Ill-Prepared

Health Care's Barriers for People with Disabilities

A Report by the Equal Rights Center

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Table of Contents

Executive Summary

The ability to find affordable, quality, and accessible medical care promotes the wellbeing and active participation of people in their communities and in the workforce. Access not only benefits individuals, but also society at large by creating healthy, productive, working citizens. However, for people with disabilities, quality health care remains largely inaccessible. The denial of accessible health care to a person with a disability too often means compromised medical treatment—equipment that is not accessible and critical exams not given at all, or given in a way that impairs diagnosis. In each instance, equal opportunity is denied to people with disabilities, and health and lives are put at risk.

Despite legal requirements and Federal government initiatives to address barriers to accessible medical care, significant problems remain for more than 54 million Americans living with a disability. These problems will only become more devastating as baby boomers age and the number of people with disabilities continues to grow.

Each year, the Equal Rights Center (ERC) receives numerous complaints from individuals with disabilities across the nation who experience substantial health care disparities and lack of access to appropriate care. The three most significant barriers cited in ERC complaints include: (1) structural barriers in health care facilities, (2) inaccessible medical equipment, and (3) policies and procedures that create barriers for patients with disabilities, such as inaccessible forms of communication.

The alarming frequency of these complaints spurred the ERC to initiate a three-pronged series of investigations concerning access to health care for people with disabilities. Conducting hundreds of tests at locations across the nation, the ERC's investigation reveals notable barriers in the structural accessibility of doctors' offices and equipment, and ineffective communication for individuals who are blind or have low vision.

Ill-Prepared National Testing Findings

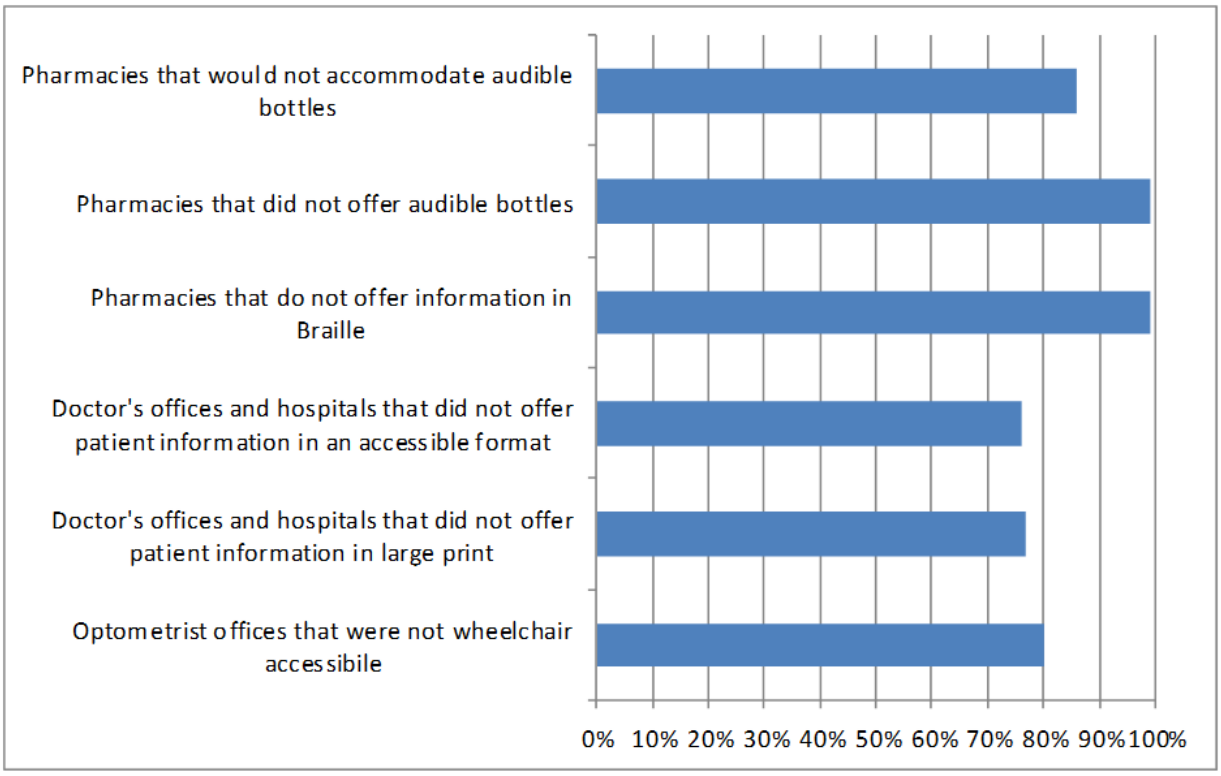


Fig. 1

Findings from ERC investigations include:

- **Only 20 percent of optometrists' offices** had the accessibility needed to perform an eye exam on someone who uses a wheelchair;
- **Only 23 percent of doctors' offices and hospitals** offered patient information in large print, and **only 24 percent** offered patient information in an accessible format; and
- **Only 1 percent of pharmacies** offered information in Braille and **only 1 percent** offered audible prescription bottles. In fact, **86 percent** of tested pharmacies would not accommodate the use of an audible prescription bottle even if provided by the customer.

These alarming statistics demonstrate why medical service and product providers must acknowledge the uniquely important roles they play in the lives of people with disabilities and change their methods of delivery to better accommodate this community.

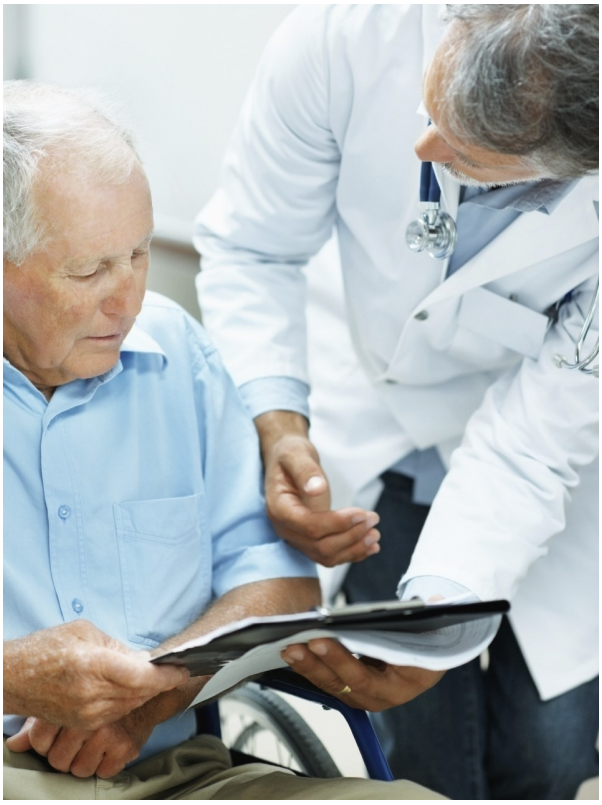
About the Author

The Equal Rights Center

Originally formed in 1983, the Equal Rights Center (ERC) is a national non-profit civil rights organization based in Washington, D.C. With thousands of members located in all 50 states and the District of Columbia, the ERC works nationally to promote equal opportunity in housing, employment, disability rights, immigrant rights, LGBT rights and access to public accommodations and government services for all protected classes under federal, state, and local laws. With nearly three decades of experience as an advocate of the disability community, the ERC has been a sounding board for scores of individual complaints about inaccessible health care.

In its nearly thirty-year history, the ERC has developed an expertise in civil rights testing that has been recognized by federal, state, and local governments, other civil rights organizations, and the courts. The ERC conducts hundreds of civil rights tests each year to educate the public and government officials of the endemic discrimination still faced by many individuals across America.

Overview of the Problem



Despite increasing efforts to ensure that all Americans are able to access appropriate and adequate medical services, health care continues to be inaccessible for many with disabilities, often with harmful consequences. People with disabilities experience both health disparities and specific problems in gaining access to appropriate health care, including health promotion and disease prevention programs and services.

As the population continues to grow and people live longer, the number of Americans that have a disability is rapidly increasing. In 2005, 54.4 million individuals (18.7 percent) had some level of disability, and 35.0 million (12.0 percent) had a severe disability.[1] Rates of disability also increase with age, with 41.9 percent of individuals over the age of 65 reporting a disability, compared with 18.6 percent of people who are 16 to 64.[2] Further, the numbers of older persons are expected to grow substantially during the next several decades. It is estimated that by 2030, the number of persons aged 65 years and older will rise to 71 million, from 34.7 million in 2000. By 2030, the number of individuals aged 85 and older will also increase considerably, to 9.6 million, from 4.3 million in 2000.[3]

Disability is closely linked to health care use. People with disabilities:

- Tend to be in poorer health and to use health care at significantly higher rates than people who do not have disabilities;

[1] Matthew Brault, *Americans with Disabilities: 2005*, CURRENT POPULATION REPORTS, (2008) at 3, http://www.census.gov/prod/2008pubs/p70-117.pdf.
[2] J. Waldrop and S. M. Stern, *Disability Status: 2000-Census 2000 Brief*, U.S. BUREAU OF THE CENSUS, at 2.
[3] Institute of Medicine: Committee on Disability in America, *The Future of Disability in America,* (Field MJ, Jette AM eds., National Academic Press) 2007.

- Experience a higher prevalence of secondary conditions and use preventive services at lower rates; and
- Experience more problems accessing health care than other groups, and these difficulties increase for those with the most significant disabilities and who are in the poorest health. Moreover, lack of access to health care has been associated with increased risk for secondary conditions for people with significant disabilities.[4]

People with disabilities experience a variety of barriers when accessing health care, including:

- Stereotypes about disability on the part of healthcare providers;
- Health care provider misinformation, and lack of appropriately trained staff;
- Limited health care facility accessibility and lack of examination equipment that can be used by people with varying disabilities;
- Lack of sign language interpreters;
- Lack of materials in formats that are accessible to people who are blind or have low vision; and
- Lack of individualized accommodations.[5]

At the national level, the scope of this crisis was recognized by the U.S. Department of Health and Human Services, when it included reduction of health disparities affecting people with disabilities as a priority in the "Healthy People 2010." People with disabilities are represented in over half of the "Healthy People 2010" focus areas.[6]

Similarly, in 2005, the national *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* identified four specific goals for the nation to improve the health and wellness of persons with disabilities: GOAL 1: People nationwide understand that persons with disabilities can

[4]National Council on Disability, *The Current State of Health Care for People with Disabilities*, (2009), http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html.
[5]*Id.*
[6] "Healthy People 2010," is the government's statement of national health objectives, designed to identify the most significant preventable threats to health, and to establish national goals for reducing these threats. Healthy People 2010, Objectives for Improving Health, Disability, and Secondary Conditions. www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm#_Toc486927298.

"To exist at the highest level of wellness, individuals need accessible housing, transportation, education, and employment. These are all spokes to a wheel that cannot move efficiently when one aspect is missing."

-ERC Member, Rosemary Ciotti

lead long, healthy, productive lives.

- GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.
- GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
- GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

  "This Call to Action encourages health care providers to see and treat the whole person, not just the disability; educators to teach about disability; a public to see an individual's abilities, not just his or her disability; and a community to ensure accessible health care and wellness services for persons with disabilities." - Surgeon General Richard H. Carmona, M.D., M.P.H., FACS.[7]

The Equal Rights Center regularly receives complaints regarding structural barriers at doctors' offices, including inaccessibility of the actual facility, and the lack of accessible medical equipment such as x-rays, examination tables, weight scales. Personal, real-life experiences gathered by the ERC demon-

[7] U.S. Department of Health and Human Services. The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, OFFICE OF THE SURGEON GENERAL, (2005).

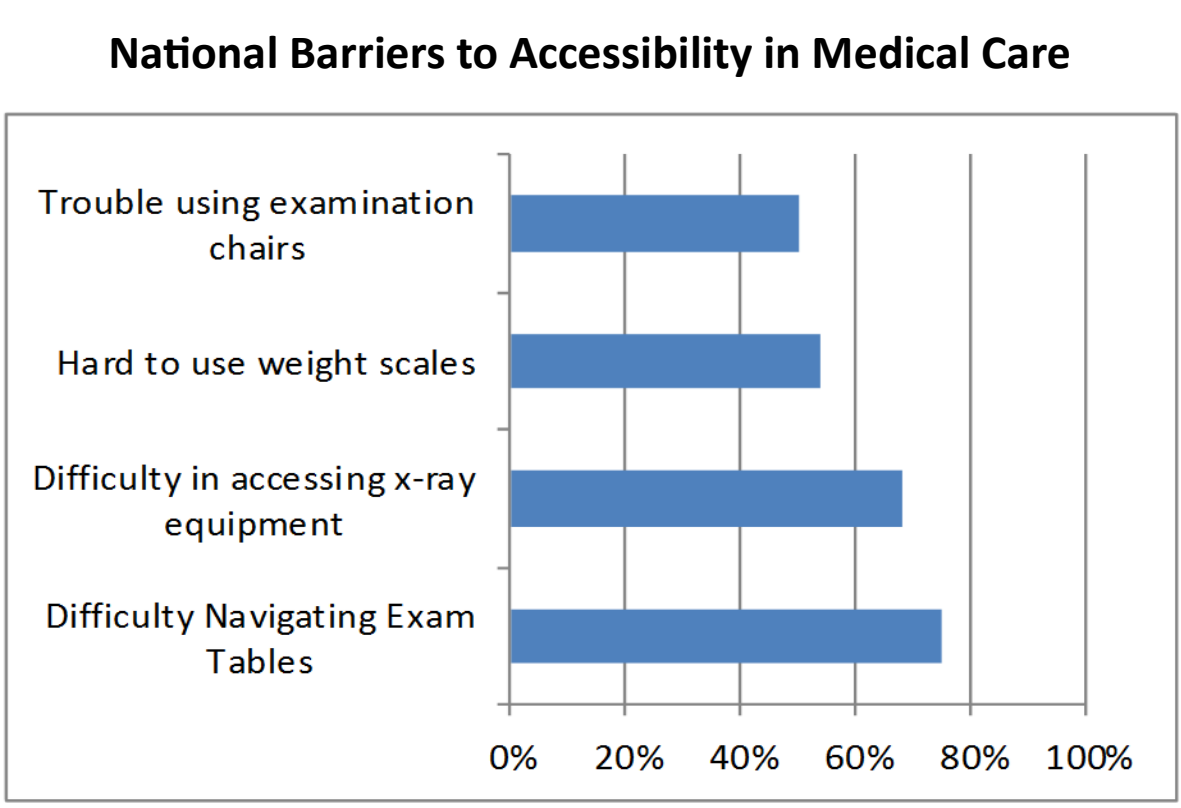
strate that doctors' offices are failing to provide the necessary care and equipment. The following situations faced by ERC members are illustrative of the problems:

- A woman with quadriplegia, who has a history of breast cancer in her family, was denied access to a mammogram screener and was told that nothing could be done to provide her access to these services.
- A man with quadriplegia was denied an accessible exam table and scale at his medical clinic, which were necessary for him to receive the same quality of care as other patients. His doctors used height and weight records that were ten years old to determine what dosages of medication to prescribe.
- A woman who uses a wheelchair was unable to find a doctor's office where she could access the examination table for a pelvic exam. Only after nearly a year of searching did she find an office where she could be examined, at which time she was diagnosed with endometrial cancer.

These stories are indicative of a large and widespread problem. A national survey revealed alarming statistics, reporting that a majority of people with disabilities experience difficulty in navigating medical facilities and undergoing medical exams.[8] Of 408 people surveyed:

- **75 percent experienced difficulty navigating exam tables**, such that 32 percent had moderate problems, 34 percent had extreme difficulty, and 9 percent said they were impossible to use. Problems reported included height and width, nothing to hold onto when getting on the table, nothing to lean on once on the table, and hard-to-use stirrups.
- **68 percent experienced difficulty in accessing x-ray equipment**, such that 41 percent had moderate difficulty, 32 percent had extreme difficulty, and 4 percent said it was impossible to use. This equipment included general x-rays, mammograms, MRIs, ultra-

[8] Kailes, June Isaacson. *Just hop up, look here, read this, listen up, don't breath and stay still! Access to medical equipment – Where are we?,* (lecture presented at the webcast for Independent Living Research Utilization program, Houston, TX, January 4, 2007).



Fig, 2. Statistics provided by June Isaacson Kailes in a January 2007 lecture presented at the webcast for Independent Living Research Utilization program in Houston, TX.

sounds, and other types of medical scans.

- **54 percent experienced difficulty in using the medical facilities' weight scales**, such that 25 percent had moderate difficulty, 17 percent had extreme difficulty, and 13 percent said they were impossible to use.

- **50 percent found it difficult to use examination chairs**, such that 30 percent had moderate difficulty, 17 percent had extreme difficulty, and 4 percent said they were impossible to use. These chairs included those relied on for dental exams, oral surgery, eye exam, and laboratory work.[9]

[9] *Id.*

Moreover, the ERC receives complaints related to accessible medical forms and health care communication. Complaints include:

- A woman who is blind was unable to obtain from her health insurance provider an accessible form detailing her policy. When she requested Braille forms be mailed to her, so that she could fully understand the type and scope of her medical care coverage, they refused to provide her an accessible form.

> "Being unable to access medical services is frustrating and embarrassing to people with disabilities and also concerning for health reasons."
>
> -ERC Member, Georges Aguehounde

- A woman who is blind had problems accessing her physicians' offices because they did not have Braille signage on their doors and elevators. The woman would often walk into the wrong doctor's office or end up on the wrong floor because she did not know where she was going due to the lack of Braille signage.

- A Deaf teenager was denied an American Sign Language interpreter for his doctor's appointment. The physician's office stated that the family was responsible for hiring their own interpreter or communicating for him.

Inaccessible health care does not end at hospitals and doctors' offices. The ERC also receives complaints from its members who are blind or low vision regarding inaccessible prescription labels. For example:

- A woman who is blind found that many pharmacies do not provide her medication with a Braille option. She expressed frustration because she had to rely on her mother to purchase her medication and explain when to take it. The inability for patients to see how much medication to take and when to take it can cause disastrous results that could easily be remedied if prescription labels were accessible to all people.

- A woman who is blind was required to answer confidential medical questions which were read aloud to her by office personnel in a busy waiting room, rather than providing her a private space or an electronic version she could complete by herself. Failure to secure confidentiality discourages the candid communication between patient and medical provider that is needed for effective treatment.

These situations illustrate a severe and systemic issue. The problems facing people with disabilities when accessing health care are wide-ranging and very serious. As noted by one group of accessibility experts:

> 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…. 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.[10]

[10] J. Panko Reis, M. L. Breslin, L. I. Iezzoni, and K. Kirscher, It Takes More Than Ramps to Solve the Healthcare Crisis for People with Disabilities (Chicago: Rehabilitation Institute of Chicago, 2004) at 42.

Health Care and Legal Protections

The landmark 1990 Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act of 1973 (Section 504), established wide-ranging national mandates prohibiting discrimination based on disability. Collectively, these two vital laws prohibit public and private health care providers from discriminating against people with disabilities, and ensure equal opportunity to participate in and benefit from health care services.

Under Federal law, a person is defined as having a disability when he or she: (a) has a physical or mental impairment[11] that substantially limits one or more major life activities; (b) has a record of such an impairment; or (c) is regarded as having such an impairment. Under the 2008 ADA Amendments, major life activities include, but are not limited to: seeing, walking, and learning, as well as the operation of major bodily functions – like the immune system. The Amendments also make clear that the ADA covers people with episodic conditions, such as epilepsy. Today, a person is protected under the ADA if he or she has a disability that substantially limits a life activity when the condition is in an active state, even if the condition is not evident or does not limit a life activity at all times.[12]

Section 504 of the Rehabilitation Act

The first Federal civil rights law protecting individuals with disabilities was the Rehabilitation Act of 1973. Section 504 of this Act prohibits discrimination against otherwise qualified people with disabilities under any program or activity that receives Federal financial assistance.[13] It directly applies to state Medicaid agencies as well as health care entities and providers that receive Federal monies through Medicaid, Medicare, or Federal block grants. In the medical setting, the Rehabilitation Act is frequently applied since the vast majority of health care providers accept Medicaid and Medicare funds from the Federal government. [14]

[11] Americans with Disabilities Act, 42 U.S.C. §12102 (1990), amended by the Americans with Disabilities Amendments Act, Pub. L. No. 110-325 (2008).
[12] *Id.*
[13] Rehabilitation Act, 29 U.S.C. §794 (1973).
[14] *Id.*

The Americans with Disabilities Act

The ADA, enacted in 1990, provides protections from discrimination for individuals with disabilities. Titles II and III of the ADA also prohibit disability discrimination and require health care providers to be physically and programmatically accessible to people with disabilities.[15] Title II of the ADA prohibits discrimination by public entities run or funded by state and local governments. These include any department, agency, special purpose district, or other instrumentality of a state or local government, including community health clinics or state run hospitals.[16]

Title III of the ADA prohibits any public accommodation from discriminating against individuals with disabilities by denial of access to goods and services. Public accommodations include all areas open to the public, including restaurants, stores, banks, pharmacies, legal offices, doctors' offices and hospitals. Title III states that "private entities are considered public accommodations for purposes of this title, if the operations of such entities affect commerce" and specifically includes "professional office of a health care provider, hospital, or other service establishment."[17]

[15] 42 U.S.C. §§12101, *et seq.*
[16] 42 U.S.C. §12115.
[17] 42 U.S.C. §12181.

Under Title III, discrimination includes:

- Establishment of eligibility criteria that screen out individuals with disabilities from equally benefiting from a good or service;
- Failure to make reasonable modifications in policies, practices, or procedures when such modifications are necessary to ensure that individuals with disabilities have access to the goods or services;
- Failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, or treated differently because of the absence of auxiliary aids and services;
- Failure to remove architectural barriers; and failure to make a good or service available through alternative methods if such methods are readily achievable.[18]

The purpose of Title III is to ensure that no person with a disability is denied goods or services offered to the public because of their disability. This language makes clear that it is unlawful for a privately run hospital or doctor's office to make its goods or services unavailable to people with disabilities as a result of a failure to take the necessary steps to ensure equal access. **Under both Titles II and III, medical facilities must ensure that their goods and services are accessible to people with disabilities.**

One component of accessibility is the elimination of "structural barriers" that deny access to people with disabilities. Structural barriers are tangible components of buildings that make it difficult or impossible for a person with a disability to enter and maneuver about a space effectively and safely, such as stairs.[19]

Another aspect of accessibility is the willingness to make accommodations for people with disabilities. Reasonable accommodations are modifications in a procedure, practice, or policy, which allow individ-

[18] *Id.*
[19] 42 U.S.C. §12182(b)(2)(A).

"It was quite shocking to me to find out that people were not getting routine basic care, and the only factor was that they were disabled. The rights are only as good as the people and only good if they are being enforced."

-ERC Member, Rosemary Ciotti

uals with disabilities to equally benefit from the goods or services being offered.[20]

Finally, **public entities must provide auxiliary aids and services to ensure effective communication between medical staff and patients.**[21] Auxiliary aids and services may include hiring an ASL Interpreter for a doctor's appointment, or providing documents in alternative formats to individuals who are blind or low vision.

Structural barriers in medical facilities prevent people with disabilities from getting proper diagnoses and treatment. Under federal law, including accessibility standards such as the ADA Accessibility Guidelines, medical facilities must be free from structural barriers and meet certain accessibility standards. These standards include but are not limited to:

- Accessible entrances with no stairs;
- Doors that are wide enough to ensure safe passage by individuals using mobility aids;
- Paths of travel throughout buildings that are accessible;
- Restrooms that have grab bars and accessible sinks;
- Items such a water fountains, pay phones, and service counters low enough to be within reach for an individual with a mobility disability or short stature; and

[20] *Id.*
[21] *Id.*

- Braille signage on elevators and restrooms.[22]

Medical facilities must provide auxiliary aids and services to ensure effective communication between medical staff and patient. Auxiliary aids are services or devices that enable persons with impaired sensory, manual, or speaking skills to communicate effectively and have an equal opportunity to participate in, and enjoy the benefits of, programs or activities conducted by the entity.[23] In the medical setting, auxiliary aids and services may include hiring an American Sign Language Interpreter for a doctor's appointment or providing documents in alternative formats to individuals who are blind or low vision.

Medical facilities do not have to make accommodations or provide auxiliary aids and services when doing so would be an undue hardship or when an accommodation would be a fundamental alteration in the nature of the goods or services provided.[24] Whether or not an accommodation constitutes an undue hardship depends on a variety of factors, including the cost of the accommodation relative to size of the business.[25] For example, a large hospital located next to a deaf university may be required to ensure that qualified American Sign Language Interpreters are available or can be made available at any time. However, for a small doctor's office with two physicians, ensuring immediate access to an interpreter may be an undue burden. While the doctor's office is still responsible for providing an auxiliary aid, another option may be to provide interpreters when a patient requests the communication aid in advance.

Likewise, a medical provider is not required to make an accommodation if doing so would be a fundamental alteration in the nature of the goods or services provided. For example, the primary care physician of an individual who uses a wheelchair is not required to treat a patient for cancer, even if the patient requests. To treat the cancer would be a fundamental alteration in the nature of the services the primary care physician would normally provide. The primary care physician is required to make an

[22] Department of Justice. *2010 ADA Standards for Accessible Design.* 28 CFR part 36, (2010).
[23] 28 C.F.R. § 36.303 .
[24] 42 U.S.C. §12182(b)(2)(A)(ii)(iii).
[25] 42 U.S.C. §12181(9).

appropriate referral to an oncologist, as he or she would for any other patient.

Finally, health care providers located in buildings that have been completed or undergone significant alterations since 1993 must be designed and constructed so that they are fully accessible. Facilities operating in buildings build prior to 1993 are required to remove architectural barriers such as steps, narrow doorways, and inaccessible toilets if doing so is "readily achievable." Such alterations are considered "readily achievable"[26] if they can be carried out without too much difficulty or expense.[27]

Health Care Reform

The recently passed health care reform law, The Patient Protection and Affordable Care Act, has the promise of making quality health care more accessible for all Americans, including people with disabilities.[28]

Of relevance to this report, health care reform will affect people with disabilities in the following ways:

[26] 42 U.S.C. §12182(b)(1)(A).
[27] 42 U.S.C. §12181(9)
[28] The Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119-124 (2010), as amended by the Health Care and Education Reconciliation Act, Pub. L. No. 111-152, 124 Stat. 1029-1084 (2010).

- As of 2014, health insurance providers will no longer be able to discriminate against people due to disability or any other pre-existing condition;

- The U.S. Access Board, in consultation with the Food and Drug Administration, is required to establish regulatory standards setting the minimum technical criteria for accessible medical diagnostic equipment for people with disabilities. While existing law requires medical equipment to be accessible, these standards are intended to clarify how to comply with this requirement;

- Medical professionals are required to receive disability awareness training to help reduce the health disparities that exist for people with disabilities; and

- Except as provided elsewhere in the law, discrimination based on disability is prohibited under any health program or activity which receives Federal assistance, including credits, subsidies, contracts of insurance, or under any program or activity that is administered by an Executive Agency. Section 504 of the Rehabilitation Act provides enforcement mechanisms for violations.

Other Legal Protections

In addition to federal protections, many states, as well as some counties and cities, also have disability nondiscrimination laws that apply to health care providers, including individual practitioners, nonprofit and commercial hospitals, and HMOs.[29] In the District of Columbia, The DC Human Rights Act forbids DC government entities and all public accommodations from discriminating against individuals due to disability.[30]

[29] *See, e.g.*, California's Unruh Civil Rights Act as applied in *Washington v. Blampin*, 226 CA2d 604, 38 CR 235 (1964). The Act's broad language of "services in all business establishments of every kind whatsoever" was intended to cover the professions. See *Leach v. Drummond Med. Group*, 144 CA3d 362, 269, 370 (1930), in which the Act is applied to a corporate medical group that refused future medical services to plaintiffs with disabilities.
[30] DC Human Rights Act, D.C. Code §2-1402.73, §2-1402.31.

The Equal Rights Center's Testing of the Availability of Accessible Medical Care

After receiving complaints from ERC members regarding inaccessible medical facilities and the lack of appropriate accommodations in doctors' offices and pharmacies, the ERC sought to determine the extent to which these anecdotal stories were indicative of larger problems across the country. Responding to specific complaints, the ERC commenced a three-pronged investigation to gather information on the prevalence of discrimination in health care settings.

The ERC's investigation studied and measured:

- Structural accessibility in optometrists' offices;
- Accommodations in doctors' offices for individuals who are blind or have low vision; and
- Accommodations in pharmacies for individuals who are blind or have low vision.

Structural Accessibility of Optometrists' Offices

Structural inaccessibility is a barrier to countless people with disabilities. Individual complainants reported difficulty not only entering the offices and maneuvering around, but also getting a complete exam due to the lack of equipment needed to perform eye exams on individuals seated in wheelchairs.[31]

In the first prong of its investigation, the ERC sought to determine if individuals who use wheelchairs would encounter barriers while attempting to get an eye exam. The ERC measured if facilities them-

[31] For example, many phoropters used by optometrists to test visual acuity are not designed to be lowered to accommodate a person using a wheelchair. Absent the ability to transfer into an exam chair, this critical diagnostic equipment is not accessible.

selves were structurally accessible, and if the medical equipment used by retail optometrist offices was adaptable for people with disabilities. The testing methodology for this prong relied largely on self-reporting. Testers posed as potential consumers who were calling in advance of scheduling an appointment to see if they would be able to access the facilities.

ERC testing revealed that optometric medical facilities routinely lack the equipment to provide services to people with disabilities. Of the fifteen locations tested for wheelchair accessibility, only three had the necessary equipment to provide an eye exam to an individual in a wheelchair. **Twelve out of fifteen (80 percent) lacked the accessibility needed to provide an individual in a wheelchair an eye exam.** Although some of this inaccessibility stemmed from the structural inaccessibility of the office itself, the biggest accessibility barrier was the inability to provide an eye exam to someone seated in a wheelchair.

"When making medical appointments, I have many of the same priorities as any individual; a convenient location where I can get an appointment. When unable to enter an optometrists' location, told I could not access their equipment, and forced to discuss my disability in public it both wasted much of my time and left me embarrassed."

-ERC Member, Georges Aguehounde

Accessible Medical Forms

The ERC also receives complaints from individuals who encounter difficulty in accessing their personal medical information, and filling out forms at doctors' offices. People with visual disabilities and mobility disabilities experienced humiliation when going to a doctor for the first time and being unable to fill out forms regarding medical history and health insurance in a confidential setting. People with visual disabilities also report numerous attempts to obtain information regarding their health and being unable to do so because of the lack of accessible documents.

Medical facilities must make accommodations for people with disabilities so long as the accommodation is not a fundamental alteration in the nature of the goods and services provided and does not pose an undue burden on the medical facility.

The second prong of the ERC's investigation was designed to determine the availability of alternative formats for medical information at doctors' offices and hospitals. The ERC tested four different types of medical facilities, doctors' offices for the practice of: (a) internal medicine, (b) ophthalmology, (c) dermatology, and (d) hospitals. All of the doctors' offices surveyed were privately run with a staff of no less than three physicians. The ERC conducted 100 tests, testing each of the four types of medical providers in 24 states and the District of Columbia.[32]

In this study, the ERC again relied largely on self-reporting by the medical services provider themselves. Surveyors called doctors' offices posing as potential patients and inquired: (1) if the office provides information in alternative formats; (2) the easiest way to fill out patient history forms prior to a visit, or (3) if there was an accommodation in place to fill out the forms at the doctors' office.

The results of this study, unfortunately, confirm that doctors' offices routinely fail to provide necessary accommodations to individuals who are blind or have low vision. The results included:

[32] Tests were conducted in Arizona, California, Colorado, Connecticut, Florida, Illinois, Indiana, Maryland, Massachusetts, Mississippi, Nebraska, Nevada, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Tennessee, Texas, Utah, Virginia, Washington, Wisconsin, Wyoming.

Accessible Medical Forms

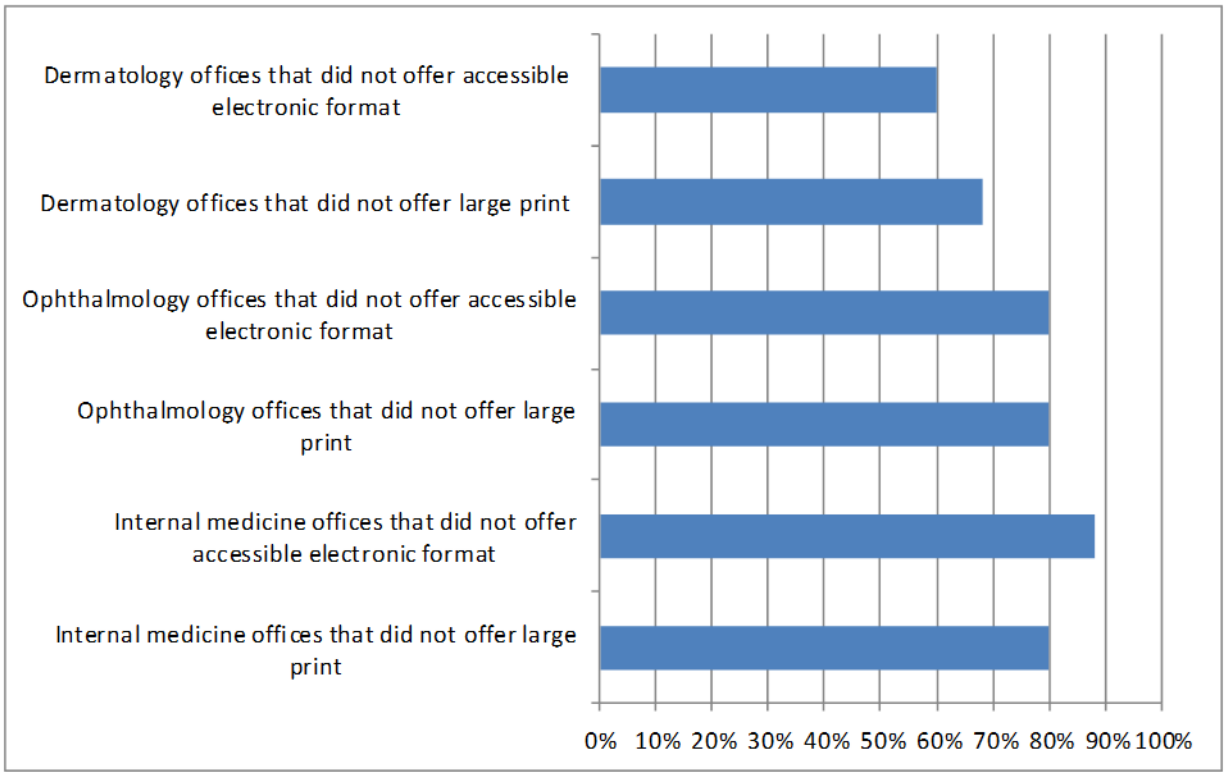


Fig. 3

- Of the 25 internal medicine offices tested, **only 20 percent offered documents in large print and only 12 percent offered documents in an accessible electronic format.**
- Of the 25 ophthalmology offices tested, **only 20 percent offered documents in large print and 20 percent offered documents in an accessible electronic format.**
- Dermatology offices were slightly better in that **32 percent offered documents in large print and 40 percent offered accessible electronic documents.**

A much larger percentage of offices offered alternative accommodations to people with visual disabilities. However, many of these alternatives failed to provide the individual with a disability the same quality of service as a sighted individual. For example, many doctor's offices stated that a receptionist or nurse could assist in filling out forms. While at first, this accommodation may seem adequate, numerous reports from ERC members indicated that office staffs fail to provide assistance in a way that

ensures the patient's confidentiality. Another accommodation offered by doctors' offices was the willingness to mail forms to the patient prior to their appointment. Again, while this may seem acceptable at first, since it assures that the forms can be filled out ahead of time, it still requires that the patient seek the assistance of a sighted individual in order to complete the forms.

The testing of hospitals proved to be very challenging. Of the 25 tests conducted, the tester was transferred among hospital staff 68% of the time, and approximately **30 percent of the time never spoke with an individual who could answer their questions.** In the instances where answers were provided, **only 20 percent of hospitals offered large print materials and only 24 percent offered documents in an accessible electronic format.**

Accessible Prescription Labels

ERC members with visual disabilities frequently report that prescription labels are inaccessible, creating problems determining what medications are theirs, the expiration dates for the drugs, and dosage information. Included in the complaints are concerns of being unable to identify medication by pill texture, shape, or size, resulting in erroneous dosing or unintended combinations of prescriptions.

Under the Section 504 and the ADA, pharmacies are required to be structurally accessible and provide accommodations and auxiliary aids to ensure equal access and effective communication. Auxiliary aids are services and devices used to ensure effective communication by an individual who has a disability. The failure of pharmacies to provide prescription labels in alternative formats thus violates federal law.

The third prong of the ERC's investigation was designed to study the availability of prescription labels in alternative formats. The ERC examined the practices of four major prescription retailers by conducting 100 tests in 24 states and the District of Columbia.[33]

[33] Tests were conducted in Arizona, California, Colorado, Connecticut, Florida, Illinois, Indiana, Maryland, Massachusetts, Mississippi, Nebraska, Nevada, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Tennessee, Texas, Utah, Virginia, Washington, Wisconsin, Wyoming.

Accessible Prescription Labels

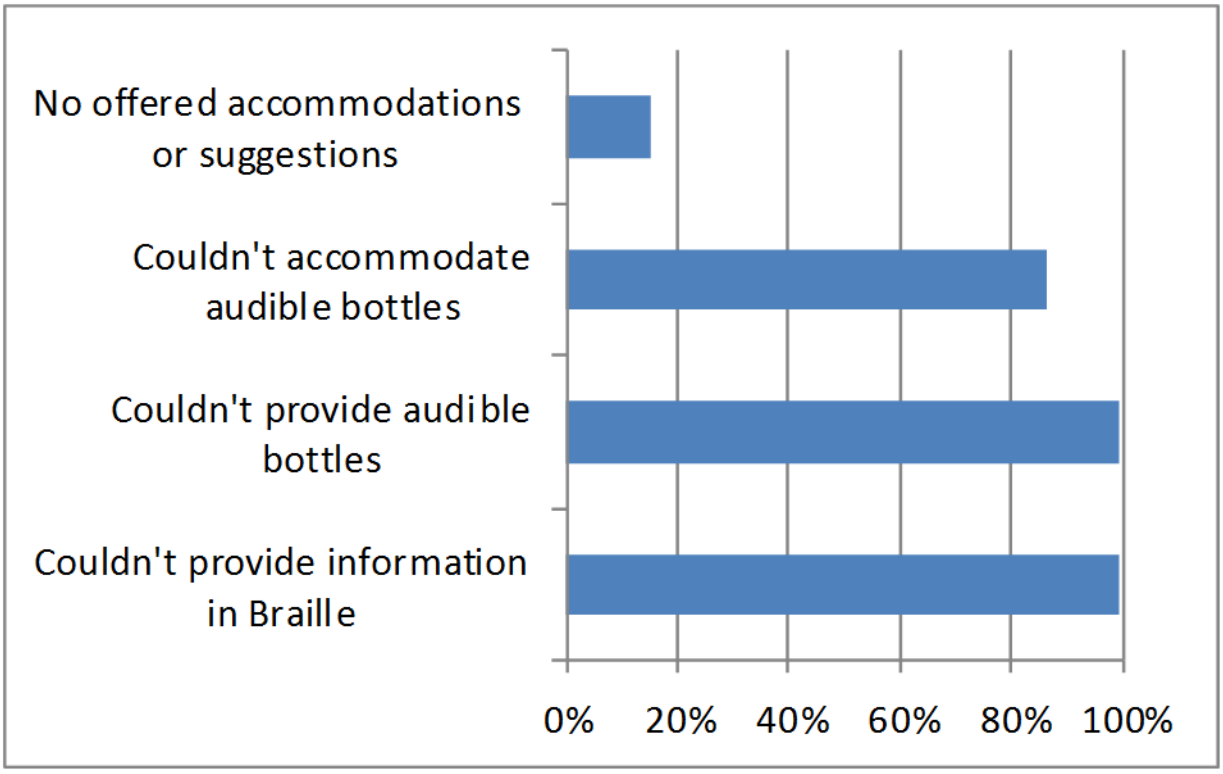


Fig. 4

The ERC's investigation sought to determine whether pharmacies had the capability to label bottles and provide medication information in alternative formats in order to be accessible to people who are blind or have low vision. Testers were instructed to specifically ask about the availability of Braille, audible bottles,[34] as well as any other accommodations the store may offer. The ERC's study demonstrated that:

- **Only 1 percent of all retailers offered any information in Braille.**
- **Only 1 percent of retailers could provide audible bottles.**
- **Eighty-six percent were unable to accommodate a customer with audible bottles,** even

[34] "Audible bottles" are prescription bottles that have a device affixed to them that provide information regarding the medication audibly to assist individuals with disabilities.

if the customer provided the bottles.

- **Fifteen percent of pharmacies did not offer any accommodations or suggestions** for how someone with a visual disability could get prescriptions labeled in alternative formats.

The accommodations and recommendations of the other 85 percent of pharmacies varied greatly. Many pharmacies recommended that the person call another pharmacy, or recommended that the tester get a personal aid, or have a family member assist with medication. Other pharmacies took a more proactive approach and offered to work with the person and provide different sized bottles and direct consultation, or assist the person in distributing their medication into monthly pill planners.

These four major retailers represent nearly 20,000 stores nationwide, a substantial share of the total pharmacies in the United States. This is especially troubling since the ERC testing reveals that there is no protocol in place to provide accommodations to individuals who are blind or have low vision. The inability of individuals who are blind or have low vision to access their own medication exemplifies the challenges people with disabilities face in trying to obtain effective health care.

Conclusion

The availability of accessible medical services, medical forms, and prescription drugs plays a uniquely vital role in the lives of people with disabilities. The Equal Rights Center's testing investigations and the many experiences of ERC members show that this community is, at best, given second-class treatment.

> "A medical clinic is one place where you should expect accessible care and services. I am thankful that some locations do offer accessible services so people with disabilities have the same quality of care as non-disabled individuals."
>
> -ERC Member, Angela Vaughn

Notwithstanding the promises of equal opportunities for people with disabilities mandated by both the ADA and Section 504, individuals across the nation are still denied adequate and necessary health care every day due to their disabilities. With more than 54 million Americans living with disabilities, a number that is rapidly expanding, the continued widespread discrimination against people with disabilities in the area of health care is unacceptable.

The Equal Rights Center hopes that as a result of the findings in this study, disability rights advocates, government enforcement agencies, and community leaders will continue to promote equal access to rectify this type of discrimination against people with disabilities. Through a coordinated, concerted effort to respond to these issues, providers of health care services and products have the opportunity to transform their current compliance with these laws from an embarrassment into a model of equal opportunity for the disability community.