and equipment reflect patient’s characteristics related to age, level of disability, and therapeutic needs.”⁹¹

COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES (CARF)

In light of its focus on rehabilitation, function, and life enhancement services, it is not surprising that CARF has a broader and more explicit recognition of disability access than does JCAHO. CARF states in its core values that “all people should have access to needed services that achieve optimal outcomes.”⁹² Furthermore, CARF states that it is committed to “diversity and cultural competence in all CARF activities and associations.”⁹³

CARF explicitly addresses access concerns in its principle statement for business practices on accessibility: “CARF-accredited organizations promote accessibility and the removal of barriers for all persons served.”⁹⁴ CARF requires a written accessibility plan that must address architectural, environmental, attitudinal, financial, employment, communication, transportation, and other barriers identified by stakeholders.⁹⁵ The standards manual states, “When a barrier is identified, a report is written that addresses the actions planned to remove the barrier. This report includes a realistic time line for removal of the barrier.”⁹⁶ This declaration does not specify who is accountable for writing the barrier-removal report or for overseeing that the actions are carried out. Requests for reasonable accommodation must be identified, reviewed, and decided upon in keeping with the intention that “a reasonable accommodation is a modification or adjustment that would assist the persons served or personnel to access benefits and privileges that are equal to those enjoyed by others.”⁹⁷

In order for accreditation standards to achieve the goal of safe, patient-centered healthcare for people with disabilities, they must apply the principles of the ADA in measures that recognize, respect, and accommodate both individual and group needs, as the CARF standards attempt to do. However, it is not enough simply to circulate standards manuals and check off items on a survey form during the accreditation process. Accreditation agencies must assert their leadership if this new paradigm in patient care is to be realized within the organizations they accredit. JCAHO and CARF must find new ways to monitor compliance with the standards, reward best practices, solicit user feedback, and incorporate that information into the ongoing accreditation effort.

PROVIDING CULTURALLY COMPETENT, PATIENT-CENTERED CARE FOR PEOPLE WITH DISABILITIES—EMBRACING THE PRINCIPLES OF THE ADA AS A MODEL.

Cultural competency has been identified as a critical element of quality healthcare services, and in particular of patient-centered care—one of the essential ingredients identified by the Institute of Medicine’s report, *Crossing the Quality Chasm*. Culture, as defined by the American Medical Association in their Cultural Competence Compendium, is “any group of people who share experiences, language and values that permit them to communicate knowledge not shared by those outside the culture.”⁹⁸

Though underserved, underrepresented racial, ethnic, and socioeconomic groups often receive the greatest focus in cultural competency education, people with physical or mental illness or disabilities are also included—not only in the AMA Cultural Competence Compendium, but also by Kaiser Permanente and other large agencies and institutions. States are also beginning to recognize disability cultural competency within the context of Medicaid delivery systems. For example, in August 2000, the Colorado Department of Healthcare Policy and Financing issued a report entitled *Self-Assessment of Cultural Competency and Disability Awareness among Medicaid Primary Care Physicians*, with recommendations for improving cultural competency for people with disabilities covered under Medicaid. The language of cultural competency can also be helpful for identifying standards by which to judge a healthcare environment:

- A culturally diverse staff that reflects the communities served
- Providers or translators who speak the clients’ language(s)
- Training for providers about the culture and language of the people they serve
- Signage and instructional literature in the clients’ language(s) and consistent with their cultural norms
- Culturally specific healthcare settings⁹⁹

One of the most progressive aspects of the ADA is its requirement for accommodations and modifications to ensure that individuals with disabilities have an equal opportunity to participate in quality healthcare. Unfortunately, many healthcare providers do not understand the intent of the ADA with respect to accommodation, practical aspects related to choosing an accommodation, or how accommodation advances the goals of safe, culturally competent care. Even when a patient requests a specific accommodation, some healthcare institutions either resist providing it or take ineffective or inappropriate action. Many anecdotal examples have come to our attention. We provide two in order to illustrate the point that cultural competency can sometimes be exemplified by appropriate accommodations. These two women, who visited the clinic for women with disabilities at the Rehabilitation Institute of Chicago, reported being treated in an unsafe, demeaning, and painful manner when they sought services from another provider in their area. One woman with cerebral palsy was lifted onto an examination table by an untrained security guard. The other woman, who has multiple sclerosis, was held under the arms in a standing position by two staff members in order to reach an inaccessible mammogram machine.

PROVIDING CULTURALLY COMPETENT, PATIENT-CENTERED CARE FOR PEOPLE WITH DISABILITIES—EMBRACING THE PRINCIPLES OF THE ADA AS A MODEL.

Such methods to accommodate are inappropriate, dangerous, and humiliating, in addition to being neither culturally competent nor compliant with the principles of the ADA. An adjustable mammogram machine that raises and lowers so a woman can be examined while seated in her wheelchair represents one example of a reasonable accommodation. As with many other disability rights innovations, such as curb ramps, this equipment inevitably will be used by others, including women of diverse ages and health conditions for whom it is uncomfortable to stand during a mammogram, thus illustrating the value of designing universally for the greatest number and type of users. In addition, using adjustable equipment meets one of the standards for culturally competent care: the facility is culturally specific to people with disabilities. Similarly, trained lifters, a mechanical lift, an adjustable-height examination table, or a combination of equipment and assistance are appropriate methods to ensure that a patient with a mobility impairment can mount an examination table safely and with dignity.

According to Anderlik and Wilkinson in a *Houston Law Review* article, “The ADA is both a powerful statement of a vision of a just and compassionate society and a collection of principles for the translation of that social vision in practice.”¹⁰⁰ As such, these principles of nondiscrimination, accommodation, and integration can guide healthcare providers as they develop methods to improve services for people with disabilities that reflect the values and goals of cultural competency.

RECOMMENDATIONS

No single solution exists that will solve the deeply entrenched problems this report catalogues. Ensuring safe, competent, high quality care for people with disabilities calls for bold and innovative strategies that create a continuum of options. We acknowledge from the outset that real solutions might require fundamental structural and systemic changes in some current policies. Such changes come with cost implications. Thus, who will pay remains a central question.

Having acknowledged the possible complexity and cost of reforms, we now present specific recommendations that recognize and leverage the capacity of the diverse stakeholders and that encompass the broadest possible range of ideas. For some stakeholder groups, the highest priority recommendations are noted.

The following themes transcend all the recommendations:

- Involving people with disabilities at all levels of decision making
- Infusing training and education about the myriad healthcare and access concerns of people with disabilities into every level of discussion and activity
- Rewarding experimentation and innovation
- Valuing solutions most highly that promote services in the most integrated settings
- Sharpening ADA compliance at all levels of responsibility

ALL STAKEHOLDERS

All initiatives, discussions, and interventions that are undertaken to improve healthcare quality for persons with disabilities should adopt a broad definition of disability that encompasses persons of all ages, from infancy to old age, and the full spectrum of cognitive, emotional, sensory, and physical abilities. Such a broad definition dispels the notion that disability is limited to wheelchair users and people who are blind or Deaf. Similarly, it challenges the idea that disability is a binary state, that either one has a disability or one does not, which further perpetuates misperceptions about the nature of impairments. In fact, impairments exist along a continuum of severity that can be permanent or temporary and will affect everyone at some point in their lives. For example, some of the people most at risk of receiving substandard care are older persons whose vision and hearing are impaired and who cannot read written instructions or hear what their physicians tell them; these people also often have trouble with inaccessible equipment. By adopting a broad definition, healthcare professionals and institutions make absolutely apparent the imperative that everyone addresses all the manifestations of disability and impairment-related issues.

PERSONS WITH DISABILITIES AND DISABILITY ADVOCACY GROUPS AND ORGANIZATIONS

The broad disability community is comprised of many diverse groups, organizations, and programs. These include independent living centers, grassroots and national advocacy organizations, law and policy groups, research institutes, service delivery organizations,

organizations that are concerned with specific impairments or diseases, university-based disability studies centers, rehabilitation centers, and many others.

Some recent reforms in healthcare delivery for people with disabilities have come about because disability advocates have focused attention on the issues through discussing relevant points with providers, developing education and community empowerment projects, conducting research, proposing policy reforms, and fostering model service delivery alternatives. They have also spurred compliance with the ADA by some health-care providers by filing complaints and lawsuits. Thus, the disability community will continue to play a central role in framing long-term reform.

Highest priority activities that disability groups and organizations should undertake, strengthen, or expand include the following:

- Partnering with healthcare professionals, educational institutions and programs, and professional societies to develop and provide training for physicians and other healthcare practitioners about diverse issues such as how disability is defined, the importance and role of accommodations, and specific health problems and issues that relate to particular impairments
- Collaborating with public policy makers, professional societies within the health-care community, and others to craft policy recommendations that could include these points:
 1. Providing additional guidance in the ADA-implementing regulations that concern the responsibilities of healthcare providers
 2. Creating technical specifications that define accessibility for common medical examination equipment such as tables, chairs, radiological equipment, and the like
 3. Creating new financial incentives for healthcare providers who purchase accessible equipment such as examination tables or lifts
 4. Increasing tax incentives and creating new incentives for barrier removal and architectural modifications based on the ADA Accessibility Guidelines for Buildings and Facilities (ADAAG), or the ADA Architectural Guidelines, and universal design principles
 5. Identifying other incentives for ADA compliance

Other recommendations include the following possibilities:

- Educating people with disabilities about specific health topics, such as the need for screening, prevention, and wellness services
- Undertaking education advocacy projects:
 1. To foster empowerment of people with disabilities by building coalitions of individuals with a variety of impairments who can advocate for reforms with local healthcare providers

RECOMMENDATIONS

2. To inform people with disabilities about barriers to healthcare and present strategies that individuals can use to challenge inadequate services, including providing information about how to file disability rights complaints
- Encouraging and facilitating participation by people with disabilities on healthcare advisory boards and committees and as paid consultants

PHYSICIANS AND OTHER HEALTHCARE PROFESSIONALS

Physicians and other professional healthcare providers must assume some responsibility for educating themselves and initiating change within their own offices and clinics. This report presents recommendations for physicians in concert with those aimed at professional societies and the disability community. Specifically, healthcare providers should take the following steps:

- Understand the broad definition of disability
- Learn about the requirements of the ADA and take steps to comply
- Review the needs of their patient populations for accommodations to improve the accessibility of healthcare services and effective communication
- Learn about resources in the community that can help them comply with the ADA and improve their patients' experiences
- Learn about IRS tax credits that are currently available for removing barriers and providing ADA accommodations

MEDICAL AND OTHER PROFESSIONAL SCHOOLS

Institutions that train physicians, surgeons, dentists, therapists, nurses, and others in the healthcare field must take steps to ensure that disability is fully integrated into all aspects of training. These institutions must do the following:

- Make a commitment to include and integrate clinical training and resources about disability concerns throughout the educational process
- Provide clinical training about disability accommodations and the role and value of screening and preventive care for persons with disabilities
- Provide clinical resources and tools for addressing specialized disability issues; such information could be developed, deployed, and updated on a web site, for example

HEALTHCARE PROFESSIONAL ORGANIZATIONS AND SOCIETIES

Professional organizations and societies are well positioned to provide leadership for their members. Organizations such as the American Medical Association, American Hospital Association, Association of American Medical Colleges, American Nursing Association, American College of Physicians, the American Board of Internal Medicine, the Accreditation Council on Graduate Medical Education, the American Academy of Physical Medicine and Rehabilitation, and other associations and societies should undertake the following activities:

- Take the lead to design and implement disability curricula in collaboration with the disability community and educational institutions
- Work with educational institutions to integrate disability curricula into training programs
- Educate their professional membership using newsletters, journals, and a web site
- Design specific hospital and healthcare provider standards on disability access in concert with the disability community
- Take the lead to encourage and reward the inclusion of people with disabilities into healthcare training programs and jobs

Furthermore, the American Hospital Association should establish a yearly award for the hospital or provider organization that takes the greatest initiative or most creative steps to implement disability access and accommodation.

HOSPITALS AND OTHER HEALTHCARE INSTITUTIONS

The challenge for hospitals and other healthcare institutions that have already made some effort to comply with the ADA is to recognize that architectural barrier removal is only the first step, not the only step that they must take to ensure that people with disabilities have an equal opportunity to receive healthcare services. Ensuring access to safe, quality care requires embracing principles of cultural competency that are embedded in the ADA in the form of accommodation and policy modifications. These institutions, therefore, should take the following steps:

- Establish a task force that includes people with disabilities and that will undertake a thorough examination of hospital policies and practices
- Undertake a needs assessment not only from the perspective of barrier removal but also from the perspective of quality of access to services. Methods to collect information could include conducting focus groups comprised of staff members, patients, and others with disabilities, interviewing various stakeholders, and reviewing procedural manuals and other written materials. Areas to explore could include the following:
 1. Evaluating examination and diagnostic equipment for accessibility, or for methods to assist patients with mobility disabilities to mount or use equipment
 2. Determining if a mechanism exists to respond to a request for an accommodation
 3. Evaluating policies and practices for indicators that they might be culturally insensitive or hostile to people with disabilities
 4. Determining how complaints are handled
- Craft an implementation plan, including a timetable, that reflects the findings from the needs assessment and sets priorities based on urgency, cost, and other factors to be determined by the task force

RECOMMENDATIONS

- Actively engage in ongoing staff education
- Apply principles of universal design—products and environments that are usable by all people to the greatest extent possible—to any new construction or alteration of existing facilities

PUBLIC AND PRIVATE HEALTH INSURERS

It is beyond the scope of this report to present the problems people with disabilities face obtaining health insurance coverage or to discuss in-depth the inequities in the services that are available for those who do have some form of public or private coverage. However, we recognize that these are threshold concerns, and we document them briefly in the section on access to care. Recommendations, therefore, are presented primarily for insurers who serve Medicaid beneficiaries and who are required to comply with the ADA. Medicaid insurers should institute the following practices:

- Pay providers for the actual time required to treat patients with disabilities rather than enforcing capitation rates
- Create case management assistance to help people with disabilities navigate both managed care and fee-for-service systems, and obtain services from appropriate providers
- Proactively extend to healthcare providers the requirements for ADA compliance contained in their state contracts
- Establish a technical assistance unit that proactively works with member providers to assess architectural barriers and remove those that can be removed in accordance with ADA regulations
- Create incentives for providing accommodations and removing barriers
- Identify, structure, and support innovative methods for participating providers to share accessible equipment such as lifts and examination tables
- Work in collaboration with states and related stakeholders to develop and support models that deliver service in new and innovative ways, such as the Massachusetts Community Medical Alliance and the Minnesota AXIS Healthcare project

ACCREDITATION ORGANIZATIONS

In order for an institution to receive the highest level of accreditation, the accrediting organization should assess the applicant according to the following areas of activity:

- The institution must establish a substantive healthcare access committee that includes medical personnel, disability community members, and hospital administrators whose mission is to identify methods to provide high quality, accessible, culturally competent care in the spirit of the ADA. A self-evaluation and transition plan (required of some healthcare providers by the ADA) could be a tool for identifying barriers as well as accommodation needs, creating a timetable for systemic reform, and establishing a mechanism for monitoring and follow-up.

- The institution must require accessibility in accordance with the ADA Architectural Guidelines (ADAAG).
- The institution must reward the implementation of “universal design” principles in healthcare settings.¹⁰¹
- The institution must set up a mechanism for assessing the need for accommodations by individual patients as well as similarly situated groups of patients, and for identifying and providing specific, appropriate accommodations. (Examples include provision of sign language interpreters, purchase and installation of a ceiling or portable lift to assist patients to mount examination tables, purchase of wheelchair-accessible examination tables, and provision of alternatively formatted materials for individuals with vision impairments.)
- The institution must provide for all personnel ongoing staff training that includes measurable outcomes. Training topics should include the requirements of the ADA in the context of cultural competency and accommodation; practical implementation methods; information about in-house resources that staff members can call on to address problems or issues that arise; and ongoing ethical and legal issues.
- CARF and JCAHO must also provide ongoing technical assistance to institutions seeking accreditation, either themselves or by contracting with qualified disability organizations. The CARF standards and Kaiser Permanente settlement policies and training materials could be used as a starting point.

FEDERAL AND STATE GOVERNMENT AGENCIES AND POLICY MAKERS

Congress

The severity of the problems people with disabilities experience in gaining access to quality healthcare calls for national policy intervention. Because the issues are complex and are partially rooted in the broader problems of healthcare coverage for everyone, Congress must take the following steps to identify the most effective points for intervention:

- Conduct oversight hearings concerning healthcare access for individuals with disabilities in which the experiences of people with disabilities can be brought to light
- Call for recommendations for reform from key stakeholders
- Craft appropriate policy responses in concert with these stakeholders

Federal Agencies

While the U.S. Department of Justice has achieved some significant ADA victories in healthcare service delivery, the systemic problems that are described in *It Takes More than Ramps* remain, for the most part, unresolved. The U.S. Department of Health and Human Services, also charged with ADA enforcement in the healthcare context, has focused much attention on implementation of the law as defined by the landmark U.S. Supreme Court decision in *Olmstead* (see note 44), and on fostering ADA compliance by state Medicaid providers. While these are worthy and important activities, combined agency enforcement of the ADA as it applies to the large body of healthcare providers and institutions remains limited.

RECOMMENDATIONS

DOJ and HHS must launch a large-scale initiative similar in scope to the *Olmstead* program, which has had a significant impact in facilitating the community integration of individuals with disabilities. This initiative could include these points:

- Increasing healthcare discrimination case investigation
- Targeting frequent violators for compliance reviews
- Creating an ADA technical assistance initiative that proactively reaches out to and educates providers (such an initiative could be undertaken in collaboration with various societies of medical and allied health professionals and disability rights organizations)
- Directing regional offices to pursue healthcare cases as a priority
- Revisiting the applicable ADA regulations and ADA Architectural Guidelines in order to identify gaps where compliance with the law does not ensure accessible healthcare (for example, the absence of accessibility guidelines for equipment or limited guidance on what constitutes effective communication in the healthcare context)

Federal agencies such as the Department of Health and Human Services, Centers for Disease Control and Prevention, National Institutes of Health, Health Resources and Services Administration, Substance Abuse and Mental Health Services Administration, Office of Disease Prevention and Health Promotion, and the Department of Justice should work collaboratively to create and support innovative model projects and programs that have the potential to increase quality healthcare services for people with disabilities. High priority recommendations include taking the following steps:

- Create demonstration projects that build on the strengths of the “carve-out” programs funded under the Medicaid program, but that do not require that only people with certain disabilities congregate in one program
- Launch experimental programs in select states that target providers and provider groups who will participate cooperatively in activities leading to increased access through architectural barrier removal, purchase and/or sharing of accessibility equipment such as lifts, and provision of individual and group accommodations, with outcomes to be evaluated as possible models
- Assemble a brain trust of highly qualified individuals—including people with disabilities, policy advocates, disability rights attorneys, medical professionals, insurers, and government officials—to identify and explore new options for delivering care in a nondiscriminatory manner that includes appropriate accommodations
- Establish partnerships of disability and healthcare service organizations that want to engage in community-based experimental models to attack the problems from a variety of practical vantage points and perspectives

Other recommendations include the following:

- Promote and fund research and development that will lead to new technology solutions to help people with disabilities gain access to quality care
- Commission specific research to reveal the extent to which leading hospitals throughout the

United States meet the threshold requirements of the ADA for accessibility, and the extent to which they have modified policies and provided accommodations for patients and others with disabilities, with research outcomes to inform future policies

- Encourage a dialogue among key stakeholders by supporting meetings and conferences that bring together diverse experts to identify possible programmatic or policy solutions
- Support policy papers that pose specific solutions and the steps required to activate them

State Governments

Of high priority are the following recommendations:

- Adopt the recommendations found in “Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs,” created and published by the U.S. Department of Health and Human Services, the Health Care Financing Administration, and the Center for Medicaid and State Operations
- Adopt the state of New York’s “Guidelines for Medicaid MCO [Managed Care Organization] Compliance with the Americans with Disabilities Act (ADA)”
- Develop contract language that incorporates these recommendations as requirements that health insurers must agree to in order to receive Medicaid reimbursement for providing services to people with disabilities
- Create an oversight mechanism for monitoring ADA compliance by Medicaid insurers
- Strengthen direct oversight and enforcement of the ADA and related state disability rights laws within large healthcare institutions
- Define the obligations of Medicaid health insurers to enforce ADA compliance by providers with whom they contract, and monitor implementation

Other recommendations for states include the following:

- Terminate or do not renew contracts with insurers that fail to implement the requirements
- Create incentives for insurers that explore and experiment with innovative health-care delivery models to enhance quality of care for individuals with disabilities
- Create incentives for state-funded teaching institutions, such as state university medical and dental schools and other professional medical training institutions, to include a disability strand in their curricula

PROMISING PROGRAMS AND BEST PRACTICES

People with disabilities, advocates, rehabilitation and other medical practitioners, researchers, policy experts, disability rights attorneys, and others have begun to tackle the challenges presented in this report from many perspectives. Approaches vary, but the universal goal is to increase access to quality, appropriate healthcare services for people with disabilities. We provide examples of a few programs and best practices here to illustrate some promising responses to healthcare problems for people with disabilities and to inspire new approaches that build on current work, including the models that have been created by enforcement of the ADA. This list is illustrative rather than exhaustive.

CENTER FOR DISABILITY ISSUES AND THE HEALTH PROFESSIONS (CDIHP) WESTERN UNIVERSITY OF HEALTH SCIENCES, POMONA, CALIFORNIA

Western University of Health Sciences, a graduate university for the healthcare professions in Pomona, California, opened the Center for Disability Issues and the Health Professions (CDIHP) in 1998. Western University established the Center “in response to the concerns of the disabled community, which is emerging as one of the nation’s fastest growing and least understood minority groups.”

Founded and managed by individuals with disabilities, CDIHP has established the following goals:

- To improve the capabilities of healthcare providers to meet the growing needs of people with disabilities
- To increase the number of qualified individuals with disabilities who pursue careers in the health professions
- To empower people with disabilities to become more vocal and active participants in their healthcare
- To conduct and disseminate research on community-based health education, prevention, and healthcare services for people with disabilities

CDIHP has undertaken a variety of projects aimed at meeting these goals, a representative sample of which follows:

- Creating educational videos for physicians and prospective students with disabilities
- Creating and disseminating disaster-preparedness information
- Providing quality-of-care consultation for selected managed care organizations
- Conducting focus groups to provide feedback about barriers to service in Medicaid-managed care plans in California
- Conducting consumer training
- Developing materials for women with cognitive disabilities
- Teaching classes on culture and disability

CDIHP is a partner with Marquette University and the University of California, Berkeley, in an important initiative, described below, to evaluate medical instrumentation and determine which instruments need to be newly designed or re-engineered to be accessible to individuals with a wide variety of disabilities.

PROMISING PROGRAMS AND BEST PRACTICES

THE CENTER FOR UNIVERSAL DESIGN NORTH CAROLINA STATE UNIVERSITY, RALEIGH, NORTH CAROLINA

The Center for Universal Design at North Carolina State University, in conjunction with the North Carolina Office on Disability and Health, produced a pamphlet entitled “Removing Barriers to Health Care: A Guide for Health Professionals.”

The Center for Universal Design is a national research, information, and technical assistance center that evaluates, develops, and promotes universal design in housing, public and commercial facilities, and related products. The founder, Ronald L. Mace, launched the universal design movement, which is defined as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” The intent of universal design is to simplify life for everyone by making products, communications, and the built environment more usable for as many people as possible at little or no extra cost. Universal design benefits people of all ages and abilities.

Universal design principles encompass the following criteria:

- Equitable use
- Flexible use
- Simple and intuitive use
- Perceptible information
- Tolerance for error
- Low physical effort
- Size and space for approach and use¹⁰²

THE NATIONAL REHABILITATION HOSPITAL CENTER FOR HEALTH & DISABILITY RESEARCH WASHINGTON, DC

The National Rehabilitation Hospital Center for Health & Disability Research (NRH-CHDR) has conducted public domain, peer-reviewed research funded by federal and private organizations for more than fifteen years. The center combines quantitative and qualitative methods to provide “big picture” overviews supported by “person level” detail, using participatory action research. Studies inform local, state, national, and international policy makers on all aspects of rehabilitation and healthcare for persons with temporary or permanent disabilities.

Listed on the NRH-CHDR’s web site are a number of questions that the Center investigates, such as the following:

- How can external review agencies monitor the quality of care for people with disabilities?
- How can the disparities in access to care be redressed for minorities with disabilities?¹⁰³

PROMISING PROGRAMS AND BEST PRACTICES

- How can people with disabilities inform physicians about the need for routine preventive and primary care, such as screening for cancer and sexually transmitted diseases?
- What are the consequences of broadening the definition of “medical necessity”?
- How does disability affect employment of older workers?
- How can we compel health plans to become “disability literate”?

PRESBYTERIAN-ST. LUKE’S HOSPITAL RUSH UNIVERSITY MEDICAL CENTER, CHICAGO, ILLINOIS

Rush-Presbyterian-St. Luke’s Hospital (Rush) is a large medical center and health sciences university in Chicago, Illinois that is comprised of Rush Children’s Hospital, Johnston R. Bowman Health Center, and Rush University. Committed to offering culturally competent services for people with disabilities that are self-generated rather than the outcome of legal action, Rush has undertaken the following activities:

- Pioneered initiatives to recruit medical and nursing students with disabilities into its university program, thereby creating more opportunities for healthcare professionals with disabilities
- Drafted its first broad-based accessibility plan for the hospital sector in 1980, soon after regulations were issued implementing Section 504 of the 1973 Rehabilitation Act
- Began implementing the accessibility plan in 1990 and commissioned an institutional accessibility survey from Access Living, a local independent living center for people with disabilities
- Established a task force composed of a culturally diverse group of disability advocates and professionals from the community and within Rush who are responsible for formulating, integrating, and disseminating ADA-compliant practices throughout the hospital and the university

The Rush ADA task force has developed policies to address the needs of patients with speech disabilities, hearing needs, visual needs, and physical and mobility disabilities. Specifically, it has undertaken these activities:

- Allocated modest amounts of money annually toward the goal of implementing the projects that the task force deems to be priorities
- Established the annual Thonar Award, which recognizes a member of the Rush community who has made outstanding contributions to advance opportunities at Rush for people with disabilities
- Placed information about its healthcare access services on the Rush Intranet and established a special ADA information line in volunteer services for both public and institutional use

PROMISING PROGRAMS AND BEST PRACTICES

REHABILITATION ENGINEERING RESEARCH CENTER ON ACCESSIBLE MEDICAL INSTRUMENTATION (RERC) MARQUETTE UNIVERSITY, MILWAUKEE, WISCONSIN

The RERC was established with a five-year grant from the National Institute on Disability and Rehabilitation Research (NIDRR) and works from the premise that all persons regardless of disability should have access to healthcare instrumentation and services and to employment in the healthcare professions. RERC has the following goals:

- To increase knowledge of, access to, and utilization of healthcare instrumentation and services by individuals with disabilities
- To increase awareness of and access to employment in the healthcare professions by individuals with disabilities
- To serve as a national center of excellence in these areas

RERC undertakes these research projects:

- Needs analyses for people with disabilities as both recipients and providers of healthcare services, and for manufacturers of healthcare instrumentation
- Usability analyses to determine what makes certain medical instrumentation essential to healthcare service provision either exemplary or problematic
- Accessibility and universal usability analyses to identify classification and measurement approaches that could be used to explore metrics for accessibility of medical instrumentation
- Policy analyses to explore how medical policies affect the way persons with disabilities utilize healthcare services and access employment in the healthcare professions

RERC is developing these projects:

- Tools for usability and accessibility analysis
- Modified and new accessible medical instrumentation
- Emerging, accessible healthcare technologies
- Design guidelines for accessible medical instrumentation and model policies for healthcare service provision¹⁰⁴

CONCLUSIONS

Evidence shows that many people with disabilities often receive substandard healthcare. Many complex factors contribute to this reality, including limitations on services by insurers, discriminatory practices and policies by healthcare providers, and widespread lack of awareness about disability within the healthcare industry as a whole. While the ADA is an essential tool for social change and has spurred important reforms, its intent is often misunderstood, and compliance is far from universal even in large healthcare facilities. Private healthcare providers, clinics, and other healthcare delivery settings, moreover, appear to have done little to abide by the ADA. Responsibility for identifying and initiating effective strategies that build on the principles of the ADA and that will lead to a shift in the current approach to healthcare delivery for people with disabilities rests with diverse stakeholders. Government agencies; law and policy makers; insurers; accreditation organizations; medical, rehabilitation, and healthcare professional associations; individual providers; private foundations; the academic community; and the disability community must participate in making this necessary shift a reality.

It Takes More than Ramps highlights three conclusions:

1. People with disabilities use healthcare services at a significantly higher rate than people without disabilities, yet they commonly express dissatisfaction with their healthcare services, are particularly susceptible to disparities in healthcare, and experience widespread lack of appropriate accommodations.
2. The roots of these quality-of-care and safety shortfalls include inadequate training of clinicians and other healthcare professionals, poor executive oversight to enforce the Americans with Disabilities Act (ADA), limited funds and few financial incentives for upgrading equipment and hiring and training support staff members to assist patients, and misperceptions and stereotypes about disability.
3. Healthcare institutions have the moral as well as the legal responsibility to take actions to improve the healthcare delivery system for people with disabilities in a way that is safe, patient-centered, and culturally competent.

RESOURCES

CENTER FOR DISABILITY ISSUES AND THE HEALTH PROFESSIONS

Western University of Health Sciences
309 E. Second St.
Pomona, CA 91766-1854
Phone: (909) 623-6116
<http://www.westernu.edu/cdihp.html>

THE CENTER FOR UNIVERSAL DESIGN, NORTH CAROLINA STATE UNIVERSITY, RALEIGH, NORTH CAROLINA

The Center for Universal Design
School of Design
North Carolina State University
Campus Box 8613
Raleigh, NC 27695-8613
Phone: (919) 515-3082
Fax: (919) 515-3023
<http://www.design.ncsu.edu/cud>

MARQUETTE UNIVERSITY REHABILITATION ENGINEERING RESEARCH CENTER ON MEDICAL INSTRUMENTATION

Dept. Biomedical Engineering
PO Box 1881
Marquette University
Milwaukee, WI 53201-1881
http://www.erc-ami.org/erc_t4-links.htm

THE NATIONAL REHABILITATION HOSPITAL CENTER FOR HEALTH & DISABILITY RESEARCH

NRH Center for Health & Disability Research
1016 16th Street, NW
Suite 400
Washington, DC 20036-5724
Phone: (202) 466-1900
Fax: (202) 466-1911
<http://www.nrhchr.org>

ACCESSIBLE EXAMINATION TABLES

MIDMARK CORPORATION

Midmark offers healthcare providers a range of user- and patient-friendly examination and treatment tables used or recommended by healthcare providers who serve people with disabilities. These providers include Kaiser Permanente in California and the Rehabilitation Institute of Chicago (RIC).

Midmark Corporation
60 Vista Drive
PO Box 286
Versailles, OH 45380-0286
Phone: (937) 526-3662
Toll-free: (800)-MIDMARK or (800) 643-6275
Fax: (800) 365-8631

WELNER ENABLED — THE WELNER EXAMINATION TABLE

Welner Enabled aims to design and build products and devices that enable people with disabilities and people with chronic illnesses to access medical diagnosis and treatment.

Welner Enabled
224 W. 30th St. Ste. 806
New York, NY 10001
Phone: (480) 213-2008

ACCESSIBLE MAMMOGRAPHY PROJECTS

BREAST HEALTH ACCESS FOR WOMEN WITH DISABILITIES (BHAWD) ALTA BATES/SUMMIT MEDICAL CENTER, BERKELEY, CALIFORNIA

BHAWD is a community partnership of women with disabilities, breast cancer survivors, medical professionals, and grassroots disability rights organizations located in Berkeley, California. The program provides an accessible clinic for breast exams, self-breast exam education and training, and referrals for mammography.

The organization has two primary goals:

- To provide consumer-driven, culturally competent outreach, breast education, and accessible breast screening for women with physical disabilities and vision impairments in Alameda and Contra Costa Counties in Northern California, leading to development and dissemination of a replicable model of education and service delivery
- To call widespread attention to the breast screening needs of women with disabilities, the numerous barriers that impede their access to screening, and the serious neglect of this population in local, state, and national programs designed to improve screening utilization

BHAWD focuses on consumer direction and enhancing the ability of women with disabilities to take control of their own lives. Women with disabilities are equal partners in project planning, implementation, and ongoing development of service delivery. Diverse community agencies, represented on the BHAWD Steering Committee, receive essential feedback about service delivery and barriers in the community from patients, focus groups, task forces, and committee members.

BHAWD c/o
Alta Bates Summit Medical Center,
Herrick Campus
Rehabilitation Services
2001 Dwight Way, 2nd Floor
Berkeley, CA 94704
Phone: (510) 204-4866
TDD: (510) 204-4574
Fax: (510) 204-5892

CENTERS FOR DISEASE CONTROL BREAST CANCER RESOURCES AND INITIATIVES FOR WOMEN WITH DISABILITIES

The CDC Breast Cancer Resources and Initiatives for Women with Disabilities has produced the following publications:

- *Use of Cervical and Breast Cancer Screening among Women with and without Functional Limitations—United States 1994–1995 MMR Report*: findings suggest that older women with functional limitations are less likely to receive a Pap test or mammogram within the suggested guidelines

ACCESSIBLE MAMMOGRAPHY PROJECTS

- *Understanding Breast Cancer Screening and Treatment Among Women Aged 40 and Older Who Have Physical Disabilities*: a qualitative study of cognitive and environmental barriers (physical and social) affecting access to breast cancer screening and treatment by women with physical disabilities, with findings suggesting that individual perception of risk, preoccupation with other health issues, not knowing where to go for accessible screening, difficulty with positioning, inaccessible facilities and equipment, and provider knowledge and attitudes affect screening
- *Increasing Breast and Cervical Cancer Screening*: a collaboration between the Disability and Health Team and the Breast Cancer Early Detection Program to improve the accessibility of screening services in several state health departments; to date Arkansas, Iowa, New York, Oregon, Rhode Island, and South Carolina have purchased and strategically placed more than one hundred accessible examination tables through this collaboration and, although they did not receive funding for tables, Massachusetts and North Carolina are collaborating with their NBCCED programs to increase provider training and improve access, outreach, and education for women with disabilities
- *Count Us In*: a health promotion initiative at Duke University Medical Center designed to increase awareness and encourage breast and cervical cancer screening among women with disabilities in North Carolina, including a training curriculum for nursing, physician assistant, and family medicine residency programs
- *Health Communication for Women with Disabilities*: a collaboration with Prospect Associates, a nationwide marketing firm, to develop concepts, messages, and health promotion materials to encourage women with disabilities to be screened for breast cancer

JoAnn M. Thierry, MSW, MS
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Road, F-35
Atlanta, GA 30333
Phone: (404) 498-3022
E-mail: jxt4@cdc.gov

MASSACHUSETTS MAMMOGRAPHY ACCESS PROJECT

The Massachusetts Mammography Access Project (MAP) responds to the research revealing that women with mobility disabilities were significantly less likely to have had a mammogram in the recommended time frame than other women (46 percent to 62 percent of women with mobility disabilities vs. 75 percent of other women). This was particularly surprising because 98 percent of women with a mobility disability reported having had a routine checkup in the last year, as compared to 84 percent to 86 percent of other women.

ACCESSIBLE MAMMOGRAPHY PROJECTS

The purpose of MAP is to increase mammography screenings among women with mobility disabilities by taking the following steps:

- Improving access to mammography facilities
- Educating providers
- Increasing awareness among consumers of the importance of mammograms and the availability of accessible facilities

In the first half of a three-year grant from the Centers for Disease Control (CDC), MAP has focused on increasing the physical and programmatic accessibility of mammography facilities and gathering information that will enable a woman or her provider to find a site that is accessible for her.

MAP addresses the objectives of increasing accessibility and gathering information through these projects:

- Ensuring that the accessibility of mammography facilities throughout the state is assessed with the use of a survey tool developed by the Office on Health and Disability (OHD)—this tool assesses core elements of physical access, program access, and effective communication, as well as aspects of administration, training, and operations that create an accessible and inclusive environment
- Visiting each of the 187 mammography facilities in Massachusetts by the end of 2003 to assess access using the survey tool—the site visit serves as an opportunity to educate their hosts followed by a letter outlining recommendations for improved access and resources and offers of technical assistance to improve access, and site visit results are disseminated to women and their providers through print publications and the Internet
- Using a combination of self-report and visits to a subset of sites to follow up with reassessments
- Conducting a pilot project at two mammography facilities that perform a total of approximately 35,000 mammograms per year in order to create a more accessible and inclusive mammography experience and to improve mammogram quality through training and changes in scheduling practices

Lisa Maisels
Project Coordinator
Office of Health and Disability
Massachusetts Department of Public Health
250 Washington Street, 5th Floor
Boston, MA 02108
Phone: (617) 624-5960
Fax: (617) 624-5990
TTY: (617) 624-5992
Lisa.Maisels@state.ma.us
<http://www.state.ma.us/dph/fch/ohd/index.htm>

MODEL CLINICAL SERVICES AND RESOURCES FOR WOMEN WITH DISABILITIES

For more than a decade women leaders with disabilities have worked to fill a void in the provision of competent reproductive health services and women's health resources by creating a variety of clinical, research, and training programs. Among the clinical programs, some serve only women with disabilities, while others are incorporated into mainstream health-care settings. The programs described below each contribute to creating a spectrum of health services and resources that offer women with disabilities the choices they require for self-determination.

RESEARCH AND TRAINING RESOURCES

BERKELEY POLICY ASSOCIATES (BPA)

BPA conducts research nationally on access barriers to mainstream healthcare services for women with disabilities.

440 Grand Avenue, Suite 500
Oakland, CA 94610
Phone: (510) 465-7884
TTY: (510) 465-4493
E-mail: info@bpacal.com
<http://www.berkeleypolicyassociates.com/>
Director/CEO: Hans Bof

CENTER FOR RESEARCH ON WOMEN WITH DISABILITIES

The Center conducts research and creates training materials on women with disabilities for primary care physicians and obstetrics/gynecology providers.

Margaret Nosek, PhD
Department of Physical Medicine and Rehabilitation
Baylor Medical College
3440 Richmond, Suite B
Houston, TX 77046
Phone and TTY: (713) 960-0505
Fax: (713) 961-3555
E-mail: crowd@bcm.tmc.edu
<http://www.bcm.tmc.edu/crowd/>

THE CENTER FOR WOMEN WITH PHYSICAL DISABILITIES

This comprehensive healthcare center for women with physical disabilities is dedicated to meeting the unique needs of these women by significantly reducing social and physical barriers to the access and application of comprehensive health services and preventive care.

Jaye E. Hefner, MD
Magee-Women's Hospital of UPMC Health Systems
300 Halket Street
Pittsburgh, PA 15213
Phone: (412) 647-4747
Toll-free: (800) 804-7750
<http://www.magee.edu>

DISABLED WOMEN'S HEALTH CENTER

This Center is an obstetrics/gynecology clinic designed to meet the reproductive healthcare needs of women with disabilities. The Center conducts research and develops education materials on the health of women with disabilities.

Amie Jackson, MD
Spain Rehabilitation Hospital
1717 6th Avenue South
Birmingham, AL 35233
Phone: (205) 934-3330
<http://www.health.uab.edu>

HEALTH RESOURCE CENTER FOR WOMEN WITH DISABILITIES (HRCWD)

HRCWD is a comprehensive health center run by women with disabilities in collaboration with clinicians and staff members from the Rehabilitation Institute of Chicago. The center offers accessible gynecological and medical services, resources for parenting and pre-conception support, and programs on domestic violence and teen mentoring. It develops training materials for healthcare providers, conducts research and advises on public policy concerning health issues for girls and women with disabilities, and offers an educational newsletter.

Judy Panko Reis, MA, MS
Rehabilitation Institute of Chicago
345 East Superior #164
Chicago, IL 60611
Phone: (312) 238-8003
Fax: (312) 238-1205
E-mail: hrcwd@ric.org
<http://www.ric.org/community/hrcwd.php>
Medical Director: Kristi L. Kirschner, MD

ACCESSIBLE CLINICAL SERVICES

NEW JERSEY DISABILITY HEALTH & WELLNESS INITIATIVE: THE NEW JERSEY CAPACITY FOR DISABILITY AND HEALTH PROJECT

This project assists the Division of Disability Services, and the Department of Human Services as a whole, in efforts to better serve the needs of New Jersey women and men living with disabilities by conducting focus groups and developing and disseminating state-wide surveys.

Focus groups and surveys explore health promotion and health prevention activities adopted by individuals of each sex and invite discussion about their primary health concerns as well as the access barriers they regularly encounter. All focus groups explore participants' own experiences of using the healthcare system and inquire about ways in which it could better serve their needs.

New Jersey Department of Human Services
Susannah Comb
Division of Disability Services
PO Box 700
Trenton, NJ 08625
Toll-free: (888) 285-3036 (New Jersey only)
Phone: (609) 341-3603

THE WOMEN'S CENTER AT PREMIER HEALTHCARE

The Women's Center provides coordinated healthcare for women with disabilities. Their practice includes primary and specialty care, dentistry, rehabilitation, and mental health services. The Center sponsors educational programs and a quarterly newsletter.

Debra Shabas, MD
460 West 34th Street
New York, NY 10001
Phone: (212) 273-6100, ext. 2132
Fax: (212) 273-6458
E-mail: thewomenscenter@yai.org

DISABILITY RIGHTS EDUCATION AND DEFENSE FUND (DREDF)

DREDF carries out its core mission of advancing the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development.

2212 Sixth Street
Berkeley, CA 94710
Phone and TTY: (510) 644-2555
Fax: (510) 841-8645
E-mail: dredf@dredf.org
<http://www.dredf.org>

DISABILITY RIGHTS ADVOCATES

DRA is a legal center dedicated to protecting the civil and human rights of people with disabilities.

449 15th Street, Suite 303
Oakland, CA 94612-2821
Phone: (510) 451-8644
TTY: (510) 451-8716
Fax: (510) 451-8511
E-mail: general@dralegal.org
<http://www.dralegal.org>

KAISER PERMANENTE NATIONAL DIVERSITY DEPARTMENT

The Kaiser Permanente Institute for Culturally Competent Care provides training, develops tools, and supports large-scale initiatives aimed to eliminate healthcare disparities and inequities.

Institute for Culturally Competent Care
Kaiser Permanente
1950 Franklin St.
Oakland, CA 94612
Phone: (510) 987-1000

NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS (NAPAS)

The National Association of Protection and Advocacy Systems, Inc. (NAPAS), is the voluntary national membership association of protection and advocacy systems and client assistance programs. It assumes leadership in promoting and strengthening the role and performance of its members in providing quality, legally based advocacy services.

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LEGAL AND ADVOCACY SERVICES

ASSOCIATION OF ACADEMIC PHYSIATRISTS

AAP published a pamphlet entitled “Facility Accessibility Checklist: Guidelines and Standards as Outlined by the Americans with Disabilities Act” in 1996 and reissued it in 1999, 2000, and 2001.

<http://www.physiatry.org/publications/accessck.html>
or email the association at aap@physiatry.org

U.S. DEPARTMENT OF JUSTICE

The Disability Rights Section of DOJ protects the rights of persons with disabilities under Titles I, II, and III of the Americans with Disabilities Act (ADA) and pursues a comprehensive program of enforcement and public education under the ADA through lawsuits and formal and informal settlement agreements.

Disability Rights Section
Civil Rights Division
P.O. Box 66738
Washington, DC 20035-6738
Toll-free Hotline: (800) 514-0301
TTY: (800) 514-0383
<http://www.usdoj.gov/crt/ada/adahom1.htm>

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The Rehabilitation Institute of Chicago (RIC) was founded in 1954 as a non-profit organization dedicated to helping people with all types of physical disabilities achieve the best life possible. Today it enjoys a worldwide reputation for excellence in patient care, research, professional education, and advocacy and community service, which not only helps people regain or improve their physical function, but also empowers them to participate more fully in family, social, vocational and leisure time pursuits. Since 1991, RIC has been ranked the “Best Rehabilitation Hospital in America” by *U.S. News & World Report*.

The RIC Health Resource Center for Women with Disabilities is a collaborative effort by RIC staff and women with disabilities that exemplifies the holistic philosophy of the organization by providing an array of programs and services, including health care, social services and education that address the life changes and unique issues of this underserved population. *It Takes More Than Ramps to Solve the Crisis of Healthcare for People with Disabilities*, is made possible by a grant from The Robert Wood Johnson Community Health Leadership Program to the RIC Health Resource Center for Women with Disabilities.



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